2011

Amish family care for children with chronic illnesses: an ethnography

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Recommended Citation

Kueny, Angela M.. "Amish family care for children with chronic illnesses: an ethnography." PhD (Doctor of Philosophy) thesis, University of Iowa, 2011.
https://ir.uiowa.edu/etd/3326.

AMISH FAMILY CARE FOR CHILDREN WITH CHRONIC ILLNESSES:
AN ETHNOGRAPHY

by

Angela M Kueny

An Abstract

Of a thesis submitted in partial fulfillment
of the requirements for the Doctor of
Philosophy degree in Nursing
in the Graduate College of
The University of Iowa

July 2011

Thesis Supervisors: Assistant Professor Lioness Ayres
Professor Toni Tripp Reimer

ABSTRACT

The purpose of this study was to understand the cultural context in which Amish families manage the care of a child with a chronic illness and how it frames the interface with the larger health care delivery system outside their communities. The aims of this study were to describe Amish families' understanding of their children's chronic illnesses, and to describe Amish families' health management and health seeking behaviors for their children within the Amish community and with health services outside their community.

Ethnographic research methods were used to paint a cultural portrait of individuals and families, using data sources such as formal and informal interviews with participants, participant observations in the Amish community and family homes, Amish newspapers, and direct observations in health care clinic settings. Informants in this study included Amish families, Amish community members, and health care providers to illustrate commonalities and differences in perspectives on the chronic illness management for children. The study made use of ethnographic analysis, guided by thematic and cultural narrative techniques, to describe Amish family management for children with chronic illnesses in a way that pulls forward how their cultural background is involved in their behaviors and experiences.

The results of this study highlight several points. a) the Amish community influences how families understand and appraise concern for their children's illnesses, and families prioritize children's function as a measure of health/illness and see children as ultimately in the hands of God; b) minimal entanglement with the health care community allows for children to be as normalized as possible into the everyday life of the Amish community; c) families prefer to use home remedies to lower costs, potentially prevent the need for health services, and alleviate their child's symptoms in their own homes and community; d) when seeking health services, families prefer treatments they can manage in their homes, health care providers who are knowledgeable about the use of Amish home remedies for their children, and the ability to make health decisions in consideration of the impact to the greater Amish community.

To provide culturally competent care for Amish children, this study describes provider competencies needed to understand and accommodate the child's family cultural orientation, values, beliefs, and health care practices into cooperative care planning. One of the most significant attributes for providers to understand when working with Amish families is their collectivist perspective. As collectivists, these families may place the ultimate Amish community goals of believing in God, separation from society, and traditional lifestyle choices over their own when caring for children with chronic illnesses. This is a difficult competency for health care providers who function within a larger medical legal system that requires the placement of individuals above other considerations. It is at the intersection of these two cultures that this study is situated.

Abstract Approved: ______________________________
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CERTIFICATE OF APPROVAL

PH.D. THESIS

This is to certify that the Ph.D. thesis of

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has been approved by the Examining Committee
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To Grandparents Irene Feeley, Patricia Kueny, Helen Gerdes, and Leo Oldenburg.
I lost your physical presence while writing this dissertation,
yet my inspiration comes from memories of your strength, courage, and wisdom.

ACKNOWLEDGMENTS

At a point during the writing of this dissertation, my advisor Dr. Lioness Ayres expressed her hope to encourage and push me to a greater accomplishment than I thought possible for myself. Without the supportive guidance and wisdom of Dr. Toni Tripp Reimer, this ethnography would not have developed so richly to resemble both a nursing and anthropologic piece of work. I am tremendously grateful to both of these women who spent their time reading, revising, and meeting with me to create a final product that exceeded my own expectations for this research study. Additionally, they mentored and assisted me in writing and successfully receiving a predoctoral Ruth L. Kirschstein National Research Service Award, F31 NR010314-02, funding this research.

Drs. Ann Marie McCarthy and Martha Driessnack gave me productive feedback and encouraged me during the preliminary and final stages of this research. Dr. Bernard Sorofman joined the dissertation committee after the proposal meeting and put forth great effort to provide rich feedback with genuine concern for the success of this project.

I want to acknowledge the ongoing and sustained efforts of the Amish families, bishops, and herbalists who enthusiastically partook in this research. Health care providers taking care of these Amish families were honest and informative. These participants made this research possible, for which I am forever grateful.

To my friend and doctoral colleague, Melissa Lehan Mackin, who spent countless hours with me refining my ideas, inquiring about my progress, supporting my decisions, and helping me to laugh through the whole process.

My family never stopped believing that I would complete this endeavor successfully and supported me in practical and emotional ways throughout the process. Finally and foremost, to my husband, who never lost faith in my ongoing work on this dissertation and my vocation in nursing. His love motivates me on a daily basis.

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CHAPTER 1

INTRODUCTION

Research Problem

As the U.S. population becomes increasingly diverse, culturally competent care is a national imperative that will involve increased cultural awareness and sensitivity in health care providers (HCPs) (Fortier & Bishop, 2004; U.S. Census Bureau, 2000). Culture has traditionally been defined as a subgroup having a common heritage, as distinguished by customs, language, symbols, or any suggestion that there is a system in persistence (Geertz, 1983). Current definitions of *cultural competence* urge HCPs not only to learn details of a variety of cultures, but also to shift attitudes, increase cultural sensitivity and awareness, build knowledge about multicultural health practices, and develop skills based on a cross-cultural approach (Chrisman, 2007; Institute of Medicine, 2006b; Leininger, 2002). Most guidelines for culturally competent care take a narrower definition and reflect the priorities of HCPs, only recently incorporating the perspectives of patients and families (Anderson, Calvillo, & Fongwa, 2007; Camphina-Bakote, 2009; Thom & Tirado, 2006). As such, HCPs are ill-prepared to have successful interactions with patients and families from diverse cultural backgrounds, especially those with beliefs that affect health outcomes of patients (Brotanek, Seeley, & Flores, 2008; Health Resources and Services Administration, 2000).

National objectives set forth by the Health Resources and Services Administration (2000), and the National Institutes of Health (2007b) aim to reduce health disparities across cultural and ethnic groups, administer culturally appropriate care, and conduct research to increase knowledge about cultural considerations in health care. However, health disparity research in the U.S. primarily focuses on racial minorities, immigrants, the poor, and other marginalized populations, and often neglect established ethnic groups of European descent (Aday, 2001; Flaskerud et al., 2002; Institute of Medicine, 2006a). One such population that has not received a lot of attention is the Amish.

The Amish are an insular group of people who separate themselves from civil systems and institutions in order to preserve their own community. Amish family and community life is governed by the *Ordnung*, the Amish blueprint for expected behavior that regulates private, public, and ceremonial life (Hostetler, 1993). The Amish remain on the outskirts of mainstream society, live self-reliant agrarian lifestyles, and resist modernization (Kraybill & Bowman, 2001; Savells, 1988). However, they may access and utilize outside health care services when a member of their community requires health care services that extend beyond their community's resources (Greksa & Korbin, 1997; Morton et al., 2003).

Commonly, illnesses are managed within the Amish community using a combination of folk and popular health care practices (Blair & Hurst, 1997; Gerdner, Tripp-Reimer, & Sorofman, 2002; von Gruenigen et al., 2001; Waltman, 1996). However, some conditions require ongoing interactions with the health care system. For example, previous research established that Amish children have high susceptibility to certain health conditions, genetic illnesses such as hemophilia, and injuries such as burns, which may require ongoing interactions with the health care system (Brensinger & Laxova, 1995; Francomano, McKusick, & Biesecker, 2003; McKusick, 1980; Morton et al., 2003; M. A. Patton, 2005; Rhodes & Hupcey, 2002; Rieman, Hunley, Woeste, & Kagan, 2008; Sharathkumar, Hardesty et al., 2008; Zangwill, Boal, & Ladda, 1988). Because the Amish have a strong family and community-based culture, research that focuses on Amish children provides the opportunity for a rich contextual glimpse into the management of chronic health conditions or illness within these Amish families

In this study, chronic illness in children is defined as children with evidence of an ongoing physical, developmental, behavioral, or emotional condition expected to last at least three months, and require long-term dependency on medical technology, health services, or ongoing treatments (McPherson et al., 1998; Perrin, Lewkowicz, & Young, 2000; van der Lee, Mokkink, Grootenhuis, Heymans, & Offringa, 2007). To date, the majority of research about Amish children with chronic illnesses is primarily epidemiological. Very little is known about particular family health practices with chronic illnesses, or how the Amish cultural context influences these families' experiences as they manage their children's chronic illnesses (Banks & Benchot, 2001; Brensinger & Laxova, 1995).

Families who are caring for children with chronic illnesses have multiple responsibilities. They must understand the health problem, make decisions within the home about health treatments, consult with lay, biomedical, and non-biomedical professional health services, treat the illness, and evaluate the outcomes of those treatments (Chrisman, 2007; Clark, 2002; Igun, 1979; Knafl & Deatrick, 2006; Suchman, 1965). In this study, this collection of responsibilities is called chronic illness management (referred to as CIM). These responsibilities are inherently influenced by the cultural backgrounds of the patients and their families (Romanucci-Ross, 1997). Amish families must consider health resources within the home, within the Amish community, and outside professional services for the care of children with chronic health conditions. Yet, very little is known about how Amish families incorporate their cultural values and health practices into the care of a child with a chronic illness at home, in their communities and interface with the health care system outside their communities.

Purpose and Aims

The *purpose* of this study was to understand the cultural context in which Amish families manage the care of a child with a chronic illness and how it frames the interface with the larger health care delivery system outside their communities. The perspectives of Amish families and their health care providers balance current provider-centered knowledge by revealing the role of Amish culture in the care of chronically ill Amish children. The specific aims were to:

1. Describe Amish families' understandings of their children's chronic illnesses
2. Describe Amish health care behavior and strategies including folk or popular health care practices, as they care for a child with a chronic illness
3. Describe the health seeking/health management behaviors and experiences of Amish families when seeking health services outside of their communities for their children with chronic illnesses, from the perspective of: a) Amish families, b) Amish community members, and c) health care providers.

Ethnographic research methods were used to paint a portrait of the cultural context of individuals and families in a way that showed how culture influences daily behaviors and experiences (van Maanen, 2004). The influence of cultural beliefs, principles, and behaviors on the care for children's health conditions was shown through ethnographic research by bringing this cultural context to the forefront (Bernard, 2006; Kiefer, 2007). The informants in this ethnographic study included Amish families, Amish community members, and health care providers to illustrate commonalities and differences in perspectives on CIM for children.

Significance

To provide culturally competent care for any child, open and continuous communication with the child's family is needed to understand and accommodate the family's cultural values, beliefs, and health care practices into the care plan. Successful care plans incorporate families in the decision-making process and consider the cultural context that frames these decisions. Health care providers, including nurses, are more likely to provide culturally competent care to Amish families when they have increased knowledge and awareness of Amish cultural beliefs and norms. Recognition of facilitators and barriers for Amish families as they interact with the health care delivery system outside their communities will facilitate these care outcomes (Health Resources and Services Administration, 2000; Institute of Medicine, 2006b; National Institute of Health, 2007b). Awareness of structural barriers that Amish families must deal with, such as transportation or insurance options, will also help HCPs to be prepared for potential accommodations in order to support family CIM. Finally, understanding Amish cultural definitions of health and illness will help providers to collaborate with Amish families in a manner congruent with the Amish model of understanding health and illness.

Nurses and other HCPs increasingly encounter cultures and population groups that are unfamiliar. The expected outcome of this study was a description of the Amish culture in the management of children requiring ongoing interface with the health care delivery system. An additional benefit of this study is the demonstration of the process used to access and analyze this information. The approaches to fieldwork in this study may assist future researchers in conducting studies about the role of culture in families' management of children's chronic health conditions. This process will be particularly useful when exploring other religious or insular cultures living within the U.S. and requiring ongoing interface with the health care delivery system.

Summary

The purpose of this research project was to understand the Amish cultural context in which families manage their children's chronic illnesses. Ethnographic methods were used to describe how being Amish affects families' experience of their children's chronic illness, use of treatment strategies, and negotiation with folk and professional health care services. This knowledge will assist health care providers in the provision of culturally sensitive health care for Amish families who have children with chronic illnesses.

CHAPTER 2

BACKGROUND AND SIGNIFICANCE

If health care providers (HCPs) wish to provide effective services to Amish children with chronic illnesses, the need to understand Amish family health decision-making cannot be overemphasized. Amish life today is guided by traditions set up by their founders during the 16th century that are centered on Christian faith, agricultural and manual labor, and the importance of family and a community separated from mainstream society (Hostetler, 1993; Kraybill & Bowman, 2001). The specific aims of this study guide this chapter, and lay the groundwork for the reader as to what is currently known about conceptualizations of illness, folk or popular health practices, and family health seeking patterns within Amish communities. A review of the Amish culture and religious origins will set the background for understanding their cultural context. Arthur Kleinman's conceptual framework (1980) about the interface of families and HCPs will be described, and will set a structure to answer the specific aims.

Cultural Applications to Health Care

Cultural Awareness

Culturally available knowledge about illness and its causation can be seen as a resource for HCPs to collaborate with patients when creating plans of care. The term illness is not meant to be interchanged with the term disease. An individual experiences a disease through physical malfunctions or changes; however, an individual experiences an illness by constructing a meaning for that disease (Kleinman, 1980; Romanucci-Ross, 1997). Cultural knowledge and experience help to form conceptions about illness causation and symptoms, and then guides individuals' decisions for curing or treating those illnesses. To better understand how individuals both conceptualize and treat illnesses, it is important to build a better understanding of how cultural contexts influence those conceptualizations and treatment decisions. HCPs, including nurses, have been interested in building this field of knowledge in the recent century, proposing that health care be delivered to patients, families, and communities in more cultural competent manner.

Culture is defined in this study as integrated lifestyle, learned and shared beliefs, values, worldview, knowledge, artifacts, rules, and symbols that guide behavior of a particular group of people; it is continuous, cumulative, and progressive (Geertz, 1973). Culture is fluid and not necessarily descriptive of every member who identifies with that culture; there may be significant differences within a cultural group across individuals. Often, culture is viewed solely by the objective traits seen from the outside, but these are only symbols. Culture is difficult to describe objectively by those who live within it, yet culture remains a subjective experience (Geertz, 1973). This insider's perspective is referred to as "*emic*", while the outsider's perspective is referred to as "*etic*" (Agar, 2008). If someone were to ask an Amish man, "What is like being Amish?" he would have a difficult time answering that question. Rather, he would likely give examples of behaviors or ideas that he does within that culture. Culture is more than the sum of its parts of behaviors and ideas; HCPS are challenged to describe, label, and summarize culture into a thick enough description to pay homage to the *emic* perspective when caring for patients.

Moving forward with the art of describing cultures risks the chance of building stereotypes because those studying it are often outsiders who then disseminate *etic* cultural description (Capell, Veenstra, & Dean, 2007; Gustafson, 2005; Tripp-Reimer & Fox, 1990). These stereotypes have the capability of creating greater distance rather than connection between patients and HCPs (Jordan, 2008). As nurses caring for individuals, families, or communities, it is important to move beyond *etic* stereotypes to remaining open and humble to unique patient characteristics and experiences within the culture.

Cultural Competence

When HCPs integrate cultural knowledge into the care of individuals from diverse cultural backgrounds it is most commonly called cultural competence. *Cultural competence* is defined as having the professional attitudes, practice skills, and a system savvy for cross-cultural situations (Chrisman, 2007; Leininger, 2002; Thom & Tirado, 2006). Primarily, its intent is to encourage HCPs to modify care plans to incorporate cultural perspectives in patient care. Although cultural competency is the term used in this dissertation, researchers and practitioners frequently use other terms such as *cultural sensitivity, cultural competence, cultural relativism, cultural humility, or cultural desire* interchangeably in their calls for improved health care services. All of these terms emphasize the awareness of and respect for the unique cultural and religious beliefs and traditional practices possessed by each cultural or ethnic group, as well as the variations within these groups (Campinha-Bacote, 2003; Hodge, Toms, & Guillermo, 1998; Jordan, 2008; Racher & Annis, 2007).

Cultural competency focuses on the delivery of health care services to diverse populations. Different ways that HCPs can respect and incorporate culture into plans of care begin with identifying that HCPs can have different health beliefs, values, and practices than patients (Thom & Tirado, 2006). Other areas include linking patients with community resources, using interpreter services, building sensitivity and incorporating complementary or alternative forms of medicine, and accepting the definition and role of family within the care provided to patients (Ahmann, 2002; Hodge, Toms, & Guillermo, 1998; Markova & Broome, 2007; Purnell, 2002).

Additionally, a call for cultural competency at the institutional and societal level moves the application of cultural competency beyond the patient-provider perspective to the public or community perspective. The philosophical shift needed to guide all individuals within an institution or society would come from incorporating concepts about cultural diversity into education curriculums, research, administration, policy development, and building strong relationships with local diverse communities (Anderson, Calvillo, & Fongwa, 2007; Chrisman, 2007; Hahn & Inhorn, 2009; Institute of Medicine, 2006b; Wells, 2000). Widening the scope and application of cultural competence towards community or institutional level intends to take away some of the disproportional power of the provider within the provider-patient relationship on deciding whether or not to use these principles. The societal imperative of cultural competence levels the playing field for all diverse groups within a location.

Addressing the need for increased cultural awareness in HCPs for the delivery of culturally competent care is a national imperative, especially with increasingly diverse population growth (American Association of Colleges of Nursing (AACN), 2005; Institute of Medicine, 2006b; National Institute of Health, 2007a; The Office of Minority Health, 2001). Evidence suggests that racial and ethnic minorities receive lower quality health care than non-minorities. Consequently, health disparities exist between minority and non-minority groups within the United States (Institute of Medicine, 2006b; Murphy, Canales, Norton, & DeFilippis, 2005). Geronimus (1992) proposes a theory called “weathering” in which compounded inequalities such as racism or practical difficulties, such as financial or health access barriers, surface in worsening health conditions in minority populations, specifically African Americans.

For these reasons, there is a national appeal for increasing HCPs sensitivity and knowledge of cultural diversity and its impact on illness attribution, health behaviors, and negotiating care plans. Yet, most definitions of culturally sensitive health care are based on research from HCPs and researchers and fail to incorporate patient perspectives into these definitions (Capell, Veenstra, & Dean, 2007). A call for additional research incorporating the perspective of minority populations may aid in ameliorating some of these disparities and improve culturally competent care across the U.S.

Cultural Applications to Evidence-Based Practice

The term evidence-based practice stems from the original definition of evidence based medicine by Sackett, Rosenberg, Gray, Haynes, & Richardson (1996) that the integration of personal clinical expertise with outside current best evidence is needed to make clinical decisions. Personal clinical judgment, or expertise, is gained through experience and clinical practice. Meanwhile, evidence refers to clinically relevant and patient based research. Additionally, Sackett et al. (1996) propose that "any external guideline must be integrated with individual clinical expertise in deciding whether and how it matches the patient's clinical state, predicament, and preferences, and thus whether it should be applied." This suggests that providers should incorporate the patient's preferences within evidence based practice. In order to do this, providers are encouraged to use effective communication and build trust with their patients in order to incorporate an accurate perspective into their clinical decisions and build positive partnerships with patients (Mechanic, 1998). Mechanic also poses that health care "inevitably involves many people and encompasses larger systems of care, all of which affect assumptions, expectations, and behavior." Nurses are at a critical position to place evidence-based practices with each patient interaction within hospital units, clinic settings, and in collaboration with communities (Everett & Sitterding, 2010). Understanding the cultural backgrounds of patients will help HCPs to understand their patients and work together towards effective plans of care for treating illness. Achieving cultural competence for caring for Amish families caring for children with chronic illnesses requires a greater understanding of the cultural context and how it impacts these families.

Amish History and Social Structure

The Amish are an insular group of people living in North America who prefer to separate themselves from civil systems and institutions. Today, Amish families live outside of mainstream society, preferring a self-reliant agrarian lifestyle, and resistance to modernization (Kraybill & Bowman, 2001). Although their community and religious tenets suggest complete separation from the modern world, the Amish must continually negotiate this separation in legal, social, and cultural domains. This is especially the case in health care utilization. When a family member's health requires resources that exceed the Amish community's resources, the families utilize outside health care services (Greksa & Korbin, 1997; Huntington, 2003; Millman, 2006).

Amish Origins

This historical account of the Amish highlights major events in their religious and community development as well as some of their negotiations with the modern world, especially with health care. The Amish originated as part of the European Anabaptist movement during the early 16th Century[1]. The Anabaptists believed that adults, rather than infants, should receive baptism into their church, unlike dominant Catholic beliefs. During the time period in which the Anabaptist ideas spread and gained membership, religious turmoil emerged across Europe. Civil and religious authority was intertwined, and the Anabaptists became threats to both, resulting in their persecution, death, and exile across Europe. With few options of where to live, Anabaptists leased land on farms from farm owners who needed tenants to tend the land (Nolt, 2003). Needing to band together, the Anabaptist brethren decided that they would remain separated from the world in order to maintain peace amongst themselves. The common thread that held this group together was their refusal to accede to the demands of the dominant church and state. They maintain separation from those outside their religion in current times (Kraybill & Bowman, 2001).

The Anabaptists established strong principles that have persisted across time to guide Amish life today. Anabaptists prioritized Biblical teachings and their belief in God

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[1] Refer to Nolt (2003) for a thorough description of Amish historical events. The pertinent information to understanding Amish position in society will be reviewed here.

above all other things. This promoted peace and humility, rather than being involved in government-led acts of violence (such as war), punishment, or coercion. But even within the Anabaptists, schisms started to occur. Menno Simons, a strong leader within the Anabaptists, disagreed with some propositions made by Jakob Ammann, another leader, during the late 17th Century. Those who followed Menno Simons became known as Mennonites, and those who followed Ammann became known as the Amish (Kraybill & Bowman, 2001; Nolt, 2003). Ammann urged a religious doctrine that shunned members who were not faithful to religious and community rules. This social avoidance of non-members, or members, who disobeyed the rules, was called *Meidung*. He also requested that members of the group keep untrimmed beards and a strict uniform clothing style (Nolt, 2003). The *Meidung* holds true to current times and often dictates Amish behaviors in order to avoid ex-communication from their kin groups and family (Hostetler, 1993). Refer to Appendix A for a summary of the religious groups that originated from the Anabaptist movement.

The Amish migrated to North America in waves from the mid-18th Century through the mid-19th Century in order to find farmland where they could live separately in peace and build their community (Nolt, 2003). Continuing with the mentality of separation from state governance, they refused to participate in any U.S. mainstream activities, including military service (Dimmig, 2001). The Amish refer to a Bible verse in 1 Peter (2:11), which urges its believers to “keep away from worldly desires that wage war against the soul” (Confraterntiy of Christian Doctrine, 1992). To further set them apart from mainstream society, the Amish developed a unique German dialect language that used a combination of German and English words (Adkins, 2010). The Amish continued to create a distinct identity with their distinct clothing and dress, and farming techniques (Hostetler, 1993).

Although the Amish preferred to live independently of the Anglo-American settlers, they were exposed to outside cultures, religions, and state institutions (Savells, 1988). During the 1860’s, the industrialization of the United States attracted some Amish members into more modern groups, such as the New Order Amish, or Beachy Amish (Klaassen, 1977; Kraybill & Bowman, 2001). Worried that they would continue to lose members to other religions in North America, the “tradition-minded”, or Old Order Amish, moved west to Ohio, Indiana, and Iowa (Nolt, 2003, p. 86). For this paper, the term Amish will only pertain to the Old Order Amish, the most conservative and traditional Amish group (Refer to Appendix A for these additional Amish schisms).

Social Structure

Amish communities dispersed across the United States organized themselves into districts, which are comprised of the number families who can fit into one home for church services. Thus, the number of districts per Amish settlement is fluid (Wenger & Wenger, 2003). One to three Amish clergymen (bishops or ministers) lead each Amish district in the United States and guide decisions about community life within that district (Knight, 1980). During the 1860’s the Amish set up the *Ordnung*, an oral tradition that guides community behaviors to be in accordance with religious and social tenets. The *Ordnung* dictates a way of life that has changed little from the 19th century. The *Ordnung* is maintained by bishops, ministers, or other elder men of each Amish community and guides decisions about health care, insurance, clothing, housing styles, allowable modern technologies, and daily life activities (Hostetler, 1993). If community members disobey the *Ordnung*, the ministers and elders of the district follow *Meidung* shunning by excommunicating members who refuse to ask for forgiveness.

Over time, the Amish flourished with economic independence. During the 1930’s, the United States government attempted to force Amish families to pay into the Social Security System and attain bank accounts in order to keep track of their farm practices and land ownership (Nolt, 2003). The Amish initially refused to participate in government programs, as these programs violated their obligation to stand apart from society. An intricate agreement allowed the Amish to pay income and sales taxes but not Social Security taxes. In general, the Amish do not accept Medicaid, Medicare, or Welfare insurance assistance, because they do not pay into these insurance programs (Huntington, 2003; Reynolds, 2009).

Of utmost importance to the Amish is separation from mainstream society, resulting in a unique community within the U.S. The Amish maintain a local and small-world perspective that focuses on immediate and extended family and others in their district. This life is multi-faceted, meaning that these local communities work, attend school, worship, and play together. Self-determination and individual responsibility is highly prized and assistance to one another helps to keep their communities strong and functioning; mutual aid to each other includes making quilts together, working together for wedding and funeral gatherings, and assisting anyone in need after disasters or health care crises (Kraybill, 2003). The *Ordnung* binds their identity together, which in turn allows the Amish to be resilient through time regardless of the opposition.

Separation from the outside world makes Amish community members reliant on one another's productivity and this makes each Amish community member a stakeholder in every other members' health (Buccalo, 1997). An ethnography about health care in an Old Order Amish community (Wenger, 1988, p. 121) points out that reciprocal caring of family and community members is *Schuldigkeit* (an obligation) but not a burden. Amish leadership guiding community decisions exemplify this attitude. In cases of long-term illnesses, they make recommendations that accord with Amish principles; these may include suggestions for restriction or acceptance of hospital stays, high technology, medical treatments, and financial investment in medical services (Dellasega, Hupcey, & Fisher, 1999; Greksa & Korbin, 1997). However, it is ultimately the parents who have the final decision for caring for their children (Huntington, 2003). Neighbors and other community members run the farms of families who are in the hospital. School teachers care for children during the school day. The entire Amish population is ready to support any of their national members in need (Hostetler, 1993; Waltman, 1996; Wittmer, 2006). Enwrapped in the Amish culture, families who care for children's chronic illnesses are guided and supported by these social support systems.

Amish Families Living in Two Worlds

There is an Amish saying that "the 'world' begins at the last Amish farm house on the edge of our settlement and that all Amish should remain 'different and apart' from it" (Wittmer, 2006, p. 4). The 20th century has challenged Amish families. Amish land and financial resources are becoming more limited as urban areas grow in size and numbers and as health care becomes increasingly expensive. It is more challenging to remain in complete isolation from non-Amish neighboring communities and industrial centers. Some families and young adults are forced to make decisions that may be resisted by the elders of their community, such as working with a non-Amish employer or using social health insurance (Greksa & Korbin, 1997; Savells, 1988). Because of limited farm-land, young Amish men and women work in handcraft jobs, such as woodworking, local factories, bakeries, and furniture warehouses (Savells, 1988). There is a sense of insularity that the Amish maintain, although they are making slow changes amongst the U.S. economic upheavals.

More recently, Amish communities and their leaders are changing their ideas about reciprocity of resources and adaptation with non-Amish communities (Hewner, 1997); tourism and Amish retail provides an outlet for some Amish families and an inlet for the non-Amish to view and access the Amish and their lifestyle. Amish women are becoming savvy in running tourist and sales businesses based on their handiwork and crafts, adding to the financial resources to their families and their communities (Graybill, 2009). These operations, as well as tourism attractions, provide an exchange between the Amish and the non-Amish, which is received with mixed feelings from the Amish (Chhabra, 2010). The Amish are pleased that they are contributing to ideas of traditional lifestyles, showing the mainstream society a different perspective on living, and they are pleased with the financial benefits they receive from these tourist attractions (Chhabra, 2010). However, the Amish remain resistive to accept modernization where they do not want it (Savells, 1988). As more Amish are in contact with the mainstream society around them, their language within their families and communities are slowly incorporating more English rather than the traditional English-German combination (Adkins, 2010). Meanwhile, other Amish communities are allowing families access to telephones in case of emergencies (Dabrowska & Wismer, 2010). These opportunities affect the level of isolation for some Amish communities. However, they still abide by their own set of rules and ideas. Because of their membership in this community, families must abide by the Ordnung, and respect the traditions and tenets of the Amish culture when making health care decisions for their children.

Children within the Amish Community

Children are considered to be gifts from God by the Amish, and Amish families take child care responsibilities seriously (Hostetler, 1993). Amish children are guided by their parents, teachers, and community elders throughout life to learn cultural health beliefs and practices (Fisher & Stahl, 1997; Hostetler & Huntington, 1992). A newsletter that many Amish families subscribe to, called *Family Life,* describes the care that parents should take for their children. This includes setting examples of living Amish principles for children to imitate, praying for children, teaching children to love God, and punishing anger in children. The newsletter declares that when childhood closes, life's training should be complete (Wittmer, 2006). Large families are beneficial to the Amish in many ways and each individual plays an important role. In order to have adequate help on the large farms, each family has an average of six to eight children (Markle & Pasco, 1977; Weyer et al., 2003). The children are taught to help with farm and household work at early ages (Wenger & Wenger, 2003). Often times siblings are in charge of farm labor while the parents remain overseers of the overall farm management (Hostetler, 1993).

Children in Amish communities are enrolled in an all-Amish school from ages of six to thirteen, or the equivalent of passing eighth grade (Hostetler & Huntington, 1992). In the year 2000-2001, there were approximately 32,432 children enrolled in Amish schools, but this number is likely to be climbing (Wittmer, 2006, p. 27). In addition to traditional education subjects at school, children learn about responsibilities and values of the Amish culture, such as humility, hard work, listening to others, efficiency, and communicating with others respectfully (Dewalt, 2006, pp. 62-63). Children also learn to speak English when they enter into school. Again, the emphasis taught to children, in addition to humility and simple living, is the continuity and interaction of their lives with others in their Amish community. “Acceptance of mature social responsibility involves total commitment to the believing church-community and material and spiritual separation from worldly standards” (Hostetler & Huntington, 1992, p. 16). Interestingly, a study by Nucci and Turiel (1993) about Amish pre-adolescent children described how these children are capable of identifying moral rules about justice and welfare according to the Amish religious authority; furthermore, they were capable of identifying what is and is not generalizable to other religions, which shows their understanding of religious boundaries.

The physical health of a child is important in order to fulfill his/her role in society as farm hands and future leaders in the Amish community. Amish communities have definitions about health and illness that reflect their Christian and functional lifestyle. Without much experience living or interacting with individuals or places outside of their Amish communities, children may develop their own perspective about health, illness, and the unfamiliar environment of the hospital and unfamiliar health care professionals. This perspective will also be housed within their worldview within the Amish community.

Conceptual Framework

Clinical relationships and conversations between HCPs and patients involve negotiating care; these dimensions of clinical conversations occur in the midst of greater social and cultural contexts (Kleinman, 1988). The relationship between health care professionals and patients is influenced by beliefs, values, and cultural practices (Kleinman, 1980). Kleinman describes three intersecting health sectors involved in the patient-provider interaction: a) popular health sector, b) folk health sector, and c) professional health sector. These sectors are shown in Appendix B, Figure 1. They are overlapping because they do not occur in individuals' or families' lives in isolation. Popular, professional, and folk health sectors interact with each other as patients flow from one to the other to fit their needs through the course of an illness. The value orientation influenced by a patient's surrounding family, community, and culture exists in the popular health sector. Individuals rely on this health sector for assistance in health care decision making according to the value system. When home or traditional remedies aren't successful, individuals and families access the other health sectors of folk or professional practitioners. Individuals and families decide when and who to consult, when to comply, when to switch treatments or find alternatives, and whether or not they are satisfied or not according to their value system (Kleinman, 1980).

The professional health sector includes biomedical and organized healing professionals. This involves clinic services, fee-for-service payment system, and insurance coverage for costly health care treatments. The professional health sector relies on scientific discoveries, diagnoses, and technology; typically, this sector refers to biomedical professionals as the main HCPs. When creating successful health plans with families, primary health professionals must recognize and incorporate the other health sectors (Kleinman, 1980).

The third orientation, the folk health sector, describes traditional healing therapies within cultures. Commonly, this includes sacred and religious or spiritual health practices. These may include the use of herbs, exercise, symbolic actions or chants, or manipulative treatment or even surgery (Kleinman, 1980). These three sectors overlap with each other and affect clinical practices, personal beliefs, and levels of interaction of cultural groups and families in health care healing plans.

Explanatory Models

Kleinman's (1980) framework about health sectors also incorporates how patients and families move in and out of health sectors based on explanatory models (EMs). EMs are interpretations, or notions, about an episode of sickness and the illness management or treatment chosen by individuals, families, and HCPs (Kleinman, 1980, p. 105). "Sickness as a 'natural' phenomenon is cast into a particular cultural form through the categories that are used to perceive, express, and valuate symptoms. The cultural construction of illness experiences…is frequently a personally and socially adaptive response" (Kleinman, 1980, p. 72). A model of a health care system, according to Kleinman's framework, includes how actors within the health care system think about health care, beliefs about health and sickness, decisions about how to respond to episodes of sickness, and expectations and evaluations of particular kinds of care. A look at the EMs of individuals must occur within the context of a large-scale picture of the surrounding culture and health care system (Kleinman, 1980, 1988).

Kleinman has identified key attributes (refer to Appendix B, Figure 2) that systematically identify how humans organize sets of information about an illness. EMs include the following: a) disease labeling and identifying a cause for the disease, b) identifying consequences to the disease and the known treatment options, c) ideas about the duration of the disease or the mode of onset of symptoms, and d) the amount of control an individual or family has about the disease and its appropriate treatment (Kleinman, 1980, p. 105). Kleinman's research results showed that families made decisions together about seeking care for ill family members. Families identified a lay referral system of treatment options and individuals to seek care from, and the context of the family provided deeper understanding about individual perceptions about illnesses. The clinical reality experienced by individuals and families included physical and spiritual/mental components (depending on cultural background of beliefs), illness problems, therapeutic expectations, and holistic care (Kleinman, 1980, p. 306). EMs are partly conscious and partly unconscious, and they incorporate views of cultural health ideology. How families make meaning out of illness may change over time, and continual assessment of family perception of illness is important.

For the purposes of this research study, Kleinman's conceptual definition and indicators of EMs guided the interviewing phase in order to understand the perspectives of Amish families and the HCPs about ongoing care for their child with a chronic illness. Kleinman's work is based off of his own research with Taiwanese families. From his research results, he created and modified an interview guide that captured family's perceptions of sickness and how they behaved as a result of those perceptions. This interview guide has been used in multiple studies and shown to be effective in identifying individual and family illness perceptions for cultures in addition to the Taiwanese (Eisenbruch et al., 2004; Levy, Mandell, Merhar, Ittenbach, & Pinto-Martin, 2003; McSweeney, Allan, & Mayo, 1997). Kleinman's conceptual framework formulated not only the interview questions for this study, but gave background insight to the findings and analysis of the study. Finally, in Chapter 9, Kleinman's conceptual framework is integrated into the findings to highlight various aspects of the framework at work with Amish families.

Children's Health and Illness

Conceptualizing Health for Children

The Amish believe that the body is a temple of God, and therefore they are responsible for its care (Graham & Cates, 2002; Hostetler, 1993; Huntington, 2003). The

Amish focus on independent responsibility, rather than independence. This personal responsibility spreads to community responsibility, holding that the individual is healthy when the community is healthy (Huntington, 2003). Health is described by the Amish as the ability to work; health permits the enjoyment of life through physical and spiritual well-being (Armer & Radina, 2002; Waltman, 1996; Wenger & Wenger, 2003). The Amish define illness as the inability to perform activities of daily life, and they do not immediately focus on particular symptoms of illnesses (Armer & Radina, 2002; Hostetler, 1993). The focus on a person's whole functional ability, rather than individual symptoms, gives the Amish a holistic approach to keeping individuals healthy, productive, and integrated in community activities (Armer & Radina, 2002; Blair & Hurst, 1997; Schwieder & Schwieder, 1975). The key to health within the Amish community is the ability of the individual to function well enough to contribute to the Amish way of life (Wenger, 1988). Particular health conditions within the Amish community draw attention from HCPs, and these are described in the following section.

Management of Illnesses within Amish Community

The quickly advancing medical technology, the popularity of medical specialists over rural family practice, and the discovery of the genome have changed health care delivery (Collins, Green, Guttmacher, & Guyer, 2003). Families must adjust to these changes and learn to navigate the system when caring for their children. For the Amish, their experience of living on the outside of society culminates into a feeling of alienation from the rapidly advancing medical services required for their children's health.

Trends in research articles about Amish health focus on two main areas. The first focuses on identifying and describing health conditions prevalent in the national Amish community, for example, genetic illnesses and farm injuries (Morton et al., 2003; Rieman, Hunley, Woeste, & Kagan, 2008). The second includes research focusing on general health beliefs and practices in the Amish community within the past 30 years

(Dellasega, Hupcey, & Fisher, 1999; Gerdner, Tripp-Reimer, & Sorofman, 2002; Hostetler, 1993; Wenger, 1988). However, very little research has addressed how Amish families integrate their cultural background into the care and health care decisions specifically for children.

Integrative review methods were used to summarize past research about the Amish, allowing for the inclusion of diverse methodologies, to summarize a more comprehensive understanding of the phenomenon of families caring for children with chronic illnesses (Wittemore & Knafl, 2005). The goals of this integrative review were to describe the development of health care research with and about Amish family care for children's health and illness. Objectives for this review were the following: a) to show a historical analysis for any research about Amish children's illnesses, health care practices and beliefs, and Amish family care for children with any health conditions; and b) to include both *etic* and *emic* research, including points of view from both HCPs and Amish individuals.

For a description of the methods of this integrative review, please refer to Appendix C. The seven articles specifically about parents' or families' perspectives on caring and/or making decisions for children's illnesses included the following: a) five articles about the Amish working with the medical system regarding a child with an illness, b) one about parents' consideration of environmental risk for children's health, and c) one literature review of general considerations when caring for Amish children. The literature review was kept because it was the only summary of literature on this specific topic. This integrative review also aided in describing the following: a) How the Amish conceptualize and define health and illness, including for children; b) A summary of illnesses and/or injuries highlighted in previous research about Amish children; c) Amish folk and popular health practices, and d) Amish health seeking behaviors, experiences, and perceptions. This section will begin by describing common Amish illnesses highlighted within the literature. Then, a summary of the seven articles will be presented to describe what is known about how families and parents experience and manage children's illnesses. Finally, a summary of the literature that provides a knowledge base about folk and popular treatments within Amish communities will be reviewed, as some of these apply to how families manage the care of children's illnesses.

Children's Illnesses

Epigenetics

Amish families experience disproportionate numbers of genetic illnesses, and this can be attributed to the following reasons: a) they do not marry outside of their closed, insular communities; b) they have a large number of children per family; and c) they have a past history of consanguinity (Adams & Leverland, 1986; Dorsten, Hotchkiss, & King, 1999; Francomano, McKusick, & Biesecker, 2003; McKusick, 1980). The total number of genetic illnesses within Amish communities remains unknown, but at least 100 different illnesses have been summarized by Morton et al (2003) and Francomano, McKusick, and Biesecker (2003). The integrative review resulted in 151 articles about genetic illnesses within the Amish. There were 94 articles published about genetic illnesses within the past 10 years, and 38 articles of these focused solely on children. A list of the ten most common are included in Table 1. Genetic illnesses that cause concern to HCPs and Amish communities include bleeding disorders, metabolic disorders, Ellis van Creveld Syndrome, affective disorders, Cystic Fibrosis, Troyer Syndrome, and other congenital malformations (Henderson & Anbar, 2009; Proukakis et al., 2004; Stein, Pachter, Schwartz, & Taras, 2004; Zangwill, Boal, & Ladda, 1988). Highlighted here are the genetic illnesses experienced by participants in this study. They are illnesses that require long-term biomedical follow-up, and/or ongoing home treatments, and remain prevalent across Amish communities.

Bleeding disorders are especially disruptive for Amish children because of their active lifestyles and risk behaviors related to heavy use of farm tools and responsibilities at early ages often predisposing children injuries that lead to bleeding episodes (Rhodes & Hupcey, 2002). Hemophilia B and von Willebrand Diseases (VWD) are specific bleeding disorders found within Amish pedigrees that prevent blood clots from forming after injuries or bruising (Ketterling, Bottema, Koeberl, Ii, & Sommer, 1991; Sharathkumar, Greist et al., 2008; Sharathkumar, Hardesty et al., 2008). Care for Hemophilia B and VWD includes life-long need for medication of intravenous clotting (Factor) products to treat bleeding episodes. Bleeding episodes result in the need for emergency care and possibly surgery to stop bleeding (Wiedel, 2002). Between medications, acute emergency care, and continual follow-up appointments, Hemophilia B and VWD can be a costly illness for any family, including the Amish.

In addition to genetic bleeding disorders, genetic metabolic disorders such as Phenylketonuria (PKU) and Glutaric Aciduria (GA) raise concerns for this population (Brensinger & Laxova, 1995; Morton et al., 2003; Strauss, Puffenberger, Robinson, & Morton, 2003). PKU and GA are metabolic disorders in which the body is deficient of enzymes to break down specific amino acids found in natural food proteins. Without the ability to break these amino acids down, high levels of toxins accumulate and can cause brain deterioration, and future systemic complications such as heart damage or dystonias if untreated. The only known successful management for PKU and GA are diets low in proteins and the use of protein supplements to ensure adequate growth and development (Morton et al., 2003; National Institute of Health, 2000; Strauss, Puffenberger, Robinson, & Morton, 2003). Protein supplement for these children is costly (The Metabolic Formula Program, 2004), yet some Amish families receive aid from the local state's Department of Public Health in the payment of protein supplemented formula.

Hereditary Fructose Intolerance is another inherited metabolic disorder. It is a mutation of the Aldolase B gene, responsible for hepatic metabolism of ingested fructose and assists in the breakdown of glucose (Bouteldja & Timson, 2010). When undiagnosed or untreated, liver and kidney dysfunction results causing signs of enlarged liver, along with symptoms of nausea, bloating, and vomiting. Long-term treatment relies solely on the avoidance of fructose and similar sucrose sugars in the diet (Bouteldja & Timson, 2010).

Cystic Fibrosis (CF) is an autosomal recessive disease that results from a genetic mutation of the CF gene that controls sweat regulations, especially in mucous membranes. This causes thick, sticky secretions over multiple organ systems including the pancreas and the lungs, preventing enzyme production to break down foods and clear airways. Symptoms of CF include persistent coughing from phlegm in the lungs, frequent lung infections, frequent greasy, bulky stools, and poor growth or weight gain (Cystic Fibrosis Foundation, 2011). Although the incidence in the U.S. is one in 3,200 births, the incidence within Amish populations has been shown to be higher (Henderson & Anbar, 2009; Klinger, 1983). Recommended treatments for CF include pancreatic enzymes, multivitamins, routine chest physiotherapy, and potentially nutritional supplements (Cystic Fibrosis Foundation, 2011; Henderson & Anbar, 2009). With increased mucous secretions in the lungs, complications in CF often include lung infections and lung damage. Without frequent chest physiotherapy to improve airway clearance, these lung complications become more severe and life-threatening; the average life span of a child with CF is 36 years (McClure, 2007). With successful management of CF in the home setting with the suggested therapies, children can remain relatively healthy. Outpatient routine visits are recommended every three months to assess for growth and development, adjustment of pancreatic enzymes, and diagnostics to assess for any infiltrates in the lungs that may develop into severe lung infections (McClure, 2007).

Table 1. Genetic Illnesses in Amish Children

Genetic Illness	Author
Affective disorders (bipolar, depression, schizophrenia)	(LaBuda, Maldonado, Marshall, Otten, & Gerhard, 1996)
Cohen Syndrome	(Falk et al., 2004)
Cystic Fibrosis	(Henderson & Anbar, 2009)
Ellis van Creveld Syndrome	(Zangwill, Boal, & Ladda, 1988)
Glutaric aciduria	(Strauss, Puffenberger, Robinson, & Morton, 2003)
Bleeding Disorders: Hemophilia and von Willebrand Disease	(Sharathkumar, Greist et al., 2008; Sharathkumar, Hardesty et al., 2008)
Glucose-galactase malabsorption	(Xin & Wang, 2011)
Hypertrophic cardiomyopathy, coronary diseases	(Xin, Puffenberger, Tumbush, Bockoven, & Wang, 2007)
Phenylketonuria	(Morton et al., 2003)
Troyer Syndrome	(Proukakis et al., 2004)

Congenital Disorders

Congenital disorders are present from birth. They are typically diagnosed in infancy and can occur with or without a family history. Hydrocephalus has presented in Amish children from unknown illnesses or Dandy-Walker Malformation, which is a rare disorder that affects cerebellar functions (Brensinger & Laxova, 1995; Zangwill, Boal, & Ladda, 1988). Hydrocephalus is a disease caused by increased cerebrospinal fluid in the brain and ventricles, and requires a shunt to be placed until cerebrospinal fluid levels are normal. Long-term effects such as an internal brain hemorrhage, incorrect brain development, infections, or malformations exist, and continual shunt maintenance and neurological monitoring may be required as the child develops (Parks & Yetman, 2000). Dwarfism has been a consistent concern for many Amish communities, and this also occurs from unknown genetic variation or can accompany Ellis-van Creveld Syndrome, which is a malformation of the skeletal system (McKusick, 1980; Zangwill, Boal, & Ladda, 1988). Dwarfism may be accompanied by heart defects, teeth and nail malformations, and polydactyly (Ulucan et al., 2008).

Injuries/Accidents

Crises, such as broken bones, head trauma, and burns remain a common reason that many Amish come to hospitals or emergency care to be treated (Gilliam, Jones, Field, Kraybill, & Scott, 2007). Some of these injuries require ongoing treatment, depending upon the severity of the injury to the child. Injuries related to farm animals and tools remain one of the highest health risks for this young population (Wenger & Wenger, 2003). Smith, Scherzer, Buckley, Haley, & Shields (2004) revealed that Amish children's farm injuries are related to animals (such as being kicked by farm animals) rather than machinery, when compared to a non-Amish cohort. As soon as they can walk, parents give children chores such as collecting eggs from the hen house. Though they are mentored by their older siblings, their curious and adventurous spirits can put them in risky situations too close to large animals and farm machinery. Injuries result from falling, being kicked by animals, buggy accidents, crushed by machinery, or chemical exposure (Rhodes & Hupcey, 2002; L. Smith, Ernst, PaulEwings, Myers, & Smith, 2004; Vitale, Rzucidlo, Shaffer, Ceneviva, & Thomas, 2006).

Rieman, Hunley, Woeste, and Kagan (2008) reported burns in Amish children from ignition of clothing, highly flammable materials (such as kerosene lamps), and hot liquids. Research on reported burn injuries in Amish children showed that burns are common, and more extensive and deeper than non-Amish children. However, it is difficult to determine the incidence of burns in Amish communities because children may not always seek biomedical services. When admitted to the hospital, Amish children experience long-lasting intensive protocols to treat and heal severe burn wounds. This exemplifies that families require ongoing care from health providers outside of their community for children with severe injuries or burns.

Family Perceptions of Care for Children’s Illnesses

When an Amish child’s illness requires biomedical services, families need a great deal of education about the illness, prefer to use less technology, and consult with the community for large decisions through the course of illnesses (Banks & Benchot, 2001; Clayton & Kodish, 1999; Gibson, 2008; Henderson & Anbar, 2009). When necessary, families are willing to have major surgery and diagnostic procedures if they think the procedure would allow the child to live a healthy life afterwards; however, aiding families in financial guidance is imperative to allow for the appropriate services for children (Henderson & Anbar, 2009).

Some families come to altercations with HCPs with differing opinions about how to proceed with their child’s care (Clayton & Kodish, 1999). One research article focused on one Amish family, who with the support of the Elders of their community, desired to leave the child’s fate to God and not intervene with surgery after a diagnosis of congestive heart failure. This left the HCPs unsure about giving the family religious exemption or to remove the child from the parent’s care (Clayton & Kodish, 1999). As other legal cases will demonstrate, this is not an isolated situation between Amish families and HCPs (Huntington, 2003). In some cases, families and HCPs who are not willing to negotiate end in having the child removed from the parents’ care with great turmoil.

