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Bedside Diaries and Caregiver Journals: Plain Authors’ Accounts of Medical Experiences

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Abstract: Plain populations (Amish and some Mennonites) write nonfiction accounts of their medical experiences as a means of networking and sharing knowledge about medical conditions and care. These stories serve as a means of creating space to normalize the condition. These accounts are written in the form of medical dramas, “bedside diaries” (such as autobiographies and caregivers’ journals), and reference books. In this article, I propose that healthcare providers read bedside diaries and medical experience stories to learn how plain people process their medical experiences, utilize community support systems, and create meaning based on their faith and beliefs. A select bibliography is included; hospital and community libraries should consider adding these titles, while healthcare professionals would benefit by gleaning first-hand knowledge of plain Anabaptist cultures.

Keywords: Amish; Mennonite; cultural competency; medical experience stories; caregivers; plain authors; plain populations; healthcare professionals

Note: The views and opinions expressed in this paper are those of the author herself. The author has no conflict of interest related to the publications described in this article.

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INTRODUCTION

When plain people are faced with medical difficulties, they attempt to learn as much as possible from the internet and books but mainly through experiences of other plain Anabaptists (Sauder 2020). One forum for sharing experiences are in-group focused medical books and articles.

In the past three decades, a plethora of such publications have emerged. The authors are mostly women. They wear an invisible badge of honor to keep their family whole, nutritionally healthy, and well-cared for. Sisters within the church read up on medical conditions, attend seminars, and constantly share (sometimes in blushing detail) tidbits of knowledge about what worked for them or their family members. “Good mothers” take pride in being educated about health. The majority of plain people are fascinated by God’s creation of the body and how it works, offering praise and worship to God.

Accounts in “medical drama” books are often based on diaries kept while a family member is hospitalized. Authors write in great detail about the conditions their children or other loved ones have. The author is usually the person who sits with the patient day after day (hence, “bedside diary”) in the hospital or at the kitchen table when needing to air the daily caregiving load.

An author writes his or her story as a means of helping others as they have been helped by the community. Medical experiences are rarely a solo voyage; the community has opinions about care and also financially supports its members. During a medical crisis, men keep the income coming in (and may take on extra jobs); the wife or mother is the one at the bedside, providing physical care and emotional support. She also learns treatments. Members of the extended family keep the house going while caring for other children at home. While in the hospital, women are actively interested in learning procedures and caregiving out of love and feeling responsible for the health of the patient but also to hasten discharge. Being at the bedside and continually learning about the patient’s condition, plain people try to shorten the hospital stay in order to cut expenses and to conceal differences (things that make them stand out in the community). Many written accounts go into detail about caregivers learning various procedures such as insertion of tubes so that it can be done at home. Out of love and a strong desire to return to normalcy, active engagement and sincere involvement in patient care makes them qualified to bring the patient home.

Writers also share these experiences as a means of protecting themselves against exploitation in the unfamiliar medical system. These stories describe good and less than stellar hospitals and staff, as well as successful and unsuccessful treatments or procedures. They also use their stories to network with the larger plain community. For example, a mother writes a story of her special needs child. A special education teacher of plain children reads this particular book and learns about the medical condition, its various treatments, and available support systems and therapies. She discovers other communities in which the same disorder is present and learns from parents and teachers who work with a similar condition. She, in turn, shares ideas or materials with other plain people.

TYPES OF PLAIN AUTHORS

Conservative and Old Order Mennonites, and most Amish, generally write realistically about their medical experiences using diary or journal format, autobiographies, casual letters, and compilations of memories. These Anabaptists face medical situations pragmatically. They believe that while telling an actual event, one should not embellish the story; the account must remain accurate. Their descriptions and opinions may even material things, opportunities, economic stability, physical appearance, or general patterns of life. For example, mothers will push to remove all visible differences (such as a medical appendage) from their child as soon as possible so that they can blend in with other children and appear “normal.” Constant trips to the doctor make them different and a seeming burden on the community.