Brensinger and Laxova (1995) and Henderson and Anbar (2009) describe families’ perceptions and care for children with genetic illnesses specifically. The parents in these studies were willing to have genetic screenings; however, counseling and education about genetic illnesses was limited. These parents would welcome genetic counseling but some were not offered this option. They were able to describe the meaning of a hereditary illness but needed extensive education about specific disease processes. Having children with genetic illnesses did not deter these families from having subsequent children, and families had mixed acceptance for prenatal testing.

Parents did not view abortion as an option, so prenatal testing was not seen as necessary. There is a great deal to learn about how parents enter into the biomedical health system, and their experiences once they get there of collaborating with HCPs in the care of their children.

When considering the environmental impact on children's health, injury, or illnesses (as non-Amish families are learning from mainstream media), Dabrowska & Wismer (2010) revealed that Amish mothers were aware that environmental risks were related to some injuries and illnesses. These mothers were aware that children might have allergies, asthma, or cancer from contaminants or pollutants from the air, water, and/or pesticides. However, few reported that they changed the level of activity and engagement their children had with the environment as a result. Children were instructed not to eat fish from known contaminated water sources, and families avoided using pesticides in gardens where children play and work. An overriding attitude came from Amish mothers that some children have health problems and others do not. As stewards of their farmland and homes, the Amish believe in taking care of the environment for the sake of future generations to inhabit and make use of the land (Dabrowska et al., 2010), rather than changing their lifestyles to avoid environmental risks. These health care studies reveal that a great deal needs to be learned about how Amish families understand their children's illnesses and make decisions about the care of their children, including seeking health services inside and outside of their communities. The following sections review the current state of knowledge about how Amish community members utilize a variety of health care practices and services.

Amish Folk and Popular Health Practices

These general concepts about health and illness provide the scaffolding to the health decisions and practices used by Amish families when caring for children within their homes and communities. Chronic illness management (CIM), as defined in Chapter

1, refers to all of the activities that families use to care for children with chronic illness. Health care practices within a specific cultural group may be called traditional, folk, complementary and alternative medicine (CAM), popular, or non-conventional (Barrett, 2003; Eisenberg et al., 1998; World Health Organization, 2006). Guided by Kleinman's framework, these health practices will be considered folk treatments. Health healers, or practitioners who practice Amish folk healing are included within this folk sector.

Health practices of the Amish are passed down orally through families or Amish folk healers (Armer & Radina, 2002; Waltman, 1996). Family therapies practiced at home are used for particular illnesses, such as the common cold or simple injuries; home therapies include herbs, special teas, salves and ointments, vitamins, or other nutritional supplements. *PoHo Oil* is a combination of peppermint oil and vaseline that can be used to bathe with, rub topically onto the body, or use in food to prevent ailments (Gerdner, Tripp-Reimer, & Sorofman, 2002). The Amish use coffee enemas or herbal garlic tablets as first-line defense for some ailments, such as constipation or heart problems (Weyer et al., 2003). von Gruenigen et al. (2002) determined that Amish women use complementary therapies such as chiropractic healing, prayer, massage, exercise as medical therapy, and nutritional programs for ailments in addition to their primary obstetrician/gynecologist care and recommended therapies. Women are the primary caretakers of children, their medical beliefs and practices influence the health therapies chosen for children (Waltman, 1996).

The most accessible community resources for families to seek guidance and/or recommended folk health remedies are herbalists within their communities. *Brauche* is the word used for faith healing practices used by Amish healers in the German dialect language (Blair & Hurst, 1997). Young Amish healers are taught traditional *Brauche* treatments for specific ailments through mentorship with older healers. A *Brauche* may include using charms or amulets in order to assist healing; these are used along with the laying on of hands, silent incantations that vary for each illness (that usually wish the particular ailment out of the body), or physical manipulation such as chiropractic or reflexology treatments (Hostetler, 1993). Although some families do seek health treatments for family members from Amish healers, this is not a consistent practice among all families (Wenger, 1988; Wittmer, 2006). Although studies about general Amish health care practices may be extrapolated to those specifically used for children with chronic illness, there is a lack of research specifically focused on the use of folk remedies for children with chronic illness (Banks & Benchot, 2001).

Popular Medicine near Amish Communities

For children within the community who are physically or mentally disabled, the community attempts to include these children in all activities as much as possible. Care for these children not only come from folk treatments, or herbal healers, but also others in their community such as school teachers. Some communities have separate schools designated for Amish children with mental and physical handicaps; the teachers run the school days similarly to the other Amish schools but are focused on the appropriate grade-level for each student. The Amish value the education experience of disabled children as much as other children (Fisher & Stahl, 1997). This way, these children still receive care for their illnesses within the framework of the Amish society.

Examples of popular medicine near Amish communities include, but are certainly not limited to, osteopathy, chiropractic, acupuncture, herbal medicine, homeopathy, or Reiki therapy (Vickers & Zollman, 1999). Many of these therapies incorporate spiritual, religious, and cultural healing beliefs (Bondurant & Sox, 2005; World Health Organization, 2006). These services are not considered part of the conventional medical health care system, but still remain outside of the Amish community. They will be included in this study because Amish families do use chiropractic services for their health needs (von Gruenigen et al., 2001). For the purposes of this paper, those services sought by Amish families outside of their community, non-conventional or conventional, will be considered care from the professional sector.

With the rise in popularity and acknowledgement of CAM use in the U.S., there has also been an acknowledgement of the growing chasm between conventional, or biomedical, HCPs and nonconventional HCPs. Health centers from 24 of the United States are adopting integrative medicine, including both biomedical and psychosocial approaches, and this is a growing trend. Integrative medicine "reaffirms the importance of the relationship between practitioner and patient, focuses on the whole person, is informed by evidence, and makes use of all appropriate therapeutic approaches, healthcare professionals and disciplines to achieve optimal health and healing"(Consortium of Academic Health Centers for Integrative Medicine, 2005). This study set out to describe how Amish families integrate health treatments from folk, popular, and professional health sectors. The forms of health care in the Amish communities help them to maintain their cultural priorities and receive care for their child's illness close to home.

Amish in the Professional Sector

Amish families consistently seek care from HCPs, either for preventive, emergency, psychiatric, or unpredictable health circumstances (Blair & Hurst, 1997; Rieman, Hunley, Woeste, & Kagan, 2008; Yoder & Dworkin, 2006). Very little is known about parent's reaction to and care for children's illnesses. Thus far, research about Amish chronic illness management is focused on the parent or family care for children with chronic illnesses who are already using biomedical services.

In general, for doctrinal reasons, the Amish do not have health insurance, so the payment of medical bills, equipment, medical care and procedures, and clinic visits rely on the entire Amish population for support (Armer & Radina, 2002; Tripp-Reimer, Sorofman, Lauer, Martin, & Afifi, 1988; Wenger & Wenger, 2003). The *Budget* publishes the names of families with financial need and other Amish families contribute. In addition, there is an Amish Aid Plan that helps to keep funds available for families in need, but not all families are involved in this plan (Morton et al., 2003; Wittmer, 2006). The burden of large medical bills rests on the shoulders of the entire Amish population. As families weigh the costs and benefits of seeking and receiving professional health services, the larger financial weight of their decision plays a large role in their final decisions.

Health Care Provider Perspectives

HCPs have the challenge of working with multiple families and patients from a variety of backgrounds and health beliefs. Research has highlighted how HCPs outside of the Amish communities would like more information about how to work with these families. Dellasega, Hupcey, and Fisher (1999) interviewed advanced practice nurses (APNs) to identify key aspects of providing culturally sensitive, comprehensive, and appropriate care for Amish patients. They learned that this process involves learning the culture, developing a relationship, individualizing care, and working two systems. These APNs were willing to adjust their own schedules, accessibility, and behaviors to accommodate Amish cultural values. These findings were noted earlier by Waltman (1996), who included some interviews with HCPs, but it was not clear whether she asked them about working with Amish families, or if she asked them for information about Amish families. Her research highlights implications for HCPs, including building “face-to-face relationships”, recognizing the hierarchy of decision making within the Amish community during consultations, and trying to learn more about the Amish home health remedies and folk practitioners.

Rearick (2003) also interviewed nurses working with Amish families to identify barriers experienced by these health providers. She found that nurses had difficulty approaching illness education because Amish families do not receive education higher than an eighth-grade level. Nurses requested more information about the Amish belief system and strategies to collaborate with Amish families' preferences within the modern healthcare system whenever possible. Finally, Stein, Pachter, Schwartz, & Taras (2004) provided a case study of cross-disciplinary communication between a pediatrician, a psychologist, and a specialist about the care of an Amish boy with Duchenne Muscular Dystrophy. This case study showed the importance of coordination of services and the challenge of an entire team being familiar with Amish perspectives of children's illnesses.

Trust, negotiation, and guarded alliance within the health care delivery process are experienced differently by HCPs, patients, and families (Johnson & Webb, 1995; Kleinman, 1988; Robinson & Thorne, 1984; Thorne & Robinson, 1989). Ethnographic research has shown that trust between a patient and provider are fluid through phases, such as naïve trust, disenchantment, guarded alliance, negotiation, acquiescence, and struggling. They are also influenced by the social judgments that patients and HCPs have of each other. The process begins with families who have needs that are unmet at home, and they must enter into the health care system. They have no choice but to hold naïve trust for the HCPs who hold knowledge about their situation that will improve their health circumstance. Then, patients and families move through a period of interacting with the providers and evaluating the care and the relationship, with either positive or negative outcomes. At this point, families begin to make decisions about their experience meeting their expectations, guarding the trust they previously held naively for their HCP. The patient seeks health care with a guarded and hesitant sense, alternates or selects a different HCP, or develops a global trust in their HCP (seeking the good outcomes for their health situation).

This process requires families to navigate from health resources within the home, within the Amish community, and outside of the Amish community for the care of children's health. Ignoring the social context of these ongoing negotiations between family, patient, and the HCP is not an option when conventional HCPs work with Amish families.

Significance

The National Institute of Nursing Research's (NINR) 2006-2010 Strategic Plan encourages research on health promotion, including the identification of factors that influence decision-making (National Institute of Nursing Research, 2006); these factors result in behavior changes that promote health and prevent disease and disability . Identification of these factors will aid in working toward community-based interventions focused on facilitating health promotion for families who seek health care services for their children. Understanding how families make decisions and care for the health of children within their cultural context will help to reach these goals.

Research about Amish families has largely focused on medical genetics, injury prevention, primary care, affective disorders, communicable diseases, and general health beliefs or practices used by Amish families (Banks & Benchot, 2001; Greksa, 2004; Roberts, 2004; Sorkin et al., 2005; Stein, Pachter, Schwartz, & Taras, 2004; Strauss et al., 2006; Thomas, Menon, Ferguson, & Hiermer, 2002; van der Walt et al., 2005; Vitale, Rzucidlo, Shaffer, Ceneviva, & Thomas, 2006). These researchers have concluded that the Amish use biomedical health care services in addition to folk health practices. To date, little research has addressed how families experience and care for children's chronic health conditions using a combination of folk, popular, and professional health care. HCPs and Amish families experience the negotiation between professional and folk health beliefs and practices. An ethnographic study, nested within the Amish cultural context will improve HCPs' knowledge about the Amish perspective with the hopes of improving future therapeutic clinical interactions.

This research is also in line with some goals of other funding agencies. The National Center for Complementary and Alternative Medicine (NCCAM) and WHO have visions to support research that develops insights and tools to derive complementary and alternative practices for the public by ensuring well-being and providing information about ineffective or unsafe practices (National Institute of Health, 2007a; World Health Organization, 2002). The Institute of Medicine is requesting that "the same principles and standards of evidence of treatment effectiveness apply to all treatments, whether currently labeled as conventional medicine or CAM" (Institute of Medicine, 2005). Upon examining health disparities within the biomedical health care system, the Institute of Medicine has begun to include both CAM practices and focused research and practice for minority populations (Aday, 2001; Institute of Medicine, 2006a). Healthy People 2010 states that "health care providers and public health professionals need to have an understanding of cultural issues relevant to minority populations; and be able to provide services in a culturally competent manner if we are to get beyond the one size fits all mentality of program development and implementation" (Department of Health and Human Services, Health Resources and Services Administration, & Maternal and Child Health Bureau, 2004).

Summary

The Amish have a history of living separate lives from dominant society and remain self-reliant; they have distinct health care beliefs and practices. An integrative literature review focused on describing literature about Amish care for children with chronic illnesses. This literature review demonstrates that the majority of literature about the Amish is epidemiological, documenting health conditions prevalent in the national Amish community, and health beliefs and practices in the Amish community. Few of these are focused specifically on care especially care provided to children with chronic illnesses. Children's chronic health conditions require families to go through a process of considering health care treatments from folk, popular, and professional resources inside and outside of their community. Arthur Kleinman’s conceptual framework aids in understanding the influences of cultural context in the patient-provider interaction. Little research has addressed how Amish families identify and care for children’s chronic health conditions, and little is known about how Amish families negotiate with HCPs about the interface of conventional medical practice and Amish health beliefs and practices for children. Nurses will be better equipped to engage with Amish families once more is understood about how families conceptualize children’s illnesses and prefer to make health care decisions within the context of their cultural bounds and lifestyle.

CHAPTER 3

RESEARCH DESIGN

Chapter 3 describes the study design. This includes a description of methods and procedures used to gain entrée, identify informants, collect data, and analyze data. A discussion of maintaining rigor throughout this process will conclude this chapter, with considerations for human subjects' protection.

Ethnographic studies from the past 30 years laid a base foundation of knowledge about general cultural tenets and history of Old Order Amish families (Hostetler, 1993; Knight, 1980; Nolt, 2003; Schwieder & Schwieder, 1975; Wittmer, 2006). In addition, ethnographic studies specifically described Amish health care practices and beliefs (Blair & Hurst, 1997; Hewner, 1997; Tripp-Reimer, Sorofman, Lauer, Martin, & Afifi, 1988; Wenger & Leininger, 1991). Ethnographic methods were selected for this study to understand families' chronic illness management (CIM) for their children within Amish cultural health beliefs and practices. Since very few studies describe this topic area, ethnographic methods using interviews and observations provided an avenue to meet the research aims. This research design, guided by an ethnographic perspective, fits well to the purpose of this study because it yields rich description of these phenomena as well as cultural and contextual backgrounds that inform the beliefs and behaviors of the participants.

Ethnography

Ethnography focuses on the shared beliefs and behaviors of a cultural group, drawing on the perspectives of individuals within that cultural group. An ethnography is both the process of studying a cultural group, and it is the final written product of that research (Spradley, 1979). This chapter will focus on ethnography as a process to answer the specific aims identified in Chapter 1. The purpose of using ethnography in health research is to understand health behaviors from the insider's point of view, and to see that phenomenon within the context in which it is lived (Kiefer, 2007; Kleinman, 1988; Morse & Field, 1995). This ethnography was used to describe various *emic* (the insider's point of view) perspectives about the management of ongoing care for Amish children with chronic illnesses (ACCI) from Amish community members and Amish families. This study also included a look at how the *etic* (outsider's point of view) perspectives of health care providers (HCPs) impact health care encounters across cultures about chronic illness management for ACCI (Bernard, 2006).

Data collection occurred over the course of 14 months through a balance of interviews and observations in order to describe the culturally embedded norms that guide behaviors of Amish families caring for ACCI and collaborating with HCPs (Bernard, 2006; James, 2001; Kiefer, 2007). The interview questions in this ethnographic study focused on the experiences and behaviors of families, community members, and HCPs caring for children's chronic illnesses (Spradley, 1979). Because data collection during ethnography happens during everyday interaction with participants, these interview questions were introduced during informal and formal conversations with participants. As families, community members, and HCP's shared their experiences, their stories became a point of comparison across individuals and groups to analyze and explain the chronic illness management of Amish families for ACCI from various perspectives (Delvecchio Good & Good, 2000). A classic portion of ethnographic research is participant observation. Participant observations allow for the researcher to partake in the research activities with participants to capture the everyday behaviors in as natural a setting as possible (Agar, 2008); this allows the researcher to identify how family behaviors occur in context. Observations took place in Amish homes, around the Amish community, and in clinic settings. Frequent field notes from these interviews and observations recorded all aspects of Amish life that contributed to the research phenomenon. These data aided in analysis of the behaviors of Amish families and HCPs as they behaved in their own comfort zones. Together, these sources of data provided complementary information within the analysis. Although conversations (formal and informal) provide a glimpse of participants' perspectives, opinions, and feelings, observations provided information on what appeared to be taking place. In some cases, observations refuted or supported discussions with participants.

Because of the fluid nature of ethnography, entire families were involved and informed the analysis of the care for an ACCI. This included the ACCI, parents, siblings, extended family, neighbors, teachers, and other children interacting with that ACCI. Ethnography has opened windows to understanding children's perspectives and experiences by including children as participants of research, rather than only objects of research (Bluebond-Langner, 1978; James, 2001; Kovats-Bernat, 2006). The final reporting of this research will open windows to children's experiences with chronic illnesses to HCPs because children were active in participation during observations and some interview conversations.

Background Experience with Amish Communities

This section, within the methods of the dissertation, will expand upon my own experience gained through work and volunteer experiences that both exposed and prepared me for this research with an Amish community. These experiences were necessary for me to gain familiarity with the Amish community leaders and families. This prepared me for this study by introducing members, hierarchies, and traditions within local Amish communities.

Working as a nurse, I cared for Amish children and their families and witnessed Amish families navigate the biomedical health care system and the high-tech hospital atmosphere. In addition, as part of a pediatric interdisciplinary team, I provided outreach clinic care for Amish children and families with bleeding disorders over the course of two years across the Midwest. Living close to this large community, I met Amish men, women, and children through farmer's markets or local public venues and shops. These first encounters were, from my perspective as a Registered Nurse, superficial in nature. Building on this knowledge during my ethnographic study gave me exponential depths to understanding these initial background experiences.

For the purpose of obtaining a Certification in Transcultural Nursing, I conducted a preliminary ethnographic pedagogical project on how Amish families care for their children using general care strategies as well as biomedical professional health care. This project included interviews with Amish parents, school teachers, and bishops, direct observations at school and church service, and participant observation in the community during the fall of 2004. This mini-study brought forth questions about how the families understand and manage ACCI, how they experience barriers to biomedical health care, and how families incorporate their health beliefs and cultural practices into the biomedical care for their children. Through this process, I gained initial access into a large Midwestern Amish community. A bishop from this earlier project aided with initial ideas for the current ethnographic study. Additionally, a public health nurse who assisted the health care team with outreach clinics also provided assistance gaining entrée. Despite these initial experiences and key support, it still took a great deal of time to gain rapport with the community involved in this study.

Through my experiential knowledge and formal training, I was prepared to maintain an appropriate position as an observer and researcher while entering into the community for data collection and analysis. Agar (2008) recommends that an ethnographer retains a strong interest in her own society, so that she can be sensitive to the stark differences in the foreign society. My experience as a nurse and with another local Amish community allowed me the experience to gain rapport with both HCPs and Amish participants. My personal background placed me in a position for a research study that involved both Amish and HCPs, and be aware of the striking differences between the two perspectives on health care.

Field Methods Overview

Following approval from the University of Iowa Institutional Review Board (IRB) (Refer to Appendix D), the sequence of ethnographic data collection techniques flowed in three phases. Rather than following three distinct phases, each phase guided a narrowing funnel from general inquiry about Amish lifestyle and families towards specific inquiries about the care of an ACCI.

The *first phase* focused on getting to know the Amish community in which I would be involved for the study. The primary focus during this phase included recruiting and consenting families for the study, and then describing the cultural context that surrounds these Amish family perspectives of managing their ACCI. Activities during this phase included mapping the community, getting to know the bishops, going to community events, and introducing my study and myself to family participants.

The *second phase* narrowed the focus from understanding the Amish cultural context to a more in-depth understanding of how Amish families and HCPs managed the care of an ACCI. Activities during this phase included both participant and direct observations, interviews with Amish families about the health management process, and collaboration experience with HCPs. It was during this phase that Amish family members identified the HCP(s) who they work (or worked) closely with for their child's illness. After the consent of families, I observed families at health care appointments, invited the HCPs to participate in the study, and interviewed HCPs.

The *final phase* was an opportunity to continue ongoing discussions with key informants, including: bishops, community members, families, or HCPs in order to fill any gaps noticed during initial analysis. As the work with families and HCPs during the first two phases of the study came to a close, the third phase involved exiting the field. I notified families and bishops of the end of the study through a hand written letter, in addition to their compensation. Although preliminary analysis notes were created throughout data collection, in-depth analysis began during this final phase of the research process. Initially, analysis involved transcribing, organizing, and entering data into Atlas.ti as data were collected. Additionally, beginning coding structures and preliminary reviews of potential categories were noted in analysis notes and memos throughout data collection. In-depth analysis began with a thorough reading, organizing, and coding of the information placed into Atlas.ti (Lewins & Silver, 2007). A more thorough description of the analysis process is described in a later section.

Time in the Field

Typically one to two years is a benchmark for data collection in ethnography, in order to complete observations and interviews through various seasons and events of the year (Agar, 2008; Kiefer, 2007; Spradley, 1979). In the beginning, ethnographers join in asymmetrical relationships, with the ethnographer acting as a student and the participant as the teacher. Over time, some relationships with key participants develop enough to resemble a give-and-take relationship, resembling a friendship[2]. Ethnographic relationships should be long-term and diffuse, taking place in a variety of contexts. This allows the participants to accept the role of the ethnographer and gain the needed trust, to express themselves in a variety of settings, and the ethnographer to achieve a level of learning needed to answer the research questions (Agar, 2008). Especially for research involving the care or chronic illnesses, the length of time in the field is important for two reasons. The first is to track the illness and management behaviors and experience over time. The second is to validate with participants what was said or observed in previous encounters (Sandelowski, 1999).

Entering into the community during harvest season and staying through the winter, spring, and summer, provided a well-rounded picture of different exposures to risks for injuries or illnesses, as well as health practices used throughout the seasons of

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[2] The ethnographer, during this time of building relationships with participants, is still clear about the intentions of the study and working with participants to learn information about the culture.

the Amish community. Data collection for this study spanned over 14 months. After IRB approval in September, I entered into the first phase of getting to know the community and participants; during this time, I was in the field 10-20 hours per week. By November, participant involvement and invitations to community events increased. From November through May, I lived half of each week in a rented apartment on the outskirts of the community. Because my home was approximately 90 miles from the settlement, one reason for renting the apartment was to replace travel time with data collection time. Iowa winters also prevented me from traveling the long distance, and staying close to the community allowed me the flexibility to collect data even during winter storm weather.

The length of time in the field for data collection increases the likelihood of observing and/or participating in behind-the-scenes behaviors or conversations (Ember & Ember, 1998). As families came to know my presence and proximity to their community, they were willing to invite me to their homes and events. I received invitations to quilt gatherings, baking days, and assisting with gardening. All of these opportunities contributed to the picture of daily Amish life, to add to the greater understanding of the cultural context. From June through November, time in the field decreased and focused more on spending key informants, discussing topics that came up during intense data collection. Additionally from June through November, I observed some families' clinical visits or other home treatments and followed up with families about these experiences. During the final phase, all of the data was prepared for in-depth analysis and writing. This phase allowed for closure, and exiting the field occurred with a deliberate approach.

Human Subjects Protection

The study was approved by the IRB in September, 2009, assuring that the proposed research procedures would protect the participants involved in the study (Refer to Appendix D). Since there were no interventions or physical interaction between myself and the subjects of this study, the only potential risks were social or psychological for the participants as they told and disclosed their stories, beliefs, and opinions. Because Amish community members are closed to outside societies on a regular basis, it may have been embarrassing for them to share information that will be shared with others. However, for the most part, this did not seem to alter their willingness to participate after gaining rapport and understanding the purposes of the study. They were reminded continually throughout the study that all participation was voluntary and they could withdraw at any point in time.

There were two levels of protection and informed consent that needed to happen in this study. One level was at the institutional level with the health care facility to protect patient information overheard in interviews and clinic observations. The other level was with the participants individually. As I learned of health care facilities that would potentially be involved with the Amish participant families and HCPs, I obtained approval from an administrative representative to conduct the research within that clinic setting. Informed consent was also obtained prior to involving any individual in this research study. The informed consent process involved families, Amish community members, HCPs, and age-appropriate assents from children involved in the study. The verbal consent and assent included information about the process of this research study, benefits and risks involved, the opportunity for participants to withdraw at any time, mandatory reporting of any potentially dangerous or abusive behaviors, and securing confidentiality throughout the study (Iowa Department of Human Services, 2007). Participants' approval of the informed consent was acceptable verbally, and continuing with the study activities showed their continual willingness to participate. All participants were provided my name, phone number, address, my adviser's name and contact information, and supporting institution.

Participants were assigned numbers for the sake of entering data into Atlas.ti. For the purposes of the study write-ups, pseudonyms were created for each participant. The only person aware of the true identify of these subjects is myself. I transferred the data into Atlas.ti, so no one else will read identifiable transcripts. The record created to log the participants' true identities and pseudonyms will be destroyed upon completion of the study and write-ups. Including these name logs, I kept all data from the study on the University of Iowa secured network-attached storage (NAS). I am the only person who can access this NAS, and it is password-protected.

For participant compensation, each participating adult received $25 gift cards to a local grocery store. The participants and key informants identified the grocery store of their choice, and the decisions were almost unanimous. The gift cards were handled according to the Cash Handling Policy of the University of Iowa, as overseen by administrative assistants in the College of Nursing. As I needed to make slight changes to the study, I discussed these changes first with my committee research advisers. Then, I made appropriate modifications with the Institutional Review Board before continuing with data collection.

Procedures

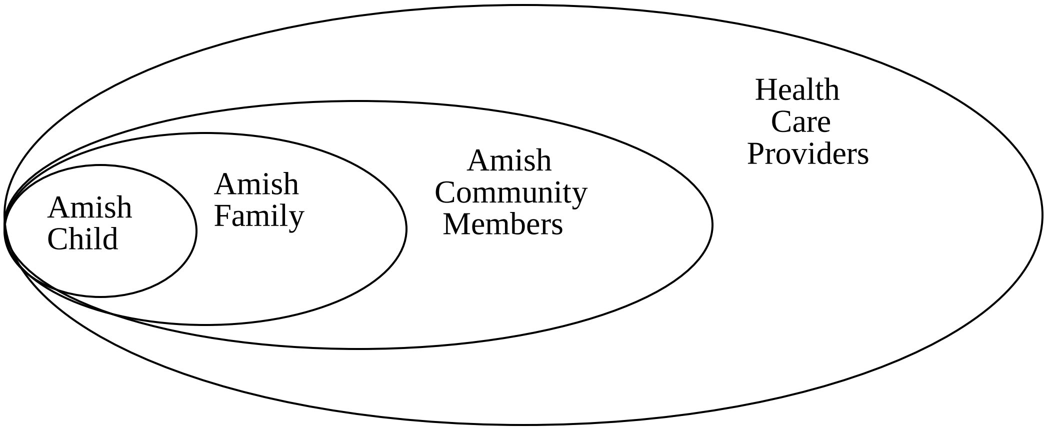
Informant Selection Methods

Informant selection for this study matched the research aims to gain an understanding of how Amish families manage the care of ACCI. Three main groups of informants give unique aspects to these aims, including Amish family members of the ACCI, Amish community members, and Amish or non-Amish HCPs. Following these aims, the informant selection method selected needed to be able to capture the large picture of the cultural context and the focal picture of the intimate care and decisions within an Amish home. Gaining validity within a study by providing different angles of information-rich cases on the same phenomenon helps to reduce potential biases or lopsided viewpoints within the data (Patton, 2002).

A purposeful case-centered informant selection method was the most appropriate for these research questions and design because it involved information-rich cases specifically about chronic illness management for ACCI involving Amish families, Amish community members, and HCPs. Sally Norton (personal communication, November 21, 2008) defined “sub-case” informant selection technique as using a focal point of the study, which is an ACCI. This informant selection strategy moved outward from that focal point to those individuals who were interconnected with the case. Once enrolled in the study, families provided names of other Amish community members and HCPs who were involved in the decision making and the management of treating their ACCI. The conglomerate group of participants using this method is called a *case-centered cluster*. Not all case-centered clusters were identical and many case-centered clusters even shared resources; these case-centered clusters were uniquely reflective of the family’s management experience, feelings, decisions, and illness trajectories. The case-centered informant selection strategy was effective in leading to clusters of participants, who in turn, led to future potential participants all involved with the family caring for an ACCI.

Families recruited for this study were located across Amish districts because districts have varying degrees of conservative to liberal interpretations of the *Ordnung* (Kraybill & Bowman, 2001). Also, criteria for children’s chronic illnesses remained non-categorical. The criteria for families to be involved were aligned with the inclusion criteria mentioned below. Recruiting informants across districts and illnesses identified some similar and unique aspects about the illness experience and chronic illness management for children with a variety of illnesses from a variety of districts (Patton, 2002). There are six total districts within this Amish settlement, and the families enrolled in this study came from five of these. This allowed for the understanding of the cultural context within the entire Amish settlement to superimpose the understanding of this phenomenon across family cases. This strategy is shown here in Figure 1:

Figure 1. Case Centered Cluster



Number of Participants

Eleven families enrolled in the study, building to 11 case-centered clusters. Previous health ethnographies range from 30-120 participants and one to eight interviews per person (Clark, 2002; Fortin, 2008; Hall, 1994; Tripp-Reimer, 1986; Wenger, 1988). As Sandelowski (1995) points out, “events, incidents, and experiences, not people per se, are typically the objects of purposeful sampling” (p. 180). Tables 2 and 3 describe the participants and the data collection events within the study. The number of families and case-centered clusters provided for ample data to achieve saturation within topics for analysis, and was the point in which the bishops within the community stopped referring families. The breadth and depth of the participants and data collection points contributed to the richness of the information received and reflected within the analysis and results chapters.

Table 2. Numbers of Participants

Group	Number of Participants
ACCI	16
Amish Parents	21*
Amish community members	12
Health Care Providers	12
Total Participants	61

*These families combined had 107 children, including some of the siblings and ACCI; this number was not reflected within the total count, but were involved with some interview and observation information

Table 3. Data Collection Points

Data Collection Type	Number
OBS: Formal observation experiences	27
obs: Informal observation in community, with families	12
INT: Interviews with Families with ACCI	13
INT: Interviews with Health Care Providers	10
INT: Interviews with Amish Community Members	5
int: Directed conversations with participants, to fill in interview information	14
F-U: Follow-up from interviews or post-appointments	11
Total Data Collection Points	92

Key Informants

Over the course of the study key informants included a bishop and his wife, an herbalist, and a HCP. Bernard (2006) defined key informants as people who will be rich with information about their culture, insightful enough to describe the phenomenon of interest, and willing to speak with the investigator (p. 196). Key informants provided the background insight needed in order to understand some of the observations or conversations occurring with other families. The bishop and his wife provided opportunities to gain entrée into intimate and social community occasions, reflecting the slow but steady trust building happening between me and the community. In addition, I spent time with these two informants and their family, learning the functioning of an Amish family without an ACCI, which served as comparison to data from families with an ACCI. The Amish herbalist was strong-willed, humorous, and opinionated. She provided a unique perspective about the frustrations and joys of caregiving within the Amish community, and her experiences with communicating across cultural boundaries to biomedical providers about the care the community provides to these children. Finally, a professional HCP was tremendously insightful into the joys and complications of working with Amish families. Although she was not directly involved in the case-centered clusters for the study, she assisted with contacting participants and describing her honest reflections about caring for these families in the clinic setting. Anne Fadiman (2009) describes key informants as those who help to translate the cultural information between the lines spoken during interviews and seen in observations. These key informants were critical, not only during data collection but in gaining insights that later became the focus of analysis and the results of the study.

Criteria for Participants

The inclusion criteria include some key definitions that were created prior to entering into the field and recruiting participants. Inclusion criteria for the first group, Amish families, were as follows: a) have at least one child with evidence of an ongoing physical, developmental, behavioral, or emotional condition; b) the condition was expected to last at least three months; and c) the condition required long term dependency on medical technology, health services, or ongoing treatments in the home setting

(McPherson et al., 1998; Perrin, Lewkowicz, & Young, 2000; van der Lee, Mokkink, Grootenhuis, Heymans, & Offringa, 2007). The ACCI follows the same criteria for illness symptoms and requirements just mentioned, and must have been a child living at home in the care of immediate families members or parents. The family unit included the ACCI, his or her siblings, and parents and/or grandparents. Because some illnesses that require ongoing care for at least three months were resolved by the time the study took place, two families' ACCI had already returned to a state of normal function during the study. Data was collected from these two families using retrospective records, journals, and interviews. Data was also collected from these families' HCPs, who spoke retrospectively about their care for these ACCI.

The second group included in the study was Amish community members. These participants were to include, but were not limited to, siblings not living in the home of the ACCI, schoolteachers, ministers and/or bishops, neighbors, and extended family members. These participants could be members of other Old Order Amish districts across the settlement. Old Order Amish, as described in Chapter 2, refers to baptized members (or children of baptized members, who are not of age to be baptized) of the religious group who resist modernity, live traditional and simple lifestyles, and follow a set of *Ordnung* tenets to set themselves apart from society (Hostetler, 1993). Exclusion criteria for families or community members included non-Old Order Amish religious members, such as Beachy Amish or Mennonite. Status as being Old Order Amish was self-reported in this study.

The third group included HCPs. These participants were individuals with a medical license, education, or qualifications to practice healing techniques or medicine for Amish families[3]. This group included biomedical providers, chiropractic, folk trained

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[3] This is an inclusion criteria created by myself, the outsider and researcher. In no way did any Amish participants claim to practice medicine or have licensed abilities to diagnose or prescribe. They were able to make educated suggestions to families but did not prescribe treatments

community health providers, nurses, social workers, physical therapists, dentists, and physicians. The break-down of providers is described in more detail in Chapter 4. All of these inclusion criteria were stated in the informed consent and discussed with families prior to beginning data collection.

Data Collection

Gaining Entrée

During the months preparing my dissertation proposal and IRB application, I arranged meetings with necessary gatekeepers to the Amish community. As a primary strategy to gain entrée into the community, I met with the director of the public health department in a nearby town to review the process and goals of this research study. She had extensive experience, both personal and professional, because she grew up as a neighbor with Amish families in the area and provided care to this community as a public health nurse. During the initial meeting, we discussed my goals for working with the local Amish community, and strategies to approach the Amish gatekeepers (local bishops) in a culturally appropriate manner. She provided a map of the area, including key parts of the Amish community (stores, schools, etc.) and where health care workers meet with Amish families.

The public health director provided the addresses of the Amish bishops within community. I wrote a letter to all of the Amish bishops, requesting a time to meet to discuss the research study ideas and hear their feedback. One bishop, who later became a great asset and key informant, organized a meeting with five of the Amish bishops from the area to be held in his living room. The meeting involved an in-depth discussion of

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formally. These Amish providers are included with this sample group because families utilize this resource from within their community.

some of the major and pressing concerns of the Amish community and the intentions of my research study. The following is a summary of the meeting discussion and decisions:

1. Amish members feel uncomfortable that the health care system is moving away from family generalist providers towards a system of specialists (a world unfamiliar to them)
2. Amish families' children have been taken away by the state when parents disagree with physicians or hospital policies (providing examples from an Amish newsletter and word of mouth experiences within the community)
3. They discussed how they share stories and strategies across Amish communities through the *Plain Interests* newsletter.
4. Cost and managed care is a big problem because the Amish want to be able to select what treatments they can afford and prioritize, rather than a "prescribed" set of expensive diagnostic tools (labs, procedures, etc.)
5. They decided as a group that the eldest bishop (the organizer of the meeting) would communicate with me and provide families' names and contact information. Each bishop would recruit families from their district and communicate with the eldest bishop who, in turn, would communicate with me.

With this approval from the community leaders in assurance that they would assist with recruitment from this community, the IRB application was completed. After IRB approval, the eldest bishop provided contacts of willing families. In addition, he provided a map of the community, including families' homes, schools, and cemeteries.

The bishop informed me that the best way to reach willing families was to go to their home personally. I then visited the first four homes of willing family participants to review informed consent and invite them to the study. These initial home visits involved communicating the goals of the study and the family spent time describing the background of their children's illnesses. This time allowed space to get to know each other and the full extent of the study; that way, the parents could communicate this information with their husband or wife and family to make a decision together about moving forward with enrollment in the study. As time in the study moved forward, the bishops notified me about inviting more families. Only one family removed themselves from the study after consenting to join the study. It hurt them too much to discuss the events of the appalling care provided to their daughter. Although other families and bishops offered stories about this family, none of this information is reported in the study, to respect that families' decision.

Phase one: Entering the Field

Once both parents in the family agreed to participate in the study, they decided when and who I would meet with. Typically, both parents wanted to set a time and sit down to have an initial conversation. In only two families the father and mother agreed that the mother could be the main communicator. While this took away from receiving both perspectives, the fathers supported enrollment in the study but did not have time in their schedules because they worked away from home. In all of the interviews, children living within the home would sit down and listen or sit with their parents; older siblings and/or the ACCI joined in the conversations in a few of these interviews.

Interview questions during this phase were used to explore family experiences of understanding and initial strategies for caring for their ACCI; these interviews took the form of informal but focused conversations (Delvecchio Good & Good, 2000; Kleinman, 1980). After introductions to the family, their farm, and their children's health, questions honed in specifically about their ACCI (Refer to Appendix E for the interview guide). Culturally available knowledge about illness and its causation can be seen as a resource that guided the interpretation of the experiences described by these families (Garro, 2000). This process began with talking to those family members regarding their story about how they came to know their child had a health problem, and how long their child had the health problem. During initial conversations, families were asked to walk through the process of identifying their child's illness and how they made decisions to treat that illness, using resources and services inside and outside of their community. These interview questions were guided by Arthur Kleinman's (1980) inquiry for explanatory models but were not rigid to his set of recommended interview questions. Use of the general interview guide ensured that specific questions were asked during conversations across all families. Probing participants for those areas that should be emphasized helped to pull out unique experiences within families and answer the research questions (Lofland, Snow, Anderson, & Lofland, 2006). One of the goals of these initial interviews and conversations was to identify key players throughout this process, in order to identify potential future participants to be invited to the study. These interviews took place in the homes of these families, as requested by the parents. Although offered other locations, all families preferred to meet in their homes.

After one or two meetings with each family, and sometimes more, I asked to join them in some of their daily life routines. These observations looked at different avenues and locations of family and community care. Participant observation allowed for the recording of information while observing and participating in similar activities as the participants (Dewalt, Dewalt, & Wayland, 1998). Observations with these families moved parallel to the collection of information through conversations with family members in order to triangulate and see information from multiple sources, contexts, and methods (Lincoln & Guba, 1985). Field entry occurred during harvest season, so many initial observations occurred helping families pick some garden vegetables or fruits, joining one family during their afternoon of corn shucking, and spending time with families in the evenings while dinner was being prepared and children were doing some homework from school. During this time, observations focused on how siblings and parents behaved toward the ACCI, if there was any special precautions used, or if there was any teaching or added instruction to the ACCI about daily life routines such as eating, playing, or working. It also provided an opportunity to see how the parents fit into their daily schedule the medications or medical treatments needed for the ACCI, and who was in charge of administering that.

Observations within the community counter-balanced the observations within the homes and farms of these families. Informal interactions with Amish community members occurred at farmer's markets, local shops, Amish-run grocery stores and Amish-run craft stores in the area. These were not as well received as the observations within the farm and homes because of their unfamiliarity with me. Over time, my presence was increasingly welcome at these venues. These observations built knowledge about the community, to give context to the conversations with families. It also allowed the community to become familiar with me in public and safe settings.

Phase Two: Focus on Chronic Illness Management

Once more established within the community, and more families were joining the study, the focus of conversations and observations moved toward families' complex decision making process about treating their children at home, within their community, and accessing health care services. By this time, families extended invitations to join in observations at clinic visits and home treatments. The additional portion of data collection during this time involved recruiting and involving Amish community members and HCPs involved in the care of the ACCI and following up with families after these encounters with these other groups.

Once identified by families as being involved with the care of their child, I wrote letters of invitation to community members and HCPs. Those interested wrote back and set up a time for discussing the study further with me, and interviewing. Interviews and observations with Amish community members could occur at any point in time, and they gave me available times and locations in which to meet with them. I met with a couple of the bishops from the earlier encounter to gain additional insight into the bishops' roles helping families. I met with one herbalist retailer, who ran a small herbal store in the center of the community. She provided more information about access to medical remedies within the community in general, not necessarily linked to any one family. Although some families mention using her as a resource, she did not act as a provider for any of the families involved in my study. Semi-structured interviews were used with these participants, and this interview guide can be found in Appendix E. Observations at schools and interviews with school teachers helped me to see how children with ACCI were cared for in community settings outside of their home and away from parents. The observations were informative of how other children and adults treated these children and viewed their illnesses. Interviews with both Amish and non-Amish teachers who ran the community schoolhouses informed their assistance to the community regarding general education, health education, promoting growth and development for these children.

The families were in control of inviting me to their clinic visits, and arrangements were made with both the clinic administrator (HIPAA clearance) and the HCP. In all cases, the administrators and HCPs allowed access to the clinic visits, as long as the family approved. Although HCPs in this study were from both folk and professional sectors, interviews and observations were similarly conducted. Observations included clinic visits or home health care visits, and then interviews with the HCP took place after these observations. Two folk healers, who cared for a child with a severe burn wound during the course of this study, allowed me to join them in all of their home visits and follow-up with the family.

For interviews with HCPs, semi-structured techniques were used because in many cases there was only one opportunity to interview some of these participants (Bernard, 2006). Examples of questions for the HCPs included their perspective on the clinical encounters with Amish families (Interview guide is found in Appendix E). Other questions focused on their preferences, barriers, and experiences about working with Amish families for the care of an ACCI. These interviews were not as in depth as the interviews and time with families, but their perspective gave different information about working with Amish families and identifying how Amish culture plays a role in clinical encounters. These alternative perspectives made visible both *emic* and *etic* perspectives of how families in the Old Order Amish cultural context manage the care of ACCI.

Observations in this phase were more direct and included less participation with more detailed observations (Johnson & Sackett, 1998). Observations at clinic visits became a critical piece of this research study and analysis to see the behaviors of these groups of participants as the clinical encounters occur. Observations with different HCPs working with Amish families in a variety of settings such as specialty clinics, outreach clinics, home visits, and routine check-ups were invaluable to provide information to describe patient-provider interactions. These observations also allowed for informal conversations with HCPs to take place on the sidelines of these visits. During these times with biomedical HCPs, HCPs revealed their questions about working with the Amish, gave small hints of their perspective or opinions with working with the Amish, and described their approach. During these times with Amish HCPs, they engaged in conversations about their frustrations of working with the families in the study, with the materials on hand, and their approach to treating the ACCI. These small encounters became crucial to understanding their perspectives in a more natural setting than a formal interview.

Follow-up

Follow-up semi-structured interview questions were used to focus on discussing families' stories of clinical encounters and experiences when they saw health providers for the care of their ACCI. These were both descriptive and evaluative perspectives of their experience leading up to, during, and after their encounters with HCPs. Example questions for Amish families are in Appendix E. This allowed the filling in of pieces discussed in the family and community stories, and identified how the management of ACCI is an ongoing process that takes place over time (Delvecchio Good & Good, 2000)

Focused Community Observations and Encounters.

Observations were used in this phase to confirm or dispute data from the interviews related to beliefs and behaviors of Amish individuals and HCPs (Johnson & Sackett, 1998; Schensul, Schensul, & LeCompte, 1999). As the community gained rapport with me, increasingly, they extended invitations to more intimate observational encounters that added to my understanding of the Amish daily and social life throughout the year. These included a wedding, multiple school days across the community, a quilting gathering, out-of-town auctions, and greenhouse gardening in preparation for the spring planting. During these activities, active participation was required as a participant observer. Again, these participant observations focused on the treatment of children in general during these activities, and especially the ACCI's involved in the study. The church service was in the Amish German dialect, which I did not understand, so participation was limited; however, one of the bishops translated what was said after the ceremony was complete. The direct observations and activities during this phase helped to identify the natural behaviors of individuals, families, health providers, and inform the discussions during interviews about caring for ACCI.

Phase Three: Confirmation and Exiting the Field

The third phase involved reviewing the preliminary findings in order to identify any pieces of information that needed to be reviewed, any additional interviews needed, or any clarifications needed to make with research participants. Pieces of information from field notes, observations, and interviews were also prepared during this phase for the analysis, described in more detail below in the Analysis section. Careful time with key informants reviewed preliminary findings and any confusion about the data.

Because of the longitudinal nature of this study, some data collection procedures from the second phase trickled into this final phase. As stated previously, there was not a distinct line between phases because of the ongoing and everyday nature of ethnography. Any clinic observations, interviews, or home treatment observations, and follow-up that remained were completed during this phase. As those began to dissipate, analysis time and preparation was able to increase.

Exiting the field occurred by communicating with participants via hand-written letter of the completion of data collection and the beginning of the writing process. These letters included their compensation for participation. Almost all of the families wrote return letters in thanks of the gift cards and the time spent with them; their graciousness showed their determination to communicate their desires and experiences with the biomedical health system and providers. Some anthropologists keep in touch with their participants after the research study is complete (Bernard, 2006). There are a couple key informants that I plan to remain in contact with through letters because of the relationships we built during the study. After data analysis and write-up are complete, I will give the findings of my study to the key informant Amish bishop prior to publications from this data. I am hopeful to remain in contact with the HCPs in their community, and the key informants with whom I built strong relationships, for future collaborative support to implement any interventions and sustain therapeutic working relationships with Amish families with ACCI.

Data Management

Data collected during this study was in the form of field notes, observations, interviews, personal journals, analysis journals, updates to committee members, audit trails of decision making, and flow sheets of the activities over time within the study. For every hour of observation and/or interviewing/conversing, approximately 2-4 hours were spent writing up and transcribing field notes from these experiences. Field notes included a description of the overall interaction with participants, the tone or atmosphere in which the information was given and received, or any difficulties that were experienced during data collection. For observations during the data collection phases, field notes were recorded manually onto notebooks and transferred into computer documents at the end of each field visit. Some observations were more like “jottings” or scribbles on notepads to aid my memory, and some observations were written out, and easily transcribed into the computer files. Anonymity of the participants was maintained by keeping notes from observations as anonymous as possible and using pseudonyms or initials within the notebooks.

Interviews with biomedical HCPs were audio-taped. After asking a couple families about audio-taping their interviews, they honestly responded that they would rather not. I stopped asking families after this. Because none of the family interviews were audio-taped, writing up interviews with Amish participants occurred within 24 hours, preferably on the same day as the interview; some of the interviews with families occurred late at night and writing up the interviews was done the next morning. Writing up the audio-taped interviews and transferring them into the computer typically took place within 48 hours after their occurrence, to allow memory to fill in any gaps from the audio-recording equipment. Interviews were transcribed before conducting subsequent interviews, so not to mix the information between interviews.

Because of the great intensity of data collection, getting to know a new set of individuals, navigating the Amish community, and working hard to live among their lifestyle, the use of journals helped reflect and track any personal opinions, hunches, and gut reactions to this process (Hesse-Biber & Yaiser, 2004). Analysis journals had a slightly different purpose than personal journals. Analysis journals noted any patterns seen in the data, or over time with the community (Bernard, 2006). In addition, records and minute reports of any meetings with key informants, colleagues, or committee members about research decisions were kept.

An audit trail helps me, the readers of this ethnography, and other researchers identify with my research process and decisions (Miles & Huberman, 1994). I was the primary instrument of data collection, data recording, and analysis, so keeping all of this data in written records allows for others to see the process and motivations. This transparency allows for checking for rigor as well as duplicating any portions of the study by future researchers. Separate documents were created for observations, transcribed interviews, personal journals, analysis journals, and decisions made with the guidance of committee members in folders called "Data Collection" and "Procedure Manual" with the secured network storage at the University of Iowa. Keeping these separate documents maintained organization, and helped to see different angles of the data collection process, keep biases in check, and recognize confirming and disconfirming evidence to the ongoing analysis.

A flow sheet helped to keep track of daily occurrences and/or decisions in brief notes. This flow sheet was kept on a Microsoft Excel file on the secured network storage. It included the date, time (if necessary), individuals involved, activities, and any brief notes about the conclusions or results of those activities. This was an index for all of the other files within the organization system. The flow sheet allowed for easy access to find the observation, interview, journal, or field note for viewing. Then, the appropriate folder, sorted by date, was found under the "Data Collection" folder. This saved a great deal of "hunt and peck" time and fit everything together from the study into one large file.

Analysis

Approach to Analysis

Data came in the forms of interviews or conversations, observations, community newspapers, and field notes or memos. Analysis of the data evolved similar to the making of a quilt. Considering these pieces of data as representing different types of fabric, analysis can be represented as working these pieces together to form quilt patterns, and finally a whole picture. Up close, these different pieces of fabric are separate and unique. When viewed from a greater distance after being woven together, these adjoined fabric squares appear as a whole. By intentionally combining complementary elements, the whole picture flows fluidly evoking a feeling of the richness of each element. Similarly to assembling a quilt with Amish women, analyzing data elements involved pulling many pieces together to form a rich contextual background to describe how Amish families' manage the care of their children with chronic illnesses.

After spending a great deal of time initially collecting and reviewing the various data sources, a process of immersion and crystallization helped to form collective, interpretive, and detailed descriptions to answer the research aims of this study. Although "much of anthropological writing is based on this type of analysis…it is left in the realm of the unspoken, the secrets of the craft" (Borkan, 1999). With the oversight of experienced research mentors, this analysis process evolved from the beginning of data collection through the finality of writing the results of the analysis. It involved in-depth immersion with each piece of data. Personal reflections and intuitions throughout data collection were recorded, revealing surprises, hunches, or any biases that I carried. This process, according to Borkan (1999) is called crystallization. These reflections and intuitions evolved slowly into categories, "hot topics", or themes over the course of analysis. Crystallization occurs at all levels during the creative synthesis of the data within these analysis steps.

The inquiry of this study lives in the shadow of Kleinman's (1980) work with explanatory models and understanding how families move in and out of health care sectors. Throughout analysis, the data drove the general themes within each research aim. These aims were crafted to reflect Kleinman's conceptual framework, but the framework was not used prescriptively during data analysis. This allowed me to reflect data that originated from the participants experiences and ideas rather than my own

Computer-Assisted Analysis

Throughout analysis, the software program Atlas.ti aided in organizing, coding, and categorizing data that was collected during the study. Within Atlas.ti, one must choose how to organize sources of data, and these are placed together within a location called a “Hermeneutic Unit”(HU) within Atlas.ti (for the purpose of this dissertation, Hermeneutic Units will be referred to as *Source Groups* from here on, to avoid confusion). These Source Groups are placeholders for sources that are linked together within case-centered clusters in one place (Refer to Figure 2). Within each Source Group are all sources related to that case centered cluster revolving around the family managing the care of their ACCI(s). This case- centered cluster was the initial unit of analysis for this study. The Source Group for each case-centered cluster included all of the interviews, field notes, and observations from all participants (families, community members, and HCPs) related to that case. This organization method allowed me to first begin analysis focused within these clusters and then move outward to compare across case-centered clusters (Lewins & Silver, 2007). Occasionally, another analysis level above case-centered cluster was created if there were commonalities across diagnosis groups, such as with families with children who had hemophilia or burn wounds. These families under diagnosis groups had common health care services, and shared HCPs with each other, which provided some common ground across the case-centered clusters within those diagnosis groups.

HCPs were included in the analysis as members of source groups, or case-centered clusters. This outside *etic* perspective shed light on conflicting perspectives in the clinical encounter. Interviews with HCPs were focused on caring for Amish families, with some background contextual information. Observations and data collection about HCPs biomedical or health care context did not mirror the time invested in doing so with the Amish context.

There were pieces of information that gave a unique perspective into the general picture of the Amish cultural context, not necessarily focused on managing an ACCI. Interviews and observations with key informant bishops were categorized in their own separate HU to give a better handle on the global community perspective. They did not have an ACCI but added to the understanding and interpretation of the Amish cultural context that surrounds other families with ACCI's. In addition, information from Amish community newsletters was summarized and categorized using Microsoft Excel to extract topics and categories to identify the common information patterns spread throughout the national Amish community.

Figure 2. Example Hermeneutic Unit/Source Group

Hermeneutic Unit: Family 102
Sources: Family observations, family interviews, HCP interviews, clinical encounters, and/or community member interviews and observations involved in caring for the child within family 102

Steps in the Analysis Process

The first steps of analysis included reading through information within journals, analysis notes, and committee updates that reflected topics that occurred and reoccurred in order to form an idea about potential themes or patterns (Lincoln & Guba, 1985; Lofland, Snow, Anderson, & Lofland, 2006). These steps helped to identify large categories to be used as the scaffolding or more detailed analysis, such as how Amish families and the community conceptualize a child's chronic illness, or the process of Amish families entering into a clinic setting.

Ethnographic studies, particularly this study, focus on description and explanation (Lincoln & Guba, 1985). With the goal to reconstruct a reality from the participants own interpretation and viewpoint, the analysis process began with inductive coding of the data within each Source Group. The coding structures were not prescribed from previous sources or coding structures. The codes were initiated from the transcripts and materials from the participants in this study. Background knowledge of topics that might arise within an Amish community, as well as Kleinman's (1980) background conceptualization of family health care seeking inherently impacted the way that I thought about the data. However, this background information did not directly impose upon the initial coding structure.

Coding is breaking apart information into smaller coherent pieces (Miles & Huberman, 1994). Questions that guided some of the coding process included, "What people, events, or situations were involved?" "What are the main concepts described here?" "What aspect of Amish life or lifestyle is this?" "What piece of a health care encounter or decision is this?" General categories of codes suggested in Miles & Huberman (1994) and the Human Relations Area Files helped with the general ideas of descriptive and explanatory codes. These codes gave the broad scaffolding to hang other codes within, such as who, what, where, and aspects of culture. After an initial read through each piece of information within each Source Group, an initial coding structure was built. Each code was defined as the code was created for future reference with subsequent Source Groups. If a better fitting code word or phrase was found in subsequent Source Groups the previous coded material was changed to the consensual code word. This way, all Source Groups eventually worked with the same coding structure, found in Appendix F.

This ethnographic analysis focused on searching for cultural regularities, patterns, and disparities across and within families, as well as provided a cross-cultural perspective involving interviews and observations with HCPs. Once information from within each Source Group was broken apart into codes and de-contextualized, information and data for each code from across Source Groups were pulled to begin across-case analysis techniques (Ayres, Kavanaugh, & Knafl, 2003). The next step involved a thorough review of the de-contextualized information and codes, which then led to placing appropriate codes and ideas within each research aim to direct the analysis in the direction of answering the research questions. These groupings were reviewed by two committee advisers, and approved for analysis to move forward. Thematic analysis within each aim required movement back and forth from de-contextualized information within codes to re-contextualized information within Source Groups. Moving back and forth between the smallest pieces of information and the larger categories is the hermeneutic spiral that gave way to finding regular patterns across families, or case-centered clusters, or unique patterns within families and districts (Geertz, 1983).

Because the nature of data in this study came from families' stories about their children's illnesses and ongoing management, cultural narrative analysis techniques helped to identify the larger Amish cultural narrative impacting these families (Tesch, 1990). Some of the information received through conversations and observations were pieces of a storyline about how the Amish family identified their child's illness, alleviated symptoms, sought various types of health services, and negotiated treatments for their child's illness. The perspectives of HCPs, community members, and the Amish families involved in each child's chronic illness management provided insights into cross-cultural understanding of how Amish culture influences this process (Delvecchio Good & Good, 2000). Information that related across stories formed general cultural narratives, or composite narratives, while pieces of information within individual stories formed individual or family narratives (Garro, 2000). Looking at these narratives was useful to capture competing viewpoints, as well as the greater cultural context that is informing these viewpoints (Delvecchio Good & Good, 2000). Contributing to the ultimate goal to capture the larger cultural narrative and deviations or unique family narratives, information from HCPs gave depth to this analysis by adding an outside perspective.

In order to give a complete picture of clinical encounters between Amish families and HCPs in this study, the clinical scenario in Chapter 8 was created. After reading and coding clinical observations across source groups, these codes aided in the thematic analysis in Chapter 8 to answer the third research aim. Once themes were developed, such as family logistics for coming to the clinic visits, or making negotiations together for care plans, or legal considerations, I found observation transcript excerpts to match these themes. All representative excerpts came together to form one continuous clinical encounter scenario. Creating a family with a child with juvenile rheumatoid arthritis allowed similar HCPs to be present as were in this study. The imaginary family in clinical scenario in Chapter 8 was not one of the families participating in this study, but represented a mixture of all of the families who participated. The clinical scenario is a combination of observed clinical encounter experiences of all of the families who participated in this study. It is actual data from the study presented in a different context, to highlight the themes presented in Chapter 8 to answer the third research aim.

Rigor in the Research Process

The complexity of involving multiple perspectives from not only Amish families but community members and non-Amish HCPs involved careful consideration of rigor throughout the research process. Traditional criteria for rigor within qualitative research include the following: a) valid results that represent participants perspectives; b) reducing bias within the research process and writing of findings; and c) transparency, and/or consistency, of my own decisions and methods during the research study (, 2006b; Lofland, Snow, Anderson, & Lofland, 2006; Morse & Field, 1995). Validity, or credibility, ensures that the participants recognize the story being told as their own; this ensures that the research report tells the story of the participants with factual accuracy (Guba & Lincoln, 2005). The main phenomenon of interest in this research study was to capture how the Amish context influenced and played a role in how families managed the care of ACCI and interacted with the biomedical health services. Using a variety of perspectives from participants who were Amish or provided care for Amish children helped to triangulate data sources and build as accurate as possible a construction of this phenomenon. These data sources made it possible to see the phenomenon from different angles because sometimes their personal reports confirmed each other and sometimes their personal reports conflicted with each other (Ember & Ember, 1998; Guba & Lincoln, 2005). Ethnographic research also allows for the triangulation of data methods, including observations and interviews in order to decipher any conflicting or converging information that contributes to understanding a) how families talk about caring for an ACCI and work with HCPs, and b) how families and HCPs actually behave when working together or independently to care for an ACCI.

Respondent validity is a piece of ensuring that a researcher has accurately portrayed a participant's perspective or idea (Stewart, 1998). During data collection and analysis, a combination of clarifying with participants and key informants about ideas or details that seemed confusing or unclear helped to clear any uncertainties within the data. By using reflective language during interviews, an activity of active listening, the participants had an opportunity to reflect on my interpretation and reception of what they were saying in real-time during data collection.

In order to bring forth the perspective of a variety of participants, and allow for their contribution to understanding the phenomenon of interest in this study, a great deal of time was spent building rapport and getting the "backstage scoop" (Stewart, 1998, p. 38). The bishops' assistance with introducing families to the study and recruitment were pivotal to entrée into the community. By attaining their approval for the project and their voluntary recruitment assistance, families knew that the research had filtered through a trusted source from within their community. Trust-building happened over a stretch of time in the first phase of the research project. After multiple conversations with mothers or fathers about the study and about their general day-to-day life, it was then appropriate to approached them about sitting down and conducting more in-depth interviews and possibly attending their health visits that year. It was not until the mothers and fathers felt comfortable before moving forward, which happened at different times for different family members.

The "backstage scoop" in this study did not only come from Amish families but other participants inside and outside of the Amish community. After four months in the field gaining trust with families and bishops, the herbalists of the community came forward to participate. At that time, the community shifted to increasing trust that their information would be protected and respected. Other families came forward or were referred, and willingly began to participate. In addition, the private worlds of families who treated their children's burns at home, without professional care, were opened. Only with prolonged engagement in the field did this trust occur and give segue into the private worlds of all of these community members. Spending time with HCPs before and after their clinic visits with these families allowed for some honest reflections about their perspective of working with Amish families and caring for their children.

Tasks throughout data collection were conducted through my own *etic* lens. Because social and historical backgrounds have a great effect on both researchers and participants, this cannot be ignored in scholarship and research processes. "Reflexivity is the process through which a researcher recognizes, examines, and understands how her social background, positionality, and assumptions affect the practice of research" (Hesse-Biber & Yaiser, 2004, p. 115). With a history of working in the health care setting, defining my position within the biomedical field was necessary. However, an underlying assumption from HCPs was that I knew what they were talking about or shared particular perspectives. The use of open-ended interview probes such as "Can you tell me more about that?" or "I don't know anything about that. Can you expand on what you just said?" clearly let HCPs know that the focus was their full perspective and information.

Some inherent biases came out when talking to both Amish families and HCPs. Notes of these biases were kept in field notes, memos during analysis, and in reports to research advisers. At times relationships with participants proved previously held stereotypes wrong. Although historically a conservative Amish settlement, it was surprising to realize that these families asked to use my cell phone, and kept generator-run and battery-operated outlets, hand tools, and even headlamps. These discrepancies were noted in order to record in the contextual information found in Chapter 4 and build a more accurate understanding of the Amish background surrounding these particular families.

Some steps taken during data collection to identify personal opinions and stereotypes included the following (Dewalt, Dewalt, & Wayland, 1998; Schensul, Schensul, & LeCompte, 1999): a) Careful and ongoing reflection on the meaning of experiences such as prayer before mealtime routines; b) understanding the setting, such as notes about the level of modernity held by these families; and c) keeping an open and nonjudgmental attitude, noting any surprises uncovered. At first, personal attitudes and opinions about the information or people were kept in journal entries and field notes. These were kept as reminders as rapport built with families. From one family, I got the consistent feeling that they wanted to be recognized publicly in “my book” in order to publicize themselves or their community. While recording my attitude towards this family, I continued my relationship with this family with some reserve. By comparing my observations with this family and information I received from other participants about that family, I was able to pay heightened attention to specific pieces of information I received verbally from this family while recognizing dramatized information. These opinions, experiences, and values shape decisions through participant recruitment, building field relationships, conducting interviews, coding, and analysis.

Qualitative researchers need to log and describe procedures clearly enough in order to allow readers and future researchers to critique, reconstruct, and understand the process (Lofland, Snow, Anderson, & Lofland, 2006; Miles & Huberman, 1994; Morse & Field, 1995). In order to create transparency of my research process and decision making, a research log was kept and communicated frequently with the research advisers throughout the entire research project from inception, gaining entrée, through analysis, and during write-up. Summaries of all research activities and insights were sent to the research advisers at least once or twice a month (and sometimes more frequently). Frequent reports allowed them to answer questions, and evaluate decisions or techniques.

Through the use of a data log, data collection activities and decisions throughout the research study were made clear. The Microsoft Excel flow sheet reflected day-to-day research activities with participants, and communication with committee members and/or the IRB. An analysis journal provided an audit for trains of thought and decisions about data analysis. During analyses, typed notes from analysis meetings with the research advisers and records of the codes used during in-depth data analysis activities were kept in a separate analysis document. Questions about choice of codes, or merging of codes, were verified these decisions with research mentors. The complexity of using multiple methods and data sources to gain a valid picture of the research phenomenon of interest, and myself as the only research tool, required a great deal of consideration for ensuring that my steps were re-traceable, transparent, and intentionally pulled forward the participants’ perspectives.

Limitations

There are inherent limitations that exist for ethnographic studies in general and in this particular study that must be recognized. During ethnography, the researcher is the key instrument of research, which creates risk in the validity of data collection and interpretation. By keeping a journal to reflect upon these personal perspectives, reflections, or annotations, these ideas were separate from participants’ ideas reflected in field notes, interviews, and coding.

A concern while working with Amish families is the level of protection and privacy they prefer to keep on a daily basis; inviting a stranger into their home was a courageous move for these families. Through spending time with each family or participant, they became visibly more and more comfortable. However, the risk in their level of privacy is that there were still things that they did not want to speak about or show a stranger. Careful steps protected and respected the privacy and seclusion that this community prefers. By working through the community bishops, an added level of trust was gained even before meeting with the families. Writing letters rather than attempting to communicate through communal telephones, families were able to respond willingly to being part of the study prior to face-to-face introductions, and I maintained a humble attitude in approaching any of these participants.

A respectful demeanor included no make-up, jewelry, or inappropriate clothing in the field; I wore skirts and families recognized and appreciated that. I remained open with families about my role as a nurse and communicated multiple times my role of a learner who happened to be a nurse. The concerns about having children removed from the state from this community came out rather quickly and honestly; I included in my informed consent that I, too, was under obligation of mandatory reporting. Yet, this may have prohibited some families and bishops to speak totally honestly about their experiences.

Summary

This ethnographic study involves phases of observations and interviews that describe the cultural context behind Amish families' chronic illness management for ACCI. Participants in this study included Amish families with ACCI, Amish community members, and HCPs. As my own research tool, careful entrance into the field and building trusting relationships with participants aided in constructing a valid representation of their perspectives and stories about the chronic illness management of

ACCI, as well as the interface of Amish families with professional HCPs. Ethnographic analysis, guided by thematic and cultural narrative analysis techniques, showed a description of Amish family management for ACCI in a way that pulls forward how their cultural background is involved in their behaviors and experiences.

CHAPTER 4

THE OLD ORDER AMISH COMMUNITY CONTEXT

This chapter will review the characteristics of the Amish community involved in this study. The demographic section of this chapter includes information about the Amish family cases, such as father's employment, methods of financing health care, household size, number of children with chronic illness per home, and number of adults in the home. Subsequently, a section describing the greater Amish community in which they live focuses on ways the community obeys, disobeys, and interprets the *Ordnung*, the number of districts, community bishop involvement, and other details about available resources such as schools and herbal retail.

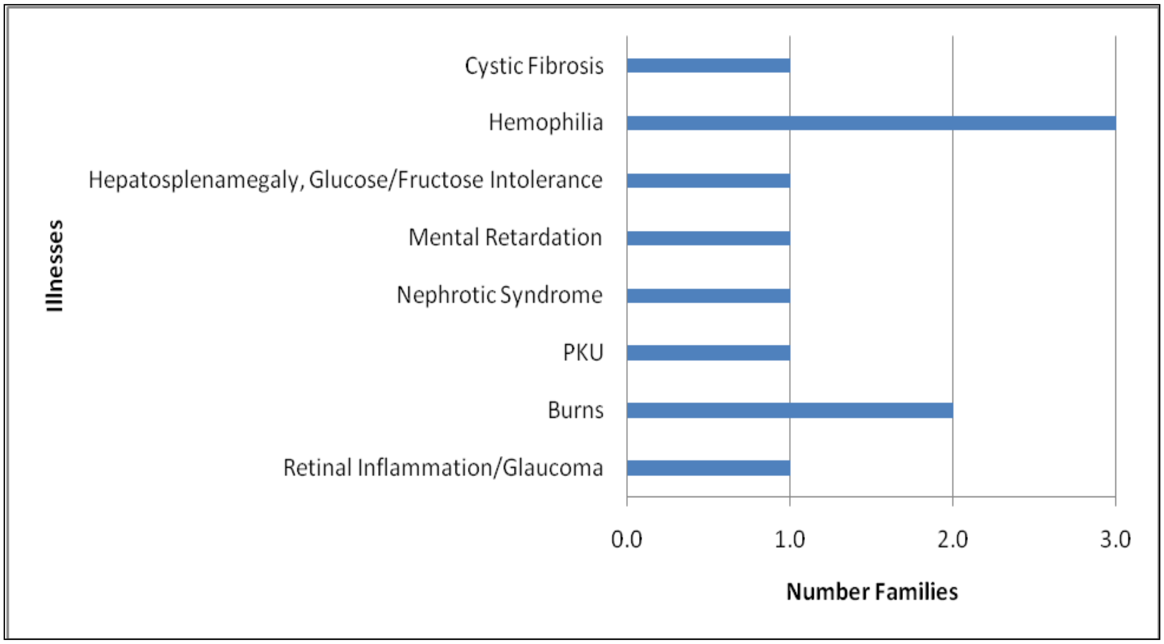
Description of the Amish Participants in Study

For the purposes of analysis, each family was given a number and then pseudonyms for writing the results sections. Only pseudonyms for individuals named in the results sections are defined in Table 4. Because of the nature of the ethnography, these demographics included other children in each family because of their past, present, or potential involvement in the care of the ACCI. In total, these families represented 107 children, many of who still lived at home with their parents or nearby in the community. The average number of children per family in this study was 9.7. The chronic illnesses represented in this study are included in Figure 3. Six of the chronic illnesses were genetically inherited, three were either idiopathic or nonspecific, and two were injury related. One of the children with burns also had Down 's Syndrome. The age range of ACCI in this study was two to twenty-nine years old, and the average age of ACCI was 10.3.

Table 4. Selected Demographics of Family Participants

Participants	Pseudonym*	Children (age)	#-ACCI (at home)	#-Children	
Family				Living	Deceased
101	Amos & Rosanna Petersheim	Lester (12), Gideon (7)	2	11	2
102	Alma & Henry Martin	Jacob (6)	1	14	0
103	Rosemary & Harvey Helmuth	Elizabeth (16), Mary (13), William (8)	3	15	1
104	Lizzie Ann&Andy Helmuth	Rebecca (10)	1	6	0
105	Melvin & Wilma Petersheim	Samuel (16), Elvin (12)	2	14	1
106	Gideon & Clara Byler	Alan (4)	1	6	1
107	Roman & Ruby Byler	Henry (3)	1	6	0
108	Betty, Elaine, Andy Wickey	Eldon (29)	1	10	0
109	Allen & Malinda Renno	David (2)	1	6	0
110	Lester & Lizzie Ann Helmuth	Joseph (2)	1	7	0
111	Vernon & Anna Schwartz	Rose (15)	2	12	0
Total			16	107	5

Figure 3. Chronic Illnesses Represented in the Study



The Amish Settlement

The key informant families for this study lived within an Amish settlement approximately ten by eight miles in size. At the start of the study, the eldest bishop provided a detailed map of this settlement, including each Amish home, school, and cemetery laid out by district. There are six districts in this settlement, led by seven bishops. The families in this study were from five of these districts; each district is influenced and guided by its own bishops, ministers, and school teachers. Drawing from a variety of these districts gave a picture of the families' experiences across the larger community. There was rarely a non-Amish farm or home in this geographic area, and it felt like a foreign country when inside the gravel road borders of this settlement. One road running North and South through the center of the settlement, and one road running East and West through the Northern portion of the settlement were paved, allowing frequent automobile traffic to travel through the community at 55 miles per hour. Otherwise, the community roads were gravel and rarely traveled by other vehicles than horse-drawn buggies or horse-drawn wagons. This quiet atmosphere often captured beautiful moments of Clydesdale horses running through flat fertile fields, farmers on horse-drawn farm equipment running silently through their fields, children walking in groups to school with their lunch pails, or groups of ice skaters on ponds off of the roadsides. At times, this gave the feel of being at a year-round summer camp, safe and enclosed from the surrounding world. A total of nine schools stood inside of this settlement, providing school houses within walking distance to children in all six districts.

Six towns surrounded this settlement, providing grocery stores, a local Wal-Mart, pharmacies, local health clinics, hospitals, emergency services, some transportation services, and public libraries[4]. The population in these surrounding towns is between

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[4] Because tax assistance and information is now almost completely online, Amish individuals preparing their own taxes used the public library for resources as they completed their forms.

200 and 7,000. A large city, with approximately 70,000 citizens is within 25 miles of the settlement, also providing multiple resources. Depending upon which side of the settlement they lived, families would use the closest town's resources to meet their needs.

Over time, Amish families who were dissatisfied with the forward movement of their own communities settled in this area and built a community that is strictly conservative in many aspects. Access to public utilities was limited inside of this settlement. Electric lines were rarely found. Along the roads every couple of miles were telephone booths for the families living in that neighboring area. A bishop said that each family had their own independent water wells; some houses near water lines that ran through the community hooked up to those but there were few families that took advantage of this option. The need for sewage lines was unnecessary because these homes did not have indoor plumbing or restrooms; outhouse bathrooms were found outside of each home in an adjoining or separate hut. Finally, many of the homes in this settlement do not change to daylight savings time, in order to have sunlight earlier in the day for planting and summer farming.

Similar to the generally conservative feel of the community, homes were built to function and hold large numbers of individuals with minimal niceties of comfortable or luxurious living. Most houses had an anteroom to hold outdoor clothing and shoes, canned goods, or occasionally the recently hunted animal waiting to be cleaned. One father explained the layout of his home, that represented many other homes,

> You will notice the way it is set up, it is for our lifestyle. We have church gatherings in here, so they have to have enough space for our churches to hold service here with all the people. There is a door on both sides of the walls because the wood burning stove needs to circulate. When the stove is going and the six children are running around in circles around the house, the warm air must circulate! You might notice that our walls are solid white. We depend on the sunlight for warmth during the day.

On the main level of homes is typically a large kitchen area with the wood-burning stoves, one for cooking, and one for heating the home. The kitchen may or may not have a wall that separates it from a large living room area, but where walls stand there are open doorways with very limited closable doors in this main living area. Homes are built in multiple levels, and the heat is run through pipes from the furnace in the floors. Windows stand every few feet in every direction of the home on the main floor, and few families used curtains. Farms typically had two adjoining or separate homes on each lot; these were either used for siblings sharing responsibility of the farm or as grandparent houses. Their homes can contain a large number of people in comfort, with plenty of space for air to move freely throughout.

Associated Schools

Half of the Amish community made an agreement with two local school districts to allow their public school teachers to teach Amish children, but they taught in the local Amish one-room schoolhouses for only Amish children. Until a Supreme Court decision in 1972 to allow Amish children to have their own private schools and graduate when after eighth grade (Hostetler, 1993), Amish children were integrated with other children in local schoolhouses. The Amish started to resist this immersion when the public school system began to advance with cognitive expectations of students and technology, introducing children to a way of life that did not resemble Amish values. When the community is in need of a teacher, they ask a young woman who has graduated from school but not yet married; that young woman finds her calling and fulfills her role to the community until she marries. This settlement is unique, as shown in Table 5, because they have both English-taught and Amish-taught one-room schoolhouses for their children.

Table 5. Source of School Oversight

School Oversight	# Families Enrolled in School
Local Public School District	6
Independent Amish School	5

The Eastern half of the settlement resisted placing their children in classrooms taught by the local Plumfield public school district because the Plumfield school district would not allow their teachers to go to the Amish community. They demanded that the children come to their public schools. One afternoon, the Plumfield public school district sent their bus out to retrieve the children from Amish Glen Forest School, and the children ran into the fields. Parents were at the school prepared to resist the school bus from taking their children away. Now, those Amish school houses in districts near Plumfield are independently run by Amish teachers, who run school in a more traditional Amish sense. The other school districts continue to provide teachers to their community with only Amish children in attendance.

The inside of an Amish classroom has limited spare space. Each wall is covered with decorations, star charts, book shelves, or windows. In the classrooms, the wood burning furnace sat in the middle of the floor with students' chairs arranged in rows around the stove. Teachers used long tables in opposite corners of the classroom to meet with students for independent lessons. Similar to houses, the bathrooms were outdoor sheds and students were allowed time periods to go outside to use the bathroom. The main courses in the classroom include: arithmetic, reading, writing, German, health, history, and spelling.

Teachers called grades up one by one to their table to review the days' lessons, grade student assignments, answer questions, and practice skills such as reading or speaking English together. Students not at the teachers' tables for lessons remained silent in their seats working independently on assignments. If they had questions, they raised their hand until the teacher saw, then moved to the teacher's desk for clarification. Older students would often help younger students. Students were not allowed to talk to their neighbors, unless given permission, so the room stayed very quiet. The teachers admitted that this good behavior might have been exaggerated because of my presence. Each day begins and ends with prayer and songs from a songbook. The teachers led the students in an *a cappella* rendition of "Amazing Grace" or other Amish hymns. All lessons and activities during the school day are spoken in English. The children learn German one day a week, but in order to learn English are only allowed to speak English rather than their traditional Amish language.

Occupations

In order to sustain an agrarian lifestyle, with nothing more than eighth grade education, fathers worked long, labor-intensive and hands-on work, while mothers took care of children, managed the gardens and home. Common occupations, as seen in Table 6, include carpentry, construction, and farming for the families in this study. Family farms varied in size, according to the level of farming done by the father. Other forms of employment around the community included raising and selling fawns and buck, or running stores. Stores within this community included quilt shops, general stores with groceries and Amish clothing and materials, furniture and carpentry, and bakery. Some of these were also managed by single women or women whose children were raised and independent.

Table 6. Father's Source of Income

Family	Father's Main Employment	Farmer Status
101	Farmer	Large-Scale
102	Carpenter	Small-Scale
103	Farmer, Carpentry Shop	Large-Scale
104	Farmer (Bishop)	Large-Scale
105	Roofing	Small-Scale
106	Roofing	Setting up Organic Farm
107	Farmer	Large-Scale
108	Retired Farmer	
10	Carpenter	Small-Scale
110	Construction	Small-Scale
111	Construction	Large-Scale

Large-Scale: Function as a high production farming, with fields of crops

Small-Scale: Function as a low production farmer, feeding family, local sales

Amish families live their spirituality in their home with their family. The Amish work hard, all day, six days a week. They work hard making a homestead for their family, and they work hard raising their family. One mother's garden measured no less than 20 x 20 feet. Although it was early June, she already had plentiful and lush green leaves on her peas, squash, lettuce, and her beet plants were already close to a foot tall. The garden was divided into two sections, and each row was equally distanced from each other with black fine dirt shining through the green leafy plants. A string was taut from one end of the garden to the other in between two rows of plants. She said, "They probably aren't that straight if you look up close because we were up making them until 11:00 on Monday evening! The children were awake, and we didn't have anything to get up for, so we thought we may as well get it finished." Sleeping in to the middle of the day is unheard of in this community, so they take naps and move forward despite the long work hours of the day before.

One evening, a father was busy carrying a large sack of oats from his barn to the machine shed. He said, "I drive back and forth to Shipman Corners for my construction; I have to keep up that business in order to keep my farm (laughing). We have 12 young mouths to feed and I want to keep farming as much as I can." The men in the community discover ways to sustain an agricultural lifestyle and large families amidst difficult economic times. For some farmers, they must work outside their homes until their sons are old enough to help them plant and sow larger amounts of crops. Until they get the helping hands from inside of their families, men must work outside to maintain their financial position to keep their farms. Once their children come of age, parents will allow their assistance on the farm with guidance. Referring to his disc (a piece of farm equipment with a row of discs pulled by six horses), Vernon said, "Sometimes this one drives it. He's 13 years old, and it helps him to feel important…. He graduates the first part of June. I think we are more excited than he is. I will need his help around here this summer."

Families work together, at all ages, to sustain their agricultural lifestyle because it feeds them all year round, gives them activities to do together on a daily basis, and allows the parents to stay at home with the children to rear them as future Amish members and leaders. The way the Rennos plan their income is around spending time with the family. Malinda Renno said,

> He built a greenhouse because he wants to stay home in March or April to grow tomatoes and stay home more. I would really like to have him home more and the children would like it a lot more, now that they are getting older.

The presence of both parents on the farm is a gift for most families. Young men, who graduate from school, will go to work with their fathers' business, on or off the farm. Allen Renno explained,

> What we've been taught is that the home is what we want: If you can walk, you can go home [speaking of hospital stays]. The home is where our family is. It's where life starts. We have our babies here. We have our funerals here. We have our weddings here. The home is the one security we have. It's where we heal the best. That might be hard for English[5] people to understand.

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[5] "English" is a term used by Amish informants in this study to describe non-Amish individuals of European descent who live in mainstream society.

Financing Health Care Services

Either with the assistance of social workers, their HCPs, or Amish assistance, families paid for their health care services independent of private insurance programs or companies. Figures 4 and Table 7 identify how many families in this study used the different types of financial resources to pay for their children's health care services. Families receive support from their local and national Amish community. Some families used more than one type of financial resources, reflected in the higher total number of families using funding sources than families in the study.

Figure 4. Source of Health Care Financing

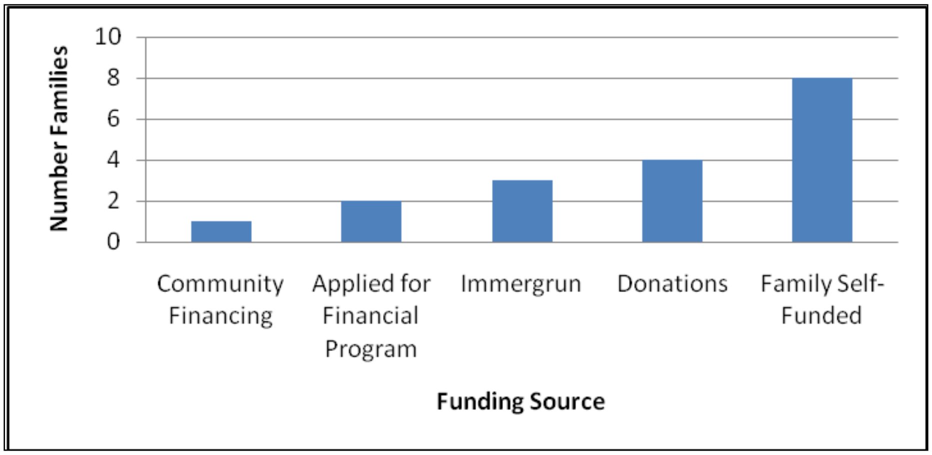

Table 7. Source of Health Care Financing

Family	Use of Community Financing	Immergrun	Applied Financing	Family	Donation
101				Family	Children's Hospital
102				Family	
103	Yes	Yes			
104				Family	
105			Discount Dental Insurance Program		Children's Hospital
106				Family	
107		Yes	Public Supplemental Insurance Program [non-Medicaid or Medicare]	Family	Cystic Fibrosis Foundation
108				Family	
109				Family	
110				Family	Children's Hospital
111		Yes			

Community financing refers to two types of funds available to these families. The first comes from donations from other families within this Amish settlement. Bishops would initiate funding support for families with extensive health care needs, and other families within the district would donate $25-50 a month. One family used these funds to pay for their children's care. The other type of funds comes from a community pot of money that is used similar to an insurance program. Families told me a great deal about this program but not one family used its resources. One man, whose children did not have chronic illnesses, said, "Right now, they take about $20 to $50 a month and put it into one area. There is one man, (my father-in-law) who is in charge of who puts in and who can take out of the pile of money. Currently, only those who have put money into the pile of money can take out from the pile of money. It's hard [for us], though, because we don't have a lot saved up right now. We actually don't put any money in right now because we're not sure what to think of it. We keep our money right now. You just don’t know, though, because what if something happens suddenly and we need more than we have saved ourselves? Then it would be good to have.”

Immergrun is a non-profit insurance company provided specifically to Anabaptist communities living in the United States (Immergrun, Inc., 2010). It is intended to provide health care at a lower cost to families by paying the hospitals directly from the funds within Immergrun. Then Immergrun charges the families a percentage of that total cost, to curb some of the costs for them. It is funded by Amish communities across the country, and HCPs were starting to be aware of this source of payment. One provider described it,

> I’m not sure about Immergrun. One family said that it was just for catastrophic, but I don’t think that the families really know what it covers, and I’m not quite sure either. I think that Immergrun pays the hospital and then charges the family, but I’m not sure that the family is saving any money that way because they have to pay Immergrun to do that for them.

Then a father described it from his perspective, “It doesn’t cost families anything to be in it. They issue us a card. Whenever we go to the hospital that is in agreement with their insurance group, the hospital sends the bill to Immergrun. They negotiate and pay the hospital a price that is agreed upon...Then, we have 30 days to pay Immergrun the rest of the bill. They get 2% for running the expenses…. They accept donations from families to pay the hospital bills.” Three families were introduced to Immergrun through hospital social workers or word of mouth.

Children’s organizations and pediatric chronic illness foundations provide additional funding to some families in this study. These donation programs supply families with outreach clinic support, free prescription medications and supplements, home supplies, and other educational materials. In addition, some HCPs accessed financial aid programs through the state University that work similarly to Medicaid but do not fall specifically under Medicaid. In one financial aid program, The University refunds the provider at Medicaid rate, and the families pay a minimal amount to the University. Amish families are more skeptical of this type of funding, however. A HCP described families' reluctance to accept this program, "I also have a program that I direct called "Care for Persons with Disabilities" that pays for treatment. A lot of times there's no interest. I will say, 'I have this program…You need to fill out an application form'…it does list their income. I'll give them the information and then never hear back. If I say, 'there are others who participate' then they're more likely to participate." With great appreciation for these services, a mother described her gratitude and awe, "You know, I just don't know what we would do without them. I know this is all so expensive…I don't know how much it would all cost, but we just are so appreciative that they have these programs." These programs allow families to be able to still maintain some control of their health care decisions rather than turning the cares of their children over to the state.

Bishops remain concerned for families who must rely on public financial aid and this is heavily frowned upon within the Amish community. One bishop recalled the story of one family whose child received intensive health care services,

> They ended up having over 1 million dollars in bills and they gave that to the state. The state took over the bills but also what cares were being provided to the child. From what I can remember, the state wanted to take away their children if they didn't do what they wanted.

Stories similar in nature to this were shared as examples of why these families preferred to use any other sources of funding than reliance on state aid.

Amish Backdrop

Once inside an Amish home, it becomes more clear that each family tends to their own decisions about their children. To expand on how being Amish affects these families, this section explores some overall Amish attributes witnessed during this study. Families have the option to take or leave some of these attributes, but others go along with following Amish tenets without exception. Table 8 describes the community members, with associated pseudonyms, in this study involved with Amish families caring for their children with chronic illnesses. Although a total of six bishops were involved over the course of the study, three of these bishops had more involvement, helping to clarify some of the data received from families. These three are listed below. The others were not given pseudonyms but are mentioned occasionally in the results chapters.

Table 8. Community Participants and Pseudonyms

Community	Community Role	Pseudonym	# in Study
100	Bishop	Peter Yutsy	1
112	Bishop	Eli Kauffman	1
104	Bishop	Andy Helmuth	1
113	Herbalist	Fannie Petersheim	1
114	Herbalist	Elaine Miller	1
115	Herbalist	Miriam Keim	1
116	Teacher(E)		1
117	Teacher(E)		1
118	Teacher(A)	Millie Yoder	1
119	Teacher(A)	Malinda Helmuth	1
120	Teacher(A)	Betty Helmuth	1
Total			12

Although historically engrained with “group think”, the Amish society is hierarchical with distinct and labeled leaders. Bishops and ministers, male-only positions, hold the highest positions in their district. The hierarchy within the Amish positions a select few to guide families to make decisions that are in line with the ultimate goals and priorities of the Amish tenets called the *Ordnung*. Initially the *Ordnung*, appears as a set of clear tenets followed by the Amish. However, it is more of a concept than a practical list. It is the Truth that lives inside of being Amish, but it means something different to every district. The pattern varied so much between families and was used as something that helped guide families toward traditional lifestyles but not in any descriptive format.

The lived *Ordnung* in this community weaves together a triad of spirituality, family, and home. One avenue the Amish use to introduce the rules and priorities of their way of life is through their church services. The Amish embody a spirituality that is based in their mundane lifestyle; in other words, it is rooted here on Earth and exhibited in their daily actions. The following is a description of the various ways that families in this study lived this *Ordnung*.

Language

Amish families speak a unique German dialect in their communities that combines English with German languages and is often referred to as Pennsylvania German (Dewalt, 2006; Nolt, 2003), Amish (Wittmer, 2003), or German. Individuals in this community call their own language “Amish” or “Pennsylvania Deitsch”, and they call formal German “High German”. Children learn to speak English when they start school around five or six years old. In school, they learn English and High German until they are in 8th grade, well enough to read and speak English in public locations. Because of frequent conversations and interactions with English individuals outside their community, the level of speech is very clear and typically without the need of a translator. Coming from a Christian background, every Amish individual either leads or attends church services held in their own Amish dialect language. When describing the difference between Amish and High German, one bishop said, “High German came from the lower part of Germany. Our language, Pennsylvania Deitsch, originated from our ancestors, I think from the Switzerland area, below Germany. Pennsylvania Deitsch is German mixed with English, but there are different vocabulary too. New bishops and deacons in their churches want to say Pennsylvania Deitsch because the little children don’t know High German or English until school. The older bishops often speak in High German because it is more formal, and closer to the older way.” Although there doesn’t seem to be any dissent towards speaking High German, the informalities of younger generations are losing some of the older language traditions. Bishops would like to keep a unified language and that language seems to be in flux during the current times.

Church Services

Districts hold formal church gatherings every other Sunday, and families are welcome to join other districts' church gatherings when theirs is not in session. When participants spoke about church and their favorite part of church, some would say with enthusiasm, "I love the songs!" while others might mention the nice quiet prayer time, and others might mention the dinner gathering after the church. Their church services include traditional Amish songs, quiet prayer time on their knees, sermons from the bishops or ministers, and scripture readings.

During church services, a row of bishops or ministers sit in the front of the room facing the rows of congregants. Bishops take turns speaking on the day's Bible readings. When at a wedding, there was no precedence set from one bishop from a specific district to conduct the wedding; they were a team who gave the sermons and the wedding blessings. One bishop's sermon told the couple a story about a sky scraper; the sky scraper started to have cracks on the frame near the top of the building. The owner of the building called in experts to diagnose the cracks and fill the holes along the top of the building. None of these solutions were working, so the owner contacted the engineer who built the building; the engineer told him to look for cracks at the foundation of the building; those cracks lead to cracks at the top of the building. Sure enough, there were cracks in one of the bricks in the foundation of the building. The bishop compared this to building a strong foundation as a married partner. Using common metaphors allows bishops an opportunity to impact the community by interpreting the days' scriptures or events into words that the district can live by.

Singing songs took a great portion of services. With no musical instruments, some of the men (particularly the bishops, called the *Vorsinger*) gave a beginning note with their voice and the rest would follow in songs in the form of Gregorian chant. Although there were no notes on the page, all congregants sang the same melody without any harmony. They sing each word slowly and drawn out, so a song of five lines might take five minutes. Singing in this form gives each family the ability to sit around on any evening, use the church song books, and sing together. They do play harmonica, so someone can play along if they like, but mostly they like to sing. The wife of one of the bishops spoke of singing as one of the activities as their family camp-out. Singing is something that transcends talking as a form of bringing people together in one space; it takes the place of dancing and group musical instrumentation at any social gathering. It can happen on any day, while doing chores, or on special/formal occasions. Each song is religious or meaningful in some respect, so they can also be guided through a sort of prayer with each song.

After church, attendees join in a luncheon, with women and children at one table and men at the other. For a few hours, this allows parents to touch base with each other on an every other week basis. Half of the districts in this community were on one rotation of every other week services, while the other districts took the other rotation of every other week. That way, if families wanted to attend services every week, they could attend at one of the other district services. Bishops in this community typically went around to other districts on their weeks off in order to learn of goings on around the community.

Bishops

A bishop's job in the Amish community is to lead worship every other Sunday, along with other obligations of leading a district as the clergy. These include conducting Communion services[6], wedding ceremonies, funerals, or baptism. For making large

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[6] Communion services happen twice a year. This is one of the Old Order Amish traditions. Ammann believed that holding communion in service only twice a year allows people to come

decisions or life turning events, these bishops work together in a similar fashion as they would in this wedding. Families might not necessarily only seek guidance from the bishop of their district. Also, bishops from the district will not try to take precedence over other bishops in dictating decisions made by families. Rather, bishops are viewed by the community as members with wisdom, and seek their guidance in making difficult decisions.

The bishops frequently would be referenced to as support systems for finding financial support for these families, and the bishops felt the financial weight of decisions made by families that placed a financial burden on the community. The bishops did not use Biblical passages as their guidance to how to instruct families, but rather met families where they are- in daily, practical life. When one bishop was asked, “There’s no rules about what they [families] can or can’t do within this community?” And he replied, “No not really. There’s one guy who goes to our church who has a circulation problem. The blood goes into his legs but doesn’t come back out. He needs to be on a machine at night that is attached to socks that squeeze his legs to help his circulation. He came to us and asked if he could use the machine on an electric [converter?]. We allowed that for health reasons. If they [Amish families] go to the bishops it is only when they might be breaking the rules and that might be electricity.” When another bishop was asked about how he helps families to make decisions, he says he sometimes asks some of the other bishops when they gather. Otherwise, he says he just helps the family do what they think is best.

Everyday Spirituality

Religious worship is the climax of every other week for these families, but it is in the everyday behaviors in between that families practice their spirituality. It is not

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clean of their sins prior to receiving it. Baptism of older teens and young adults occurs once a year prior to the communion service.

through rote prayer or over-enthusiastic expression of their love for Christ that portrays their spirituality. At Christmas dinner with the bishop, Peter, he announced the time of prayer just after everyone sat down at the table. My expectation coming from a Christian household was for the family to hold hands and say a prayer together, or listen to my grandfather pray a meaningful prayer out loud. Instead, each person (eight children under the age of ten and nine adults) held his or her hands in her lap, bowed the head, and stayed silent for a time period of one to two minutes. It wasn't until Peter started to stir that everyone else followed, raising their heads and passing the food bowls. Then, at the end of the meal, this series of prayer actions was repeated. Similarly, when someone died they would typically say nothing in response to condolences. This left a moment silence typically, and they hold still in silence of respect for the deceased individual. Their religious expression comes from within their soul and not proclaimed in a proud fashion.

Forms of Communication

Without telephones, computers, or Skype webcams, the Amish use newspapers to communicate and bridge together ideas across the nation. With the guidance of the bishops at the forefront of the study, I subscribed to two commonly read newspapers across the national Amish community. The first is the *Budget* and this is widely read by the Amish; it is their source of national communication about events that occur in each community. It is a weekly newsletter written by the same person from each community; there is about three or four paragraphs to sum up the week's activities. Information about individuals from the community might include who is in the hospital, who is healing from an accident or injury, what family hosted church in their homes that Sunday, who is traveling and for what, and births and/or deaths in their community. The *Budget* is organized so you can read all the way through or look up a community of interest in the index.

Plain Interests is an edited compilation of stories from various Amish authors across North America (Canada and the United States). Stories in *Plain Interests* range from gun safety during hunting season, to opinions about Wal-Mart, to memories of school teachers, to farm accidents. This newspaper is an avenue for families to share their concerns, experiences, and opinions. More so than talking to any of the bishops or families, a flavor of the overall essence of life in an Amish community that exists within a larger English nation is present in this newspaper. Any person who wanted to express opinions and stories would do so using *Plain Interest*s as the venue. In an article discussing whether to use horse or tractor farming (each community decides differently about this topic), the author expressed,

> In general, the degree of modernism of a people can be gauged by the ratio of animal and human labor, to the amount of fossil fuel type power that is used. Today, for us Amish, the greatest help to profitable farming lies not in bigger horse hitches or using more tractor power, but in learning to use our animals (milk and beef animals) to do more of the work harvesting perennial grass, for the longest time in a location.

Allowing the cows to do the grazing work gives rise to more and stronger horses to run a farm.

Plain Interests also allows authors to plea to other families to continue using traditional herbal remedies known among their communities. For Amish families, they expressed struggles with the high cost of medicine, a lack of knowledge about illnesses and disease processes, and uncertainty about the balance of biomedical and natural remedies to use for their children's ailments. Their desire to use home treatments as a priority to any biomedical treatment is a common theme in every issue of *Plain Interest*s. One mother proclaims, "Although we usually are more for natural than medical, we feel very, very thankful for all the medical world has done for us! They have been a tremendous help in our years of serious health problems in the children, broken limbs, and surgeries….And to God we give all praise and honor for the help we have received!"

However, some stories in *Plain Interests* capture some of the turmoil and challenging relationships between Amish families and HCPs. Families would often take treatments into their own hands once outside of hospital care, and wrote of physicians and nurses being either appreciative or frustrated with their patients, despite positive outcomes with some of their home remedies. After a farmer smashed his elbow in a buggy accident, he went in for surgery and a cast. With orders from a physician to keep his bandage and staples in place for the next two weeks, the farmer decided to take the bandage off and use B&W ointment with Burdock leaf treatment to eliminate any infection and pain he was having (Described in more detail in Chapter 6). After a week, his wound was healing and his staples became loose, so the family removed the staples prior to his 2-week-appointment. At the 2-week-appointment, "the doctor came in. He looked at it very surprised and exclaimed, 'how did you dare to take the bandage off after we strictly warned you not to? People like you give me stomach ulcers!' But it was very plain to see that the injury was completely healed, so he did not say anything further." This is not a unique story among the authors of these articles, and the community at large is concerned about how to work with HCPs. *Plain Interests* serves as a communication and information network for family preferences and loyalty to Amish ways.

Variations to *Ordnung*

Some of the rules that set the Amish apart from other societies are their avoidance of electricity, motor vehicles, and telephones. These forms of technology are avoided by Amish communities across the United States. However, this even has its accepted variations within the homes of Amish families. DeWalt power tools, run by batteries, were in all of the homes in this study. The DeWalt powered flashlight was the most common. They still use kerosene lamps to hang on their ceiling, but one family hung a DeWalt Flashlight from their ceiling. Inside of their welding shop just off of the main boulevard through the community, four shelves full of DeWalt tools and batteries make up the majority of their items for sale. Two miles south of the welding shop is Amos Persheim's shop who sells hand tools; Amos thinks of his shop as more of his dad's tools handed down and used occasionally by some of the families in the community or bought by non-Amish collectors.

A new set of doors opened to the Amish when batteries were introduced and accepted by Amish communities. When Roman Byler described the home treatment options for his three-year-old son with Cystic Fibrosis, he said:

> Roman: Well, they have this vest that's like a vibrator. I guess he puts it on and it moves around what's in his lungs. We could probably hook it up to a 12-volt battery. We always have that option if we want but he hasn't seemed to need it yet.
>
> Angela: How does the 12-volt battery work?
>
> Roman: We take an old engine, like from a Honda or something, and hook it up to the car alternator to charge the battery. That's how we do the buggy lights.
>
> Angela: Oh, you could get the car engine at the junk yard, or somewhere?
>
> Roman: They're easy to get a hold of. You just hook up the engine. That's what we use for the vibration vest.

This is not the only family who used automobile motors running large generators. When visiting Eldon Wickey for his burn treatments with Elaine and Miriam, his older brother Andy asked to use my cell phone:

> Angela, "My cell phone died on the drive here. I have the charger but I would need an outlet to plug it in. I don't see one here…."
>
> Betty: Do you have the power cord? We have a generator that you can plug it into for him to use. It is hooked up to a 12 volt battery in the garage, and we run it into the house to run the inverter. That way we can plug in dead batteries, like for our flashlights. We also have a detoxifier. Do you know what that is?
>
> Angela: To me, that means that you are removing the toxins from the body.

> Andy (entered the room by this time): It has straps that go around your waist and around your wrists...We got it for Dad's feet [who had Parkinson's Disease]. We all use it on our feet though. It works!
>
> Angela: Is that allowed by the community?
>
> Andy: Oh yes, well everyone has one of those generators because they need to recharge their batteries. That is allowed, so we don't need permission.

Individuals have clear ideas about what they need permission for, but it is not clear to me the boundaries of these items they would need permission for. The obvious, would be any form of electronic device; however, they don't avoid electronic devices- only the electricity connection to the local civil generator. The main idea was separation from outside resources. Whatever they could do independently of paying bills to a local city or state government, they would flex their traditional ways or ideas to conform to efficiency and easiness for their lifestyle. A young bishop asked, "If something went wrong on the farm, and we needed to have an IV, do you think they would let us have treatments in our homes, like an IV drip even?...We could get a battery run IV machine, and then replace the batteries." This community used of batteries, while technically inside of the boundaries of avoiding electricity.

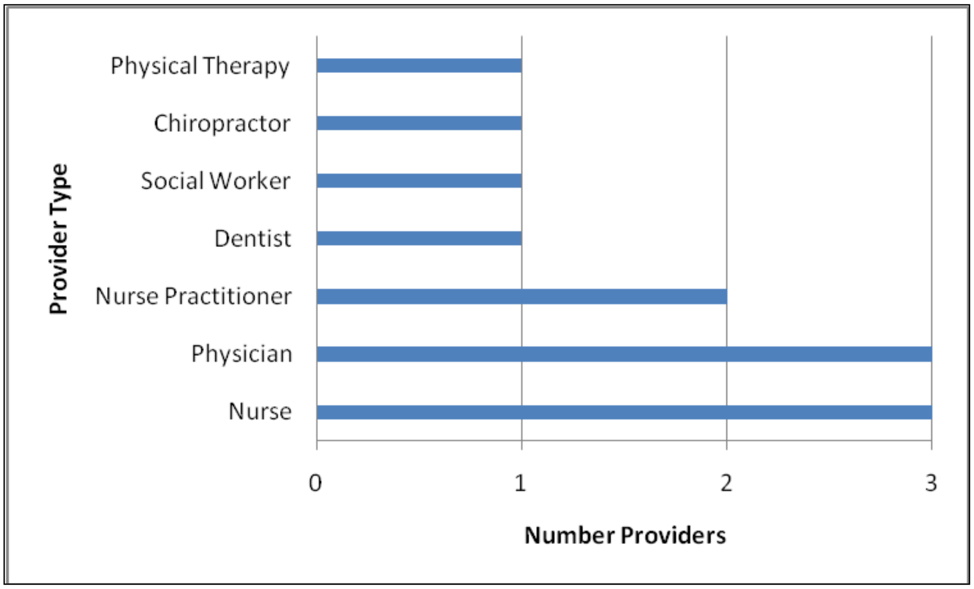
Amish within the Hospital Context

In stark contrast to the rustic living environment in which the Amish live, the hospital represents the fast pace and highly technical lifestyle of modern society. The HCPs in this study are represented in Table 9 and Figure 5. The majority of the HCPs worked for clinics and hospitals. One physician and one chiropractor ran their own independent practices. Because of the requirement of specialty health care services for the participating families, many of the HCPs in the study were pediatric specialists housed within specialty clinics at major health care institutions. These large institutions were located geographically distant to families, without the availability of hitching posts for horses.

Table 9. Health Care Providers in the Study

HCP			
121m	Hemophilia	Dentist	1
122m	Hemophilia	Social Worker	1
123m	Hemophilia	Physician	1
124f	Hemophilia	Nurse	1
125f	Hemophilia	Nurse	1
126f	Hemophilia	Dental Nurse	1
127m	Hemophilia	PT	1
128f	CF	NP	1
129m	General	Physician	1
130m	Opthalmology	Physician	1
131m	Nephrotic Syndrome	Chiropractor	1
132f	Phenylketonuria (PKU)	Nurse Practitioner	1
Total			12

Figure 5. Health Care Providers



Parents were amazed at the magnitude of the specialty clinics and hospitals they visited. One family whose child had hemophilia B mentioned the barrier of receiving the urgent treatment they needed because of the required diagnostic procedures in various places in the hospital. The mother gave their son his factor IX, and by the time they walked all over the hospital and completed their diagnostic procedures, the medicated factor IX had worn off and the treatment was delayed to the following day. Because hemophilia B is a life-long illness, the families in this study were accustomed to the technology and machinery in both the hospitals and clinics. During observations, families appeared comfortable although subdued, amidst the ambient technical machines, computers, and noises. During an average visit to these hospitals, families would encounter mechanical blood pressure machines, digital temperature probes, computers in every room, x-ray machines, beepers/pagers, electric dentistry tools, telephones, and other examination machines.

This foreign environment elicited some frustrations and resistance from Amish community members. In my original meeting with the community's bishops, they were open about their concern for the increasing specialists and decreasing family medicine doctors. An ideal health care environment, according to these bishops, would supply family care providers in rural locations, with more independent practices. Multiple bishops thought that doctors didn't make independent decisions about disease based on their expertise assessments but rather the use of "machines" and "special technologies". In addition, bishops did not appreciate that it seemed doctors and nurses did not know the price of health care treatments or procedures. Families had to deal with financial departments elsewhere in the hospital about the costs but would prefer to know the costs before making decisions for their child's care. One mother told the story of her son's reaction to being hospitalized,

> When they would come to take him to the play area with the other children, he wouldn’t go because he was afraid a stranger would take him. We teach the fear of strangers in children but thought that was extreme of him! He also wouldn’t speak to the doctors. He didn’t know that he was allowed to talk to doctors. When I told him that it was OK to speak to the doctors, then he started to speak with the doctor.

Accepting this type of service was a means to the end of caring their child, with parents making the adjustment to work with HCPs in this environment.

CHAPTER 5

AMISH FAMILIES' UNDERSTANDINGS OF THEIR CHILDREN'S CHRONIC ILLNESSES

This aim focuses on the portion of parents' journeys when they find out that their child has an illness and begin to formulate constructions of that illness. Parents describe their child's chronic illnesses in depth as well as injuries that create minor stumbles in their everyday management of their family and child's life. This chapter is laid out in three large sections. The first section is a description of parent's identification that their child has an illness, with and/or without the influence of others in their community or HCPs. The second section is a description of how the parents come to understand their children's illness, and their appraisal of concern for that illness. The final section is a description of how parents understand the injuries in their children with chronic illnesses.

We Knew Something Wasn't Right: Parents Identification of their Child's Illness

After they first notice changes in children's behavior or appearance, parents move quickly in order to remedy the abnormality. With the great wisdom of the community, friends, and family members, parents keep communal information and experience in their back pockets to help them reason through any changes in their children's health condition. Parents come to identify their child's illness from: a) sorting and applying communal information and experience, b) professional interventions such as newborn or school screenings, or c) a trip to the physician or emergency room when neither of the previous two options helps them to identify the illness.

Family or Community Teaches Parents

The Amish community teaches parents what to look for as abnormal or to recognize as symptoms of diseases that are either common or remarkable across other

Amish families. Parents reported that they knew family members who had the same genetic illnesses that their children were showing. Some had aunts, uncles, cousins, or first degree family members with the illness, and some had relatives who spoke of others in the community with the illness. One mother whose children had Hemophilia B described her reasoning for having her own children tested, “Amos’s [husband] brother had two sons with it. They got it treated. So we had everyone tested and no one had it….we thought we wouldn’t have it but then Lester came along and had it.” Similarly, another mother described her motive for screening her children, “we wanted them checked when they were babies because it’s in my mother’s family. She said to have them checked out right away because the boys might have it.” Another mother of a child with a recessive genetic illness said, “I know that on my mom’s side-real distant- she knew of some with Phenylketonuria (PKU) over in Indiana. Also, my husband’s father had some on his side with PKU…I knew enough that it was in the family but didn’t think we were that connected to those individuals.” These families had a head start to know to look for these genetic illnesses in their children but still found it difficult to think that their children could actually be affected.

Friends also helped families to identify when illnesses needed to be taken seriously. One family had a child who did not survive past infancy and they knew he needed treatment immediately because of suggestions from a friend of theirs. “When the infant started to seize, I remembered one of my friends who had a baby that shook like that. Her baby stopped after a while…that night, our baby wouldn’t stop seizing so we knew needed to take him to the emergency room.” In addition, illnesses that were common in the community helped to inform parents of signs to look for in their children, such as Down’s syndrome. One father recognized the symptoms he heard about around the community,

> When we were in the hospital having Philip, we didn't know he had Down's. When he was born, he looked pretty normal and nothing was too wrong… It wasn't until I was feeding him later with a bottle that I noticed that his tongue was doing that thing when they eat, and I had my first thought that he had Down's

Although he couldn't pinpoint exactly who told him, that knowledge was logged in his memory to recognize in his own child.

Caught by the System

For those parents whose children had illnesses either new or unrecognized by family or other community members, the biomedical health care system's already-installed screening programs helped to identify children's illnesses. "I found out from a friend. When he was at the doctor's office, the doctor asked if he would bring the news to me and ask me to call the doctor's office because the doctor didn't know how to get a hold of me. It was the newborn screening that caught our first child's PKU at five days old." And another father said,

> They [clinic] do the PKU/CF screen a few weeks after they are born. After we had our screen, we received a letter from the doctor saying that he has this Cystic Fibrosis. We thought, 'well, what is that?

We don't know anyone in the community with it and we have never heard of it before. We did not even know the test included CF screening." After finding out from their newborn screens, both of these families were referred to specialists for their child's condition for continued treatment and education. Without newborn screenings, these families did not think about these illnesses as reality for their children.

Half of this Amish community has a unique circumstance to be working with a local community school district. Through this public school district, school health nurses come to the Amish schools for annual hearing and eye screening. One of the children in this study had a condition caught during one of these eye screens at school. Her mother told me, "The school nurse was actually the one who caught it, up here at school." Her father added, "She had some inflammation in the back of her eyes that caused her to have increased pressure like glaucoma." Although the family didn't have a clear picture of the name of the illness, the school nurse helped to refer the family to the correct HCP they needed to improve their daughter's eyesight.

Once some of the families in this community were screened and tested positive for bleeding disorders, outreach clinics helped to identify several other children in other families and continue to screen these families' descendents. Two families reported that the screenings hosted by this outreach team caught everyone in their families. "Finneola contacted us that they were going to have it [screening] in our school. They just took their blood and then contacted us with the results. I guess they set it up with the schools." The families were tremendously grateful for this because of the convenience and their concern for the continued effect of this bleeding disorder in their descendents.

Parents see it On Their Own

When there is no community support, no biomedical interventions, parents identified their children's abnormal symptoms and sought care with local HCPs or at emergency rooms. Because these families do not take their children in for annual or routine checks with local HCPs, they use these facilities when they have concerns for their child's health. For the most part, parents do not know what is causing their child's symptoms but have great concern when their child stops functioning or developing as their other children do. A father explained, "She had diarrhea that wouldn't stop during the first year of her life. Lizzie Ann's mom gave her some medicine that came from the bark of a tree and we tried Pepto-Bismol, but I think we gave her too long before taking her in. We went in two times before they gave her anything." And another father explained their dilemma, "He kepts looking irritable and uncomfortable…and he would cry….every time we picked him up to hold him, he squirmed and wanted free…he would crawl to the kitchen wood floor and sleep. We both knew this was not normal so we started to get worried." Although parents recognized that some of these symptoms happen to any child on occasion, when it was sustained and disturbed their child's energy, then parents inferred that it was an illness severe enough to require professional health assistance.

Even local access hospitals do not recognize children's symptoms as severe and neither the family nor the emergency services identify the illness correctly at first. Before community screens for bleeding disorders were offered in this community, one family struggled with identifying what was wrong with their child. The mother said, "They just gave him ice and sent him home. We got home and he started bleeding again. It was very frustrating because we had a new baby and couldn't do much for him…we didn't think to tell them about the other times that he bled a bit longer…I couldn't believe it at first because I thought I wouldn't be a carrier." After returning with their son, he was checked for a bleeding disorder and they were referred to specialists in a different town. A different family had their son in the hospital for pneumonia, and his other condition of hepatosplenamegaly was not identified because HCPs were focused on other illnesses. A father explained, "…his belly looked like a 'malnutrition boy'. His arms were thin and his belly was real big. We noticed it in the hospital because all he was wearing was a gown; here he has so many clothes on, we didn't notice it….At that time, a Dr. White (female) noticed that his abdomen was large but didn't think to have him tested for anything at that time. He was so sick and so young it was hard to say why his abdomen would be bigger than usual." Common symptoms that were exaggerated in their children were challenging for parents and health care professionals to identify until parents noticed that their child was behaving abnormally enough for concern.

Getting it Through Our Head: Parents Understanding of their Child's Illness

For all of the illnesses the families lived with, there was a learning curve that came with the diagnosis. Within this Amish community, though, it was not just the families themselves that were practicing the learning curve but the whole community. No matter who was speaking, he or she had a general idea of many of the illnesses that children experienced in their community; some of this was because they were somewhat related to many other families in the same geographic community. Stories of family experiences within hospitals, failed diagnosis, or sudden and severe diagnosis spread throughout the community quickly. Bishops, school teachers, herbalists, and other visible leaders within the community also tried to understand some of these illnesses in order to support these families appropriately. Three main areas of discussion within households included, a) genetic inheritance of illnesses, b) varying degrees of acceptance of a child's diagnosis, and c) deciphering causes for concern.

Marry Too Close: Genetic Inheritance of Illnesses

Families, for the most part, understood the basic concepts of inheritance of genetic health conditions. However, sometimes they received mixed messages or incomplete messages from HCPs about the core facts of their child's illness. In order for families to receive newborn screens, they must take their infant to the local HCP. As the specialists understand, it is these local primary care providers who inform the family of their diagnosis and refer them to the specialists. However, when speaking to the local community HCP, he informed me,

> I send them to the screening, and if there's something wrong I get a letter…I send out the information that the family needs to follow up with so-and-so but they really take it from there. I just get them to the screening. I think the county health nurses or a state agency or something like that is notified and they then make sure they let the family know they have whatever it is.

According to the family, "A doctor [in Finneola] explained the genes to us…another doctor was telling us that it had to come from me and her. He was from a different land…maybe his name was Mohamma-something…but we never heard of this before." The follow-up coordination with this family prevented an easy transition to trusting one provider from the time of diagnosis. Each time they go to a clinic appointment, they have the option of seeing five different specialists and it is not always the same specialist who sees them. Although it was obvious during the interviews that the parents could not articulate just why he had his illness or specifics about the abnormality in his physiology, they were able to follow a home regimen for treatments. A great deal remained unclear and unknown to them.

Some families received mixed messages from their HCPs. Families found it frustrating that HCPs didn’t all know and treat their child’s illness in the same pattern or protocols. A physician explained one family’s daughter’s condition as “bilateral idiopathic inflammatory condition…because she had to receive frequent steroid injections of the eye she developed what we call a ‘steroid-responsive glaucoma’”. Meanwhile, the clinic nurse would ask the girl during their appointments, “Any family history of glaucoma? I see your grandma had it….does she still have that?” Because her mother was frequently with her for these appointments, during the family’s interview with me, she reported, “My mom has glaucoma and it is in the family”, while the father reported, “She had some inflammation in the back of her eyes that cause her to have increased pressure like glaucoma.” Their different responses weren’t clear to me until I observed their appointment and understood why they were receiving mixed messages from their providers. In a different experience with a child born with an omphalocele (intestinal and abdominal organs at birth extend into a sac outside of the abdomen), the Amish midwife informed the family that she could push the organs back in with a quarter and stitch the abdomen. Meanwhile, the physician working with this midwife recommended that they transfer down to Finneola to have surgery. The family appreciated upfront honesty because the health care team took care of this condition quickly and assuredly.

Within the community, there was a sense of trying to figure out inheritance with each other and even the origin of the specific illnesses within the community. One night, in conversation with one of the herbalists and her family, someone mentioned,

> It’s more common in the East to have families marry their 3rd or 4th cousins so they have a lot of strange disease out there that this community doesn’t have as much; we only have one family with a lot of mentally retarded babies.

Although the effects of consanguinity were clear to this family, some nuances of X-linked disorders, such as with Hemophilia B, were still a source of confusion to some. One woman said, “I think those end with the boys.” But her daughter corrected her, “No, the sons could still pass through their daughters to their grand-sons.” Conversations similar to this happened while community members would speak about families with genetic illnesses. Meanwhile, some of the families with hemophilia were still trying to sort out the genetics. One father said,

> Someone in our group asked the nurses, ‘Who was the first one?’ She said it was some sort of Queen…You know the ‘weaknesses’ come out when someone gets married and it’s too close [in the family].

Since these parents were confused about whether Hemophilia originated in the boys, girls, or cousins marrying, the mother asked,

> We don’t have anyone that gets married any closer than a second cousin but it still seems to stay with us. Someone told me that it is more common in the Amish than it is in the English! Why is that?

With the general idea of how inheritance works, it is clear that this community is aware that consanguinity affected the prevalence of genetic illnesses in their communities. However, there were still some missing pieces to the puzzle that families were not completely clear on.

The significance of passing these illnesses to their children is something that the parents thought about, but not as much as marrying within family. One mother said that she was concerned for her non-affected children to be carriers because they have not been tested for it. She said, “They might get married and pass it to their children but they would have to get married to someone with the disease in order to pass it to their children. And how would they know who does or does not have the disease?” The idea of having non-affected children tested across the community has not occurred to these families as one feasible solution to the fear of passing these illnesses on to future descendents.

Finding Acceptance of a Child's Diagnosis

Parents were not afraid to meet the medical community with some skepticism, rather than seeing the biomedical diagnosis and recommendations as the final say for their child's well-being. "It takes a while to get it through your head to understand it," said Rosemary Helmuth, the mother of four children with PKU. With plentiful education and monthly pamphlets in the mail, Rosemary took her time to understand the disease and how to make daily accommodations (this is discussed at more length in future chapters). Similarly, even with education from specialists, Roman Byler, the father of a son with Cystic Fibrosis (CF) struggled the first year with knowing how severe his son's illness was. His explanation was,

> He can't digest like everyone else…Once when he was five months old, he was very sick. He looked awful, he was pale and weak, and it scared us. We took him to [hospital] and they said he was so dehydrated he was in the hospital for four days. The first year was the hardest because we didn't know, if he was sick, was it from this sickness or was it something else that wasn't as serious?

Until parents were more certain and comfortable with the symptoms related to their child's chronic illness, they described periods of uncertainty and just trying their best.

The family informants in this study tried sorting out their child's disease and how it would fit into their Amish lifestyle, using the available resources within the community. Some families were left without others who share the same illnesses. When asked about other Amish families with these illnesses, some would know of others in the state but were not in touch with them about management strategies. One family with a child with Hemophilia B moved into the area halfway through the year and they were informed by others in the community who told them who to talk to about support in treating their son for hemophilia. The English families who had a child with Cystic

Fibrosis hosted parent’s night a few times a year, but the Byler’s[7] never went to meet these families because of the time and cost of traveling to Finneola to that meeting. Without this network, many families were left to try and sort out the coping and management of their children’s illnesses on their own.

The Amish families in this study showed great strength in receiving these diagnoses as part of a bigger plan in their life, and that some of their children’s illnesses were the way that it was meant to be. Although very difficult for families, this resolve was present in their explanations of understanding their child’s illnesses. This is a longer story from one father but captures how families are willing to accept what has been given to them by God, rather than attempt super-human measures to correct their child’s condition:

> Well, we didn’t know what was wrong with him when he was born and we were in Walnut Ridge where they don’t have a lot of equipment. They wanted to transfer him to Rockland in case he needed a ventilator or something that they just weren’t equipped for. I pulled the doctor aside and told him, “What if I asked you to keep in mind that we had him here for a reason, and if it’s God’s will that he needs more than what you have, we are ready to accept that what you have isn’t enough to save him? We are ready to let him go if it’s God’s will.” He told me that it wouldn’t matter because his hands were tied. He had no choice! We had to go to Rockland. But you should have seen the looks on the nurses’ faces when I was saying “No” to everything. They looked at me like I was a monster! I’m his father. Later, when we knew he had Down’s, then we knew he was going to be OK. It took them a couple days to get his blood work back that he had the extra chromosome. When they asked us if we wanted to do the other tests that usually go with Down’s, we said ‘Yes! Of course!’

The poignancy of this father’s journey through learning the diagnosis of his son’s illness exemplifies when families are prepared to take what God has given them in their children. This was not a unique story or expression from families across this community.

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[7] Amish informants identified families by stating the name of the father (typically), in addition to the family’s last name with an apostrophe, rather than identifying families as “Byler Family”. The first format is used throughout the dissertation, to reflect how the Amish speak about families.

HCPs, in some cases, helped ease family's understandings of their children's illnesses. Families appreciated HCPs who spent time with them to educate both the parents and children about the illness, and HCPs who were honest about the severity of the illness. Nurses spent a great deal of time with the families of children who have Hemophilia B, including children, to explain everything that is happening when their bodies are unable to clot after a cut or injury. Using metaphors such as dominoes to explain the purpose of Factor IX during clotting helped the younger children to understand why they needed to take their missing Factor IX, or domino, in order to stop bleeding. On a converse note, families felt they could only decide how to move forward once their HCPs were completely honest with the full extent of their child's illness. When the Petersheim's had a son with a brain tumor, the physician had been hesitant to tell them the news of the diagnosis, causing the parents a great deal of frustration (even when talking about it years later). Amos Petersheim said, "That the doctor would know this diagnosis and not notify the family and be honest and straightforward!" When Amos Petersheim had to ask the doctor about whether the chemotherapy he was offering would cure or just prolong life, the doctor finally admitted it would most likely prolong life. Once knowing the whole picture, the Petersheim's were able to make their decision confidently to allow their child to come home and pass away in the comfort of their home rather than live through chemotherapy. Families want HCPs to be honest with them before they make decisions about protecting the welfare of their child over using drastic treatment measures.

Deciphering Causes for Concern

Naturally, these parents are concerned for their children to grow and live healthy and happy lives. When one of their children is diagnosed with a chronic illness, this hope may be adjusted but is never diminished. Some of the main priorities spoke about for their children are to grow and have families of their own, with children. Rosemary

Helmuth, the mother of the children with PKU, said that she and her daughters took it a bit more seriously than her sons because the daughters will need to especially watch their diets when they are pregnant. When women with PKU are pregnant, if their phenylalanine levels are high, it can be toxic to their fetus. Their nurse practitioner warned them of these diet habits, and Rosemary takes great concern over this. She says, "I know that the boys sneak more than the girls because this scares the girls as they are looking to start having children in the future." As the ultimate goal of the community to continue to grow and flourish, healthy children in the future is a requirement and hoped for, even from the children with chronic illnesses. Rebecca Helmuth has idiopathic mental retardation but there is no lost hope when thinking about her future of having children and raising a family. When asked about what the future looks like for Rebecca, Betty quickly responded,

> I think she'll be a great mom. She's always smiling, she's always happy, and she's always thinking of someone else. You can see that she has a smile on her face almost all the time. If she could just learn some things, she could be a great mom.

Even if these children are delayed in school or have difficulty running equipment on a farm, their parents are raising them to provide for their future community in the capacity that they are able.

When learning to perceive an illness as more or less severe, parents measure the level of childhood development that the illness is impacting. Since children, especially younger ones, are not necessarily producing large amounts of income on their farm, their job is to grow up as healthy and strong as possible to function in that capacity for the community in the future. Concerns of parents arise when children slow their eating, their growth, or sleep. After Rebecca's mental retardation was beginning to be apparent to her parents, her mother described this phase, "She stopped walking…the look in her eyes was 'dull' as though she's asking 'where am I at?'. She only gained one pound during her second year of life…I get really blue because I see how much slower she is than others.

Her teacher works really well with her, so I am happy. She should be at the fourth grade level but I think she is at the first grade level." Rebecca's family practices with her in the evenings and in the summers to read books appropriate for her age. Although slower than the rest, they provide incentives and encouragement to continue her growth into adulthood. Another family described their son with a hiatal hernia, "He knows he has to chew his food very thoroughly. At one time it was worse, but he seems to know now what to do." When he was an infant and he would throw up his food or not eat, his parents became concerned and took him to specialists until they understood how to help him to eat properly. This is not an extreme case but parents are willing to seek a diagnosis if they are worried about the growth of their child.

Conversely, if children are developing appropriately, parents are less concerned about illnesses that do not interfere with this process. While talking to one mother in her garden about hay fever, she casually mentioned,

> Actually, the one who gets it the worst is Eli. I think he has asthma…When he goes up to work on the hay in the barn, he comes down wheezing something terrible…I think there are a couple younger children [in the community] who have it but not too bad. We don't do anything about it, but it's something he's always had. He's our most active!

Other individuals would occasionally mention children who had "asthma" but none seemed too concerned about it. These cases were not severe enough to cause parents to request or seek long-term treatments because their child could recover.

Injuries

Once parents identified their child's chronic illness, their daily challenge of treating children's injuries did not subside. The types of injuries mentioned by families regarding their children with chronic illnesses are described in Table 10. Most of these injuries required parents to take their child in for professional treatments, but if the parents felt confident that this was a part of the bigger chronic illness, then they attempted professional treatments at home. The most frequent injuries came from working with farm or other machinery or tools.

Occasionally, hospital workers would be less capable than the parents at recognizing the signs and treatment needs of their children's chronic illnesses. The mother of boys with hemophilia described, "Samuel had a wagon run over his ankle on the inside and broke it to pieces. We took the factor along, and they had to operate on the ankle…well, one morning I think they were short of help and didn't give him his factor shot. I noticed a quarter sized red/orange spot on his cast behind his heel. The doctor said it was just 'iodine' and we could just clean it off. Well, the spot got bigger and bigger. I gave him factor for two straight days and it finally stopped. He was in so much pain though!" Families knew that the local access hospitals did not carry Factor IX, and were accustomed to bringing their own Factor IX with them if their children with Hemophilia B were injured and require medical attention. Parents would bring their children with hemophilia to professional care if they had head injuries, need for stitches, broken bones, or signs of infection.

Table 10. Types of Injuries Reported by Parents

Type	Type of Injury (cause)	Family/ Source	Seek Prof. Care?
Machinery/ Tools: Outside Work	Fall (ladder)	111	Yes
	Finger puncture wound (staple gun)	105	No
	Blunt Trauma (sawmill)	(Dentist)~ 101	No
Machinery/ Tools: Farm Work	Broken ankle (wagon wheel)	105	Yes
	Broken hand (gate hinge)	105	No
	Fall (Grain elevator)	101	No
	Knee puncture wound (pitchfork)	102	Yes

Table 10-Continued

Animal	Blunt head trauma (horse kick)	(dentist)	Yes
	Multiple broken bones (horses trampled)	101 cousin	Yes
	Injuries, non-specified (from farm animals)	Nurses	
Burns	Wrist (stove)	104	No
	Arms (boiling water)	Story-104	No
	Extremities and body core (boiling lard)	109	No (herbs)
	Leg (boiling water)	108	No (herbs)
	Eyes (house fire)	111	Yes
	Leg (hot engine muffler)	105	No
Play/Personal	Forearm lacerations (fall through window)	105	Yes
	Neck injury (fall from couch)	109	Yes
	Mouth bleed (pulled own tooth)	110	No
	Facial lacerations (collision during play)	105	(gave factor)

Summary

Families' understandings of their children's illnesses are influenced by their community and family input and experience, as well as education or interactions with HCPs. Without access to outside support groups or other families with similar illnesses, families come to their own terms with their children's chronic illness. The degree of concern from parents depends upon the level of developmental and functional impact the illness has on their children. Parents are also willing to accept that severe illnesses are in the hands of God and resist life-prolonging measures to severely ill children with little hope of survival. Children have the potential to expand the Amish community by developing into adults and having children of their own. Maintaining their health in order to function as Amish adults one day is of utmost priority for parents and family members. Finally, parents recognized injuries within their children with chronic illnesses as either separate or a part of their child's illness, and managed accordingly.

CHAPTER 6

AMISH FOLK AND POPULAR HEALTH CARE PRACTICES FOR ACCI

Families' Use of Home Prevention and Treatments

Decisions about how to care for a child with an illness or injury helps to keep the Amish family and child in the home and support their purpose in living an Amish lifestyle. Two significant areas that families pay attention to for all children, especially children with chronic conditions, include safety precautions and "building up" their children's strength and well being. In addition to pharmaceutical medications taken by families, families described using ointments, vitamin supplements, natural herbs, various treatments, or other complementary treatments. Each family makes independent decisions about when or why to use these remedies. There is no set guideline for families who are members of the Amish community for using home remedies. This chapter describes in depth families' use of home remedies for children with chronic illnesses.

Safety Precautions

Early involvement in farming chores and associated machinery place these children at risk for injuries. The families with children with Hemophilia B were especially cautionary to their children but there was always a sense of "letting children be children". At the hemophilia outreach clinic, the nurses went over safety precautions thoroughly with the families. They came prepared with teaching materials about a variety of ideas about avoiding injuries when playing or working. Activities children engaged in for entertainment often came at risk of injury. Despite instruction to avoid certain activities from HCPs and parents, children engaged in activities with some caution. First the nurses asked the boys what they did for fun, to see what activities they were involved in. Children tend to play a lot of team sports when they are together for family functions, such as volleyball and basketball. There might be 30-40 children of all ages playing these games, and they are athletic and strong, so they play whole-heartedly. One family set up a basketball hoop in their barn, so the boys would often practice basketball. In addition, siblings will exercise their creativity to play out-of-the-ordinary games, like riding in a sled or skis pulled by a horse off the side of the road.

The boys admitted during their meeting that they sometimes ride scooters on the highway so they can play on the blacktop (their driveways are all gravel). I saw children on roller blades on their driveways or in the ditches. There are few black top roads in the community, so children who live near these roads can ride easier on the roads. Another favorite activity that I saw children involved in is ice skating. Many families own ice skates and find the nearest frozen pond or stream that is frozen over. One day, I drove by a large crowd of children ice skating on a large pond off of one of the main roads. Some were playing together and some were relaxing by skating long distances. In school, the children play a game called “Andy, Andy, Over”. The game is played with two teams standing on both sides of a wall. They throw balls over the wall, and if someone catches it three times, they can run to the other side to bring someone back over to their side. The team with the most people at the end wins the game. There’s a chance of running into each other, or getting hit by a ball. The nurse asked, “ And sometimes it gets pretty rough doesn’t it?” Samuel, a 17-year-old with Hemophilia B admitted, “Yeah, it can.”

Children were often playing while completing their chores, and parents permitted this approach as long as they completed their chores and stayed safe. For example, one afternoon my observations included Malinda Renno, the mother of 3-year-old David who was burned head-to-toe when he was 1 ½, completing her daily tasks in the kitchen while her children were doing their chores after school. It was a snowy, blustery day. Two of her children, including David, were jumping on a couch inside of the living room to jump up and peak out of a window halfway up the wall to see the children outside. The children outside, who were filling the bird house with seeds, were throwing snow balls at the house as the boys on the inside were viewed through the window. Malinda laughed, rather than scolded, but kept a close eye on the children bouncing on the couches. This approach allows children to make their own decisions, while being watched rather than parents stepping in to control their behavior. Rosanna Petersheim, the mother of two boys with hemophilia said,

> You know, they want to play in the hay pile, and I know that they might fall. They have to be careful when they are wanting to play, but they have to be children. We have to let them live.

The nurses at the hemophilia clinic asked specifically about precautions and responses to injuries. This was particularly important to the health care visit of families with hemophilia because of their tendency to bleed with any physical accidents. Barb, one of the hemophilia nurses, asked the Petersheim boys, “Well, maybe you can wear helmets or pads during these games, or not play them sometimes?” Elvin said right away, “We can’t have helmets.” Wilma Petersheim said over Elvin, “Maybe we can get you some helmets…” Elvin, “We wear hats when we’re playing.” When young girls are outside of their house, they either wear white or black bonnets depending upon their age and where they are. When young boys are outside of their house, they wear large-brimmed straw hats or large-brimmed black hats. When they are working or playing it is typically their straw hats. Part of their identity and membership to this community is their apparel, including headwear.

There is more precaution for allowing children to partake in chores involving farm machinery than in playtime or other farm chores. Vernon Schwartz’s oldest boy, at age 13, just started to help him run the disc. The disc is a large piece of equipment with about 13 circular blades, with a seat for someone to stand or sit on while running the disc, and is pulled by a team of eight horses. Vernon’s son sometimes drives the disc. Vernon’s son doesn’t have a health condition, but that is the age that Vernon lets his boys work the farm machinery. But then another father will say, “I let him [older brother] “rake” at age ten. The rake is a lighter thing. I raked hay when I was pretty young myself…The rake is behind the horse. I always let the younger ones have the safest horses." Their children could start helping with raking or other light chores involving machinery around age 10 or 11.

Chores that carry varying levels of risk motivate parents to decide when to allow their child to participate with farm machinery. One father says, "Like mowing the lawn they have to be older because that can be pretty dangerous if you fall off….it's two horses across a sickle that runs over the grass and cuts. I think the girls and John were about 13 [years] when they started." Their mother added,

> There is a difference on what they have behind them [experience], to let them do something. Sometimes if the older ones can do some things, we let them because then we don't have to worry as much because they know how…The younger ones keep pushing us because they want to learn how. They are itching….The difference is the families. A lot of families have ponies, and we don't. There's a lot of children who get a pony when they are six or seven years old…I guess we don't like them really. The boys would like to have one.

Another family down the road allows their children to have ponies, and even take ski rides attached to the ponies. Their mother said, "If they bump themselves they really have to 'take care'. They have to sit still the minute they get a bruise or a bump until it stops bleeding." Their father has another occupation than farming, so the older sons in this family work less with farm machinery and go to work under their father's supervision when they reach their middle teenage years.

Prevention: "Built Up"

When speaking to HCPs, they do not often recognize the Amish as particularly preventive in nature because families choose not to come to annual or regular health care appointments or dental cleanings. Amish families have their own way of prevention that is not necessarily practiced by rote from sources such as the Centers for Disease Control and Prevention or the Maternal and Child Health Bureau. They do not have easy access to this type of information that spreads through sources requiring electricity, or common newspapers or magazines. Their way of prevention is focused on keeping their children active in the community, working, and "built up." "Built Up" is a phrase that parents would use to describe a strong immune system. One of the key strategies to get a strong immune system was typically through vitamins, and garden food. Since their summer gardens provide plentiful varieties of fruits and vegetables, they focus heavily on vitamin supplements during the winter months.

Rosanna Petersheim, the mother of 11 children including two boys with Hemophilia B described her strategy to keep all of them built up,

> We don't give them a lot [vitamins]. Mostly the winter time, when the flu season starts. We give them a chewable multivitamin, or the gummy kind…just whatever I have I guess. Through the time they do have colds or runny noses, we give children a lot of garlic and vitamin C and things like that. But for the ones with hemophilia, we give them a lot of juices and vitamins because they can't have garlic and 'C'. We have a list of what we can't give them. Some of the herbs cause the blood to thin, too, and there's some that they can take with colds that are OK. I think Echinacea….I went to an herbalist in Rockland to see if they would recommend anything and they didn't seem to have anything that would work for children with hemophilia. I asked Fannie [an Amish herbalist] if she had anything, but she doesn't really have anything either."

Rosanna has a large garden in the front of her home. Women are often found during the spring and summer months in their gardens, planting or weeding or picking. Children who are home, or after school, will spend that time with their mothers in the garden. Some children assist while others might just be playing in the dirt or eating the fresh produce. Rosanna relies heavily on this healthy food to build up her children; although some of these fruits, like strawberries, are packed with vitamins such as Vitamin C, she never commented that food replaces specific vitamins that her sons with hemophilia should avoid. She says,

> The big problem with Lester [with hemophilia] is that he is not a good eater like his brother Gideon [also with hemophilia]. If Lester could eat chocolate milk and cake all day he would be perfectly happy. The milk is good for him. He will grow and get some nutrients, but he doesn't ever eat meat. I can barely put anything into his lunches that he will eat. In the meantime, I am struggling with finding vitamins that are appropriate for children with bleeding disorders.

Another mother of children with hemophilia said, "Nothing works for their bleeding….Iron is important, and we make sure they take iron." She made sure the children with hemophilia had more iron than her other children. She said, “David [with hemophilia] did take Vitamin C when he had terrible nose bleeds this winter… We haven’t been taking Vitamin C since they told us [not to] in the clinic and he hasn’t had a nose bleed since.” Wilma, “They need to get built up. They take a multivitamin if I set it right in front of them in the morning; that doesn’t always happen though. I wish they would take them.”

Another mother with a young boy with Hemophilia B said,

> Because he’s little it doesn’t take long for him to lose a lot of blood. They told us we need to keep him ‘built up’ so he doesn’t bleed as easily. Since he was in the hospital we have been giving him two multivitamins each day (LiquiVite), and extra Iron through the winter….he’s a lot healthier since we’ve been giving him the Liqui-Vite. Before that, he was a bit slow. He was slow in gaining, and now he’s growing.

Her other children get some vitamins, but do not take the increased amount he takes. She was not as concerned for them because they were stronger without the hemophilia.

Building up their child who had just been burned was especially important for the Renno family. In their diary, Malinda mentioned that on the second night after the burn he would not drink or eat anymore. He was awake and fussy at one in the morning, so they give him garlic, Vitamin A, and Emergen C. Malinda wanted to help his skin and to “build him up”. On the first night after the burn they were worried that he would dehydrate because he wasn’t eating anything. They gave him Emergen C for general vitamins. They gave him Vitamin A (a bottle of capsules that is from fish liver oil) to help his skin. They gave him garlic to help his immune system. Malinda had an idea of what to give for everything that she was observing as a sign of illness related to the burn, in order for David to heal. Some of this comes from a book her husband owns, some from her previous knowledge that she can not remember learning, and some of this knowledge comes from the recommendations of a local herbalist.

When the Helmuth’s try to build up their daughter with mental retardation, they use Omega-3’s. They have fish oil pills or other pills that are Omega-3 gel camps. They give her a lot of these if she is starting to show heavy signs of slowing down in school or when she seems more confused. When their daughter, Rebecca, is built up with vitamins, especially Omega-3's, her mother notices a remarkable difference in the way that Rebecca responds to questions, appears more focused, and can remember things for a longer period of time (such as setting the kitchen table). The challenging part for Rebecca's mother is that there hasn't been anyone to help her specify a treatment for Rebecca that will work in the long-term. Rebecca's confusion waxes and wanes. When her confusion increases, they start building her up with Omega-3's again in hopes it will help her. They see a temporary improvement in her condition but it does not prevent her condition from worsening or from her having "bad memory days".

Betty Wickey, whose brother was badly burned, said,

> Sometimes it can be too much. We use them because we know about them and we grow up with them. People will tell us to try one thing so we try that. But some people take too much and then they don't know what's helping what.

This is the common way that these families prevent illness and encourage their children to grow strong and develop appropriately. Families are less concerned with biannual teeth cleanings, or frequent check-ups with HCPs. Although no one has done a cost analysis, families think that it is less expensive to keep their children healthy and make these continual but lower payments for supplements than to pay for health care appointments that are costly without insurance. Their agrarian lifestyle lends itself to many injuries, and the requirement to have their bodies as functional machines on the farms motivates men and women to talk about ways to keep their bodies in health. Herbs are functional and available, can grow in a garden and be dried for the winter, and can avoid or prolong visits to health care clinics for some. With the high importance of the topic and frequent occurrences of physical accidents or ailments, natural remedies are an accessible and commonly used treatment.

Self-Reliance: Trial-and-Error

As soon as a child’s symptom is noticed by an adult or sibling, problem solving begins and allows for some trial and error with home remedies. The inherent attitude of Amish families, especially in this isolated community, is to remain independent of outside worldly needs and thought. The long tradition of the Amish lifestyle as being self-sufficient and separated impacts their approach to treating their children’s injuries or illness symptoms. Before seeking outside sources of help, the Amish are inclined to use their own resources. In an early encounter with a community Amish herbalist, she stated matter-of-factly, “We try to use these things [herbal treatments in her store] before going to the doctor, so they [parents] will try something at home before going in.” Sometimes parents referred back to treatments their mothers showed them growing up; some parents would refer to the herbalists in the community, and some would tell me that they just wanted to try it to see if it would work. Either way, they look inwards first to improve or maintain their child’s health. One father explained,

> We don’t take our children in [to the doctor] as much as other people. We just stay away [from hospitals] because our parents told us to avoid the doctors. The stress at home is only about one third of the hospital because they don’t have their siblings in the hospital. They get better and heal better at home.

When Rosemary Helmuth discovered that her oldest son had Phenylketonuria (PKU), she was trying to balance the new diet requiring added protein powder and making meals without any amino acids. They were struggling with keeping his phenylalanine levels low in his blood, because the more amino acids are eaten, the higher the levels in his blood would rise. “At first I tried to give him some extra pills to keep his numbers down. We would get fliers from different companies telling us to try this or that for blood disorders. At first, we didn’t know what would work and what wouldn’t work, so I tried a few.” After Rosemary was able to control her son’s diet, learning how to cook completely differently than she traditionally would for the rest of the family with plenty of proteins, his phenylalanine numbers dropped. She felt more comfortable stopping these suggested “natural pills”. In addition, once the Helmuth’s developed a relationship with their nurse practitioner, she recommended that they don’t try other treatments unless she can look to see if it will help the children’s PKU. Rosemary decided to ignore the advertisement fliers that continued to come to her door.

When Rosemary’s son with PKU developed idiopathic thrombocytopenia (ITP), Rosemary turned first to her community’s recommended treatments. Rosemary noticed that he had increased bruising on his leg, and a bruise that wouldn’t go away after injuring his leg one day. Before seeking health care from the nurse practitioner, she went to speak to an Amish nutritionist or chiropractor in a nearby town, who suggested a few herbal remedies to try to build up platelets. Rosemary recalled the name was something like “bloodwill”. The family’s nurse practitioner told me that Rosemary mentioned taking her son to South Dakota to see a chiropractor for his platelet problem and she didn’t recommend this option for him. Despite the final conclusion that surgery was imminent and required to heal his symptoms, Rosemary wanted to try other avenues before surgery. Without knowing that surgery was inevitable, they were willing to try other options to see if they would take away the symptoms.

One example is the Andy Helmuth family, who continuously struggle with Rebecca’s idiopathic mental retardation. After multiple accounts of disagreeing with HCPs for what should be done for her care, they have come to rely on herbal remedies, Amish chiropractors, and school teachers to help Rebecca stay as healthy as possible. After years of frustration, Lizzie Ann wrote an article in *Plain Interests* about Rebecca. She asked anyone to send them suggestions of how to treat Rebecca to help her to catch up in school. At the age of 12, Rebecca is developmentally at age 5 or 6 years old. She can read but slowly. In response to her request and story, she said,

> There were some advertisers just trying to sell us things. We did receive a lot of letters from people telling me about their treatments. I should probably go talk to Fannie about those suggestions. One was ‘fermented cod liver oil’. I received a book called ‘The Gut and Psychology Book’, saying that if you eat a certain diet then you can cure some of your mental disorders. …you basically eat a lot of fish.

> The book recommended no sugars, no bread, and even apples that have high sugar content are not allowed. I am worried to start that diet because Rebecca eats so well right now, I don't want to change that. Another person sent me something about a stem cell enhancer.

Lizzie Ann had some intentions of using these recommendations, but not before seeking the guidance of her community herbalist, Fannie.

Over the winter, Rebecca's family could not afford the travel to go see the Amish chiropractor across the state. Her mother said,

> Oh, she's not doing very well. She hasn't changed that much….I think she ate too many sweets over Christmas. Just the other day, I got a letter from Goshen, Indiana for P&P oil. They read my letter in the *Plain Interests*. David told me I could send away for it because by then the goats will have milked and we would have money.

On another occasion, Lizzie Ann said the P& P oil didn't work and Rebecca was still the same. After inquiring about seeing the chiropractor, she told me, "Oh, we don't have any money! We just don't. We can't do anything until that changes. The goats will need milking now every morning around four thirty or five o'clock in the morning and then again in the afternoon."

The closest thing that Rebecca receives to cognitive therapy is one-on-one time with her school teacher, Betty Helmuth. When Betty does not have a helper for the school day, she assigns Rebecca's older sister to work with her one-on-one. When Betty does have a helper, Betty works with her one-on-one. They work on reading, memorizing, and arithmetic. During the summer, Betty continues to work with her one-on-one once or twice a week. That way, Rebecca can start fresh with a new school year rather than forgetting everything from the past school year. With repetition, Rebecca can remember what she learns. Betty reflects on this challenging student, "I always thought that I would be interested in special education….I feel like I make a difference with Rebecca. I can work one-on-one and see her do better after we work together." Betty was upset about Rebecca's previous teacher, who set inappropriate expectations for her because she "looks so normal." Although Rebecca does not receive professional non-Amish services, the services that Betty provides are consistent and help Rebecca to maintain her current knowledge and skills. The future of an Amish child might look different than an English child, but the community works very hard to bring Rebecca to a level that will help her to function as an independent adult in the community.

Throughout data collection, families would mention alternative treatments or home remedies that they would try. Sometimes these treatments resulted in successful outcomes and sometimes without successful outcomes, as judged subjectively. These are highlighted in Table 11[8], besides biomedical treatments, to display the variety of treatments that families used and for what purpose. Vitamins remained a staple in every home, and every child (with or without illness) was encouraged to take their vitamins, especially during the winter months. Natural herbs were used for minor illnesses such as colds or flu's or upset stomachs. Some families didn't hesitate to use over-the-counter medications if natural remedies, such as Microlyn, honey, lemon, or Echinacea didn't work. The variety of plant or animal based treatments were used with varying levels of skepticism. Many of these treatments are newer, and parents remember a time when they were frustrated with Burdock leaves around their farms. However, as success stories spread about these treatments, others are more willing to try it for themselves and their children. The alternative treatments of salves, ointments, or teas were often recommended by one of the herbalists to families, or public vendors who advertise in their community.

Every single family in this study used a chiropractor at some point during the 14 months of the study, for a variety of reasons. Families would travel to Klocton, two hours away, Indiana, or South Dakota for their most trusted chiropractor. One family worked frequently with a chiropractor who came to the community. Although there are ample chiropractor offices in towns within 30 miles of their community, families

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[8] Only the treatments that families could articulate clearly were kept. Those that families fumbled through, or could only remember vaguely were left off of the table.

preferred to travel to their trusted chiropractor. In order to explain why families traveled such great distances to see these HCPs or chiropractors, the bishop explained,

> Maybe you haven't known us long enough to know that the further the doctor, the better we think his care [with a chuckle]. The Amish will go to the furthest doctor for care. If there was a doctor on the moon, the Amish would go to see him.

In order to receive care within the framework of their beliefs, families were willing to travel great distances.

Table 11. Home Treatments Reported by Families

Home Treatment	Purpose
Home Pharmaceutical Treatments:	
Amacar Benefix Steroids Enzymes	Hemophilia Hemophilia Nephrotic Syndrome Cystic Fibrosis
Over The Counter Medications:	
Ibuprofen Pepto-Bismol Tylenol Vick's vap-o-rub	Persistent cough Upset stomach Fever Cold, cough
Ointments:	
B&W Ointment	Burns
Salve: peppermint, eucalyptus, honey	Lump on skin
Calm Cream	Soothe irritated skin; treatment after burn is mostly healed
Cocao Butter	Soothe irritated skin
Union Salve	Minor foot burn
Natural herbs:	
Echinacea Garlic Honey Lemon Liquid Golden Seal Melaleuca PoHo Oil	Prevent/treat cold Post-burn, runny nose, heart Cold/flu Cold/flu Post-burn, to "build up" Toothpaste General, colds, flu, sore throat, cough
Plant/Organic Treatment:	
Burdock Leaves	Burns, wounds, "relieve pain", decrease swelling
Fish Oil/Fish	Improve concentration
Fermented Cod Liver Oil	Improve concentration
Fruit Juice	Treat cold
Shredded Potatoes	Cover eyes to treat sore eyes, relieve pressure
Alternative/Complementary Therapies	
Essiac Tea	Clean out system when taking chemotherapy for cancer

Table 11-Continued

"Basic H" (alcohol solution)	Clean skin
Red Pepper Pack	Stop bleeding in a cut or wound
Red clover/burdock leaf	Blood cleanser
Tree bark	Prevent/stop diarrhea
Warm vinegar cloth	Bruise, scrape, or "bone pain"
Cloth soaked in urine	Conjunctivitis
P&P Oil	Mental retardation
Microlyn	Colds, sore throat
Infaflu	Colds
"Herbal Respiratory"	Colds
Vitamins	
Calcium	Teeth
Emergen-C	Build Up
Iron	Build Up
Multivitamin	Build Up
Vit A	Skin
Vit B	Nervous system
Vit B Complex	Immune system, relax babies
Vit C	Build up
Vit E	Skin
Vit K	Avoid for bleeders
VisioPlex & Gold State	Eye vitamins
Chiropractor	Sore legs, platelet disorder, renal dysfunction, concentration, "straighten out"

Treating Burns

A specialty area, in addition to these other home remedies, that the Amish have nearly perfected is treating burns without any professional health care assistance. Herbalists and families were confident in their ability to heal burns within the comfort of their own homes, and the two families shared their experiences of treating their children with major burns. Two of the community's herbalists (discussed later in detail), Elaine and Miriam, attended classes held in Pennsylvania by an Amish farmer and natural healer who created an ointment that helps to prevent dehydration, prevent infection and inflammation (Hall, 2009). The legend heard within this community says that when he was in need for a remedy to treat the burns on his own son, he had gone to the woods to meditate and seek Divine guidance. In due time, his attention was drawn to some nice, big plantain leaves right before him which he believed would serve as an ideal non-stick barrier between the salve he had applied to his son's body and the gauze body wrap. It worked, but later, it was discovered that burdock leaves are more effective, although plantain leaves are still used under certain circumstances. The Amish inventor of B&W ointment treatments for burns hosts classes throughout the year across the country in order to train representatives from each community to heal burn wounds. These classes are advertised in the *Plain Interests*, along with those who attended these trainings, to communicate who families can turn to in their community if their child is burned.

Burn &Wound (B&W) Ointment is made from honey, lanolin, olive oil, wheat germ oil, aloe vera gel, wormwood, marshmallow root, comfrey root, white oak bark, lobelia, vegetable glycerin, and beeswax. Some of the ingredients herbalists stated were used for anti-inflammatory, while others protect moisture from escaping from out of the wound. B&W Ointment is rubbed onto the entire surface of the burn wound. It is yellowish in color, and whipped with a wooden mallet until soft enough to spread without pain. On top of the layer of B&W Ointment, healers lie soaked Burdock leaves to help with pain control and additional anti-bacterial treatment. Over these layers, gauze is wrapped around and around until a thick enough layer will prevent any wound seeping to be absorbed by the bandage. Then, a blue chux is taped on top of the gauze layer to keep the child warm and prevent the bandages from falling off (Refer to Pictures in Appendix G). Ideally, this entire treatment is done twice daily, and the wound stays completely covered for the first few weeks after the injury. Then, with tolerance, there might be a possibility to air the wound for a short time period in between bandaging. With both of the individuals using this treatment, they did not tolerate natural air to their wounds for very long without wanting them covered again.

With confidence in this treatment, the two families whose children had extensive burns and participated in this study were able to treat their child with this B&W ointment and without seeking professional medical services. One child, David Renno, was burned when he accidentally tipped a bucket of boiling lard over the top of his body. According to the herbalist's journal, he was burned from head to toe, with 3rd degree burns on some of his extremities[9]. The other child, Eldon Wickey, was burned when he dropped a bucket of boiling water down the side of his right leg; the water pooled inside of his boots, and he suffered 3rd degree burns around his ankle and the top of his foot.

The Renno's sent their older daughter to the neighbors for help immediately. Within hours, the two trained herbalists, Elaine and Miriam, were there to help treat the burn with B&W Ointment and Burdock leaf. They kept David Renno completely wrapped for six weeks, and Elaine and Miriam stayed almost full-time in the house for the first two of those weeks. After that, David's mother helped with the changes and other women who came to help the family throughout this difficult time. They gave him a large amount of Emergen-C, and as many vitamins as they could give him to build him up starting on the day he was burned. Whatever he would take, they would give to him. They gave him as much water as he would tolerate, or orange juice. They tried anything that would give him liquids and protein without too much sugar. They were savvy in telling me about what would heal the burns fastest.

As David's father described their decisions, he would say, "We just wanted to be at home," or "since he never went into shock, we left him at home," or,

> We were concerned for the first few days about a shock. We asked Elaine and Miriam, 'What will we do if he is in shock?' They said 'Call 911'. They don't want to get into that [healing shock] because it requires a lot of education, and they don't have the money to keep the materials on hand. They don't want to charge and if they knew more they might have to charge for their equipment.

David was healed within a five to six months, and today has a minor pink scar on the inside of his right foot, and a 2 cm pink scar below his left thumb; his mother figures that these scars are there because the ointment might have rubbed off or air got to those spots

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[9] This is a retrospective case, so personally observing this burn was not an option, and there are no pictures. Citing this burn as partially 3rd degree is from the journal of the herbalists while they were treating him. Her assessment was based on burn depth and skin appearance.

during the healing. The burn happened in the fall, and David's mother said that she could tell he was still sensitive the next summer when walking across their gravel driveway barefoot. Other than that, he seemed comfortable without any trouble with his skin.

Eldon's family, on the other hand, have a different story for treating his burn, although they used B&W/Burdock treatment on and off. Although Elaine and Miriam are not confident that his results were as good as they would have been with consistent B&W/Burdock treatment throughout his entire healing process, Eldon had a minor reaction to the strength of the Burdock leaf and this treatment option didn't seem ideal to his family. Eldon's family thought that his skin under the Burdock leaf was too red and irritated, so the family switched treatments in between visits with Elaine and Miriam without their consent or recommendation. They would try olive oil under saran wrap on his wound. Or they would try "chickweed salve" or "calm cream". Elaine told me, "The Chickweed has lavender and vitamins in it. Calm Cream has aloe vera that helps healing and soothing for his skin. They both would work fine if you wanted to use one of them consistently." Finally, Elaine and Miriam stopped helping Eldon's family in treating the burn because they didn't feel like Eldon's parents were working cohesively with the same goals or treatment choices as they were to heal the burn.

Elaine and Miriam lived a few miles from the Wickey home, so it was more difficult for them to get to that home; in addition, without telephones, the Wickey's didn't know what to do in between the herbalist's visits when Eldon's skin looked irritated. Elaine and Miriam told them about the signs of infection, and the Wickey's said that if it looked infected at all, they would take him right in to get some antibiotics. Eldon's burns healed within a couple months, but he has severe scars on his right calf. The scars don't bother him or his family because he wears pants year-round and no one sees that part of his body.

Parents prioritize this home treatment for burns because it saves a large amount of money, it possibly avoids skin grafting (a deep fear in many parents for their child), and their child can heal at home where everyone is more comfortable. In order to avoid the risk of nosocomial infections that often accompanies children with open burn wounds in the hospital, families would rather stay at home than go to the hospital. In addition, families were eager to share about this remedy; the community takes pride in this method because of the wide array of success stories within the past few years of its existence.

The deep-rooted detestation of skin grafting is ever-present in articles within *Plain Interests,* with ample stories from parents of examples of seeking elective surgery for their children to remove skin grafts. One family took their young girl went to Mexico to have her graft removed surgically. Another family took their daughter to a physician in the U.S. who was willing to remove the graft and oversee the parents use B&W ointment with Burdock leaf to heal the skin back to its natural state. The reasons that skin grafts are so upsetting families include a) the inability of the skin graft to grow with the child and requirement for ongoing treatments over the child's youth until fully grown, b) the heightened sensitivity to heat and cold within the grafted skin areas, c) a skin graft does not look or function as well as natural skin.

This impacted the participants in the study, and to no surprise, they also avoided medical intervention at all costs for burn treatments. When speaking to the bishop in the Renno's district, he said,

> Lindley Renno ran the risk of not taking his child in because they are worried that if they do those things to try and cure the child and it doesn't work and they take the child in, the child will be taken away. They heard of a family (maybe in Indiana?) where the parents tried to take care of the children on their own, and the state came to take the children away [shaking his head]. The children were crying so much that they had to leave their parents.

The legal implications of treating children's burns without professional help is discussed later, in Chapter 7.

Complementary Therapies: Integration

There is a distinction between families in regards to integration of complementary or alternative medicine and conventional medicine. There was a balanced mixture and even some families who used only conventional medicine for their children with chronic illnesses (besides daily vitamins). Children’s chronic illnesses ranged in severity, but for children with diagnosed chronic illnesses families trusted and relied on professional guidance for their child over traditional home remedies or Amish herbalist treatments.

Despite varying rapport with their long-term HCPs, families continued to relinquish as much of their independence on choices for treatments for their children. Families remained “compliant” to biomedical treatments in the eyes and perspectives of HCPs, but not one HCP was aware that families were also using their own remedies at home in between visits or biomedical treatments. Families were using both, and trying to satisfy both their own tradition and the biomedical recommendations of their HCPs.

Although the Petersheim’s follow closely to their regimen for taking Factor IX their sons’ hemophilia, they use red pepper packs as complementary therapy when the boys have minor bleeds. Red pepper packs involve taking a pinch of cayenne pepper, or powder red pepper, and place it inside of a cut or wound until the bleeding stops; if necessary, she places a cool cloth over top of the red pepper pack to keep it in place. If the boys need Factor IX, Rosanna doesn’t have a problem giving them a shot as soon as they need it. If it’s something like a small cut on their hand, she will try the red pepper pack first. Since the boys shy away from needles, sometimes they prefer this treatment. Rosanna doesn’t necessarily have a specific threshold of when to stop using red pepper packs and start using Factor IX and doesn’t discuss her use of this remedy with their nurses or physicians.

Similarly, Alma Martin tried complementary treatments on her son’s kidneys when they would flare up with nephrotic syndrome. Part of his follow-up care is to seek a HCP for the appropriate treatment if his kidneys flare up during other illnesses such as a cold or if he gets dehydrated. If Jacob becomes ill and his fluid balance is compromised, or he starts to experience edema or spilling protein in his urine, then the medical treatment likely involves steroids. However, she was willing to experiment a bit with home remedies that she knew worked in similar situations. She explained,

> When David was sick for a couple of days with a pain in his back, I thought for sure we were going to have to go in with his kidneys. I had some Burdock around, and I decided to try laying them on his back- over where his kideys are. I soaked them and put them on there, and wrapped his body with saran wrap to keep them in place. The next morning, he woke up and peed and it was dark brown. I thought we were in trouble and his kidneys weren't working. I checked it for protein, and it was clear. So, then I wondered if it was the Burdock leaves flushing the toxins out. Then his next pee was a little more like it should look, and it was clear. Then, by the next time he was back to pretty much normal. So, I just wonder why not try it if you know it can't hurt!"

Although Alma takes her son in for steroid treatment if his kidneys are spilling protein or if he has edema anywhere, she also uses this method frequently to try and calm the kidneys before medical intervention is required.

Rose Schwartz battles a severe case of glaucoma secondary to a congenital retinal disease; she requires multiple eye drops daily. Recently her eye pressures have been well regulated. Vernon (her father) confessed, "…She started sneaking in her own remedies, and then it got much better! She went back for her check-up and they said her eye pressure dropped so much, she can go down in her eye drops and get glasses." Rose clarified, "I shredded potatoes and put those on my eyes." Her mother said that she also takes extra vitamins called VisioPlex and Gold State. After inquiring about where they heard of these medications, her father said, "She heard it from her uncle's wife." Rose's mother filled in,

> She said that when her children get dirt in their eyes, she puts potatoes on them to draw it out. So we thought we'd try it on her eyes….We didn't tell the nurses because we didn't know what they would think….they don't want us to use them unless they are proven!

During her clinic appointment, she denied using any other medications besides the prescribed eye drops to both her nurse and physician; her mother said that they were concerned that they might think they were "weird" for trying these other treatments. At Rose's eye appointment months after she said in between health visits that she said she stopped using the potatoes on her eyes. There wasn't a need to continue using them when her eyes were consistently at a tolerable pressure level.

Complete reliance on biomedicine did not suffice for some families, and they were willing to try other options. If results were positive, such as with Rose's eye condition, then they continued using their home treatments in addition to their biomedical treatments. Amish families live outside of common stream society, and must use a degree of self-reliance, even though they have scheduled check-ups with their providers. If it isn't harmful, families tend to try out remedies suggested by their neighbors, families, vendors, or herbalists. Why not at least try what those who are close to them recommend? These resources influence their decisions about treatments just as much as their HCPs, or even more sometimes, because they live with these resources on a daily basis.

In addition to these home remedies, families sought the assistance of alternative types of healers, such as reflexologists or chiropractors. Some families went to see chiropractors in other towns, as described earlier, and other chiropractors were willing to come to the Amish homes in this community for regular visits. Each family had a unique chiropractor, but some chiropractors were well known across the community. One chiropractor in South Dakota was used when local chiropractors didn't seem to be satisfying the family's needs; families would travel together for week-long intensive visits to try and heal their ailment.

As in many cases with Amish families, when a treatment option becomes tradition and common in the community, then families use them. However, one mother described her confusion about the point of physical therapy because she was so used to chiropractic treatments. She said,

> I don't really think we needed that [physical therapy]; I'm not sure what that was for. We usually go to a chiropractor. We are so hard on our bodies. I think we do work that is a bit too hard for what our bodies are made for, and we have pain in our necks or backs and we go to a chiropractor. [She was rubbing the back of her neck as she said this.] I'm just not sure what a physical therapist does…

Children with hemophilia see physical therapists once a year to be sure that their joints are functioning correctly and not developing any deposits or inflammation over time. However, families would prefer to work on their bones using a chiropractor instead. So, families with hemophilia, see both physical therapists and chiropractors throughout the year.

The mother of the child with nephrotic syndrome consults chiropractic treatment from a professional chiropractor who focuses in on kidneys. Dr. Hunker has been the family's chiropractor since their mother was a little girl, so they know each other very well. Alma prefers that Jacob see Dr. Hunker at least every six weeks, in order to straighten him out. This past winter, Jacob had an ear infection that delayed his chiropractic treatment, and Alma said to me,

> So, then it was six weeks again that he didn't have it [chiropractic treatment]. He just can't go that long without a treatment. Hunker said he was really crooked, and I think that's probably what caused the ear infection. He [Jacob] wasn't right….Dr. Hunker says that he has an 'octopus' at the top of his spine where his spine met his brain. If that is messed up, then he just doesn't do well. Dr. Hunker corrects the alignment of his spine so that it's straight.

Alma notices that Jacob's condition maintains in a place where she would prefer if he has these treatments. The other children do not have as frequent of treatments as Jacob, but Alma will give them treatments as they need.

Within this Amish community was a reflexologist, who is not practicing or seeing families any longer. Families would mention seeing this reflexologist to help after injuries or with illnesses. After David had completed his burn treatments, his mother took him to both a chiropractor and the reflexologist to help build his energy and strength again. She told me, "He would sleep and his arms were heavy with the bandages and that would weigh down on his shoulders. Seeing the reflexologist helped a lot." She believes that these treatments helped him to recover fully without any slowed development in his muscles. She didn't mention how the reflexologist was different than the chiropractor, but families can ascertain the services they need from their child's symptoms. These treatments were complementary to his burn treatments and not necessarily a “routine” part of Elaine and Miriam’s burn therapies. Decisions to see additional therapists remains in the control of the mothers, most often. Fathers sometimes will travel with the women and children to chiropractic or reflexology therapies, but not always. Also, the use of these alternative therapies is not consulted with the family’s full-time HCPs. Alternative therapists become one piece of the network of treatments that families use for their children, in addition to home remedies and biomedical interventions, therapies, or treatments.

Room for Increased Integration

Elaine, the herbalist in the community, stressed that there is an increased need for acceptance of some of the Amish remedies within the hospitals where they receive treatment. She said,

> We want them to let us know if it’s not going to work with theirs. We need to know what will interact and what we can use at home. We know that people need to see the doctors when they have to….We just want to use home medications as much as we can if that’s possible…. We want to use our treatments if they will let us and if they will help the patient, like we know they will. If we can’t use our treatments and the answer is ‘no’, give us a reason.

Bishops and herbalists alike urged the acceptance of more of the Amish remedies by physicians. Families were hesitant to bring their use of herbal remedies up to their providers. Stories of some providers (physicians and nurses alike) allowing the use of Amish remedies inside of hospitals spread through *Plain Interests*, and this is still a growing interest among the Amish community. Their intent would be to use home remedies as much as possible in the safe care of the hospital if hospitalization is required. In one story from the herbalist, she applied the B&W ointment to her uncle in the hospital, after great hesitation from the staff. After his wound had healed, she remembered the doctor’s final exchange with her, “And you know what? I passed the doctor one day in the hallway, and he grabbed me right here on the arm (pointing to her forearm) and said, ‘you’ve done a good thing here’.” These moments give the Amish courage bit by bit.

Family Insights About Herbs

Families used these aforementioned treatments for their children’s remedies, but did not always verbalize the pattern of use. However, some insights into the final decisions to use these treatments aid in understanding parental motivations for their behavior. These insights from herbalists in the community, bishops, or parents help to connect the pieces of how and when families use certain remedies.

Because so little research is readily available about natural remedies, vitamins, and herbs, Amish herbalists and families use intuition and experience to guide much of their opinions about these treatments. Some herb and vitamin books will clearly define side effects and dosages but often have disclaimers that these same treatments haven’t been tested in clinical trials. With a reliance on word of mouth and personal experience, Amish parents are willing to try these remedies. One herbalist said, “I get strep throat frequently, and I take six of these tablets (from a jar that says, ‘Throat’) every half hour until the soreness goes away.” Looking at the bottle, she read “Take four tablets every one to two hours. Oh well, you can’t have too much because it’s natural.” Although the ingredients were not obvious because they were all abbreviated, “kerr phos” was part of the list. She added, “Go ahead and try it if you want. This is the medicine that most mothers give to their babies and children, so I know it’s safe.”

Not once in discussions with parents about any of their home treatments did safety concerns arise. However, families with children with Hemophilia B had been taught by their nurses about herbs that were contraindicated for children with hemophilia. When referring to herbs and vitamins that they do give their children, including those safe to administer to children with hemophilia, parents didn’t mention any sort of strategy to decipher a safe amount.

Some herbal remedies are costly, but families perceive the costs of these remedies cheaper than a clinic visit, or worse, a hospital stay. Microlyn (used for common cold symptoms and sore throats) costs around $30 a bottle, but families are quick to purchase this large bottle. A chiropractor who works frequently with this community said,

> I know the families rotate through a lot of natural methods before they go in to see a doctor. They want to save $5 here and there, but then they'll line up for any new gimmick that comes their way. They've got a lot of naturopaths who will go out to the community and set the families up with some natural medicine to take, and they all go nuts.

Although these families do not spend the money on preventive recommendations of health care visits or teeth cleanings, they will use these other remedies to keep themselves healthy along the way.

After David healed from his burns, the cost of treatments, including donating money to Elaine and Miriam for their time and supplies (including other oral treatments such as vitamins purchased), was around $900. They compared this to their daughter's stay in the hospital for four days with antibiotics, costing them around $10,000. When considering the cost of medical care for children in the hospital, the father accounts for missed days of working. David's father said,

> We spent over $12,000 for Suzanne in the hospital. They said if we could put some money down, they could discount the bill. They got it down to around $10,000. We took a bank loan out for three years to pay it off and save up the money. Then, a couple years later, we got billed for something else that they didn't charge us for before. We had to come up with that money because it wasn't in the loan.

Even if families are willing to spend more money on some natural remedies, the elimination of these frighteningly high costs of hospital stays or other health care procedures, is worth it from their perspective.

The Amish community holds a great deal of trust in natural medicine. This trust allows them to practice with herbal/natural remedies frequently because they have more access and familiarity to these than pharmaceutical or even over-the-counter medications.

The community chiropractor described this story to me, to explain this deep-rooted belief in herbal remedies,

> The Amish are the first to see what the body can do before they will run off to see a doctor. They hold back. I had one Grandma—I was working on her 3rd and 4th generation family. When I went to the house, her blood pressure was 200's over 100's, and I was worried she was going to have a stroke in front of me. She was pale and sweaty. I gave her an adjustment and it came down some, but I told the family she needed to go see the regular doctor…She ended up having a small stroke. She is coming back slowly with talking and that. The family is convinced that if I hadn't done the adjustment she would be a lot worse, and I think there's something to that. They really believe in it.

Sources of Guidance: Popular Health Care Practices

Without access to the Internet, television, or radio, Amish families find alternative resources to help guide and provide their home remedies for children's illnesses and injuries. These include Amish herbalists, herbal stores, *Plain Interests*, their families, neighbors, and word of mouth. One of the herbalists described that families learn about treatments from "…reading papers mostly. I guess, it's word of mouth. There's a woman in Montana who reads up on herbs and mixes her own. She has advertisements and stories in the papers that we can read." Discussed in the following chapter, letters from HCPs guide these families' decisions and care management involving biomedical treatments. In between these biomedical treatments lies a web of support within the Amish community to support the daily management for these children.

Herbalists

Fannie, Elaine, and Miriam are the individuals serve the community by giving advice and providing medicinal products to families through their herbal stores. They are informed by books about natural remedies, other Amish community members who also have a vested interest in health and health remedies, and by those who served in these positions before them. Each has her own domain in the community, and families know those boundaries. For minor injuries or illnesses, or questions about herbal remedies, they sought advice and resources from Fannie. Miriam joined Elaine in workshops to learn about burn treatments, and they are both well equipped with both materials and education to handle burn treatments in the homes of the families in their community, without the support of professional HCPs. The community respects these three as knowledgeable herbalists in burn specialty.

Malinda Renno describes how she decides which herbalist to involve in the care of her one and a half-year-old after his burn. She kept a journal during his recovery, that included a description of his symptoms, who they involved with his care, and how they treated his symptoms. Miriam and Elaine supported the burn treatments, as described earlier. They gave recommended herbs to help his skin heal, such as Vitamin E, yogurt and pretzels. Echinacea and Golden Seal were used to build up the immune system, recommended by Elaine and Miriam. Malinda received Golden Seal from Fannie, who gave the family a small bottle from her large bulk container.

Although Fannie wouldn’t describe herself as such a widely used resource, families described story after story of relying on her advice prior to giving their children some recommended herbal treatments. Fannie’s domain included selling these herbs to families, and providing them information as she learned it from books or her own experience. Fannie had two text books that helped her to identify doses and possible remedies for common colds or similar illnesses, one of which she purchased at a garage sale. When interviewed about her position in the community, Fannie described herself more as a vendor than a community care resource.

Fannie has very specific limits on the care she provides for others in the community. She told me, “Most of the illnesses I see are things like diarrhea, cough, cold, ear ache, throat, flu...illnesses that are more common and not chronic. Once in a while, someone will come in who has something more progressive, or terminal type of illness like cancer. I usually have to tell them that I don’t have anything that will take it away but I can give them something to help out a bit.” Fannie had a variety of treatments that she would give to individuals who stopped by her store who had chronic conditions;

she was more than happy to suggest something to complement their biomedical treatment, but always encouraged them to seek a cure or treatment with a professional doctor or specialist besides her care. Elaine and Miriam also agreed by saying, “We go to Finneola if it is beyond vitamin help and alterative medicine. We don’t mess around with that if we know they are going to need stronger care anyways.”

Some of the examples Fannie gave to me for those with cancer,

> A good one is ‘Essiac tea’ (she spelled it out)]. That cleans out the system. There’s another blood cleanser but I can’t think of the name right now… the tincture is a liquid with like glycerin or alcohol in it that sits on the red clover and burdock for a long time. Then, they take out the herbs and use the left over glycerin or alcohol to make the tincture.

She told me that Burdock and red clover help to cleanse the blood and the system to help the individual feel “cleaned out”. Another Brazilian herb she mentioned was “pau-d-arco” to help with cancer as a tea or steeping the leaves. She knew both doses and preparation of a variety of herbs such as these. However, she is the aunt and cohabitator with the family with a child with Hemophilia B, and was unaware of their treatments and did not assist with any of the administration of their Factor IX. This showed that some things she had great knowledge about, while others she did not involve herself with.

She stated, “I bought the products from a woman who was getting older and wanted to quit….I am in charge of ordering large supplies for families [straight from the companies].” She brought me a pamphlet, copyrighted in 2002 from one of these companies. There was a disclaimer on the inside cover that said that this pamphlet by no means is meant to treat symptoms and someone should seek medical advice if they have a medical problem. There was also a children’s section in the pamphlet to describe herbs and vitamins that are especially good for children.

This not the only community with access to Amish members who are passionate about accessing and caring for families with herbal remedies. Inside of the nation-wide newsletter *Plain Interests* is a list of herbalists in communities across the country. This helps Amish families to know who to contact if they are traveling or new to communities.

In addition to herbalists inside of this community, two families mentioned visiting an Amish healer/herbalists in a local community. When one family noticed their son had an enlarged belly and grew weaker as he aged, they tried to work through decisions about when to go seek professional care. His father said,

> We went down to Klocton. There's a man there who will help with illnesses of some kind. He felt that Alan had a hard lump in his liver and that worried him. He understood what was wrong with Alan but couldn't do much for him without medical care.

This family ended up seeking professional care in Mexico for their son, but never sought professional services for his condition in the U.S. There are access points within Amish communities that help families to make these difficult decisions that are not clear-cut, especially for children with chronic illnesses.

Herbal Stores

There are three locations that families can find herbal medications or vitamins. Two of these stores were owned by the herbalists described in the previous section, while another store is owned by an Amish man who also runs a farm. His store has other tools inside of it, but has some basic vitamins that families in the Northern part of the community can purchase.

Fannie's store is located in the center of the community, where two of the main roads intersect. Her herbal store is about 10x4 square feet, a long room separating the two houses. It has its own door to the outside and two doors to both houses. Most of the shelves are filled with treatments that serve as antidotes, "building up", or cleansing the system. Fannie's vitamins had manufactured labels from two large vitamin companies. The third store is owned by Elaine's father, Dan Miller. Immediately upon entering the store is an aisle of remedies. The remedies were in the form of hand-labeled dropper bottles, and small type-labeled[10] ointment or salve containers. These remedies were for

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[10] Because there are no computers, these labels appeared to be typed with a type-writer or a label machine. Both of these latter options can be run without electricity.

treatments rather than prevention or daily maintenance. They included spider bite salve, brown glass medicine bottles in a small box labeled “poison remedy”, eucalyptus cream, and glass green bottles for arthritis and gangrene; none of these had ingredients listed on them. Dan, the proprietor, provided information sheets for PoHo Oil. He said, “Poho oil is a sort of ‘traditional’ kind of thing that has been around for a looong time. I can get you a sheet that will tell you how to use it, if you haven’t ever seen it before.” Dan started with a story as he walked back with the instruction sheet, “A man had a rare skin disease, and his doctors couldn’t seem to find a cure. I gave him some of this salve [pointing to a silver tin] and told him to just rub it on his skin where he needed it. He came back in a couple weeks and it was all cleared up. I couldn’t believe it!” Not only were these stores easily accessible to families, but the owners were heavily involved and cared about the success of these treatments.

Plain Interests

Two newspapers permeate the Amish community. The long-standing *Budget* is a place for each community across the country to update everyone else on who is in the hospital, who is visiting the community, baptisms, weddings, funerals, etc. *Plain Interests* lies on the table or on the shelf of almost every home, and it crosses the lips of most families during conversations about current events in the Amish community or natural treatments. This newsletter served in close comparison to a paper-version blog or Wikipedia in which Amish community members across the country (and Canada) would write in with their stories, experiences, and a variety of advice for others to follow. *Plain Interests* has much longer and more in-depth articles than the personal entries in the *Budget*. Health and health treatments are among the most popular topics, providing readers an abundance of experiential knowledge from fellow Amish community members.   As a venue for both requesting help and giving suggestions, or just sharing stories, *Plain Interests* serves as an information-packed resource for these families to treat their children's illnesses.

One of the recent hot topics in *Plain Interests* is the burn therapy discovered by an Amish man in 2007. Families can read case after case of others who tried this remedy and the outcomes. A few Amish individuals, including the man who created B&W ointment, presented the information and success stories of this therapy to a few hospitals. Hospitals around the country are allowing Amish families in their areas to use this specific remedy combination for burns alongside their biomedical treatments. *Plain Interests* stories highlight nurses who let families slip their treatments in the back door. Other stories describe when families get in trouble with hospital administration for using their refrigerators for their salves, even when permitted by the hospital employees. Other stories express the ideological standings of the Amish community on items such as the FDA standards, proper education, organic foods and farming, farming techniques or tools, vendors considered trusted, etc. There are calls to action on political levels if needs be, or results of some government decisions that might impact their community. Although Amish families don't talk about the tenets of their religious stances on day-to-day passing, this newspaper reflects examples of what the Amish stand for and decisions as a large group.

Family

The hierarchy in an Amish community clearly places the bishops and ministers among the highest in decision making in the public eye. For families making decisions about the management of their child's health condition, however, bishops allow families to work within themselves without oversight from the church. One bishop described, "We are not in those decisions. I help families with what to do about the cost of things… Usually families will talk to their own families about what to do; a younger couple they will ask their parents." Another minister agreed,

> Well, you have to be careful about that because we don't know how to give medicine…I can't think of a time that people couldn't do something for their own health. That's their decision. They don't come to us to decide what to do. They usually just go to people in their families to think about what to do. We just help to pay for it as a community. They have to live their lives within the rules.

Parents echoed the sentiments of the bishops. Rosanna Petersheim said,

> I have cousins who have it. My mom has it and it's in their family….she has four or five sons [with hemophilia], and she has one story after the other of what she does…I remembered my aunt who told me about the red pepper pack. We finally were desperate enough we just did that. He screamed pretty hard. It was probably pretty strong for a little mouth like that.

Rosanna knew the seriousness of hemophilia and the requirement for biomedical treatments because of her family background.

Bishop Involvement

Familial advice impacted important and ethical decisions for parents of children with chronic health conditions. Meanwhile, bishops were used by families for tactical recommendations of what other families have done in these situations or what might not be inside the bounds of the Amish traditional tenets. The Byler family who took their son with an enlarged liver to Mexico asked Eli to help them make a decision about where to go for care. Gideon Byler, Alan's father, told me, "When we wanted to go have him checked out, Eli recommended that we go to Mexico for treatments to the same doctor that Eli and his wife went to for her appendix operation. Eli said they treated him very nicely and gave me the phone number to contact the clinic…they told us that they recommended we go to see this doctor and the best thing would be to bring Alan right over to their clinic."

The bishops carry the global perspective of the weight of decisions that families make for their children because they see a bigger picture that one singular family might not see. Bishops can sympathize with families because they have their own children and families. In observations, I did not observe a time when a bishop dictated a decision to a family; their guidance and wisdom serve as support systems for a family making decisions for the care of their child. Bishops aid families in seeking payment from the community to assist with their treatments and leave any final decisions about treatments to families. One district in this community raised $50 each month to help the family with PKU pay their bills, and this is overseen by the bishop.

One winter, a large home with 12 children living at home burned down in the middle of the winter. It was a horrific fire that caused total destruction to their home, requiring that they rebuild it from the foundation. Their father, describing the help they received during the fire, said,

> The Red Cross came the night that our house burned down, and said that they could help us out and give us a place to sleep. I told them that we had so much help- and we did!- that they should help those who don't have so much help. They kept insisting, so I asked Peter [the bishop of his district] if we could take their assistance. Peter thought that since they kept insisting that it would be OK to accept some of it, what we needed. Well, we're not allowed to take government hand-outs, so I wasn't sure….

Another bishop's input was sought when a man needed to be put on a leg compressor that required electricity. The bishop approved it because that was the only use for that electric device and it would keep him healthy. For temporary treatments, these technologies passed the bishop's approval. In these circumstances, the bishops were trying to help families stay in the Amish community but also lead healthy lives.

School: Health Education and Children Fitting In

Schools served in general health education, health promotion, and supportive care for children with chronic illnesses. Health education happens through student self-study using the books and workbooks available to the classrooms. Unfortunately, most books in the private Amish schools are outdated including their health books. On the top shelf of one of the prominent book shelves in the classroom was a set of World Book Encyclopedias, copyrighted from 1961. The health and science books were copyrighted from the 1940's through the 1970's.

Betty said that they all use the same books donated by the other school districts. From a brief skimming of these books, a chapter instructed readers to receive all of their immunizations. Betty never commented on any of the specific material that she covered with the children about these health books. "They pretty much just read them at their desk. The younger children, I talk to about the cleanliness and tooth brushing. But the older ones are usually able to just read the books and answer the workbook questions on their own." There was a lot of complex information, such as how the immune system works, but Betty lets them primarily learn this material independently from their texts and then answers any questions. An hour for health class happens once a week at all of the Amish schools, and children use this hour to complete their workbooks. Betty's approach to health education echoed the other schools. Shady Oak had two young Amish teachers, both in their first year of teaching. They also allowed the students to primarily learn health through independent study, using outdated health books donated to the community from the local school districts.

The English teachers working in other districts had concerns about the health education but no resources beyond what the Amish schools were working with. One teacher said, "I just don't feel that they're educated on health issues. We don't educate about health here at school…." A school nurse comes once a year to screen children's eyes and hearing, but minimal education. The teacher admitted, "This was a book I found here, provided by the school. It's an Amish text book from Pennsylvania, published in 1957. The topics are mostly nutrition. You can see that the things that give energy to children are things like lard and meat and eggs. I do not have them read from this. They do have workbooks that they do that match the more recent edition of this book (1992). I've probably, since I have no other health materials, I will probably use this with them when I run out of things to do."

Despite the concerns of these teachers, children learned health promotion through their daily activities, not necessarily from books. All of the classrooms had sticker charts for children who brushed their teeth in the morning before school. The teachers gave time to the students to wash hands before and after eating their lunches. Betty said, "There's a nurse who comes out here sometimes to see about their flu shots…." For other school checks, the Amish run schools don't have an associated school nurse, so it's really up to the parents to watch for anything abnormal in their children; the schools don't take part in it.

Families who are part of the English-taught school districts rely on school nurse for annual screenings with the children. Vernon Schwartz told me, "The school nurse was actually the one who caught it [daughter's glaucoma], up here at school. She would have been about 12 at the time they caught it." Although not their main source of health education, schools are an outlet to practice community health for children. The schools in this community provide access points for HCPs to reach children for health promotion, check-ups, and screenings.

Amish teachers do not take responsibility for the medication or treatment management of the children with chronic illnesses; they leave all of those cares to the parents. English taught schools monitor that treatments are being given appropriately but do not administer treatments in their schools either. One of Betty's students had a tumor removed from his leg, but he brought his own dressings to school and she didn't help him with the dressings at all. One teacher at Shady Oak called Malinda is a sibling to children with PKU who attended the school where she teaches. In regards to these children being teased (with unique lunches and diet restrictions), Malinda said,

> I think maybe my older brother had some of those problems, but we really try to avoid any teasing between students. We teach the students not to talk down to anyone else for being different. My brother and sisters with PKU now in school don't seem to have a problem. But they might know a bit more about it than my older brother did.

Strict behavior rules in these classrooms provide support to those students who are different and require additional care.

As described earlier, Betty takes great care in Rebecca, treating her with special accommodations to her best abilities while managing the remainder of the class. She said, "At first, we had her going to school with the other children…It didn't seem right to be holding them back when she needed help and she wasn't getting any better…." As much as possible, teachers try to integrate and keep children together, even if they have special requirements or medical conditions.

Families Decision to Seek Care Outside the Community

When a child was starting to have abnormal symptoms, a cascade of decision making drove parents to treat those symptoms with their own means and/or go to see professional care. The wealth of knowledge about herbal remedies within this community did not necessarily preclude parents from seeking professional health care services. Parents who were comfortable in giving those herbal remedies to their children, were also hesitant to manage their entire illness independent of professional health care recommendations from experts. Parents knew when their child had an illness that was different than a temporary cold or flu. From the moment that a child's symptoms were not being alleviated by home remedies, parents sought outside help. Some parents chose to try treating their child with their own remedies before taking him or her to the doctor's office. Some parents decided to continue to use their own home remedies to complement the biomedical treatments they received from professional HCPs.

Refer to Table 12 for a summary of when and why families sought care, as they mentioned during interviews about their children. As families told their stories about receiving the initial diagnosis of their child's chronic illness, the time varied for them to recognize symptoms depending upon whether or not they had it in their families. Those children caught by newborn screens included children with CF and PKU. Children whose families had a history of hemophilia knew to screen their sons immediately. One mother of children with hemophilia was unaware that she was a carrier. She remembered her aunt telling her that if her sons lose their teeth and start bleeding heavily in 9-10 days, they may have hemophilia. She waited that long after her oldest son lost his tooth, and when he started bleeding she took him to get screened immediately. Another family, unaware that hemophilia was in their family, took their son in to the emergency room 24 hours after he continuously bled from hitting his lip. Other symptoms that cause parents to act immediately were severe burns or infected burn wounds; one family tried to treat their burn wound at home for one whole week before consulting the herbalists, but needed to contact them when the wound began to show signs of infection.

Other families struggled when they were uncertain what condition their child might have. When one of the children with PKU developed thrombocytopenia, the mother wasn't sure what to treat his vague symptoms with until he hit his knee and it swelled with blood; she took him immediately to the emergency room when that happened. One of the children had such a vague symptom as unrelenting diarrhea, the physician was unable to track down her diagnosis and trialed a few antibiotics until the diarrhea ceased. Unfortunately, the family attributed this child's mental retardation to the final of these antibiotics and perceives the irreversible damage due to the physician's error. Finally, it took months of vague discomfort symptoms for the parents of the boy with an enlarged abdomen to take him to medical care. These families with children with vague symptoms were hesitant to bring their children immediately to a clinic, and received diagnoses later than those families who understood the illnesses or had their children screened.

For injuries, families who were trying home remedies had a slight delay to take their children to urgent or emergent care. When one mother's son hit his knee with a pitchfork, she tried home remedies at home first, but when the swelling and pain wouldn't go away within two days, she took him to the hospital to receive antibiotics. Symptoms that scare families, such as consistent and heavy bleeding, seizures, or sudden palor and weakness brought these parents to bring their child to the emergency or urgent care immediately. Children who had fevers or ear aches that families tried to treat at home first, took parents multiple days to make the decision to take their child to receive professional care.

Occasionally, parents were bringing their child to services beyond their family care when their child's symptoms weren't drastic but they didn't want them to have permanent damage or continue in discomfort. Regularly, Rebecca's parents take her to an Amish chiropractor when her confusion seems to be increasing. Although there is no "cure" for her confusion, these treatments seem to ameliorate her symptoms temporarily. Her mother says, "Every time a chiropractor looks at her spine, they know that it's not aligned right. After [seeing] the chiropractor in Klocton, [Rebecca] looks more bright when she gets done and lasts for a couple of days." After his skin was healed after drastic burns, David's mother took him to both the chiropractor and the reflexologist to help build his energy and strength again. She told me, "He would sleep and his arms were heavy with the bandages and that would weigh down on his shoulders. Seeing the reflexologist helped a lot." She believes that these treatments helped him to recover fully without any slowed development.

Herbalists also warn families about symptoms that are concerning enough to take their child or children to professional services. For the children with burns, Elaine and Miriam told the families about the signs of infection, and recommended that if they show any of those signs to not hesitate to seek professional services for antibiotics. Additionally, with the infant who was burned, they were very concerned about shock and told the family that if he was sleepy or unresponsive to " Call 911" immediately. Families heeded this warning but fortunately didn't need those services.

Table 12. Timeframe, Symptoms for Families to Reach Out for Medical Assistance

Diagnosis/Health Seeking	How many days it took from recognize symptom to take child in (family reported)	Symptom that triggered family to take child in for care
PKU-Diagnosis	Newborn Screen	N/A
Hemophilia (1)-Physician	10 days	After a pulled tooth; kept bleeding (tried red pepper packs at first)
Hemophilia (2)-Physician	Screened the sons because mother had hemophilia symptoms	When cut, swell and bruise more than other boys.
Glaucoma-Optometrist	School Nurse Screen-Immediate	Failed screening
Hemophilia (3)-Physician/ER (diagnosis)	One Day (24 hours)	Bumped lip; wouldn't stop bleeding
Unkown Illness-Physician gave antibiotics family considers toxic	During first year of life	Consistent Diarrhea
CF-Original Diagnosis	A few weeks after he was born	Positive CF screen
Nephrotic syndrome-Physician (diagnosis)	Unkown	Swelling when sick
Hepatosplenamegaly-	Noticed first when he was 7 mos. when in hospital for RSV. Within five to six months, he went to Mexico for treatments	-large abdomen; irritable; uncomfortable in bed; crying in bed; didn't want to be held; wanted to sleep on hard wood floor near furnace; catch cold easily
Burn-herbalists	Immediately	3rd degree burn over arms and legs, 2nd degree burns over chest, back, and face ("Since the 3rd degree was not on his core body, we thought the chances were good enough to stay home")
Burn on leg-Herbalists	One week	Signs of infection: reddened, over the burn area, pain, foot swelling
PKU-ER (thrombocytopenia)	Weeks (after noticed he wasn't "quite right", attempted herbals)	Bumped leg-continuous swelling brought him to ER

Table 12-Continued

Injuries/Accidents involving ACCI		
PKU/injury-Physician (antibiotics)	Two days	Swelling didn't go down after a pitch fork injury to knee
CF-Emergency Room Visit (dehydration)	Same day as symptoms arose	Pale and weak
Hemophilia (2)-Emergency room (stitches)	Same day (bring own factor)	Cut on eyebrow from accident; bleeding down face
Daughter-Urgent Care (misdiagnosis at first; had UTI)	"Days on end"	Fever for multiple days, hands were cold, seizure made them take her to the ER
Nephritic syndrome-Physician (infection)	Three days	Ear pain, unrelieved by home remedies

Summary

From the families' perspective, their home remedies used for treating symptoms prolongs the time between needed health care appointments and improves their children's health. This allows for greater independence, lower cost, and alleviating their child's symptoms without causing the child any discomfort in leaving home and visiting a doctor's office unnecessarily. It allows the families to continue with their daily lives, without disruption to the rest of the siblings and household chores to take the time to go to a doctor's office. Finding a cure for these chronic illnesses would be ideal, but in the mean time, families take ownership in caring for their child with the means they have. Some families would rather combine their home remedies with biomedical treatments, while some families hesitate to try their own remedies (or don't know about home remedies for their child's specific illness). Just as one bishop noted, "Some families run right to the doctor while others might wait as long as possible." There isn't necessarily demographical differences between these types of families, but their threshold for seeking outside care is different from one another.

In addition to the ideas about these home remedies coming from a familiar and trusted source, families frequently added information about the cost savings that they experienced by using non-pharmaceutical treatments. If they could decrease the amount of prescription medications, prolong the need for a procedure or surgery, or prolong the time in between health care appointments, then the advantage of taking home remedies is to save money spent otherwise.

Children with chronic illnesses in this community are normalized as much as possible into everyday life with all of the other children. Minimal entanglement with health care appointments and medical treatments allows for this to happen, and parents make great attempts to keep their child's life normalized. It is best for the whole family if this is the case, and children with chronic illnesses can function along with their other children. Over time, parents of these children become masters of accommodating biomedical treatments into their preferred lifestyle without the use of electricity, refrigerators, freezers, or telephones. These families prefer to have as little outside help as possible in order to fit the illness into their own everyday lives the way it makes sense for them. That way, the illness is never in the foreground of the family's concerns but mixed into the background of living a spiritual and agrarian lifestyle together as a family. Outside of the Amish community, other non-Amish students with chronic illnesses might be treated or behave differently. Being wholly in their own schools allows the teachers, along with the parental and community desires, to blend these children into the everyday life of all of the students and school goings-on without legal or medical involvement at a school level. Finally, by attending schools by themselves, these Amish children are able to be integrated into the rest of the class because that is the way of this community.

CHAPTER 7:

AMISH FAMILIES SEEKING HEALTH SERVICES OUTSIDE OF THEIR COMMUNITY

Introduction

Children's chronic illnesses require some specific treatments that cannot be replaced by home remedies. Without other alternatives, families follow these treatment protocols without hesitation. After initially trying home remedies to alleviate their children's symptoms, such as ongoing fatigue, fevers, or a swollen abdomen, parents turned to professional health care providers (HCPs) to treat their child's illnesses. Once within the guidance of professional HCPs and with a greater understanding of the seriousness of their child's disease, parents learned to accommodate and adjust their daily life to fit these treatment protocols into an Amish lifestyle.

The mother of a young boy who has nephrotic syndrome reflects,

> A year ago, he [Jacob] got really sick with the syndrome; they put him on steroids and hospitalized him. He has been decreasing his doses since then and will be off of steroids at the end of the month. We are supposed to have an appointment next week with our nephrologist but we are switching to a new doctor in the same service and can just have lab work around our area.

There is a constant give and take for these parents to incorporate biomedical protocol and follow-up into their lives. This mother is a proponent of using home remedies for her son but knows that these medications will work with his illness on a deeper level than the home remedies she might try. The authority of those treatments comes as a priority for parents once they recognize the severity of their child's illness.

This aim provides a deeper understanding of how these Amish families fit biomedical treatments and plans of care into their lives for the sake of their child's health. Although the biomedical health care perspective is foreign to their perspective, they seek to meet HCPs in a place where they feel comfortable and competent to care for their child. Observations of encounters between HCPs and Amish families brings forward challenges to making negotiations between these two perspectives. By merging observations from clinical encounters, I created a synthesized clinical appointment between a nurse practitioner and an Amish family, found in Chapter 8. The details of the clinical scenario in Chapter 8, such as the disease and specific treatments, were not taken directly from observed encounters during data collection. These details were applied to exact scenarios that I witnessed. I highlight examples from the clinical encounter scenario in Chapter 8 through this chapter, and can be referenced by the line numbers found in Chapter 8.

Managing Health Care within an Amish Life: The Logistics of Accessing Health Care Services

Access Points Close to Home

The logistics of who to see and how to get to health care appointments comes as a challenge to these families, due to their remote location and limited access to health care services. The first physician these families will typically visit is what they refer to as the “band-aid” doctor. There are several of these “band-aid” doctors in small towns and clinics surrounding their community. Three main physicians were mentioned by families and bishops. One in particular is from a town approximately 30 miles away. Families seek care with him more than other physicians in closer towns because he and his partner used to make house calls to Amish farms. Because of the great convenience of this service, families worked with these physicians for years. One of the partners was relieved of his job and the other no longer makes home visits, except on rare occasions, so families are turning elsewhere.

There are two main access points for families when they notice children having severe symptoms. If there are not recommendations, families use emergency services as a primary access point of care. One father explained his strategy for what HCP to see for what condition,

> Most things we can do at home. We don't like to go to the doctor unless we have to. If [child with hemophilia] gets a cut or nosebleeds, we would call [nurse] and she would let us know how much factor to give. But if it's something like a head injury, we would go in right away. For the other children, if it's something small, we would go to [family physician]….I think the last time we saw him was once a few years ago. If it's an emergency or something big, it seems we get sent to Finneola or the hospital anyways, so we may as well just go right there. We will go to [family physician] for a real bad flu or cold that won't go away.

Newborn screening through local providers presents another access point and directives to services most appropriate for their child. Similarly, families will pick emergency services from these nearby towns as access points to refer them onward to other services or providers they need. This story, told by one of the bishops, emerged from multiple families during my first conversations with them,

> Concord will give us 50% off, and Lindley will only give around 20% off. However, Lindley is more inexpensive to start with so we end up choosing Lindley. Two people from this community just had their appendix taken out, one was done at Concord and the other at Lindley. The one at Concord, after the 50% off was around $10,000 or $11,000 and the one at Lindley, after the 20% off was only around $7,000.

Stories like this spread around the community, often by word of mouth, and families will choose the one that is cheaper with fewer stories of disrespectful encounters. For families whose children's illnesses are caught during newborn screenings, such as Cystic Fibrosis or PKU, they receive letters informing them to seek care from the Children's Hospital in Finneola. Because these families do not typically take their children in for well-child visits with local pediatricians, these remain the two forms of access points for families to seek care when they notice their child's symptoms.

Transportation

Once it is clear that a child needs to be taken to a hospital or clinic for care, parents face many logistical options and decisions. These include finding transportation to the appointment, taking care of the farm while they are away, who will be attending the health care appointment, and who takes care of the siblings while the parents are away. It is not customary, or accepted within Amish tenets, that baptized members own or drive any motorized vehicles. Any transportation besides way of buggy requires renting or requesting a driver to transport families to their clinic appointments.

Although these drivers are plentiful around Amish communities, the cost does deter some families from making trips in to a health care appointment. One mother told me,

> When we have to go down there [Finneola] for clinic visits, we always have to get a driver and that's costs money and too much time." Another father explained the costs, "If there's a van for one family, it can be something like .75 cents per mile. But if it's a big 15-passenger van, it is usually .85 cents per mile. One trip to Finneola in one of the big vans can be $140. They have to make a living too. I understand because gas is expensive.

Many of the older individuals will reminisce about using bus or train services, but in recent history those services have decreased while independent automobile transportation increased.

There are professional driver services in the surrounding towns around this community that offer services for long-distance travel. However, one mother vented her frustration with using public vehicles that must obey public laws. She says, "One thing that is hard is that you have to have car-seats for the young children. I have a car seat but it's outdated. I figure the police won't pull me over to look at my car seat, so I don't purchase the new ones every year when a new model comes out." Other than professional drivers, friends or neighbors of Amish families will offer to drive if they have time. Many of the fathers work in businesses with non-Amish partners or coworkers, and they often employ drivers learned about through these business connections.

Farm and Family Management While Away

Managing a farm requires constant attention, even when a child is in emergent or long-term hospital care. Often times, older siblings will babysit younger siblings and manage the farm when parents bring their child to a scheduled or emergency health care visit. However, if there are no siblings old enough, parents will have neighbors or extended family will watch the children at home. Conveniently, many grandparents live on the same farm in a small house next to the main family home; this provides back-up babysitters for when parents need to leave for a day. Some farms include two farmhouses, and siblings will raise their own families in these houses adjacent to the other; this works well for sharing familial responsibilities, such as caring for each others' children. One father explained that when his son went to the emergency room and then was admitted to the hospital, he went with his wife until they were settled in the hospital. Then, the driver brought him back and forth to stay with the other children over night. One of his brothers came over to feed his animals while he was away during the day. This was a typical story from parents as they described caring for the siblings and farm while managing their child with an illness.

Anywhere from one to five family members attended the clinics that I observed. These family members included older siblings, infant siblings, mothers, and fathers. Mothers were always present at every appointment, and fathers were occasionally present. On the annual PKU check-up, the father joined his family in the trip to Finneola. Similarly, the father came to the clinic appointment with his son with CF; those appointments typically involve recommended procedures that he wanted to personally negotiate with the nurse practitioner. However, for the more frequent visitors for routine check-ups, mothers brought their child (and perhaps an infant sibling, for feeding) alone.

Arranging and Deciding on Service Location

Arranging health care appointments is a constant negotiation with the weather, community events, and the availability of drivers. Although these Amish families would set up their next appointment at the current appointment, just as any family would do prior to leaving the clinic, these clinic appointments were considered very tentative. One mother walked away from setting up the appointment, knowing that she would likely be changing it in the future when their other children's Christmas program at school was scheduled. The response of one father when asked about setting up an appointment for the following fall was,

> Well, our big season that's really important is the planting season. Now that that's over, the harvest isn't quite as picky. October is usually when we are thrashing beans, and that gets tricky because we really have to wait for the good days for that. For the corn, it doesn't matter as much because if it rains we can still go out and pick corn the next day.

The unpredictability of the agricultural lifestyle and demands makes it difficult for these families to plan far in advance, as is often required in order to fit in an appointment at large medical centers.

Despite expensive traveling, Amish families do travel independently to Mexico to receive cheaper care, from clinics and providers they feel are more closely in line with their priorities and lifestyle. After receiving information about the benefits and positive experience of a Mexican clinic from their bishop, one family opted to treat their child solely in Mexico. The Mexican clinic prescribed some minor follow-up to the initial diagnosis. While maintaining a daily regimen for their child, including strict diet changes and blood sugar administration, the Bylers kept a daily journal as documentation to share with the clinic. This report was then mailed to the clinic, and the clinic staff was able to give subsequent instructions. Gideon Byler, the father, recalled,

> We were there [in Mexico] until October, and they wanted to do a liver biopsy in October and then give him a life cell therapy through IV in February…. It's a shot that goes into his hip. We didn't know what to think about that, but we went back for it. After that, he started to pick up weight, his color was better, and he has looked very healthy that last year or so. They told us it was a metabolic imbalance.

Without question of the "life cell therapy", the Bylers agreed to a medical intervention that might cure the primary illness of their son. The Bylers have never seen a HCP in the U.S. for their son and don't feel that they need to. When asked why the Bylers chose to treat their son in Mexico, the father responded with cost as the major reason. Meanwhile the mother responded that the hospitals were simpler, and it didn't feel like they were dealing with a large system but fewer people. They appreciated that they were working with a physician who seemed to make independent decisions about cost and treatment, rather than forcing a payment or treatment within a scheduled protocol.

Encounter

In order to provide a summative example of the observed encounters between HCPs and Amish families, the clinic appointment scenario in Chapter 8 will be referenced. The clinical scenario in Chapter 8 represents actual behaviors and quoted phrases from providers and families from a variety of clinical encounters. The family involved in the visit and the health condition of the child with Juvenile Rhematoid Arthritis was used because both of these are inclusive of the many HCPs and family members involved in the visits of the families in this study.

This analysis highlights themes, or common occurrences, within these encounters, including the following: a) body language as facilitator and barrier, b) the use or misuse of communication/appropriate language, c) culturally congruent education, and d) checking compliance. In addition, information from the previous section about the logistics of families coming to and making appointments is highlighted within this clinical scenario. This information includes farming or family responsibilities under consideration while the family is at the appointment and transportation considerations.

The body language observed in clinical encounters of both the families and HCPs initiated either rapport-building and honest interactions or barriers to effective interactions. Whether sitting or standing, HCPs who spoke directly to the child and his or her family, making eye contact, and avoiding restless movements, created a more comfortable environment for families to communicate and collaborate honestly together. HCPs who avoided eye contact, or faced the computer rather than the child and family created less open environments for positive interaction. With the introduction of computers inside of appointment rooms, the temptation for HCPs to sit by the computer and fill it in while speaking to the family created barriers in some situations. In the clinical scenario in Chapter 8, lines 44-47, the nurse exemplifies body language that does not support an effective interaction. The nurse logs on to the computer, with back turned to her patient, and asks questions in standard formatting with haste. Her patient, a 11-year-old girl, also breezes through the answers with haste and incomplete information. Of particular note, the girl denies any use of multivitamins or supplements and admits to using the medication as scheduled. However, later when speaking to the nurse practitioner in lines 177-189, Sarah admits that she does not use the prescribed medication as scheduled. The nurse practitioner was facing Sarah while speaking to her, and used open questions rather than polar (yes-no) question format. This provided Sarah the opportunity to speak honestly about her choices.

Also highlighted in the clinical scenario during the physical therapist examination is a picture of what happens when a HCPs moves through a “one-size-fits-all” examination. Amish female patients do not wear pants because they wear traditional Amish dresses that end below the knee. In the clinical scenario, lines 142-148, the physical therapist was measuring joint movement without providing her a blanket or sheet to cover her legs, revealing her entire lower half during this examination.

Communication

Communication and language differences also caused some barriers and facilitators to effective interactions. Amish families speak a unique German dialect in their communities, and learn to speak English when they start school around five or six years old. In school, they learn English until they are in 8th grade, well enough to read and speak English when in public locations. Because of frequent conversations and interactions with English individuals outside their community, the level of speech is very clear and typically without the need of a translator. However, without access to television, movies, radio, internet, or other forms of public communication, Amish individuals are unfamiliar with slang or popular idioms. For instance, one bishop said he noticed that all of a sudden people were using the work “like” in conversations with uses than just for metaphors. The societal swing of dialect is observed by Amish individuals but not always picked up or understood. In one appointment, a technician was teasing the Amish 12-year-old girl and then said, “I’m just pulling your leg,” which provoked her to look town at her leg in confusion. Sometimes this causes general confusion or misunderstanding, and sometimes it causes frustration for Amish families. One father explained to me,

> [Wife] wouldn’t dilate after 2 days, so they induced labor. I was so frustrated but the doctor kept trying to make jokes to make light of the situation and it seemed inappropriate. I remember saying to the doctor about something, ‘Surely you can’t be serious’ and he said ‘I am serious and don’t call me Shirley’. I was so frustrated because I was so nervous and I didn’t know why he was making jokes. Maybe that would be funny on the outside, but not when it’s my wife.

This bishop had never seen the movie, “Airplane” to remember the quote from Leslie Nielsen and had no appreciation for this humor.

Many HCPs were unaware that the Amish spoke a different language, even when working with children. As seen in the clinical scenario in lines 163-168, the nurse practitioner is attempting to speak to their younger child who doesn’t understand English. Without realizing, the nurse practitioner attempts multiple times to communicate with failure. Although this is a sibling, this exact situation also occurred during the study with the children with chronic illness, preventing effective communication with that child.

From the HCP perspective, communication is challenging with families in between appointments and arranging appointment. One NP said, “I guess #1 [frustration] is communication….I want to see him get the best he can for his condition. It is difficult to reach them. It’s probably communication more than anything.” She struggled with arranging appointments because of the lack of telephones. Families communicate with HCPs at varying levels, but most commonly at a very minimal level. The communication patterns are different for HCPs than these families. Rather than letters, HCPs are used to phone calls, emails, or via their secretaries or clinic nurses. Those HCPs who use letters to communicate with families have better results and don’t feel so disconnected to families. The NP taking care of one family who needs monthly blood draws writes to the family every month with the results of their blood work and with any other concerns or education material. Both the family and the NP appreciate this open communication line.

Education

Many HCPs spent a great deal of time with education with these families, knowing their limited access to public information about their children’s illnesses. This is exhibited nicely in the clinical scenario by the physical therapist and the nurse practitioner. One father explained his perspective of some of the teaching when their child was first diagnosed with Cystic Fibrosis. He said,

> [Doctor] explained the genes to us. There was another doctor there too who was telling us that it had to come from me and her [pointing to his wife]. He was from a different land…he wasn’t dark, but….maybe his name was Mohamma-something….

After I asked him if it was in his family, he said, “Well, years ago, they might have had it but we didn’t know. We never heard of it before this.” However, from the HCP’s perspective, she tells me about working with the Amish in the following quote:

> They don’t have any access to read….any information they learn about Cystic Fibrosis is at our appointment. You know, what’s going on out there in the Cystic Fibrosis world. You know…what does the future hold….all kinds of studies are being done, and I have to remember to talk to them about all of that when they come. But they don’t come for a while and there’s so much to cover….

Not only do HCPs think about how much information these families need, they must consider how to make it accessible and applicable to the Amish lifestyle. For example, the physical therapist did a nice job of discussing exercises with the mother involving milking cows or holding a hammer. However, education about some exercises or safety precautions do not fit into the Amish lifestyle. Nurses of families with hemophilia instruct children to wear padded protection on their joints or helmets if they are outside working or playing. Later, when speaking to Amish families about using these forms of protection for their child, mothers will admit that they don’t do that for their children; they just tell them to “take care” and be cautious. Although not applicable to the Amish form of traditional clothing, nurses suggest wearing helmets in hopes that maybe some of these children would wear helmets. Until other negotiable solutions arise, these are some of the gaps between the cultures of the HCP and the Amish are not resolved.

Checking Compliance

Finally, checking compliance was a typical procedure during every health care visit with Amish families. HCPs tried multiple avenues to ask about the home treatments that the families were using either under prescription or over-the-counter. In the clinical scenario, lines 177-206 represent multiple aspects of compliance that HCPs check and confirm with patients and family members. HCPs want to know if the child has been taking medications as scheduled, performing any home procedures or therapies as prescribed, and who in the family is assuring that these are done for that child. In this appointment, Sarah is honest with her HCP that she doesn’t take her prescribed medication and she doesn’t exercise as much as the NP would like her to. So, that signaled the NP to educate her more. During the study, HCPs tried to work with these children to adjust the medications to their lifestyle schedule, including general time frames for these activities. In one instance for a 12-year-old girl with glaucoma who was skipping her prescribed eye drops, the physician took some time to ask her to describe a typical day (including the time of day these occur). Then he talked to her about the best time to take her eye drops, and she was able to respond with a time that she thought was a good time to take the drops. He then re-wrote the prescriptions so that instead of taking three times a day, she could take them twice a day as she requested.

HCPs recognize that, in many cases, the children are responsible for remembering their medications at home, with less parental control than non-Amish parents. Therefore, HCPs recognize that talking directly to children old enough to care for themselves is a necessary component in assuring compliance with their recommended medication or therapy schedules. One of my conversations with a physician describes this accommodation for Amish families:

> Physician: There were times when she was younger, her mother just had a baby….If she [patient] was doing medications, she was probably doing them herself. I don’t think mother was providing any eye drop care. I assumed, and she told me that Rose does her own drops. She does her own drops when she was 12 or 13 years old. She was given that responsibility. Most regular families, parents are involved in providing medical things. I’m pretty sure that Rose had to do it herself. Either that or she didn’t do it. Somebody else would do it.
>
> Angela: Did you make recommendations, or worked with her any differently, knowing her parents weren’t as involved?
>
> Physician: Every time I see her, I look her straight in the eye and ask her about how she’s using her medications.

HCPs respond to this different lifestyle and different parental control over children’s medication responsibilities.

In regards to compliance, HCPs who understand these families and work hard to accommodate to their lifestyles, provide some leniency towards their compliance. One nurse practitioner said,

> You can see that we allow them to have a little bit higher [PKU] levels that we would like, and I show them their levels so they can see the difference in their behavior and their levels. I give this family a little bit of special treatment. If we had a 7, 8, or 9 year old [non-Amish] who had consistently high levels and nothing was being done about it, we would probably take action and make sure that the parents are more strict about their diet...then we think about involving the state. With this family, the

> children have a lot of responsibility for their own care but it's different than if parents were ignoring their child and not caring for them. These children live a lifestyle that's not always conducive to all of these diet plans. They don't have a freezer to store all of the diet options, they don't have all of the access to things that some of these diet plans are made for, and that's hard for them. They are doing the best they can but they're not necessarily going to have the best levels.

However, not all HCPs consider this leniency and keeper a closer watch on Amish families in case there are concerns about negligence.

For the most part, Amish families met with HCPs out of their comfort zone and in a busy hospital setting. In the clinical scenario, lines 72-76 are quoted from one mother during an appointment. Not only are there barriers present during these encounters, but these barriers are so foreign to Amish families that they're not sure how to think or speak about them. Their local HCP, who is trusted by most of the families in the community said,

> I just try to be on their level when they come in. I think they get really intimidated by doctors in their white coats, and their gadgets. Look at me. I wear normal clothes that don't look like I make a lot of money. I still do the job like they want it but I don't intimidate them. I sit down and make sure that I am either eye level or below them. I don't do the thing where the patient is sitting and I am standing over them, towering with my power or anything. I talk about fishing and the farm and their crops. I know that some of them are carpenters, but I don't know what everyone does, so I don't make that assumption. I just ask them about their life so that I can get to know them.

These sentiments are reflected in a conversation with some of the bishops in the community. They discussed the opportunity and preference to HCPs who would be willing to make house calls and not have to be so formal at the appointments. One father said, "What we want to come forward would better come from you than us. You have training and experience and a lot of knowledge, and we are just peasants in their eyes." Although families trust that HCPs are doing the best job they can to recommend care for their eyes, it is the underlying approach to these encounters that creates some of this distance that Amish families feel from HCPs.

Missing Connections: Natural Remedies

The missing conversation in all of the observed health care encounters was about home remedies that involved herbals or vitamins. During interviews with Amish families after the health care appointments, families noticed that providers didn't ask about their use of home herbs. During health care visits, some families asked about using herbal remedies without receiving solid answers from their providers. Families with hemophilia asked about using Vitamin C and the risks with bleeding disorders and the nurses and physicians didn't give an answer. One mother with a son with hemophilia said, "…when I asked the doctor about vitamin C for his teeth, the doctor didn't really say, no', but he really stressed the brushing and the fluoride in the toothpaste." No hemophilia families discussed using red pepper packs for their children's small bleeds with HCPs. Another mother decided not to speak of or ask questions about their home remedies. She said, "We didn't tell the nurses because we didn't know what they would think." Although HCPs are very thorough in asking about the prescriptions and treatments they provide, there was not conversation about other things that were working to treat the child's illness. Yet, parents are searching for safe ways to keep their children healthy and "built up" yet prevent bleeding episodes. A mother of a son with hemophilia described her frustration in the quote below:

> The thing is that I can't find a multivitamin that will work for the children with the bleeding problem. They can't have vitamin E. When Lester gets vitamin E, he gets bruises all over his body, especially his legs. I just can't find any that work for him. I went to an herbalist in Rockland to see if they would recommend anything and they didn't seem to have anything that would work for children with hemophilia. I asked Alma, but she doesn't really have anything either…. I am struggling with finding vitamins that are appropriate for children with bleeding disorders.

During interviews with HCPs, they described being perplexed about the families' use of herbal medications but didn't seem to have any strategies or ideas of resources to aid in bridging this gap.

Health care professionals remain very cautious about natural remedies. One nurse taking care of the families with hemophilia commented,

> … one big thing that they [families] do is use a lot of herbs and vitamins. Some families say that they were using Vitamin C and they were noticing more nosebleeds. I'm not sure how much they're using so that gets tricky. We don't even know a healthy amount from the FDA. Those herbs and vitamins are regulated and it's hard to know what they are using at home or what to recommend for them to use at home. It would be one thing if they were taking just one multivitamin per day, but I think they are taking concentrated doses of specific vitamins, and you can overdose on some of those.

On the ride home from the outreach clinic, the medical student accompanying our team said, "And what I want to know is whether or not all of the herb companies make these preparations consistently. If there's no FDA approval on them, they could have a variety of doses and a variety of herb mixtures on their own, and no one would know what the combination does!" Families come to health care visits or clinic with questions about herbal remedies, or how much or often they can give these to their children. HCPs often do not feel confident or comfortable answering specific questions about natural medicines. Although this was a concern among Amish families and HCPs to bridge understanding about the use and combination of home remedies with biomedical treatments, no HCP referred families to pharmacists with their questions and no HCP mentioned using pharmacists as a resource to aid in their understanding of the home remedies.

Negotiating Plan of Care

Despite the differences in perspective between Amish families and HCPs on approaches to caring for children with chronic illnesses, there is great effort from both parties to negotiate in order to create a plan that will provide the greatest health for the child. From both HCPs and families, the consensus from everyone was to keep the child as healthy as possible. How this is done, however, is not in general consensus. HCPs focus on providing avenues for families to use professional treatments at home, provide outreach clinics in Amish communities, lower costs, and minimal follow-up or travel. Amish families focus on abiding to these regimens as best as they can during the course of their agrarian lifestyle, with lower costs, and minimal travel.

HCP Recognition of Community Involvement

Physicians were able to see that there was a sense of belonging with the families they worked for. They consider what will impact the community and make their decision based on the impact of their treatment, cost of treatment, and their own contribution to the Amish community. One HCP, recognizing this communal source of finance, said, "…I learned that the way they finance their medical care is that they have a communal fund that everyone in the community contributes to..." While another provider reflected, "I think they get paid out of their community. I'm not sure how they pay for their enzymes…." This uncertainty of how the communal funds work is prevalent among another HCP who mentioned, "If they had their way they wouldn't be taking any handouts. They would do everything in their community. I don't profess to have a clue. The elders, the way I understand it, the communicate and talk and if somebody needs something, as a group so and so will get covered the cost of the services."

It was clear to HCPs that the source of communal coverage allows these families to receive treatments but it places their decisions and needs within a community context rather than a singular or independent context. In addition, a HCP thought that it removed the sense of entitlement from greater society because they can depend upon their own community to support them in times of need. He said, "When you start valuing money a little bit more, then the free handouts that some of our underserved populations get accustomed to and this entitlement philosophy, you don't see with them."

HCPs see the tip of the practicality and the meaning to families of being part of this community, but they don't know how or in what ways the community is involved. There is some sense of understanding that there are elders who help to make decisions, but they don’t know who or how these “elders” truly impact families. In amazement, one HCP reflected on his revelation of how the community was involved with his patients. He told me,

> They’re much more community based way of living, and so I think it’s important to realize that whatever or however you deal with your particular patient from that Amish community will have an impact on the rest of them, just because of their societal structure is such that every member is a part of a community, and that community sort of acts together to usually help that member, help their own community member…The medical decision for an individual was being discussed and made by a community of people.

Placing their patients and patient’s families within the Amish context, HCPs describe how elusive that philosophy is to them, but some reflect their priorities as, “if it doesn’t hurt, I’m getting along OK”; “Less is more”; “If it’s hard I don’t want to do it”; “If it’s in the confines and parameters of the way we live our lives”. HCPs understand that these families turn to their community members and community philosophy to make decisions for their children. Although this looks slightly different than the biomedical HCPs might expect, they are searching to understand more about that philosophy.

Home and Community Professional Care

Because of the remote location and distance from nearby healthcare facilities, HCPs prefer to allow families to keep prescribed medications or treatments at their homes in case the children are in need of these immediately. The children with PKU need their blood drawn every month but don’t need to be seen except for once a year at the doctor. Initially, a county nurse would come out once a month to do the eldest son’s blood work until about six months into his illness. Then, the mother asked if she could do the blood draws and the county nurse agreed. Once a month, two daughters and one son poke their fingers, place drops of blood on a foldable cardboard square with specified perforated circles for the blood, slip them into a pre-addressed envelope to a town a couple hours away, and mail the samples in to a lab. The lab reports their results to their NP, and the NP writes them a letter to tell them results and if they need to change anything in their diets.

During our interviews, the mother didn’t elaborate on details of how this fits into a typical morning, so I was able to observe one of their blood draws. Just after breakfast, as the girls are finishing with the dishes and the young boys are preparing for school, their mother lies out the materials on the table and calls them over. Each child pokes their own finger with a lancet she purchased from Wal-Mart after washing their finger with rubbing alcohol. Their mother said that the lancet at Wal-Mart is cheaper than traveling to a local clinic once a month for blood draws. It took the children about 10 minutes to complete the whole process, and one of the girls helped her younger brother with his poke while their mother helped the other girl draw blood because her hands were cold from washing dishes. Prior to drawing their blood, they are responsible to collect a few days of a diet record to send to their nutritionist. Their mother tries to schedule the blood draws on the same day every month, but this was moved three months in a row because of some other circumstances that came up, such as a visit to a chiropractor or a wedding.

The families with hemophilia are allowed to keep factor in their homes in a cool place. The nurse provided these families with a detailed record sheet to place the date, time, factor bottle, factor dose, and response in these records to review at their next appointment. Although typically this option is given to moderate to more severe bleeders (including non-Amish families), the nurses and physicians prefer to leave factor with these families no matter their bleeding severity because of their remoteness to an emergency service with factor available. The nurses working with the hemophilia center went to this community twice over the course of ten years to teach the families how to administer the factor correctly. One of the families hosted a night when all of the families with hemophilia in the community could come. They sat around their kitchen table, practicing poking pillows with factor needles. All of these families greatly appreciated this education and spoke highly of the nurses they work with on the hemophilia team.

In addition to allowing home treatments such as medication administration, monitoring, or therapies, the families in this study with hemophilia benefitted from outreach clinics hosted in their community every other year. These outreach clinics have been held in one of the local Amish school houses, or in nearby clinics on Saturday mornings. These clinics are held at convenient times before the planting season in the spring or after the harvest season in the fall. The team provides dental checks, nurse education, physician assessments, laboratory, physical therapy, and social work. Families with hemophilia talked in interviews after the outreach clinic about how grateful they were for these clinics and the factor this team provided free of cost, as it saved these families a tremendous amount of money and provided ample opportunity to communicate with their HCPs. Options for home professional care work well for these families and others in the study. Families reported that it allowed them independence, adjustability to their schedules, and control over their child's care. Families are content to follow treatment protocols that allow them the least amount of back-and-forth communication as possible, and as much independence as possible to adjust the treatment to their daily lives.

In order to facilitate the families' ability to stay at home, many medications and treatments for children's illnesses were mailed or delivered to their homes. This prevented the families from needing to go to a local pharmacy. The families with hemophilia contacted the nurse coordinators if their Factor IX has expired or been used completely. The nurse coordinators send Factor IX to the families or give them the Factor IX personally at the family's next appointment near Finneola. The family with PKU contacts their nutritionist to order new protein supplements, the nutritionist makes an order, and the supplements are then mailed to the family. The family with CF picks up their enzymes at a local pharmacy, although it is ordered to that pharmacy by their provider. They do not work personally with the pharmacist at the pharmacy; their contact is with the personnel working at the retrieval counter. The families made no mention of the impact pharmacists had on their decisions for using medications.

Collaborating with Local Providers

HCPs and families appreciated using local community providers in between appointments with their primary care provider in Finneola. As the local providers are often the first access point for families, providers in Finneola Hospital recognize the importance of communicating and educating these providers about conditions within the Amish community. Furthermore, local providers work with chiropractors in the area to try and treat the family with complementary methods. The gap in knowledge between specialty services and local generalists makes it difficult for HCPs to trust the care Amish families are getting elsewhere for their health conditions. The HCPs in Finneola have some frustrations about educating local providers about these conditions, in order to treat their Amish patients if they seek local care. One provider said, “As I understand it, there’s not one local doctor that they all see. I think they all see different doctors. Last time, we did an in-service for a group of doctors in the Walnut Ridge Clinic but they don’t see all of the patients.” A NP told me, “I think some of those providers put them [information sheets] in the back of their folder…”

Other providers benefit greatly from local providers who can perform routine checks that prevents the families from the required hour and a half drive to Finneola. Rose Schwartz sees a local optometrist to check her eye pressures in between visits with her primary optometrist in Finneola, and the local optometrist sends in the pressures; this saves the family a tremendous amount of cost and time traveling to Finneola 90 miles from their community. In more acute circumstances, families appreciate providers who are knowledgeable about their child’s disease even if not a specialist. One father told me,

> When he was about 6 weeks old, we went to the ER. He looked awful. We just got the letter from the doctor saying what he had. They asked us in the ER about certain illnesses, and I didn’t think of it at first. He was lying on the floor and pale and we were both so worried about him. Not what your boy should look like.

> Then I thought about the letter and told them he had this Cystic Fibrosis….Then they said, 'Well that explains it.' Then they really moved fast!... They know about CF and seem to know what to do about it.

Within the clinical scenario, lines 60-62, provides an example of how discussions of the use and practicality of these local providers allows families to at least see a provider if their driver doesn't show up, inclement weather, or other barriers to making their appointment in Finneola.

Cost Considerations

Cost drives many decisions about how much and which treatments will be agreed between families and providers. Without insurance, these families acknowledge the price of every single detail within their appointments, down to how many individuals they see when they are there. One family noticed that in one appointment, although they didn't see a physician, they were charged for a physician visit. First, they review their bills in detail before paying them, and second, they are willing to discuss differences with the payments departments within hospitals. Any discrepancies are frustrating to them. Prior to making decisions about treatments, families also want to know the cost of these. They need to know this so they can make a decision about when or if they can afford it at the time. Also, they may need to prioritize some of these treatments, and taper them over time so that they can keep up with the payments.

Although not always on the minds of HCPs, it is always on the minds of these Amish families as they sit through their appointments. Those families with access outreach clinics also acknowledge their gratitude at the cost savings that these clinics provide to them. Every attempt to lower costs for these families is appreciated, noted, and remembered. One father remarks,

> What we need is to deal with the same people at the hospital. The people in the billing office go to college to learn how to get money from people. Well, I only have a school education until eighth grade and I don't know all of those ways about dealing with money like they do. The doctors don't always know how much things cost.

However, other providers keep cost constantly on the surface of their mind when recommending services. Although not completely understanding why Amish families don’t use insurance to protect their families, a nurse describes her approach, “That just goes to show how different our mentality is from theirs. We would want to be covered in case anything happens. They just wait and see what happens and figure out how to pay once they see their tremendous bill. We would never let that happen. They don’t seem to be need that in advance, *just in case* something happens.” HCPs are mostly unaware of how Amish families pay for their treatments and health care visits. Some assume that all families are covered by their community but this is not the case. One Amish father explained that it is optional to donate to the community in order to receive payments from this fund in times of trouble, but he does not because he thinks he is not as bad in need as others in the community. Understanding that Amish families are hesitant and sometimes incapable of paying for all of their prescribed protocols, health care teams attempt to find avenues to eliminate costs for families.

Cost was the major reason one family went to Mexico for all of their treatments for their child’s illness, and cost is the major reason why families choose not to complete all prescribed treatments and medications. The clinical scenario lines 230-256 exemplifies a NP working through financial and cost issues with this family, and this section is taken from various other clinical observations I noted during the study. For the Byler boy with Cystic Fibrosis, the HCP was having a hard time getting them in for any of the necessary procedures such as CAT Scans (CT) or Bronchoscopies, and the family was frustrated that she was expecting them to have all of these without a good reason for each one. Roman Byler, the father, said,

> That’s one thing. The appointments. They want us to go every three months. We would like it maybe more like two times a year or less….It costs $900 for labs when we go, and the visits usually cost about $1500 by the time we get to see everyone. Our last visit was scheduled for November 10. It was finally a nice day out so I needed to do some bean thrashing….I just called them and explained that I couldn’t go that day, and cancelled the appointment. They wanted us to have cat scans and bronchoscopy [he said it, “bronchoscy”] for over two years but

> I don't see the point in doing that either. The doctor told us they would be thousands of dollars. They have to do a throat culture every time he goes to the clinic, and that costs a lot of money too…. I think they recommend these things because that's what they know works best for families with children with CF.

At their appointment, their nurse practitioner laid out the reasons, prioritized the treatments, and asked the family to consider when they would like to do any of these. Finally, the father agreed to do one at a time, starting with the CT next October. Although not the most ideal from either perspective, working together with choices broke through their frustration with each other and gave them a place to start.

Legal Considerations

All of this, however, comes at a cost to some Amish families because state authorities disagree with decisions made by parents for their child. In order to avoid these confrontations, Amish parents minimize their contact with the health care system to prevent being judged and having their child removed from their care. Five families brought up legal concerns about having their child removed from the state, or hearing stories about other children being removed from the state. David Renno, burned at 1 ½ years old, never went to see a HCP for burn treatments. The family was confident in the abilities of B&W Ointment and Burdock leaves and thought they could call if he became septic or dehydrated; he never experienced either of these conditions during his treatment fortunately. His mother said, "At the time we did not want anyone to see it because we knew they would not know what to do and want to take him in [to a hospital]. They wouldn't know what to do with David the way that we are treating him."

The Schwartz's experienced a massive burn to their home during one winter, and missed their daughter's doctor appointment. Vernon Schwartz commented,

> We completely forgot about it. They called my neighbor, and my neighbor came running over to me and said I needed to call them back right away because they sounded pretty serious. I got on the phone and they were pretty upset that I didn't call ahead to cancel my appointment. They told me that they were going to send a social worker out to our house to make sure I was taking care of the children, because she was under 18. That really scared me because at that time I had only one child over the age of 18 and they could have taken them all away! I told them

> that our house burned down and in the midst of it forgot the appointment. Then, they understood and didn't need to send out the social worker. But they wanted us to make the next appointment before hanging up the phone.

He felt their lack of trust that he would take care of his daughter's appointment.

Later, when speaking to his physician, he said his side of this story, "There were times they couldn't make their appointments. I had to make a phone call a couple of times, …especially because she's a minor. 'What's going on?' I don't know exactly what happened but I seem to recall they had this issue with rides. Maybe money." Physicians are extra careful, too, about the care that minors receive because of their critical health care conditions. They are willing to be assertive with families if need be about involving social services to ensure that the care they recommend for these children is followed by the family.

Bishops feel the weight of this discrepancy between social services, physicians, and Amish parents about what's best for their children with chronic illnesses. Bishops were able to tell me multiple stories about families in their community who had police show up to their doorstep, social services removing children, or removing the parent's rights to make decisions for children's care until the parents abided by the recommended treatment of the HCP. Bishops told these stories with great sadness and concern that it will continue to happen this way. Families are also nervous about the legal implications of avoiding or disagreeing with their HCPs. Families walk a cautious line of trust with their HCPs. Some feel trustworthy and respected by their providers, while others feel a constant paranoia that one wrong move on their part will either take their children away or remove their rights as decision makers.

Conclusions

Because of their desire to integrate biomedical care into their home rather than requiring outside intervention, some providers help to accommodate these families. Children with PKU are allowed to do all of their monthly blood draws in the comfort of their own home, after a family breakfast, and mail the results into the lab in Des Moines.

They communicate by letters with their provider who continually monitors those lab results. The family caring of their child with cystic fibrosis goes in to receive care when his symptoms become questionable, but not every time the HCP requests a “regular check-up”; this allows them to continue their everyday life with as few interruptions as possible.

The Gideon Byler’s are an example of obeying the health care professionals’ advice. Gideon told me, “At first they wanted us to come back once a year. Then, when he was doing so well with his sugars, they thought they would just want to see him come back in three years. That will be this year already, so we will probably go back down there. We just call the clinic when we have questions or if we want to make any arrangements to see them again. We have their phone number.” Their follow up is minimal, and they can do most of the cares at home with independence.

Similarly, the families with hemophilia have treatments that give them a lot of independence. The clinic staff expects to see the families with hemophilia once every two years in a clinic hosted in their community; other than that, the families seek their HCPs’ services when they have an emergency. With hemophilia, the herbalists in the community agree that it is a disease that is beyond their knowledge about home treatments. The hemophilia nurses allow families to keep factor in a cool location in their homes to administer when the boys have a bleeding episode; this decreases the needs of those families to go in to the emergency room or the clinic. With emergent cases, most families find it worth their time and money to go straight to Finneola Children’s Hospital to receive treatment, rather than go to the local emergency room where they might not have the appropriate medication available or the in-depth knowledge of each of their child’s medical history.

HCPs will need to pick their negotiations with these Amish parents because parents want to have choices and be in charge of decisions about what’s best for their child. Sometimes, these decisions are not in line with HCPs. However, through observations and conversations with both HCPs and families, I see that giving parents options improves the outcomes from both parties’ perspectives. In a society where they feel like outsiders and prefer to maintain their own way of life, the one thing that keeps the Amish community together and long-lasting is their ability to make independent choices without interruption from the non-Amish.

CHAPTER 8

CLINICAL SCENARIO

Introduction

Each family in this study had a different experience during their clinical encounters with a variety of Health Care Providers (HCPs). This clinical scenario is a combination of clinical observations of encounters between families and HCPs during this research study. The methods used to create this clinical scenario are described in more detail in Chapter 3, *Steps in the Analysis Process* (p. 68) section. This clinical scenario supports Aim 3, found in Chapter 7. The third research aim intended to describe the behaviors and experiences of families as they seek health services for their children with chronic illnesses. In order to give a full description, this clinical encounter is used to portray their experiences, and Chapter 7 described the themes of those behaviors and experiences. I placed myself as the researcher/observer within this scenario to shed light on the different information families gave to me as opposed to their HCP. The lines in this clinical scenario are numbered to aid the reader in referencing this material when reading Chapter 7.

This is a routine annual appointment for Sarah Miller[11]. She is 11 years old with Juvenile Rheumatoid Arthritis. She has her annual examination today with Nurse Practitioner, Sue Overlang, her physical therapist, Jim Young, and a nutritionist, Gale Johnson. Her affected joints include her right knee, her left elbow, and her left hip, and her right wrist.

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[11] Sarah Miller is not a pseudonym for any participant in this study. This is a fictitious family with a child with juvenile rheumatoid arthritis, representing a combination of the actual participants in this study. Additionally, the HCPs are not pseudonyms for actual participants, but representative of the participants in this study.

Clinic Visit Introductions

When I walked into the clinic, the receptionist directed me to the nursing station. As I turned the corner to the nursing station, I saw the Miller family standing by the vital signs station. They gave me big smiles as I rounded the corner. Sarah's two older sisters and two-year-old brother were there with them in the waiting room. Mr. Miller told me that Mrs. Miller came too and was in the bathroom. We all walked together into the clinic room to wait for the nurse to come and assess Sarah.

Mr. Miller: Sorry about my hands, I got some stain on them and it won't come off. [He looked embarrassed but I said that was fine].

Angela: How is the staining was going for them?

Mr. Miller: They got the staining done over the weekend and the girls were varnishing.

Angela: One or two coats of varnish?

Mr. Miller: Four coats of varnish because the wood really soaks up the varnish. [One of the daughters chimed in that the first coat just goes right into the wood.]

Angela: Are you both out of school?

Together: We only go to 8th grade. Now we stay home to help mom out.

Mrs. Miller: We will probably put the third coat of varnish on tonight when they get home. They can only put one on a day. They had a heater on it, but they really want to be sure it is dry before putting on the next coats of varnish.

Angela: So, how is the farm coming along?

Mr. Miller: Good. We got everything planted. The beans we finished just last week, so now we wait and see. I wanted to make sure that we weeded the first part of this week. Last week when we called for the appointment, they were predicting rain. We didn't get much up there, but I could see it down in the South border. It sounds like you got a lot of rain. We got one inch on Friday night, one inch on Saturday night. It's good when it rains at night because then at least they can see the sun for a bit and get nice and green. The beans and the corn were looking a little yellow with all the cloudy weather.

Angela: How do you weed out in the fields?

Mr. Miller: We have a thrasher that has shovels at the end of it that digs them up. It takes a while, but at least the beans and the corn are bigger now than the weeds so they will grow them out.

Angela: How is the garden coming along?

Mrs. Miller: Oh, it's really good so far. We had strawberries. We eat mostly beans and peas and greens right now. The children get a lot of good things to eat. They help a lot with the weeding and taking care of the patch.

Angela: Good. I bet that keeps them all busy.

Sarah was crocheting some small circular green and teal yarn pieces. I asked her what she was making and she said they were going to be butterflies for her sister. Her sister wanted 18 of them when she finished. When she was done with crocheting the yarn, she folded them in half and placed pipe cleaners for the body. They were cute little crafts and her hands were moving so swiftly I could barely keep up with her technique.

<u>Nurse</u>

The nurse entered the room.

Nurse: OK, have a seat right there Sarah. [The nurse logged on to the computer, opened up a few windows, and began to ask the cued questions. The nurse sped through the questions without looking at Sarah. The nurse had a sweet voice but was speaking very quickly.] Are you having any pain today?

Sarah: No.

Nurse: How old are you? What's your birthday?

Sarah: 11.

Nurse: Have you had any problems with your vision in the last six months to a year?

Sarah: No.

Nurse: Are you still taking Cataflam when your joints hurt?

Sarah: Yes.

Nurse: Are you taking anything else? Multivitamin? Supplements, etc?

Sarah: No.

Nurse: Ok! Let’s see how your vision is doing! Do you have glasses! [Finally, looking at Sarah] Oh! I see you are wearing glasses. Let me go “read” those for you.

Mrs. Miller: She got those in April when we went to see [Local optometrist]. Our driver didn’t show up to bring us down here so we went in to see him. He gave her those glasses, so they’re pretty new.

Nurse: OK…..you can give me those glasses honey. [The nurse scurried out the door for a few moments. While she was gone, I asked Sarah and her mother what “reading” glasses meant and neither of them knew. In a few moments, the nurse returned with a slip of paper the size of a receipt and typed some things into the computer. She wiped off Sarah’s glasses for her and gave them back to Sarah to place on her face.]

Nurse: Can you read the bottom line for me? [pointing to a Snellen Chart on the wall behind her.]

Sarah: V-K-H-C-R [The correct version should have been V-K-N-C-R]

Nurse: Good. Now how about the line right above it…..[Followed a couple more times until she got to the big numbers. Without looking at Sarah, the nurse would instruct her to put the “spec” over her eye and continue reading. Sarah would move a black patch with holes punched in it over her eye that she was reading with.] Your eyes are about 30/20. [She didn’t explain what that meant and Sarah didn’t ask what that meant.] Your right eye is a little bit better than your left eye. Okayyyyyy? You can stay sitting right there and I will send in Sue.

Sarah looked at her but didn't say anything.

The nurse left the room.

Mrs. Miller: I just don't get those things (computers). It's something that I don't think our kind would understand.

Angela: Yes, they have this program on the computer where they can see what other people are writing about Sarah so they can all be on the same page. It makes it easier than writing notes in a book.

Mrs. Miller: I just don't really understand it….

Physical Therapy

Jim: Hi everyone. Sarah, how have you been?

Sarah: Good.

Jim: Any injuries or hospitalizations in the past year?

Sarah: No.

Jim: Any flare-ups?

Sarah: In October, my wrist was pretty bad. I had to rest for an entire day with hot packs on it. I took some Ibuprofen and it went away in a couple days.

Jim: That's great you treated it right away! Early treatment means few complications. That will prevent the bones from becoming deformed over time with early and effective treatment. For a couple days, you should really keep that wrist still so it can heal. Then it's good to start using stretches to stretch that muscle out. How often do you stretch?

Sarah: When I'm sore.

Jim: How many times in one week do you think you stretch?

Sarah: Maybe twice I do stretches for a while.

Jim: And how many times do you take a rest in one day?

Sarah: I rest when I sit down to eat.

Jim: It’s good to take frequent breaks and rest your joints, especially when you are physically active. Take a nap in the afternoons when you get home from school if you can. Be sure to splint or position your joints (knee, elbow, wrist) while you are sleeping to minimize pain and prevent deformity. Rest on a firm mattress with no pillow or a low one; no support under the knee. Or lie on your stomach to stretch out that hip and knee.

Sarah: Okay.

Jim: I have some exercises here that you can use for your wrist. One easy one is to bring your hands together over your head and bring the down slowly to your chest. That really stretches your wrist out. I have a couple worksheets to help you with those stretches on some target joints. Another good one is to pretend that you have a rag in your hand and that you’re rinsing it out. Another one is to take a hammer (maybe start with a small hammer) by the top of its neck. Then, with your elbow and forearm in the same plane, move the hammer side to side with your wrist, bringing the hammer over your hand. [referring to radial movements]. You have two bones in your forearm. They are parallel when your hand is palm up. When you move to make your palm down, then those two bones look like they are criss-crossed. The hammer adds extra weight to strengthen the wrist muscles where these bones meet your hands. Another stretch is to find a weight and hold it with your palm pointed up. Practice lifting the weight with your wrist. You can do that with your palm down too. You can stand at the table and practice stretching your wrist by pushing your hands down flat onto the table. You can do that anywhere, when you are waiting for dinner, or whatever.

Mrs. Miller: Would milking help his wrist?

Jim: Oh yes. That would be perfect because you have to practice squeezing something over and over. Once the area is healed, you need to stretch the joint back out by doing exercises.

Mrs. Miller: Well, I let her feed the baby goats for a while and take a rest from the milking. After a couple days, I told her we needed her to be back milking the goats. After a few days, she was back to normal! I think the milking worked for her! Now she doesn't have any excuses to not milk the goats any more…

Jim: Whatever works I guess! Do you play any recreational activities, like volleyball?

Sarah: I play some volleyball, ice skating… Volleyball you need a lot of people but ice skating we can just do in the back yard. It's harder to find things that are fun in the winter, though.

Mrs. Miller: They love ice skating.

Jim: That's great. I think what I'd like to do next is to have Sarah get up on the table and lie down and I can measure her joints.

During Sarah's exam, Jim had her lying down on the table. Without using a sheet to cover up her legs when her skirt came up, he was lifting her legs into the air to measure her hip extension and flexion. She tried to bring her skirt down the first couple of times, but then finally gave up. When she sat up, her bonnet had fallen off and she looked a little out of sorts. She pulled herself back together and sat down on one of the chairs off of the exam table. Sarah stayed quiet through the whole exercise although she closed her eyes a couple times as if in pain.

Jim went through some stretches for her butt muscles, to stretch them out with her back standing tall. He also had hand-outs for her to take that would explain the back stretches. He emphasized not slouching when she stretched and to keep a straight back. Although more difficult with a shallower stretch, that is better for her back support.

Jim made some notes on the computer. Then he said, "OK, it was great to see all of you. Take care."

Family, "Bye"

Nurse Practitioner

Sue walked into the room, logged on and read the computer for a moment, and then sat on a stool next to the examination table facing Sarah.

Sue: Good morning. Hello there (crouched down, talking to Sarah's younger brother). Oh, he doesn't speak?

Mr. Miller: Oh, he talks a lot when we are at home. It's a little different here.

Sue: Yes. [To Sarah's younger brother] Are you one? [She held up her finger in between their faces, and he wrapped all of his fingers around the finger she stuck out.]

Mr. Miller: He just turned two years old.

Sue: Can I have you sit over there?

[Her brother froze still, staring at Sue. Mr. Miller whispered the Amish translation into his ear, and he immediately moved to the open seat.]

Sue: How has your health status been since I last saw you?

Mrs. Miller: She still had the arthritis.

Sue: Have you needed to use any steroids or stronger medicine to help with your hurting joints?

Mrs. Miller: My wrist was bad in October and I just rested it for a couple days with hot packs.

Sue: Are you hurting at all today?

Sarah: No.

SUE: Can you tell me what medicines you take and when?

Sarah: I take ibuprofen or aspirin sometimes when my joints hurt.

Sue: And how often is that?

Sarah: I don't know, once a month maybe.

Sue: I gave you a prescription the last time for diclofenac, or Cataflam. Did you ever take any of that?

Sarah: No.

Sue: Can you tell me why you don't take the medicine that I ordered?

Sarah: I don't know….

Sue: I like you to use ibuprofen or Cataflam rather than Aspirin can have some side effects in children such as potential bleeding problems, liver problems, or upset stomach. Sarah: I try not to take it a lot[12].

Sue: It's important that you use something if you are in pain, or your joints might swell and become deformed and you might not be able to use them anymore. If you need a prescription refill or if you need to use some steroids if the pain is really severe remember that you can go to see Dr. Anderson in Rockland. Have you seen him at all in the past year?

Sarah: No. We didn't really need to.

Mrs. Miller: Does fish oil help?

Sue: What we recommend is an anti-inflammatory drug first, such as ibuprofen and if that doesn't work to use the prescription I gave you for Cataflam. If those don't work then we try steroids. Do you stretch before you exercise?

Sarah: Sometimes….

Sue: How are we going to get you to do your stretches? [No answer]. When you're having pain, try to use moist heat around the joints. You could take a bath, use hot packs, dip those joints in hot water for about 10 minutes. If you can, go swimming. Or try taking a bath first in the morning, take your Cataflam, and stretch before your other chores. Try to take breaks during the day to put heat on your joints if they are sore.

Sarah: OK.

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[12] Sarah takes fish oil and uses alternative treatments when her joints swell. Mrs. Miller doesn't think they need the prescription medicine with only one flare-up in the past year.

Sue: Be sure to ask if you are having troubles combing your hair or brushing your teeth. You may need to stretch or use a hot pad for a while when you get up before you do these things.

Mrs. Miller: She pretty much takes care of herself. She hardly ever asks me to help her in the morning. It’s kind of hard because there’s so many of us getting ready in the morning. She’s very good about letting me know if she’s hurting, though.

Sue: Alrighty. Can you have you sit on the table, Sarah, and I will do a quick exam? Let’s see your hand. I notice that you have some warts on your hand. How long have you had those?

Sarah: Maybe five or six months.

Sue: Have you done anything to help them?

Sarah: No.

Sue (to Mrs. Miller): I think you may need to see a dermatologist for her warts to get them frozen off. They will do that for you there. Or, you can use duct tape to smother them. Then, sometimes they will fall off because they don’t have air to breathe.

Mrs. Miller: Yes, we can use duct tape for a few days and then see what happens.[13]

Sue: Maybe we can tie a string around them and pull them off! I’m just pulling your leg...[Sarah looked at her leg]

[Sue continued to measure the lengths of her arms and legs, palpating around her joints for any swelling. She was careful to always have Sarah covered with a sheet, not to expose any part of Sarah that might be uncomfortable. Sue helped Sarah to lie down and sit up so that she didn’t have to strain.]

Sue: OK. So, I need to fill out these forms and get them copied for my office. I think you need to fill out the information about his birth certificate and your income and

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[13] After Sue left, Mrs. Miller told me, “We never do anything for warts and they just go away.”

then it’s ready to send in. It looks like there is a program that will help people who do not have any reimbursement (A.K.A. private insurance) [Mr. Miller: No we don’t have that], Medicaid, or Medicare and are less than 200% below the U.S. poverty level. I don’t know how you know what that is…..do you do taxes?

Mr. Miller: Yes, we do taxes. I’m not sure what “gross” versus “net” income is. I will just attach the taxes to the form and that is usually good enough.

Sue: Great. That will help to cover these appointments and any X-rays if she needs to have them done. Speaking of this, it’s typically recommended that every few years, we get an x-ray of Sarah’s joints to be sure that there are no overgrowths or undergrowths around them. What month can I set one up for you?

Mr. Miller: Do you really think she needs that?

Sue: Well, it is what is recommended so we have a baseline in case she starts to have growth or movement problems. I really don’t want her to go without that. When would be a good time for you to come back and have it done? It doesn’t need to be in exactly six months or anything, but anytime would be fine in the next year. October? November?

Mr. Miller: Well, our big season that’s really important is the planting season. Now that that’s over, the harvest isn’t quite as picky. October is usually when we are thrashing beans, and that gets tricky because we really have to wait for the good days for that. For the corn, it doesn’t matter as much because if it rains we can still go out and pick corn the next day.

Sue: I can get you in on a morning, so that you can be home by the afternoon to do what you need to do. So then November would be a better time for you? Should I make an appointment for November?

Mr. Miller: That would be fine.

Sue: Great. Remember when she does have sudden, unexplained swelling, redness, and pain in any joint or red eyes, eye pain, and vision blurring call me immediately. We will need to bring her in to have a look at her. Sometimes, a condition of inflammation in the eyes is a side effect of JRA, so we need to treat that immediately so she doesn't lose any sight. Sarah, it's great to see you looking so good. You're all doing a great job it sounds like, without too many problems. Please take care until we see you next time.

Mr and Mrs Miller, simultaneous and smiling: Thank you so much! Bye.

The secretary brought in a note from their driver that she was going back to the parking ramp to wait for them to finish.

Mrs. Miller: The guy who usually takes us wasn't available so his daughter brought us down. She brought her 9 month old along in the car, so the little ones were together. Her baby slept almost the whole way!

Angela: Are you doing anything else today after the appointment?

Mr. Miller: We might go shopping and then go home. We are going to her family's wiener roast tonight at Park, and we are stopping at Aldi's to get some stuff on the way home. There's one that we like to stop at on the way home.

<u>Nutritionist:</u>

Gale: How is your raspberry patch doing this year?

Mrs. Miller: If I trimmed my raspberry patch I would only get them in the fall, but if I leave them they would come in the spring, too. This year, I decided to leave them so we had a lot of raspberries!

Gale: My strawberry patch came in the spring and then I only had to wait a few weeks in between those patches and my raspberry patch starting.

Mrs. Miller: Do you have black raspberries. If you do, you could taper those with the red raspberries. This was an awful year for my tomatoes. I struggled with getting blight on them more than any of the others that I can remember. Every year, we just hope that next year is better. We just do what we can. Last year, we were pulling beans until the end of October.

Gale: Well, Sarah is looking very good. We worry about gaining weight because that is hard on your joints, but you are at a healthy weight for your age. Thank you for filling out your diet diary for me last week. We'll continue to have you do that every year before you come in, to be sure you're getting enough of the nutrients you need and are keeping a healthy diet. We don't typically have to worry about your family because I know you eat healthy foods and get a lot of exercise.

Mrs. Miller: She pretty much takes care of that herself. She eats if she's hungry and has a good appetite. I don't have to worry about her snacking on cookies or cake, like her brothers.

Gale: I'm sure not.   Ok, it's great to see all of you. Sarah, you look great. You can just continue what you are doing.   Thanks so much everyone.

CHAPTER 9

DISCUSSION

Introduction

One summer afternoon, I sat with the bishop's wife, Susannah, cleaning beets underneath the shade of a tree. I wanted to know what it was that connected all of the Amish together. I was looking for the essence of being Amish, so I asked her, "Do you have a word to describe belonging to this community of people?" She said the closest word she could think of is *gegend*, which translates literally to region. Although there might not be a specific translation used by the Amish, there is an underlying tie that binds this community together. Theologist James W. Fowler , presents a slightly different and less tangible approach. He presents this idea and translation,

> "In German one of the terms for imagination is the compound word *Einbildungskraft*: literally, the "power" (*Kraft*) of "forming" (*Bildung*) into "one" (*Ein*). Here I want us to reflect about faith as a kind of imagination. Faith forms a way of seeing our everyday life in relation to holistic images of what we may call the ultimate environment. Human action always involves responses and initiatives. We shape our action (our responses and initiatives) in accordance with what we see to be going on. We seek to fit our actions into, or oppose them to, larger patterns of action and meaning. Faith, in its binding us to centers of value and power and in its triadic joining of us into communities of shared trusts and loyalties, give form and content to our imagining of an ultimate environment." (p. 24)

Susannah's word, *gegend*, represents the practical perspective of Amish members. The *Ordnung* helps them to define their membership to this community, and within this membership they create their ideal environment separate from the mainstream society. The membership within the Amish community gives individuals a set of ideals and values to live with, lies underneath their behaviors, and binds all individuals and families to this greater community.

The remainder of this discussion section will review ways in which the Amish cultural context plays a role in how Amish families identify and conceptualize their children's illness, make decisions about how to care for that inside of their community, and then make decisions about seeking appropriate health care services. The discussion section will first review the Amish as a collectivist culture. Then, the results of this study will be used to review and address their place with other research involving the Amish. Finally, the implications and significance of this study will be addressed.

The Amish as Collectivists

Collectivism refers to a dichotomous concept that lies on the opposite end of a spectrum with individualism. The United States has been categorized as an "individualistic" country, implying that it contains the following attributes: a focus on the personal self more than belonging to a group, movement towards modernity, an openness to science and innovation, use of work to fulfill personal life goals, and seeing the individual experience as the ultimate truth. Conversely, an individual who belongs to a collectivist type of society may carry these opposing attributes: places society's goals over her own goals or interests, works hard for the sake of working, tends to maintain traditional roles and ideals, and prioritizes family integrity and solidarity over other areas of her personal life. Individualists are shown to be more competitive, with more emotional detachment than collectivists; however, a collectivist doesn't typically waylay her work habits because she knows that the work will better the society around her. Individualists can be seen as people who are separated and differentiated from one another, while collectivists can be seen as a group of people who are relational and assimilate to one another. A person in an individualistic culture tends to think about how others are like him or her. A person in a collectivistic culture tends to think about how he or she can fit with others in that society. Individualism places person first, while collectivism places society first. This list of general characteristics about both individualism and collectivism carry room for individual adaptation, and most individuals carry both collectivist and individualist traits to varying degrees. Previous research identified these attributes for each construct, and the current trend is to find ways these attributes carry meaning in people's behaviors, thoughts, and psyche (Kagitcibasi, 1997).

Anthropologists work to bridge the binary constructs of self and culture. By seeing someone in the particular is seeing a reflection of the historical, economic, political, or familial aspects of the cultural context that surrounds her or him. The inner/outer dichotomies are central to anthropological discussion, placing culture as a construct that lives in and is exhibited through individuals within that culture (Kondo, 1990). Because Western society places high importance and distinction on the individual, it loses sight of the overarching cultural influences surrounding each person. "The Amish" is a collective noun I use that describes a set of characteristics and a way of life that is set apart in some ways from other traditional European and Western cultures. It is not meant to be static, but ever-changing with the political, economic, and social atmosphere surrounding it geographically. However, within that collective are individuals who can be differentiated from other individuals in this same society. These individuals experience boundaries from the collective Amish that allow them to create their own opinions, decisions, and resulting behavior.

Amish Collectivism and Health Decisions for Children

Living with and being Amish is a definitive choice that individuals make as young adults. Their membership in this community comes before most other choices in life. Families prefer to live, work, play, and experience major life events in their homes within this community setting. Fathers choose to work close to home or at home on the farm, and mothers and children tend to the home and gardens. Each member of the family has a role managing their home, in order to spend time there together throughout their lives. Staying in their homes and close to other Amish members allows them to make health care decisions in line with their preferred Amish traditions. Healing at home within this setting provides familiarity, comfort, and family and community connectedness for children who are ill. This perspective underlies the health decisions of families for their children.

Presence of God in Health Decisions

Families in this collectivist community tend to place the ultimate goals of the community over their own goals, and maintain the traditional roles and ideals of the Amish collective as they make their decisions. This approach impacts their decision making for their children's health. A fundamental belief within this collective community is the presence of God in its members' daily lives and decisions. Huntington (2003) identifies the Amish as being first devoted to God, then to their family, then to their community, and participants in this study confirmed these priorities. The term *Gelassenheit*, meaning yielding to God's authority, guides Amish behaviors (Weyer et al., 2003). Other research with Amish communities support the heavy influence of their faith in God on their health beliefs and decisions (Gerdner, Tripp-Reimer, & Sorofman, 2002; Sharpnack, Griffin, Benders, & Fitzpatrick, 2010). Families in this study recognized that the ultimate fate of a child's health is in the hands of God rather than the health care system.

Parental Authority in the Care of Children

Bishops and parents in this research study both admitted that it is the families who have the final say in a child's health concerns. One of the fundamental beliefs within the Amish is that they baptize their members as adults, to assure that their baptized members are consciously and deliberately making that decision (Hostetler, 1993). Prior to children's baptism into the Amish community, parents are the sole guardians for children. The church leaders do not govern over children until they are members, although the church does oversee that parents raise their children according to the Amish traditions. If parents or family members make decisions that are not in line with the Amish traditions, they risk excommunication but the responsibility lies on their shoulders.

The way that families conceptualize an illness or symptoms guides their decisions about available providers and treatments (Rao, 2006; Schantz, Charron, & Folden, 2003; Sorofman, Tripp-Reimer, Lauer, & Martin, 1990). Family goals for treatment included alleviating their child's symptoms, reducing the cost of care, receiving honest and open communication from HCPs, and being allowed to make decisions in collaboration with HCPs. If these goals were not met with one HCP, then families would switch without hesitation. Because they are not members of Health Maintenance Organizations (HMOs) or other private or public insurance options, families were not obligated or confined to seek care from a select group of providers. This gave families additional flexibility in their decision making for seeking care for their children with illnesses in congruence with their beliefs and their Amish membership. A national Amish financial resource for health care called Immergrun allowed families to seek care where they preferred. As seen in this study, multiple families including a bishop's family, sought care in Mexico. Families were restricted neither to biomedical health care services nor biomedical therapies in the U.S. Sometimes, families went to great distances to meet their goals and the goals of the Amish community.

Amish Community Supporting Family Health Decisions

For families, being part of this collective meant that community members were involved and supportive of their health care decisions to meet the goals of greater Amish community. Some researchers refer to collectivism a form of "restrictive conformity" which is what Amish individuals may appear from an outsider first glance (Kagitcibasi, 1997). Bishops and the community at large support families making those decisions as most appropriate for their circumstances but do not restrict them to decisions. Bishops helped families to navigate their collective communal beliefs in order to make a decision about a child with chronic illness. Additionally, bishops who understood and lived in this collective felt the weight of decisions that impacted the community as a whole. If there were treatments that didn't seem in line with Amish traditions, then families went through bishops to clarify their responsibilities to the *Ordnung*. Families asked bishops about options such as receiving free government services, assistance from the Red Cross after an emergency, and temporary technological support in their homes for their children. Herbalists were resources for families to ask about certain treatments or herbal remedies appropriate for their child's illness. This allowed families to use the resources of the community prior to seeking care elsewhere. Families sought advice from herbalists about appropriate vitamins for their children, which burn treatments to use, or specific therapies for uncommon illnesses. During this study, if families and herbalists were not cooperating, herbalists allowed families to make the ultimate decisions for their child. Bishops guided families in understanding the ultimate goals of being Amish and keeping their children healthy, while other community members supported families in reaching those goals without the use of outside health services.

Kleinman's Conceptual Framework and Collectivism

Kleinman (1980) describes illness as a psychosocial experience, giving meaning to the process of having a disease (a biological or psychological malfunction). Furthermore, Kleinman uses the term *explanatory model* to explain an individual cognitive process, constructing beliefs about illness and beliefs about treatments for that illness. In addition, explanatory models exist in individuals and/or families and aid individuals in moving between the folk, popular, and professional health sectors of his conceptual framework (these sectors are described in more detail in Chapter 2). In essence, explanatory models are impacted or "channeled" by the cultural context, but Kleinman's conceptual framework remains individualistic in nature (p. 119). For the Amish, this individualistic approach leaves their collective orientation in the shadows of understanding explanatory models. In order for HCPs to understand how Amish families understand and experience illness and make health decisions, understanding their collectivist perspective is paramount. Kleinman’s (1980) conceptual framework of the three health sectors remains helpful to see how Amish families move through these sectors and make health care decisions for their children. However, their explanatory models influence this movement, and individuals have an overshadowing obligation and responsibility to their collective Amish membership. Kleinman’s framework allows for families to move through health care sectors but fails to focus on families under these similar bounds as Amish families. This research study adds to Kleinman’s work by illustrating how families use explanatory models and make health decisions within a collectivist perspective. This was not anticipated in the forefront of the study but was elucidated with field work and understanding the greater Amish culture within which these Amish families live.

The remainder of this discussion emphasizes how this collective identity within Amish communities impacts how families conceptualize health and illness and make health care decisions for their children with chronic illnesses. These aims are framed within Kleinman’s (1980) conceptual framework of understanding how families move between folk, popular, and professional health sectors. Understanding the collectivist Amish approach will help to clarify and interpret the interface between Amish families and HCPs. Some providers had varying success when working with Amish families, depending upon their understanding of the Amish responsibility and connectedness to their greater community. This is expanded upon in later sections.

Situating the Research Aims within the Literature

Amish Conceptualization of Health and Illness

The first research aim of this study was to describe Amish families’ understanding of their children’s chronic illnesses. Families’ understandings of their children’s illnesses are influenced by their community and family input and experience, as well as education or interactions with HCPs. Families came to their own terms with their children’s chronic illness, and focused on the level of developmental and functional impact the illness had on their children. Parents were resistive of life-prolonging measures to severely ill children with little hope of survival. Maintaining children's health in order to function as Amish adults one day is of utmost priority for parents and family members.

As part of a collectivist perspective, the health of Amish individuals is considered a means to Amish participation. If Amish members were not in perfect health, but able to function in their daily roles, they were satisfied. During my initial meeting with the bishops, they explained that if HCPs did not fix their ailment or injury perfectly, the Amish accepted the treatment as long as it relieved pain and resumed their functional state. However, their experience is that HCPs strive for perfection because they are worried they will get sued; not only is this in opposition to the Amish perspective, the Amish do not practice or engage in law suits. The level of caution and satisfaction that Amish families use with health care treatments is different than non-Amish because of their consideration and definition of health as a means to functionality within the Amish community. Many Amish members have less than perfect appearances, with missing teeth, missing limbs, or scars, but their outside appearance is less important than their functionality to work in daily life. Highlighted throughout the literature is this functional approach to health within the Amish, and their high priority in maintaining function (Armer & Radina, 2002; Wenger & Wenger, 2003). This is in line with the World Health Organization's (WHO) definition of health as the state of well-being and not merely the absence of disability or symptoms. WHO acknowledged the impact of social context and environmental supports or constraints on individual health and functionality (World Health Organization, 2007). Those within the Amish community would add that functionality has purpose to their community, and don't think that HCPs within the U.S. in an individualistic society come from this orientation.

Amish conceptualization of health reflects how they conceptualize illness; they base health and illness on a continuum of functionality that allows individuals to contribute to their community. Individuals who experience illness within Amish communities are not isolated and defined by these illnesses. All Amish members are identified first as their membership and contribution to the Amish community. Children in this study, regardless of their disability, were seen as playing important roles in community responsibilities. One child with a mental disability was seen as a future mother and wife, while another child with physical disabilities had his appropriate tasks to assist with the management of the farm. Rather than focusing on children's disabilities, Amish members who influence their future development focus on their future contribution and role in the Amish community (See Chapter 5).

Amish families hold differing views of death than HCPs in this study. Families experienced hesitant and judgmental HCPs when making end-of-life decisions for their children. When children had end-stage cancer, disabilities too great for the community to manage within their means of technological support, or incurable illnesses, families preferred to allow their children to die naturally (See Chapters 5 and 7). Banks and Benchot (2001) also support that children's death, although unfortunate, is one portal for these children to a better life in Heaven. HCPs struggle with this approach and how to handle it, but very little literature has addressed these contrary approaches to treating children with end-stage illnesses (Clayton & Kodish, 1999).

Previous research established the prevalent occurrence of genetic illnesses with the Amish community (Brensinger & Laxova, 1995; Francomano, McKusick, & Biesecker, 2003; Henderson & Anbar, 2009; McKusick, 1980; Morton et al., 2003). Previous studies show that Amish families have an average of six to eight children (Hewner, 1997; Weyer et al., 2003), although in this study the average was 9.7 children, ranging from six to fifteen, per family. The likelihood of passing on genetic illnesses (symptomatic or carrier status) to at least one child increases as there are more children in each family. In addition, Amish individuals are not allowed to marry non-Amish individuals, keeping gene pools with limited variability. Genetically recessive genes, that require homozygous alleles from each parent to be expressed, occur in this community, with parents who have similar gene pools. Six of the eleven families in this study had children with genetic illnesses.

Previous research identified the need for Amish families to receive genetic counseling and disease or treatment education regarding various illnesses within the Amish community (Brensinger & Laxova, 1995; Henderson & Anbar, 2009). However, some of the education about genetic counseling and illness education may not take into account Amish responsibilities to their traditions. This study supports that families needed a great deal of education about their children's illnesses and appropriate treatments or therapies recommended for those illnesses. However, families did not mention a desire to seek genetic counseling. They were all aware of the inheritance of their children's illnesses, and all of them continued having children after receiving the diagnosis of their children's illnesses. There was no discussion about preventing future childbearing, although all parents were capable of explaining that the disease would continue in the family to future children and grandchildren. When approached by HCPs about decisions for the children with illnesses having future children, the topic was subdued by parents who preferred not to have that conversation in the clinic setting.

HCPs recognized that Amish families needed additional educational support when making decisions for their child's care. Most non-Amish families had access to technology-based education through web sites, television or home videos, and internet support groups that helped them to gain some preliminary education before meeting with HCPs (sometimes these were accurate and sometimes not accurate). However, Amish families needed a great deal of education, in written and verbal forms rather than technology-based, when they came to their initial clinic visits after diagnosis (See Chapter 7). An initial assessment of families' knowledge about their children's illnesses resulted in mixed results in this study. They were also able to acknowledge a potential source of inheritance for their children. Some parents shared distant relatives, while some parents were able to trace the experienced genetic illnesses within both of their distant families. For families with hemophilia, they were able to trace the illness through the mother's inheritance, for an X-linked disorder. Although these family members did not necessarily use biomedical terminology to describe the inheritance patterns, some knew the exact terminology and how the inheritance patterns worked. Families in this study were willing to receive the recommended treatments for their children's illnesses, but needed a great deal of education about prioritizing treatments identifying alarming or emergent symptoms in their children with chronic illnesses.

Folk and Popular Remedies used for Amish Children

The second research aim of this study was to describe Amish families' behaviors and strategies using folk and popular remedies for children with chronic illnesses. Kleinman (1980) describes three sectors of a health system for cultural groups, and two of these sectors include folk and popular. Folk health sector includes the traditional healing methods held within families and communities that are passed informally from one generation to the next. Meanwhile the popular health sector includes those remedies recommended by other families within the community and the overall value system of the community. Families in this study were influenced by recommendations from both the folk and popular sector within the greater Amish community. This study found that families used folk and popular remedies extensively for their children with chronic illnesses, for both preventive and curative purposes. From their perspective, their use of folk or popular remedies prolonged the time in between needed health care appointments and improved their children's health. Families had varying degree of use of folk or popular remedies, with some families relying solely on these treatments and some families combining these therapies with biomedical recommendations for their children. Minimal entanglement with HCPs and biomedical treatments allowed children to remain in their community and as normalized as possible into everyday Amish life.

A substantial amount of literature describes families' use of herbs and vitamins as sources of prevention and treatments (Eisenberg et al., 1998; Tindle, Davis, Phillips, & Eisenberg, 2005) for their children, especially those with chronic health conditions (McCann & Newell, 2006; Vohra, Brazil, Hanna, & Abelson, 2004; Wheaton, Blanck, Gizlice, & Reyes, 2005). The use of these traditional herbs and vitamins for prevention or treatment purposes can be categorized as either complementary or alternative to prescribed biomedical treatments (World Health Organization, 2006). Although less than half of families report the use of alternative forms of treatments for their children, pediatricians reported that when these remedies were discussed it was brought up by families (Sikand & Laken, 1998). HCPs are not beginning conversations about alternative health practices used by families at home for their children, and few families are discussing it with their providers. This leaves a great deal of miscommunication between families and HCPs about the use of alternative treatments. Amish families were using these alternative treatments for both prevention and treatment purposes. This study adds to our foundation of knowledge about what types and how frequently these treatments are used for children.

Amish Approach to Illness and Injury Prevention

In order to keep children healthy, Amish families ascribed to a variety of health prevention strategies. As seen in Table 11 from Chapter 6, Amish families use extensive amounts of both herbal and vitamin blends for their children's health. These natural products helped to keep children's immune systems and strength "built up". In addition, families employed strategies to prevent children from being injured. These illness and injury prevention strategies might not fit into typical prevention strategies recommended by HCPs but allowed children with illnesses to be cared for in line with Amish lifestyle.

Previous research identifies the likelihood of children's injuries within Amish communities related to animals, farm machinery, and falls (Rhodes & Hupcey, 2002; G.

A. Smith, Scherzer, Buckley, Haley, & Shields, 2004; Vitale, Rzucidlo, Shaffer, Ceneviva, & Thomas, 2006). Vitale et al. (2006) highlight that injury prevention education from national organizations and HCPs do not match the parents' approaches. The approach of professionals is to avoid these activities, wear protective pads or helmets, or assess children's readiness to partake in farm work. Amish parents taught extra precautions to children with hemophilia, but the mothers' perspectives were to let children be children and to teach them about avoiding injuries while they played or worked. Ascribing to the traditions of the long-standing Amish lifestyle and rituals, Amish families do not consider preventing children's participation in community activities such as play and farm work an option. Nor do families consider placing children into protective pads, so children maintain their plain appearance in the typical jean trousers, plain shirt, suspenders, and straw hat while working or playing.

The use of herbals and vitamins within this community needs more attention by HCPs. Within observations in this study, families repeatedly asked about how these natural treatments affected their children's chronic illnesses. In all cases, HCPs were not prepared to answer families' questions. Yet, HCPs did not consult with or refer families to pharmacists to aid in this knowledge gap. As a guide to providers, refer to Appendix H to identify the use and purpose of each of the remedies mentioned by families during the study. This table highlights the remedies used in their homes and communities, including the ingredients found in these remedies. The table includes the Amish community or family members' stated reason for using each remedy, in addition to a referenced pharmacologic action for the herbs from various published sources. This way, it will be easy to identify *emic* (insider) and *etic* (outsider) purposes of natural treatments discussed in this study.

Amish families saw these preventive strategies as keeping their children healthy. Without discussing these strategies with providers, HCPs had a difficult time gauging how the Amish were using preventive measures for their children. Dentists recommend bi-annual teeth cleaning; although Amish families did not abide by those recommendations, they had daily tooth care charts in their classrooms in the community to keep their children's teeth healthy. In addition, Amish mothers gave their children calcium to make their teeth strong. HCPs were unprepared to have conversations with families about other strategies than those recommended by biomedical or research sources, and this disconnect frustrated families after their encounters.

Using Folk and Popular Remedies as Treatment

In addition to preventing illnesses and injuries, families used folk and popular remedies for curative or healing purposes for their children. Many families resorted to health decisions and practices recommended to them by immediate family members such as grandmothers, brothers, or sisters. If those treatments or decisions did not work to the families' satisfaction, then the family branched outward to the community herbalists, bishops, or national Amish newspapers such as *The Budget* or *Plain Interests*. These community references helped families by making recommendations that the family might not have considered, or giving these families reviews of remedies that worked for other Amish families in similar conditions. If both of these avenues for treatment for their children failed, families turned to the professional sector and sought care from the local health care system. This pattern of focusing first on health treatments recommended within the folk and popular sectors has been found in other research involving the Amish (Armer & Radina, 2002; Weyer et al., 2003). This study added to this previous research by highlighting their use of these remedies for children's illnesses specifically.

Previous research supports that Amish families use vitamin and herbal remedies, in addition, to the use of manual healing, such as chiropractic and reflexology, or "powwowing" referring to the use of words or charms by an Amish healer called a *brauche* (Blair & Hurst, 1997; Gerdner, Tripp-Reimer, & Sorofman, 2002; Sharpnack, Griffin, Benders, & Fitzpatrick, 2010; von Gruenigen et al., 2001; Wenger & Wenger, 2003). This study supports the use of home remedies as well as manual healing treatments such as chiropractic and reflexology. However, the use of “powwowing” was not described by any of the families in this study.

This study described the community’s treatment of burns using a combination of B&W ointment and Plantain or Burdock leaves. Refer to Appendix H for a summary of the identified pharmacologic effect of each of the ingredients of this treatment. Although burns have been identified as particularly concerning for Amish children (Rieman, Hunley, Woeste, & Kagan, 2008), this study adds new insight into how these burns are being managed by families and herbalists with the Amish community. Research on reported burn injuries in Amish children shows that burns are common, and more extensive and deeper than non-Amish children. When admitted to the hospital, Amish children experience long-lasting intensive protocols to treat and heal severe burn wounds. No previous published literature describes Amish home therapies for burn injuries or the experience of Amish children who are burned and do not seek biomedical treatments. Insights from this study show that herbalists in communities are prepared with other Amish herbalists across the country to care for children in their communities who are burned. A network of communication about caring for children’s burns lies within *Plain Interests*, and the national Amish community is paying a great deal of attention to treating burns and avoiding skin grafts and biomedical treatments when they are able.

The use of folk and popular remedies allowed families greater independence, lower health care costs, and alleviating their child’s symptoms without causing the child any discomfort in leaving home and visiting a doctor’s office unnecessarily. It allowed the families to continue caring for their child without disruption to the child’s daily life attending school, working with their siblings on household chores, or playing with their siblings. Attending clinic visits breaks this daily routine for children, and parents were disturbed by this. Finding a cure for these chronic illnesses would be ideal, but in the mean time, families and the Amish community cared for their child with the means they had.

Amish Families in the Professional Health Care Sector

The third research aim of this study was to describe Amish families' health seeking behaviors and experiences for health services outside of their community for their children's illnesses. This study showed that Amish families actively seek health services for their children's illnesses until they are satisfied with the care and the child's illness is managed according to their goals. In a society where they feel like outsiders and prefer to maintain their own way of life, the one thing that keeps the Amish community together and long-lasting is their ability to make independent choices without interruption from the non-Amish. HCPs for Amish families who recognize the greater Amish collectivist perspective, and are willing to negotiate care with families have greater success. This discussion section highlights the perspective of HCPs when working with Amish families, differing perspectives on the authority of managing care for an Amish child, integrating treatment strategies, challenging and successful aspects of Amish seeking health services outside their community, and some cost and legal considerations that add complexity to these encounters.

Cultural competence requires health care professionals to build professional attitudes, practice skills, and a system savvy for cross cultural situations (Chrisman, 2007; Leininger, 2002; Thom & Tirado, 2006). This study portrays and describes what happens when cultural competence is applied or not applied. In the encounter between Amish families and HCPs, Amish families were unfamiliar with navigating the biomedical health care system, biomedical therapies, and recommended treatments. Meanwhile, HCPs were unfamiliar with aspects of the Amish culture, Amish comprehension of children's illnesses, and Amish home remedies. This made for some challenging encounters. Although pleasant on surface, the clinical scenario highlights some missed opportunities to bridge these differences. Some of the confusion and frustration with each other was discussed in conversations with me, or during interviews.

Health Care Providers Seeing Collectivism

At times during this study HCPs recognized the impact of the families' commitment to the larger Amish community on their health decisions. Because of previous research and publications about the Amish, there is some sense of understanding that there are "elders" who help to make decisions (Armer & Radina, 2002; Wenger, 1988). Only some of the HCPs in this community identified that the Amish consider their community when making health care decisions. Although some HCPs knew or learned the practicalities of working with Amish families, that was not enough to gain cultural competency. Understanding the collectivist perspective of Amish families helped HCPs to provide competent care and make decisions with the family, in consideration of how the child's illness and treatment impacted their greater community.

HCPs learned quickly that families made decisions in accordance with community resources and support, rather than solely the parents' decisions. Families consider what will impact the community and make their decision based on the impact of their treatment, cost of treatment, and their own contribution to the Amish community. In addition, HCPs were able to recognize that families also received some community financial support but were often unfamiliar with the form of that financial support. Often times, HCPs referred families to social workers to alight appropriate financial resources and were largely unaware of the results of those meetings with social workers. HCPs see pieces of the practical aspects and the meaning to families of being part of this community, but they often don't know how or in what ways the community is involved.

Negotiating Authority for Child Care

The approach by families about health and illness on a continuum of functionality is a surprise to HCPs within the U.S., where HCPs are prepared to care for non-Amish patients who set different standards of health as the absence of disability or illness symptoms. However, HCPs are affected by their indoctrination into the mainstream biomedical health system and education, focusing on identifying disease and treating symptoms or eliminating disease in individuals (Kleinman, 1988; Mechanic, 2006; O'Connor, 1995). HCPs and parents find it challenging to bridge the difference in these approaches when caring for their children's health (Gray, 1995). Kleinman's (1980) theoretical framework suggests that explanatory models occur within the context of both culture and the health care system.

HCPs are under restraints about allowing families to be the ultimate authority for treating a child with different treatments than what is recommended as best practice. These two different perspectives on authority over the child's care come to the forefront during family-HCP encounters. This study does support Kleinman's (1980) conceptual framework that families make health decisions based on how they conceptualize their child's illness within their Amish background. Yet this is in great contrast to the U.S. health care system in which HCPs situate the authority within a legal system of community oversight for the care of children.

At the same time as gathering information about their child's illness and making decisions about treatments inside and outside of their community, families are often making difficult and deliberate decisions about which service to receive. In some instances, HCPs and families perceived health services with differing levels of necessity. One family saw routine diagnostic procedures as overly expensive, taking time from the family's routine schedule and not necessary unless their child was actively ill. Meanwhile, the provider knew that these were the recommended regimen of procedures for children with that condition, and wanted the family to receive all of those recommended treatments. This negotiation came to a head during their appointment and both sides had to give up something to continue their working relationship. It was difficult for families to make these decisions because they often did not understand the reasons for all of the recommended procedures, nor the immediate benefit to their child. It was difficult for providers that families did not want or accept all of their recommendations.

This study supports the results of other studies about making negotiations with Amish families, but there is often no clear-cut answer. HCPs are learning that Amish families with children with chronic illnesses will permit highly technical treatments and medications (Gibson, 2008). However, these families require extensive education about the purpose, cost, and benefits of such treatments (Henderson & Anbar, 2009). It is not without the consideration of the cost to their greater community and guidance from the greater community that these Amish families move forward with their difficult decisions for children with chronic illnesses (Clayton & Kodish, 1999).

Integrating Health Strategies

Rachel Remen (1999) called for a new movement in medicine to integrate alternative forms of treatment with conventional forms of treatment. She stated, "It [Integrative Medicine] requires rethinking the assumptions on which medical relationships are based, rethinking the goals of every health care interaction…This field… goes far beyond these techniques to recognize the potential for wholeness in everyone. Integrative Medicine is a call for all health professionals to commit to strengthening the wholeness in their patients by all means possible." This study supports this urge for integrating medicine or health strategies. Herbalists and bishops desire to have their folk remedies recognized and understood by HCPs, while HCPs desire for Amish families to understand their recommendations for the betterment of the child's health. This study identifies that encounters need to improve between HCPs and Amish families to bridge these differences and integrate their perspectives on care for children with chronic illnesses.

Of high priority to Amish families is to have conversations with their HCPs about the safe use of herbal or vitamin supplements or treatments for their children with chronic illnesses. In response, HCPs recommended over-the-counter alternatives to families rather than supporting the use vitamins or herbals for children, or didn't know how to answer family inquiries. The inability to have these conversations with their HCPs drove families to seek recommendations from herbalists in their own community, other Amish communities, or through *Plain Interests*. Outside of their visits with Amish families, HCPs would inquire about why the Amish want to take so many herbs and vitamins. Rather than focusing on learning more about those herbs and vitamins and the impact on children's illnesses or health, HCPs were curious about why these families wanted to use so many.

Vohra and Cohen (2007, p. 880) ask the important questions, "Who can own knowledge of indigenous traditions?" and "Who should own such knowledge?" Amish families have a great deal of experience and knowledge about the use of herbal remedies for ailments in their communities, and they are not hesitant to use these remedies in conjunction with provider recommended treatments (Reiter et al., 2009). Although Amish individuals reported using similar health care services as non-Amish individuals, Amish families reported more frequent use of complementary and alternative medicine therapies (Reiter et al., 2009). The challenge for HCPs is to confidently and safely build care plans for Amish children in conjunction with the Amish use of home remedies (Committee on Children with Disabilities, 2006).

There is a national need for HCPs to pay attention to their patients' use of complementary and alternative medicine (CAM). There are still unclear protocols for providers about how to construct this conversation with families and make negotiated care plans (Dokken & Sydnor-Greenberg, 2000; S. Vohra & Cohen, 2007; Wade, Chao, Kronenberg, Cushman, & Kalmuss, 2008; Wheaton, Blanck, Gizlice, & Reyes, 2005). This study showed and described how body language and communication can assist or hinder HCPs when talking to families about the use of CAM. As seen in the clinical scenario in Chapter 8, when the nurse asked about taking other medications at home besides her prescribed medications, she denied it. However, she told me later in our interview that she was using alternative treatments for her condition. The nurse's communication was closed because she was not looking at her patient or speaking with open questions, and her body language was closed because she had her back turned to her patient while looking at the computer to fill in answers. No other HCP asked specifically about the Amish children using other remedies or medications at home besides their recommended medication regimen. Discovering that families own a great deal of knowledge and experience of using traditional, or home, remedies, HCPs are searching for ways to safely and ethically incorporate these into an evidence-based care protocol for their children. This study brings forward the challenges that HCPs have with this recommendation. Without background research about these home remedies to support its use for children, the HCPs in this study struggled to make educated suggestions to families about their use with their recommended care protocols.

Logistics for Families to Seek Health Services

HCPs were aware that there were some barriers and additional considerations when working with Amish families coming to appointments. Providers struggled with contacting families in between appointments. Amish families in this community did not own telephones in their homes, and HCPs were unsure if families received the clinic routine letters from the appointments office. Providers also recognized the challenge for families to come to clinic visits because of the lack of owning transportation vehicles or driver's licenses. Providers made a strong effort to have families see all possible services in one day's visit because of the distance they travel, and their lack of having their own vehicles. Providers knew that families hired drivers to bring them to clinic visits but were unaware of who the drivers were or the costs to families. Although some providers acknowledged the language barrier, some were unaware that children under school age were not able to speak English. Continually trying to reinforce their statements, rather than offering interpreters or a different form of communication, some providers failed to communicate with young children.

Understanding that these families were very large and that children and/or siblings had a great deal of independence regarding daily health care management, providers took the time to understand who was in charge of the child's care. In some cases, siblings were in charge of re-ordering supplies or medications. This allowed them a better handle of who to communicate with about the plan of care. HCPs continually strategized about working with families who live in a culture that does not use common technologies. Practical solutions for working with these families included writing letters, leaving messages on community telephones, using parents to translate with children, and providing written educational material. These strategies helped to improve the connection between HCPs and families but these strategies were a minimum requirement to understanding and working with each other. These strategies allowed for health care visits to occur, but not necessarily with success.

Addressing Health Care Costs from Different Perspectives

The financial costs to families for the care of their children weighed on the family and the Amish community. As a collectivist community, the wealth of the Amish community lies within the potential to carry their traditional and separate lifestyle into future generations. If families use up their financial resources, there will be nothing to carry on their independent traditions. HCPs recognize that some Amish families were able to pay for services when they need to. However, they are confused when they are met with such resistance by families for receiving all of their recommended services. As stewards of their community wealth for future generations, families took that into consideration when making decisions about health care services for their children. A bishop in this study described the struggle of this community to meet the financial needs of health services because it is a much smaller community than others across the country. Seeing the Amish as uninsured is accurate from outsider perspectives, but they are insured by their community to make payments where necessary (See Chapter 4 for a detailed description of the financial resources within this community). The cost to individual families is felt across the entire community.

In the meeting with the group of bishops at the beginning of the study, all of the bishops expressed their concerns that HCPs don't realize the expense of the care they are recommending to families. The majority of Americans have insurance as a middle source of paying for health services, and many HCPs don't know the actual costs of the services they are recommending. The Amish community finds this lack of knowledge about costs frustrating. The family who went to Mexico for their son's treatment also expressed their appreciation of working with a provider who knew how much his services were going to cost the family. They prefer to negotiate their child's care with providers, including an honest discussion about the cost implications. Rather, most families are referred to hospital financial services personnel, who don't know or appreciate the financial position of Amish families. However, many families in this study worked closely with social workers to decipher the best way to pay for their health care.

Henderson and Anbar (2009) also recognized that the families in their study needed additional support to finance their health care services. HCPs acknowledged the financial burden for families and tried to ease this burden in order to provide the most services for their children. Some providers were willing to make adjustments to their costs, such as the nurse practitioner for the family with PKU and the independent provider located near the Amish community. However, this is not common practice, and is commonly frowned upon by larger institutions. Most providers recognized that the institutions they worked within would not allow them to make those adjustments for families at their own discretion. Some providers held outreach clinics near Amish communities. Providers found financial assistance through grants, foundations, or other donations to pay for families' medications, or treatments. Families appreciated this to a degree that they were not able to put into words; they knew that their children would go without some of those medications and/or treatments without that financial support. HCPs did find discounted financial programs for families to join that is separate from government aid but are often the middle manager of filling out the proper forms. The Amish families had a challenge navigating the health care system to find these financial aids themselves, and HCPs were assistive to families in accessing these financial supports.

Legal Implications for Health Care Encounters

If parents or family members make decisions for children that are not in line with the U.S. legal system, HCPs have an obligation to intervene on those decisions (Huntington, 2003; Iowa Department of Human Services, 2007). The Amish don't deny that they are part of the larger legal system that oversees parental decisions, but this comes in contrast to their fundamental beliefs that parents have the authority for care for their children. The Amish families and community accepts a great deal of responsibility for their own actions and care for children. A sign in one of the Amish bishop's shops that represents an attitude within this community stated, "God helps those who help themselves. The government helps those who don't". Misunderstandings between Amish families and HCPs result in some tragic situations with legal implications. The Amish and HCPs have two different understandings of who is ultimately responsible for the care of their children. The initial meeting with the community bishops brought these concerns forward. Members of this Amish community were concerned that when they disagree with HCPs there is a high risk that their children will be physically removed from their care, or their rights to make decisions for their children would be removed.

Huntington (2003) described examples of complications between the Amish and the legal system, and this section will contribute new examples and insights from this study.

A long-standing tenet within the Amish tradition is that their belief in God and membership in the Amish church dictate their separation from the U.S. government and legal matters. They do not vote, they do not run for city council or any government position except in rare occasions, they educate their children within their community, they do not appear in court, and they do not contribute taxes to the social security system in the U.S. (Dewalt, 2006; Hostetler, 1993; Huntington, 2003). According to Amish parents, the hierarchy of those responsible for the care of a child is the parents first, then the Amish church and their local and national Amish community, and lastly the State (Kraybill, 2003). This sometimes contradicts the perspective of HCPs who see their role as responsible for the care of a child, with the state having a direct impact on their decisions in practice. While it is widely recognized that the laws in the U.S. apply to their community, parents resist involvement with these laws unless necessary. The Amish collective tradition is to avoid participation, and representation, in government decisions. Yet, the Amish fall under laws that don’t necessarily represent their interests or perspectives. One mother was frustrated about her forced use of up-to-date car seats in order to travel to health care visits with her children. However, families recognize that they must abide by laws such as these, furthering their hesitation to come to health care appointments.

Ample examples of children being removed from parent’s care involve circumstances when parents didn’t show up for recommended appointments or refused some of the treatments recommended by providers. Once families entered their children into hospital or clinic care, they risked this outcome. Examples from this study involved parents resisting routing diagnostic procedures such as CAT scans, or major treatments such as bone marrow transplants if they saw more harm to their child than benefit. These families were approached by officials and bishops had to step in to support the family’s decisions to refuse this form of treatment. Families in this study feared using social welfare support, such as Medicaid, because of the perception that their rights as parents to make decisions for their child will be removed when someone else is paying for their child's care. Within *Plain Interests* and Huntington's (2003) accounts, families also struggled with decisions with HCPs about skin grafts and surgery for children with burn wounds, open-heart surgery, and aggressive chemotherapy (Clayton & Kodish, 1999).

HCPs who recognized that the Amish community took care of their children with different approaches and priorities than the health care system might recommend had successful relationships with the families in this study. These HCPs kept in continual and frequent communication with their families, adjusted expectations to something that was comfortable for both the HCP and the family, and took the time to understand the family's circumstances if not following the medical protocol precisely. For example, one provider understood that some of the recommended therapy involved refrigeration, which was not an option with her family's children; rather than focusing on non-compliance for that therapy, she closely monitored and assessed for physical signs that the children remain healthy. However, some providers admitted that if non-Amish families had the same behavior and poor health results, they would consider discussing the case with social services to step in and ensure that the child was being cared for. When providers were in close contact with Amish families, they could assure that the families were taking care of the children, even if it wasn't matching the medical protocol exactly.

The individual responsibility of parents, and the social responsibility of the Amish community, is to raise children to be the future members and continue their traditions into future generations. Amish parents consider the care of their children very seriously, but sometimes this comes into conflict with recommendations of HCPs who are working within the standards of a health system run by evidence, research, and state laws or mandates. When parental and HCP authority come into conflict, it was difficult for both parties to see the child's welfare over the conflict of these perspectives. When relationships between HCPs and families allow for discussion and education to each other about these different approaches, trusting relationships form and children's health is overseen by both parties. When these discussions and opportunities for education are not fostered between providers and families, unfortunate circumstances lead families to lose greater trust in the health care system and the rights to care for their children.

Limitations

As reviewed in Chapter 3, there were inherent limitations of conducting this ethnographic study. Because I worked closely with the Amish bishops in this community to recruit and contact families on my behalf, I may have received information that was approved by the community and not a complete representation of all of the families' experiences within this community. As I became more familiar with the community, families who were not originally recruited by the bishops came forward and decided to speak with me. It took a great deal of time to build trust with families in this study, and observations may have been missed during this trust-building period. Without community events to "bump into" the families, it took a while to be comfortable enough to stop and visit the families for follow-up interviews and conversations. I will never know the information withheld from me, but I am concerned that honestly disclosing my position as a nurse had an impact on how honest some families were with me about some of their decisions for their children.

Finally, working with the public school system about inviting their teachers within the Amish community to the study brought me some challenges in the recruitment of those teachers. Amish teachers within Amish school houses were willing to participate in the study and provided that avenue of observation in the study. The school administrators overseeing the English teachers on the other half of the community were hesitant to allow their schools to be used in this study. They expressed to me that those schools were often the target of other research about one-room schoolhouses or Amish education and children. The administrators did not feel that they had good standing with the community and avoided making any decisions about research involvement. They invited their teachers as a third party but with hesitation and caution to the teachers. One set of teachers participated but did not allow observations in their school setting. Therefore, the findings in this study represent interviews and observations in the Amish-run school houses, rather than the English-run school houses, missing some of the children's experiences who were involved in this study.

Implications

Implications for this study focus on the areas of practice and research. Those implications for practice are broken apart into institutional level and patient-provider level. When working with caring for communities, such as the Amish, within the U.S. healthcare system, it is important to pay attention to the institutional level because policies and national implications of this research can trickle down to affect patient-provider interactions.

Institution Level

Noel Chrisman (2007) identified that health systems do not often provide culturally competent care. Broader views of incorporating cultural competence in nursing include community-based research and approaches to care (Anderson, Calvillo, & Fongwa, 2007). Community involvement into discussions, planning, and implementation of health services for that community will improve the cultural sensitivity of those health service organizations into meeting the needs of that community. Additionally, health care organizations can allow for specialists and HCPs to have some flexibility in their decisions to the treatment of individuals within a community. Many HCPs described the oversight from their institution that prohibited them to negotiate costly services, provide adjusted service options, and even communication with patients in between health care visits. Organizations that set up an avenue for providers to operate with adjusted services for patients will increase the satisfaction of those providers and their patients.

The contribution of anthropology and ethnographies to public health and health care service organizations who serve communities within the U.S. is to provide rich data about the health knowledge, attitudes, and practices of communities. Understanding these perspectives will help to identify the community's acceptance and/or rejection of the health service innovations and recommendations. In order to change or improve health from within the community, it is important for health care organizations to acknowledge the orientations of that community to work together (Hahn & Inhorn, 2009). This study exemplifies one community living within the U.S. with different perspectives about health, illness, and appropriate health treatments for their children than the dominant biomedical model and perspective. When caring for the Amish, health care institutions can recognize that they are responsible to be knowledgeable about the collectivist world and approach to health. O'Connor (1995) proposes that health care institutions acknowledge that they are part of *one type* of health system within the U.S., and not that they are *the* health system within the U.S. In order to bridge these health systems between Amish communities and health institutions, a greater effort to educate the Amish about the biomedical approaches will increase their security in making decisions together for their children.

Legal implications are challenging to work with at an institution level regarding mandatory reporting of families who are not compliant with HCP recommendations. More thorough inspection by institutions into reports from HCPs that Amish families or communities are negligent or providing inappropriate care for children can help to identify situations that are merely differences of opinions and/or not harming the child. In those cases where children are being harmed, it is important to keep these protections in place. However, there is a fine line between having differing opinions about the best care for children with chronic illnesses and maltreatment of children (Huntington, 2003).

Institutions can assist providers in creating care plans with Amish families by providing full and easy access to the cost of services within their facilities. Many HCPs in this study were unaware of the costs of services and referred families to social workers or financial offices for that information. Amish families in this study were frustrated by this and would prefer to communicate with their providers about the costs of services when making decisions together about the care of their children's illnesses. Even for myself, during data collection, it was difficult for me to track some of the costs of services provided to one family. With this accessible information, patients, families, and communities can make educated decisions about the services they prefer to use for their children.

The Institute of Medicine (IOM) (2006b) calls for multi-level strategies across the health system to address health disparities in racial and ethnic groups. Also supported by the Affordable Care Act of 2010 (U.S. Department of Health & Human Services, 2011), reducing disparities for rural patients and communities involves providing more geographically available health centers and increased numbers of primary care providers. The bishops expressed their frustrations with the increasing number of specialists and limited number of primary or generalist providers that they are required to see for their care. The Amish in this study would appreciate closer health care services to their communities and primary care providers who can treat general health conditions. The Amish bishops suggested even having home visiting nurses and providers would also help them to remain in better contact with their children's providers and keep up with the recommended treatments. It is a significant part of Amish families' satisfaction to work continuously and build trust with one provider, rather than receiving segmented care. The IOM and the Affordable Care Act call for increased numbers of primary care providers, which meets these needs and requests of the Amish community.

The cross-cultural education of all health professionals is a necessary step for future culturally competent providers in the health system (Institute of Medicine, 2006b).

In order to support nursing students in building cultural knowledge, sensitivity, and humility, it must be taught and role modeled by leaders within health education institutions (Chrisman, 2007). Within practice and classroom settings, education is needed about how to work with patients, families, and communities of different health care backgrounds than nurses are trained. In pediatric health care, specifically, there are layers of influence on the care that these children receive when they are not inside of hospitals or clinics. Educating future pediatric nurses and providers need to focus on the understanding the cultural and familial context these children reside within, including the cultural values and perspectives on children's illnesses (Brotanek, Seeley, & Flores, 2008).

In this study, the design of nursing units and hospital or clinic rooms was seen to make a difference to families, and institutions can address how this affects the care given to their patients and families. Modern rooms often have computers and technical devices present. One of the Amish mothers, during a clinic visit, expressed her bafflement at computers and focused on this during her daughter's visit rather than the interaction with the provider. When computers were present in the clinic rooms, they were up against walls or positioned on desks rather than directed towards the patient seating area. This forced clinicians to choose between the following two options: a) work on the computer while speaking to their patient (saving time), and not looking at the patient while speaking, or b) looking at the patient during the encounter and then type their notes into the computer afterwards. Considering the placement of technology in ways that support patient-provider body positioning would improve this encounter.

Patient-Provider Level

A set of behaviors and attitudes from providers can open doors to working with Amish families. As providers are assessing patients and their families, one key assessment is the level of understanding about the biomedical system and its position on the treatment recommendations for children's illnesses. In order to make decisions, Amish families in this study and others express the need to understand more about treatment options (Henderson & Anbar, 2009).

In order to understand families' understanding and decisions about the care of children with illnesses, the use of Kleinman's explanatory framework questions can be used as a general guide (Kleinman, 1980). As exemplified in this study, providers can begin by asking questions about how families identified the illness, and how long those symptoms persisted from the time they were noticed. Understanding how the family identified the illness might give a picture of how their community influenced their symptom attribution. Next, the provider can ask about the first steps in caring for those symptoms, including resources families used to care for those symptoms (such as community support or home remedies). And, finally, what brought the families to seek care with the provider at a clinic. These questions will highlight aspects of families' explanatory models for their children's illnesses. Additionally to Kleinman's recommendations, when working with Amish families, HCPs should include and assessment of how the community will be involved in decisions about the health decisions for the child.

Patients have the right to make their own decisions about the medical care they receive, and are entitled to be educated sufficiently to make those decisions coherently (American Nurses Association, 1991). However, the Patient Self-Determination Act does not state clearly about decisions made for children. Concordance is a term referring to incorporating patient perspectives into health care decisions (Hobden, 2006). The term is meant to re-adjust the mentality of providers using terms adherence and compliance suggesting that treatment interventions are one-way authoritative. Concordance suggests that patients can be empowered to make decisions as part of the care plan. This is also the initial intentions of evidence-based practice but many times gets lost in the priority of providers to have their patients take the research and guideline-supported treatments they recommend. As seen with this Amish community and the families in this study, providers who viewed their recommended treatments as the authority did not always have agreement or participation from the families in receiving those treatments. Families occasionally ignored those recommendations, or refuse to accept those treatments. Using concordant behaviors, such as asking patient's perspectives and incorporating those perspectives into the recommendations, providers and patients can build more trusting and effective relationships.

Practically, providers can learn about cultural norms within the Amish community. Cultural norms that were missed by HCPs in this study included language, education practices, financial resources, herbal practices, those individuals inside of the family involved in direct care of the child with chronic illness, and daily routines within the average Amish home. Some HCPs would ask questions to fill in their knowledge gaps, but there is a great deal of this information that is available from research reports. When HCPs accept the care of Amish families, it is part of their responsibility to understand the cultural context and normative behaviors or values within that culture (Brotanek, Seeley, & Flores, 2008; O'Connor, 1995). In addition, providers can reflect on their own acceptance and differences from their patients' community and cultural backgrounds.

As seen within the clinical scenario in Chapter 8 and then in other families' observations at clinic visits, body language of HCPs played a role in the types of answers they received from the Amish children and their families. When providers were looking at the computer rather than the patient, their patient was not giving full or accurate information. When providers sat in comfortable positions facing the families and making eye contact, using open questions, patients were providing more accurate information and felt comfortable responding to questions.

The importance cannot be overemphasized with this Amish community for health providers to become more familiar with natural remedies and their use by the families caring for children (Committee on Children with Disabilities, 2006). Appendix H is meant as a starting guide to some of the treatments used by families in this study, but future effective practice with Amish families will require baseline knowledge about the safe practice of natural treatments for children with chronic illnesses.

Providers who take the time with Amish patients to gain rapport and trust result in better relationships, as seen from this study. Many providers discussed gardening seasons, or play time with the children and families at the beginning of their clinic visits, allowing the Amish patients to feel more comfortable and build their relationships. Although understanding normative cultural values and behaviors is helpful as a starting place, providers who resist stereotypes and assumptions can reduce marginalizing their patients. Seeing each patient as a unique part of a larger cultural context will help to identify unique idiosyncrasies.

Research Implications

Future research implications from this study leave room for great opportunities in furthering scientific knowledge in the areas of: a) caring for children from populations living in the U.S. who do not subscribe to individualistic lifestyles or biomedical perspectives; b) complementary and alternative medicine advancement; c) cross-cultural patient-provider encounters in clinical settings; and d) educational interventions for HCPs and Amish families and communities.

The research methods in this study were used to access and recruit participants in a remote community setting of Amish families. For example, methods such as case-centered sampling and working with local community members for recruitment of participants was successful in this study; practicing these methods with other marginalized populations will test the effectiveness and develop the methods over time and use. Kleinman’s (1980) explanatory model helped in guiding conversations and interviews in this study, and future studies can also use this framework to support describing cultural perspectives on illness conceptualization and treatment preferences.

In this study, families with hemophilia expressed their desire to use multivitamins that are safe for bleeders, without promoting increased bleeding. Future research involving herbs and vitamins involved in platelet aggregation or bleeding times would be beneficial not only to this community but all patients with bleeding disorders. Understanding what natural products interfere with clotting abilities will allow this population to prevent bleeding episodes. Combining safe natural products into a multivitamin would be beneficial not only for hemophilia patients and families but all patients with precautions against bleeding excessively.

Future observations in clinic settings during cross-cultural patient-provider encounters will bring to light additional considerations for building successful interactions and relationships. This study found that the location of computers, body language, communication patterns, and knowledge gaps in both patients and providers prevented smooth interactions. Additional research will unfold other aspects of the clinical encounters in modern clinic rooms that can guide future institutions and providers in creating comfortable spaces and interactions with patients and families in the health setting.

A major finding in this study was the burn treatments used within Amish communities for children and other Amish community members. Amish families would like HCPs to know about these burn treatments and their efficacy in treating burn patients. Future research can test these wound interventions prior to expanding its use to other patients inside or outside of the Amish community will promote safe practice for this population. Ways in which to incorporate these treatments with Amish patients is another area of future investigation. Amish community members would prefer to practice these home remedies within the safety and proximity of hospital support, but want to use their own remedies when possible. Research of the efficacy of these treatments and the negotiations between providers and the Amish families to safely provide care for children severely burned will attempt to satisfy both parties involved.

Educational interventions are called for both with the Amish communities and with HCPs. Education interventions for Amish community members, especially families with children with chronic illness, can be focused on learning about biomedical interventions, navigating the biomedical system, and financial resources besides private or public insurance would give support to families. This support would potentially allow these families to partake in decisions with more confidence trusting their HCP. These interventions would ideally (depending upon feasibility) take place in their communities by trusted researchers, over a period of time, to allow families to learn this information before or during their discovery of their child’s illness. Since Amish communities do not have access to technological educational formats, they prefer anything written, demonstrated, or verbally communicated.

Educational interventions for HCPs focus on closing the knowledge gap between the biomedical education and the health care system within the Amish communities. Interventions could be focused on learning more about cultural norms within Amish collectivist communities, such as their tendency to incorporate community participation and family care prior to seeking professional care, the heavy use of natural treatments, and how families would like to be approached by providers about recommended treatments. Education does not always lead to behavior change, and (as mentioned above) these educational strategies can be reinforced inside of schools and institutions for HCPs to adjust their practice to be more open to patients from cultural backgrounds that do not prioritize biomedical treatments or use individualistic perspectives.

Major Findings From this Study

The purpose of this research study was to understand the cultural context in which Amish families manage the care of a child with a chronic illness and how it frames the interface with the larger health care delivery system outside their communities. This study addressed this purpose by describing the chronic illness management within the Amish community and how families interact with HCPs for the care of their child. Eleven case centered clusters with children with chronic illnesses participated in this ethnographic research study that lasted over 14 months. These case-centered clusters included families with children with chronic illnesses, Amish bishops and community members involved in the care of those children, and HCPs who worked with those families. Participants participated in interviews, daily conversations, informal and formal observations about the care of their children. Through family participation, they connected me to other community members, health care visits, and HCPs involved in the care of their children's chronic illnesses. Through a triangulation of data collection methods and sources, a variety of perspectives helped to answer the purpose and aims of the research study, as described in Chapter 1.

As collectivists, Amish families live and make decisions in accordance and with consideration of the traditions of the community, and work in order to contribute as members to their community. The authority for children's care lies within the parent and family first, then with the Amish community. Amish families can turn to other family members, community members, and finally to bishops with questions about how to make decisions for the care of their children, to ensure that it is in line with Amish tradition and will maintain health and functionality in their children. The Amish community prefers to rely on internal resources for the care of children, and a fundamental tradition within the Amish is to remain separate from mainstream society in all aspects.

Amish families described a variety of treatments and strategies that prevent injury and illness in their children-both healthy and with chronic illnesses. These strategies do not always match the recommendations of non-Amish HCPs and often go under-appreciated or unnoticed. Amish families prefer to use herbal and vitamin therapies prior to over-the-counter or prescription medications and they know a great deal about the purpose and outcomes of a variety of natural therapies. Again, this is largely unrecognized by non-Amish HCPs, and HCPs did not understand the importance of the use of these natural remedies by Amish families. Amish families did not know how to talk to HCPs about the safe use of natural remedies for their children with chronic illnesses, and the majority of HCPs in this study did not question families about their use of natural remedies for these children when considering their health plans. Amish families voiced their concern and frustrations with HCPs' lack of knowledge about the use of natural remedies for their children with chronic illnesses, and would like to have these conversations with their providers.

Amish community members, such as herbalists and bishops, helped families to make decisions about the care of their children. Herbalists made recommendations to families for natural treatments based on their experience in the community, texts about natural treatments, or education they received from other herbalists. Two herbalists in this community had extensive experience and knowledge about treatments for burn wounds and helped two families in this study in treatments of their children's burns with varying success. Bishops were used by families as resources and guidance for using treatments in line with Amish priorities. Some technologies and public aid resources were acceptable according to the bishops because of the circumstances of the child's particular illness. When herbalists and other community members were unable to assist families with the care of their child, and the families remained concerned about persisting and severe symptoms in their children, they sought care from HCPs.

The recommended health treatments by HCPs for children with chronic illnesses were accepted by Amish families with discretion. Families made decisions about which and how much of those recommended treatments to use, based on their assessment of the benefit their child would receive, the cost of the treatment, and how the treatment would fit into their daily life and benefit the Amish community. Amish families do not typically hold non-Amish private or public insurance, and pay for health services with a variety of financial resources within their communities (such as Immergrun) or from resources found by their providers. Careful consideration about which treatments to use for their children included their concern for the cost of treatments that they would pay out-of-pocket prices. HCPs had some frustrations and confusion about how Amish families made decisions for their children. Those providers who spent a great deal of time with families educating and explaining priority treatments, and were willing to accept that families might not choose all of the treatments, felt more satisfied with their relationships with families. Those providers who had a challenging time asking appropriate questions to families about their preferences and priorities with treatments, felt less satisfied with their relationships with families.

Encounters between HCPs and Amish families involved a great deal of teaching and learning from each other, and careful negotiating on the care plan for their child. Observations from clinical encounters and interviews with HCPs shed light on the integration of biomedical health care recommendations with cultural and traditional medical perspectives. HCPs who kept open communication patterns through body language and discussion were able to learn about the Amish perspective and priorities. HCPs who focused on the authority of research evidence and protocols rather than asking families about their particular Amish beliefs and home health practices did not build trusting or effective relationships with their Amish patients and families. In those cases, Amish families were hesitant or refused to follow all of their recommendations, make all of the scheduled appointments, or sought care with other providers. One family sought care for their child solely in Mexico because of cost containment and to work with a simpler health care system.

Some providers, who were not connected to their Amish patients and families, were concerned about the welfare of the child and considered turning families over to social services. In accordance with the mandatory reporting laws that HCPs are obligated to follow, some HCPs used the authority of these laws to enforce the evidence-based care for children in this study. However, other HCPs trusted that although families did not perform all of their recommended services, the families were doing everything in their power to care for their children with illnesses.

Significance of the Findings

There is little research addressing how families care for children with chronic illnesses using a combination of folk, popular, and professional health care. This study highlights Amish families who prefer to use folk and popular health treatments over seeking professional (such as biomedical) services. HCPs did not know how to communicate about these preferences, or how to address them when negotiating plans of care. Other cultural groups who use folk and popular treatments for their children, such as the Hmong, Taiwanese, or Ayervedic traditions, will also have extensive knowledge and experience with folk or popular treatments. Knowledge from this study will show HCPs what is effective and not effective when working with families to incorporate those treatments into the overall care plan for their children.

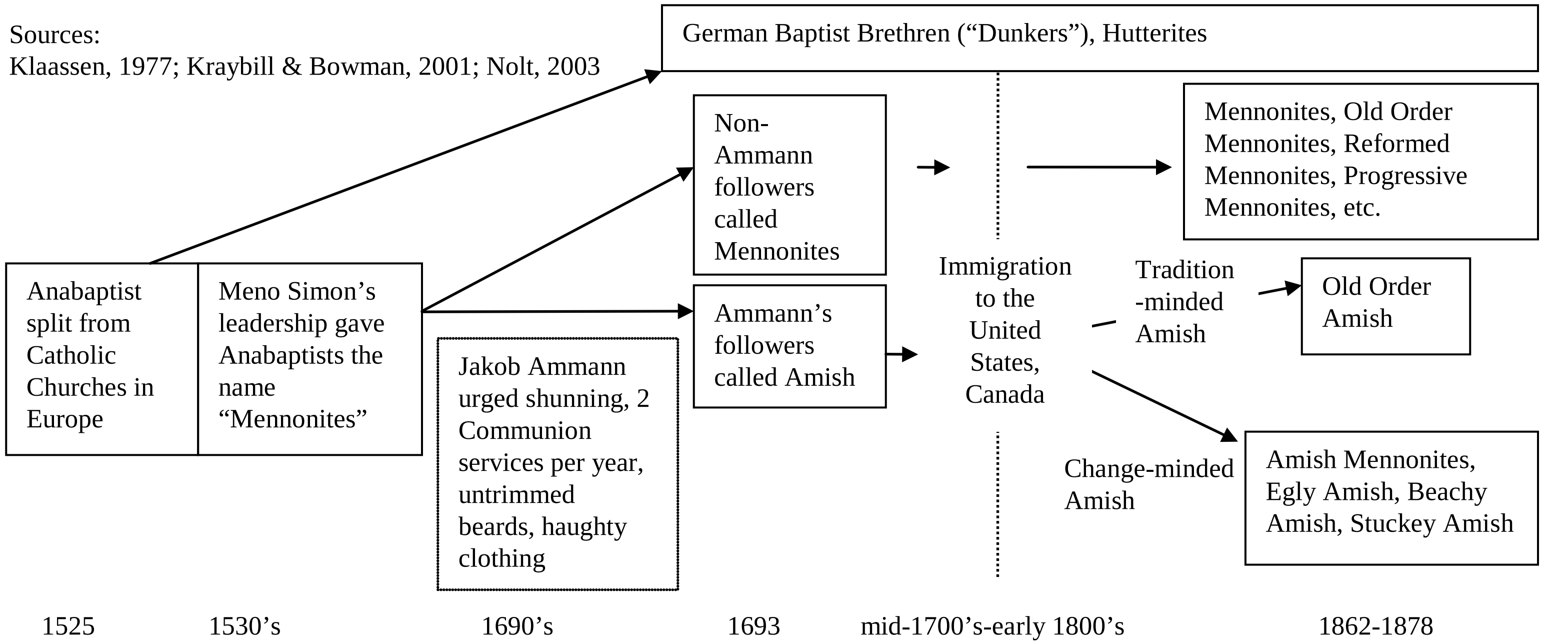
The Institute of Medicine (2005) and the National Center for Complementary and Alternative Medicine (NCCAM) support future research endeavors to support information about effective or safe practices of complementary and alternative practices, in hopes that similar standards of evidence are available for all types of treatments (National Institutes of Health, 2007a). This study identifies multiple requests from Amish families, herbalists, and bishops to address similar goals in order to incorporate their folk and popular treatments into the care for children's illnesses. Amish communities have experience with burn treatments and the use of vitamins or herbals for their children; they would like to use them together with HCPs in a common understanding of their effectiveness. Without the ability of HCPs to have these conversations, or access research to support these practices, a chasm will continue between patients who want to use complementary and alternative treatments and providers who feel most comfortable using biomedical research-supported treatments.

The research methods of this dissertation were successful in meeting the goals of the specific aims, despite working with a cultural group who prefers to remain separate, lives in remote locations, and does not frequently visit health services. The case-centered sampling method, recruitment techniques of letters and meetings with gatekeepers, and strategies to remain respectful and patient are all examples of methods that can be used to assist future researchers working with Amish populations and other hard-to-access groups within the U.S., such as homeless populations, various ethnic groups such as Hasidic Jews or Native American tribal communities, or even home-schooled families.

The results from this study represent one community's experiences and do not presume to apply to all Amish communities. However, these results shed new light on aspects of Amish care for children with chronic illnesses that do apply to other Amish communities and other cultural or social groups living within the U.S., especially those with collectivist attributes. The NINR (2006) calls for a greater understanding of factors that influence decision-making, and the findings from this study demonstrate that individuals from collectivist communities make decisions differently than individuals from individualistic communities. This creates conflicting perspectives during patient-provider interfaces. When families are part of a collectivist cultural group, they will tend to place the group's ultimate goals above their own. This has a direct impact on the decisions that they will make for their children's health and illnesses. A significant contribution of this finding is to aid future patient-provider interfaces by adding depth to seeing each other more wholly to create collaborative care plans for children together.

APPENDIX A. ANABAPTIST RELIGIONS

Figure A-1. Anabaptist Historical Timeline


Sources:
Klaassen, 1977; Kraybill & Bowman, 2001; Nolt, 2003

APPENDIX B: KLEINMAN’S THEORETICAL FRAMEWORK (1980)

Figure B-1. Local Health Care System: Internal Structure

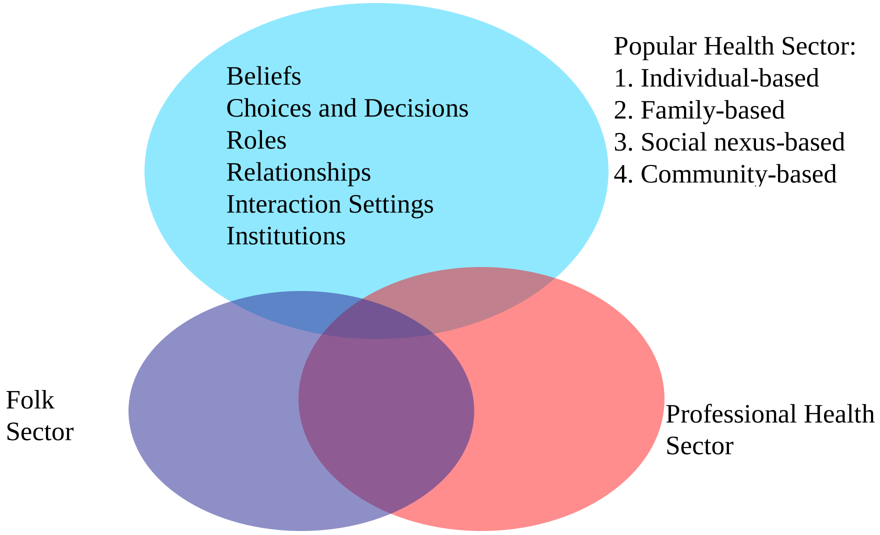
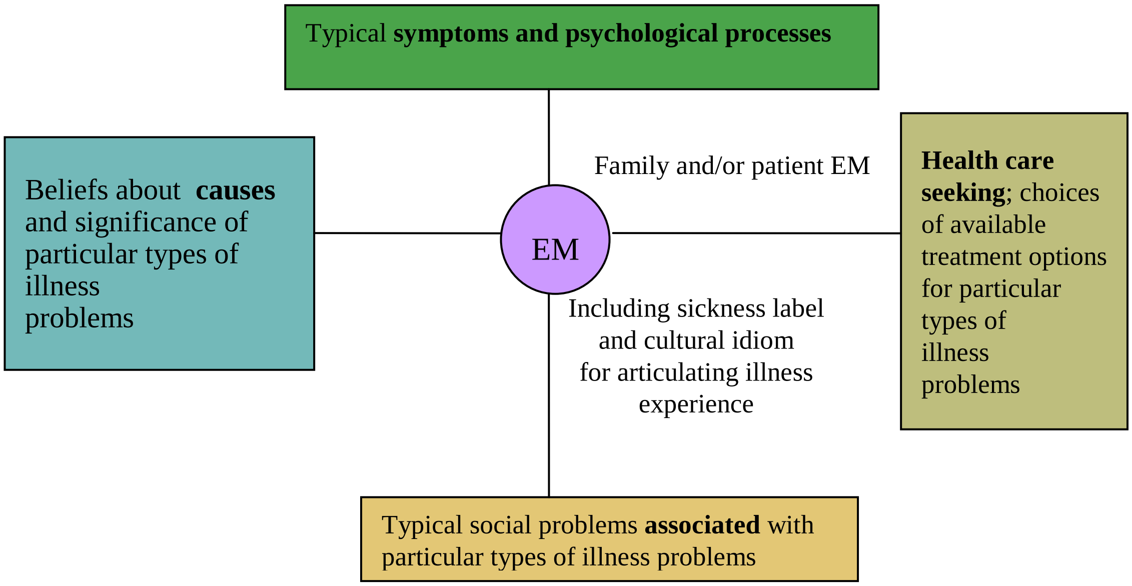


Figure B-2. Explanatory Model Conceptual Framework



APPENDIX C. METHODS FOR INTEGRATIVE REVIEW

Methods

The methods for this integrative review were guided by Whittemore and Knafl (2005), which involved searching, screening and coding, descriptive synthesis, and assessing and appraising quality.

In order to capture the most pertinent and extensive research literature, the following databases were used in this review (Refer to Table C-1): CINAHL, PubMed, ERIC, Anthropology Pluse, PsychInfo, and Web of Science; ProQuest was included for any pertinent dissertations on the topic. Because the intention of this review was to portray a historical analysis of all published Amish research to date about health care within Amish communities, year limits were not set. The search was limited to English-only, inclusive of "all children", and primary research, based on my inclusion and exclusion criteria. Peer-reviewed secondary research articles were later included if they added new insights to the integrative review.

Initially, the intention of the literature search was focused on general health or illness considerations for Amish children. The intention was to narrow the search to research specifically about how Amish families care for children with health conditions. When the search term "Amish children" was used, some articles were missing because the authors did not use "children" as a keyword. These articles were about Amish in general and inclusive of children (ie: genetic illnesses occurring in the Amish community at large, and general Amish health care practices). These applied to children but were not specifically about children. So, the search terms changed focus to "Amish chronic illnesses" and "Amish" to catch those types of articles. Then, during the screening phase, some of these articles were narrowed to fit the inclusion and exclusion criteria. Because of the different MeSH (Medical Subject Heading Terms) terminology within databases, some of the search terms were not precisely duplicated across databases.

Table C-1. Search Strategy, Including Databases and Search Terms

Database	Search Terms [MeSH terms]	And/Or	Results
CINAHL/ ERIC/ Academic Search/ Primary Source	Amish [411] Amish Children [68] Amish Chronic Disease [5] Amish family Care [17]	Or	408
	Amish Amish Children Amish Chronic Disease Amish Family Care	And	0
PubMed	Amish Children [173] Chronic Disease	And	8
	Amish Children Amish Chronic Disease	Or	179
	Amish Children Family Centered Care	And	*1
	Amish Children Family Care	And	5
Anthropology Plus	Amish	n/a	181
PsychInfo	Amish Chronic Illness	And	**1
Web of Science	Amish chronic disease Amish family care	Or	19
	Amish chronic disease Amish family care	And	0

Overall, duplicates were not included in the number results in this table.

*This is a case series of letters written by some pediatrician colleagues about Amish and Mennonite children with Cystic Fibrosis (Henderson & Anbar, 2009)

**Repeated in both PubMed and CINAHL

[#] represents how many articles resulted in these independent word searches

Screening and Coding

Several inclusion and exclusion criteria guided the screening process for the synthesis of literature:

I. Inclusion Criteria:

a. Study Purpose:

        i. Quantitative: Measures of home health practices used by families for children with ongoing illnesses, patterns of use of child care health services for children with ongoing illnesses, any survey or descriptive studies about families using Amish health beliefs/considerations for caring for children with chronic illness
        ii. Qualitative: Studies must have specifically focused on family care for children with ongoing illnesses, or health care beliefs that influence family care for children with ongoing illnesses
    b. Design: Original research of quantitative or qualitative research designs, meta-syntheses included
    c. Participants: Sample must include HCPs who care for Amish families, and/or Amish participants
    d. Language: English only

II. Exclusion Criteria:
    a. Studies that did not meet all of the inclusion criteria above were not included.
    b. Studies that focused on Amish home remedies and family health practices not inclusive of children (ie: article focused solely on health beliefs and practices for elderly).

Substantive Coding:

To assist with narrowing down to literature focused on health care beliefs and practices used by Amish families for children, 344 articles were screened in two phases. During the first phase of screening, substantive codes were created for each of the articles found during the database search. The substantive codes answer the question “what is this study about?”. In some instances, double coding was appropriate, so the total number of codes does not add up to the total number of articles found in the original searches. All of the titles were read and codes were created to match the substantive topic of each article. As substantive codes recurred across articles, these became categories (Refer to Table C-2).

The second screening phase involved labeling all articles with these categories and narrowing down to the most applicable literature. A second reviewer double checked these categories to ensure accuracy and validity of terms and definitions. If the title was unclear as to the content of the article, a second reviewer aided in decisions for categories, and the abstracts or full texts of articles were reviewed for clarification and accuracy of categorizing. Then, each article was reviewed using the inclusion and exclusion criteria to select articles that were about Amish health care beliefs and practices, including or exclusively about children. Table C-3 represents the total number s of articles related to various categories. Articles were excluded for the synthesis of findings related to family, parent, or community care for children with illnesses if they focused on: a) genetic epidemiology, b) disease/injury epidemiology, c) general Amish information, no health care discussion included, and d) childbearing practices (Refer to Table C-4).

Data Synthesis

To understand the type and quality of research and to establish a baseline of evidence, all studies that met the inclusion criteria were included in the analysis. Each of the articles were reviewed (specifically about Amish children) to identify the methodology, sample, and whether they specifically focused on family care and/or children’s health and illness. After this review filtered out articles that did not fit the inclusion and exclusion criteria, 7 were left for data synthesis. These seven articles shed light on the perceptions and experiences of Amish families caring for children requiring health care services.

Table C-2. Categories and Definitions

General Amish: no health care	Anything about Amish culture (not including health care practices within the larger study context)
General Amish: health care subset	Anything about Amish culture, including health care practices within a larger study context
Child-bearing	Pertaining to Amish child birth, birth rate, birthing practices, etc. [I do not consider this part of Amish health care practices for children.]
Children	Articles focused on Amish children
Amish Health Beliefs, Practices	How the Amish culture is influential to their health beliefs, practices in general [the entire article is devoted to Amish health beliefs/practices]
Health care access and use	Anything pertaining to how the Amish access care (insurance, transportation, location, etc.): both adults and children included as sample
Genetic (epidemiology, findings)	Anything pertaining to genetic illnesses within the Amish population
Attitudes, knowledge about genetic cond.	Amish perspective articles about their attitudes toward genetics and health
Provider point of view: Care for Amish	Anything written by HCPs, or for HCPs, or about HCPs: The topic must be about caring for Amish populations
Disease and Injury	Anything pertaining to biologically-oriented illnesses or injuries (including mental illnesses) within the Amish populations

Table C-3. Studies Related to Integrative Review

Specifically about Children	
Disease and Injury (prevalence, risk factors, etc.)	30
Health (physical activity in Amish children; childbearing practices)	6
Genetic Illnesses	38
Parent or family care for children with illnesses	6 (1 literature review)

Table C-4. Studies about Family and/or Community Care Specifically for Children

1	The Amish: Perceptions of genetic disorders and services	Brensinger, Laxova	Genetic: Family Experience of Illness: Children	1995
2	Baby Aaron and the elders.	Clayton, Kodish	Amish children	1999
3	Unique aspects of nursing care for Amish children	Banks, Benchot	Care for Amish: Children	2001
4	Personal reflections. Special Children	Armstrong	Amish children	2005
5	Caring for a critically ill Amish newborn: An application of Leininger's theory of culture care diversity and universality.	Gibson, Elizabeth A.	Amish Health: Children	2009
6	Care for Amish and Mennonite children with cystic fibrosis: A Case Series	Henderson, J.F.; Anbar, R.D.	Family Care: Children	2009
7	Inclusivity matters: Perceptions of children's health and environmental risk including Old Order Mennonites from Ontario, Canada.	Dabrowska E; Wismer SK	Health: Children	2010

APPENDIX D. IRB APPROVAL

IRB ID #: 200907735

To: Angela Oldenburg

From: IRB-02 DHHS Registration # IRB00000100,
Univ of Iowa, DHHS Federalwide Assurance # FWA00003007

Re: How Old Order Amish Families Manage the Care of Children with Special Health Conditions

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Approval Date: 09/18/09
Next IRB Approval
Due Before: 09/18/10

Type of Application:	**Type of Application Review:**	**Approved for Populations:**
☒ New Project	☐ Full Board:	☒ Children
☐ Continuing Review	Meeting Date:	☐ Prisoners
☐ Modification	☒ Expedited	☐ Pregnant Women, Fetuses, Neonates
	☐ Exempt	

Source of Support:US Department of Health & Human Services, National Institutes of Health

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This approval has been electronically signed by IRB Chair: Janet Karen Williams, PHD

IRB Approval: IRB approval indicates that this project meets the regulatory requirements for the protection of human subjects. IRB approval does not absolve the principal investigator from complying with other institutional, collegiate, or departmental policies or procedures.

Agency Notification: If this is a New Project or Continuing Review application and the project is funded by an external government or non-profit agency, the original HHS 310 form, “Protection of Human Subjects Assurance Identification/IRB Certification/Declaration of Exemption,” has been forwarded to the UI Division of Sponsored Programs, 100 Gilmore Hall, for appropriate action. You will receive a signed copy from Sponsored Programs.

Recruitment/Consent: Your IRB application has been approved for recruitment of subjects not to exceed the number indicated on your application form. If you are using written informed consent, the IRB-approved and stamped Informed Consent Document(s) are attached. Please make copies from the attached "masters" for subjects to sign when agreeing to participate. The original signed Informed Consent Document should be placed in your research files. A copy of the Informed Consent Document should be given to the subject. (A copy of the *signed* Informed Consent Document should be given to the subject if your Consent contains a HIPAA authorization section.) If hospital/clinic patients are being enrolled, a copy of the signed

Informed Consent Document should be placed in the subject's chart, unless a Record of Consent form was approved by the IRB.

Continuing Review: Federal regulations require that the IRB re-approve research projects at intervals appropriate to the degree of risk, but no less than once per year. This process is called "continuing review." Continuing review for non-exempt research is required to occur as long as the research remains active for long-term follow-up of research subjects, even when the research is permanently closed to enrollment of new subjects and all subjects have completed all research-related interventions and to occur when the remaining research activities are limited to collection of private identifiable information. Your project "expires" at 12:01 AM on the date indicated on the preceding page ("Next IRB Approval Due on or Before"). You must obtain your next IRB approval of this project on or before that expiration date. You are responsible for submitting a Continuing Review application in sufficient time for approval before the expiration date, however the HSO will send a reminder notice approximately 60 and 30 days prior to the expiration date.

Modifications: Any change in this research project or materials must be submitted on a Modification application to the IRB for prior review and approval, except when a change is necessary to eliminate apparent immediate hazards to subjects. The investigator is required to promptly notify the IRB of any changes made without IRB approval to eliminate apparent immediate hazards to subjects using the Modification/Update Form. Modifications requiring the prior review and approval of the IRB include but are not limited to: changing the protocol or study procedures, changing investigators or funding sources, changing the Informed Consent Document, increasing the anticipated total number of subjects from what was originally approved, or adding any new materials (e.g., letters to subjects, ads, questionnaires).

Unanticipated Problems Involving Risks: You must promptly report to the IRB any serious and/or unexpected adverse experience, as defined in the UI Investigator's Guide, and any other unanticipated problems involving risks to subjects or others. The Reportable Events Form (REF) should be used for reporting to the IRB.

Audits/Record-Keeping: Your research records may be audited at any time during or after the implementation of your project. Federal and University policies require that all research records be maintained for a period of three (3) years following the close of the research project. For research that involves drugs or devices seeking FDA approval, the research records must be kept for a period of three years after the FDA has taken final action on the marketing application.

Additional Information: Complete information regarding research involving human subjects at The University of Iowa is available in the "Investigator's Guide to Human Subjects Research." Research investigators are expected to comply with these policies and procedures, and to be familiar with the University's Federalwide Assurance, the Belmont Report, 45CFR46, and other applicable regulations prior to conducting the research. These documents and IRB application and related forms are available on the Human Subjects Office website or are available by calling 335-6564.

APPENDIX E. INTERVIEW GUIDES

Interview Guide for Amish Families

Tell me about your community.

Tell me about your farm.

Tell me about your family.

How many children do you have?

How is her/his health overall?

What kinds of illnesses do your children get?

Tell me about [name of child].

Tell me about [name of child]'s health issue/condition/concern

Talk about the kinds of care your child received in your community?

Are these common kinds of care? Unique to your child's health issue?

Are there things done within the family first?

How does larger community learn of child's health concern?

How does larger community participate in this care?

Talk about the kinds of care your child received outside the community?

How did you decide to go outside the community?

Who was involved?

What were the expectations?

What were the experiences?

Any that were particularly facilitative? Obstructive? Explain

Interview Guide for Amish Community Members

What do you see as your role and/or the role of the Amish community in caring for a member

with a health condition?

Is it different when the member is a child?

When the health condition is ongoing?

Requires outside community intervention?

Tell me how you came to know about and care for this child.

How were you involved?

What were your expectations?

What were your experiences?

Any kinds of care that were particulary facilitative? Obstructive? Explain.

Interview Guide for Health Care Providers

Tell me about your experiences providing health care to members of the Amish community.

Do you tailor recommendations to Amish families/members compared to other families?

If so, how?

If not, talk about when you do tailor interventions for someone.

My particular focus is on the care of Amish children with a chronic condition or illness that requires care beyond the Amish community.

What is your experience with these children?

Anything unique?

Particularly helpful, positive?

Particularly challenging/negative?

APPENDIX F. CODE BOOK

Table F-1. Code Book

Code	Definition
PEOPLE	
ACCI	Amish Child with Chronic Illness (Defined in Chapters 1, 3)
Bishop	A leadership position within the Amish church hierarchy; ranks at the top of the leadership chain above ministers
Children	Individuals, typically under 18 years old, or daughters or sons of parents within the study
Chiropractor	Alternative medical practitioners who practice diagnosis, and treatment of mechanical disorders of the body
Community Health Provider	A person who diagnoses, and/or treats medical conditions, living in the proximity of the Amish settlement in this study
Dentist	This includes seeing the dentist, home dental care, professional dental care, follow up dental care
Dietician	A specialist regarding nutrition needs; especially for PKU families
Herbalist	A person who knows about, administers, and accesses natural medicines
Nurse	Healthcare professional who cares for patients according to nursing activities and plans of care
Nurse Practitioner	Health care professional who diagnoss and prescribe treatments for patients
Physical Therapy	Of, or relating to, physical therapy or a physical therapist.
Physician	Health professional who diagnoses, manages, and prescribes treatments for patients
Reflexologist	Alternative medical practitioner who applies heat/pressure on individuals for healing purposes
Siblings	Any other child of the same parent of the ACCI
Social Worker	A professional whose main concern is advocating for the welfare of patients or individuals living in society

Table F-1-Continued

Teacher	An instructor at school
Neighbors	Individuals who live within the Amish settlement and next to a participant
BEHAVIOR	
Accommodation	Modification of actions in response to the needs of the other individual(s) involved
Assumption	A guess or supposition of what the other part needs/wants
Body Language	Non-verbal communication that reflect ideas and/or emotions
Collaboration	Working together towards a common goal
Communication	A method to express or transmit
Comparison	The act or process of examining two or more people or things in order to discover similarities and differences between them
Compliance	Obeying, adherence to recommended course of treatment
LOCATION	
Amish Home	Regarding the location of an Amish home (house, family living within that house, yard, etc.)
Church	A religious gathering (actual location or individuals comprising this gathering)
Health Care System	A large conglomerate of HCPs who care for individuals who seek treatments within that conglomerate
Health Seeking	The act of pursuing the needed services to treat an illness, injury, or improve a state of health; can refer to the actual act of pursuing that care or thinking about it
Mexico	The country to the South of the United States
School	Refers to the actual location, building, events during a school day, students present in classroom

Table F-1-Continued

DESCRIPTOR	
Clash	This is something that happens between the Amish and English, and families and providers, or families and teachers....that is unfortuitous.
Family Demographics	Descriptive factors about individuals within a family (gender, occupation, age, etc.)
Identity	A set of characteristics that defines the network of individuals and lifestyle in which the Amish live; although this could be used for HCPs, its purpose is to learn more about Amish identity
Knowledge Gap	When it is obvious that someone is missing some key concepts, cues, understandings
Personal Traits	This means the personality of the participant. It can refer to current attitude, or a permanent character trait that might influence their perspective, experience, or care decisions. (ie: stubborn, optimistic, flexible, etc.)
Positive Interaction	Encounters with other individuals that were regarded as fortuitous, pleasant, helpful or other affirmative descriptors
Trust	Describes the feeling of someone having confidence, feeling comfortable, and accepting the other individual(s)
Uncertainty	Lack of knowledge or lack of confidence in predicting something
LABELING ILLNESS/INJURY	
Genetics	Referring to the science of genes; regarding heredity; includes families understanding or discussion of these topics
Illness Identification	The point in which families notice something is "wrong" with their child and/or label it
Illness Story	This can be related to dealing with or coping with illness symptoms or exacerbations.
Injury/Accident	Anything that causes minor or major trauma to the body system
SEEKING TREATMENT	
Biomedical Treatment	Coming from the biomedical paradigm focusing on the diagnosis and treatment of a disease/illness
Cost	The value or expense of services rendered
Dental Care	Any care provided by a dentist
Family Care	Any form of care provided by the family, within the family.

Table F-1-Continued

Health Care Decision	Coming to a conclusion about what to do regarding any services to improve health or treat an illness
Health Care Decision for Children	This is for ways that the Amish think specifically about health care decisions and options for children. It can be in comparison to adults, or just focused on children.
Health Care Visit	An instance in which a family seeks care from HCPs at a clinic, or other location including the home
Hospital Care	Receiving treatment in a hospital; requiring overnight stays
Immunization	Regarding receiving immunizations/vaccines; can be actions or thoughts about
Insurance	A payment plan issued with someone or institution outside of the family's own finances
Integrate Care	This is combining different forms of care. It can be herbal with pharmaceutical. It can be care from one practice mixed with care from another practice.
Legal Perspective	Regarding laws, enforcement of laws, enforcement personnel, etc.
Outreach Clinic	Describing the events of the clinic provided in the community to Amish families with hemophilia
Priorities	Something set as precedence of other things
Resources	A generic term that describes anything or anyone participants use as a source of help
Stop Professional Care	A decision made by anyone in the study to avoid, decrease, or eliminate any care modalities for the ACCI
Technology	Either professional or Amish use of technology. This could be for health care or for Amish lifestyle.
Transportation	A method of getting from one place to another
Treatment Restriction	Times when the family deliberately doesn't give a treatment or remedy, based on previous knowledge, experience, or health care prescriptions.
Vitamin/Herb Use	I differentiate this from Home Remedy because this is talking abstractly about the use of herbs and vitamins in their home. This is not linked to one particular story.
CARE MODALITIES	
Education	The process of teaching another; can include verbal, written, or other forms
Home Professional Care	This is referring to prescriptions, methods of treatments, or decisions/behaviors that are prescribed by a physician, pharmacy, or lab.

Table F-1-Continued

Home Remedies	This can refere to any treatment done in the home to help someone who is ill or injured. This is independent of professional care, although may include community resources and information. Includes, but not limited to vitamins/herbs.
Manage Symptoms	As defined in Chapter 1: Includes the process to identify and understand the health problem, make decisions within the home about health treatments, consult with lay, biomedical, and non-biomedical professional health services, treat the illness, and evaluate the outcomes of those treatments (From Amish perspective)
Management	This I use to refer to the ways that health care professionals typically manage someone's case or disease. Then, this can be compared to the ways that the Amish manage symptoms, rather than "management".
Prevention	Anything either spoken about or acted upon which intended to avoid injury, illness, or other unfortunate events
Safety	Being protected or protecting others from harm
AMISH	
Amish Lifestyle	Tasks, decisions, or behaviors that reflect general Amish ideals and values
Community Involvement	Any member of the Amish settlement who performs a supportive act for the family and/or ACCI
Crops	Non-animal food product, grown on farms, require harvesting and planting
Farm Activity	This includes chores. I will merge these together. This is any activity on the farm, related to living specifically on a farm. Deals with work load, fun time, play in hay bails, etc.
Farm Life	Pertaining to farm routine, farm activity, farm involvement. This is more focused on the business side of running a farm.
Fun Activity	Any physical exercise done for entertainment
Language	The system of communication; this is not intended for use of inappropraite or appropriate but rather the type of language used (English, Amish, German, etc.)
Spiritual	Relating to the Spirit; worship, prayer, pensiveness

APPENDIX G: BURN WOUND TREATMENT

Figure G-1. Wound

Figure G-2. B&W Ointment

Figure G-3. Burdock Leaf

Figure G-4. Coverage Over Treatment

APPENDIX H. REFERENCE TABLE FOR HERBAL REMEDIES USED IN STUDY

Table H-1. Herbal Remedies Resource Table

Name of Remedy	Amish Use	Ingredients	Purpose
Burn & Wound Ointment (B&W)	Burn wound treatment	Honey	Protective barrier
		lanolin	Protective barrier, moisturizer
		olive oil	Protective barrier, moisturizer
		wheat germ oil	Vit E (skin, nerve, blood vessel support)
		aloe vera gel	Analgesia, anti-inflammatory, antibiotic
		marshmallow	Expel excess fluid, soothe and heal skin/wound, flush kidneys
		wormwood	Astringent, anti-infective properties
		comfrey root	Aid in wound healing
		white oak bark	Astringent, anti-infective properties
		lobelia	Relaxant, sedative, diuretic
		vegetable glycerine	Moisturizer
		beeswax	Protective barrier, astringent, anti-infective properties
		myrrh	Astringent, anti-infective properties
Burdock	Burns, wounds, “relieve pain”, decrease swelling		Antibacterial/antifungal, anti-inflammatory
Ecchinacea	prevent/treat cold		Immune stimulant
Garlic	post-burn, runny nose, heart		Antibacterial, blood thinning
Honey	cold/flu		Protective barrier
Lemon	cold/flu		Diuretic, anti-scorbutic, astringent, and febrifuge
Liquid Golden Seal	post-burn, to “build up”),		Anti-inflammatory, antiviral/antibacterial, used for gastritis
Melaleuca	Toothpaste	Alias: Tea Tree (oil)	Immune stimulant, antiseptic
Fish Oil	Improve concentration	Omega-3 Fatty Acid	Anti-inflammatory, anti-embolus, vasodilation, reduce LDL's

Table H-1-Continued

Essiac Tea	Clean out system when taking chemotherapy for cancer	Vit A Vit C Burdock root Sheep sorrow leaves extract slippery elm bark extract Indian rhubarb root citric acid alcohol	Immune stimulant, antioxidant, repair epithelial tissue Antioxidant, metabolic function Antibacterial, antifungal, anti-inflammatory Antiscorbutic, astringent, diuretic, laxative, antipyretic, vermifuge Analgesic Laxative Antiviral, demineralizing agent Cleansing
Red Pepper	Stop bleeding in a cut or wound		Proinflammatory, vasodilation, analgesic
Red clover	Blood cleanser		Purify blood, anti-infective
Salve	Lump on skin	Peppermint Eucalyptus Honey	Slight anesthesia Decongestant, antiseptic, anti-inflammatory Essential nutrients, antiseptic
Vinegar	Bruise, scrape, or “bone pain”		Topical: cleansing; ingested: antibacterial, anti-hypertensive
Cocoa Butter	Soothe irritated skin		Moisturizer
P&P Oil	Mental retardation		Memory

Table H-1-Continued

"Calm Cream"	Soothe irritated skin; treatment after burn is mostly healed	Methyl Sulfonyl Methane Emulsifying Wax Glycerol Monohydrate Glycerin Almond Oil Coconut Oil Vit A Vit E Vit D (fat-soluble) Aloe Vera Gel Calendula flower extract	Anti-inflammatory Emulsify product Lubricant Lubricant Moisturizer Moisturizer Immune stimulant, antioxidant, repair epithelial tissue Antioxidant, improve circulation, promote strengthening of blood vessels, nerve support Bone growth, muscle development, thyroid function, blood clotting Analgesia, anti-inflammatory, antiviral/antibiotic, immune stimulant Anti-viral, anti-inflammatory (wound healing)
Union Salve "Drawing Salve"	Minor foot burn	Petrolatum Sheep tallow Oil of tar carbolic acid castor oil mineral oil lanolin beeswax	Skin protecting Skin protecting, skin softener Antiseptic Disinfectant, antiseptic Lubricant Lubricant Protective barrier, moisturizer Protective barrier, astringent, anti-infective properties
Microlyn	Colds, sore throat	Inulin Lactobacillus acidophilis (friendly bacteria) Bifidobacterium Thermophilum Dextrose	Food sweetener, maintain intestinal flora Digestion of proteins, anti-pathogen Synthesizes B vitamins, maintain intestinal flora Antibacterial, especially for streptococcus Sweetener

Table H-1-Continued

Calcium	Strengthen teeth		Improve cellular function: bones, teeth; aid in forming blood clots
Energen-C	Build up		Antioxidant, electrolyte support, improve metabolism
Iron	Build up		Produce hemoglobin, assist enzyme process, immune boost
Vitamin A	Skin		Immune stimulant, antioxidant, repair epithelial tissue
Vitamin B	nervous system, immune system, relax babies		Support nerve, skin, muscle, support brain function
Vitamin C	Build up		Collagen/tissue formation, lipid/protein production, metabolizes iron, immune stimulant
Vitamin E	Skin		Immune system, promote oxidation, support skin function
Vitamin K	Avoid for bleeders		Aid in blood clotting, bone formation, convert glucose to glycogen
PoHo Oil	Multi-Purpose: colds, flu, sore throat, cough, daily prevention	Essential Oils: Peppermint Eucalyptus Juniper Fennel	Slight anesthesia Decongestant, antiseptic, anti-inflammatory Decongestant Digestive assistance
Visio Plex	Eye vitamin	Multivitamins Minerals Copper Bilberry Powder Gingko-Biloba extract	Promote Eye Health

Sources: Balch & Balch, 2000; Chan et al., 2010; DeVries, 2010; Fronza, Heinzmann, Hamburger, Laufer, & Merfort, 2009; Gerdner, Tripp-Reimer, & Sorofman, 2002; Guimeraes et al., 2010; Johnston & Gaas, 2006; Kress, 2011; Marciset, Jeronimus-Stratingh, Mollet, & Poolman, 1997; Osman et al., 2008; Singletary, 2011; Sohn et al., 2011; Thomson Healthcare, 2007; Wren & Norred, 2003

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