The book Home Remedies out of Conewango Valley, NY, suggests keeping diaries or records so that there is “less chance of mistakes.” It suggests writing down medications, doses, and times they are taken; recording blood pressure and temperatures when taken; and the name of the nurse/aide, date, and care given. (p.88).

These groups would have more lines concerning transportation, dress, and technology. They may or may not participate in missions. Examples would be non-evangelical Amish, Eastern Pennsylvania Mennonites, Groffdale Mennonites, Fellowship Churches, and Weaverland Mennonites.

1 Image equality is very strong whether this is personality,
come across as blunt or frank. For example, one story revealed a family’s thoughts about the poor service they received as two hospitals battled each other in an attempt to win over a plain community in the area. Another story tattled on a certain doctor for his rude manner. Another author wrote that it was insulting for a plain woman to be referred to La Leche classes after she had already birthed and breast fed numerous children; something else was obviously going wrong.

Thus, these types of stories give clear insight into plain people’s interpretation of medical experiences. Cultural-specific perspectives and activities in these books provide background for the “outside” reader. By revealing their humanness, the exposure of the plain population’s emotional, social, and inner struggles is valuable in understanding patients and their families. Due to the intimate nature of these writings, they are largely self-published, compiled into a book, or submitted to specific magazines.

More progressive and evangelically-minded Mennonite and Amish-Mennonite authors tend to write medical and inspirational dramas using a generalized style. Writers from these groups tend to borrow heavily from evangelical doctrine, especially on topics of being born-again and evangelization. Their medical dramas are generally accounts of real experiences influenced by popular Christian writing styles. While these books “are based on true stories,” it is accepted that elements are added to the story to make it “flow better,” be more positive, or religiously inspiring. These stories are published through plain publishers and stories are modified to meet their style and set of standards. Similar to popular Christian publishers, Amish and Mennonite publishers that distribute these accounts need to be inclusive of a very broad range of Anabaptist beliefs, so these accounts are not as culturally specific.

4 Pull Through Blessings (Sensenig) and I’ll Leave My All to Him (Zimmerman) are two examples.

5 These churches are automobile groups, mission-minded, and have minimal technology restriction. They include Beachy Amish-Mennonites, Southeastern Mennonites, or any variety of independent Mennonite churches.

6 Sales become limited when a story is featured about one group. Visual identifiers and a sense of our people versus your type of people are so strong that books depicting an Eastern Mennonite, for example, on the cover will generally generate sales only from that group.

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Without insider knowledge or knowing people personally, it is often difficult to place which type of conservative Anabaptist church the story represents. Thus, while these books have some gems of understanding plain culture and thinking, it is less reliable for understanding deeper and harder issues of the individuals.

Medical and inspirational genres were birthed within plain circles from popular Christian medical drama books in the 1990s. Although already participating in medical professions, plain people who read these books were prompted to seek “exciting” professions in emergency rooms, fire and rescue departments, and as emergency medical technicians. The evangelical portrayal of saving souls near death was reason enough to become acceptable (or at least tolerated) occupations, especially among single women, in search of a higher status occupation without “formal” higher education. From this lens, plain writers began to interpret medical and rescue efforts in the same way.

Inspirational dramas also mimic the popular Christian model with the high ideal of turning a trial into a blessing or lesson from God. These stories can border on sensationalism when connecting to dramatized, subjective religious experiences.

STORIES OF THE BROADER MEDICAL EXPERIENCE

Styles of medical stories authored by plain writers vary from medical dramas, to inspirational descriptions (what God taught me through this), to diaries and autobiographies of people living through similar experiences, to compilations of reflections on a family member’s accident or death, and casual letters which include daily life and ordinary things that happen around the house. These diaries, compilations, and letters network people who are going through similar experiences. Diary forms are especially useful in learning about population-specific medical conditions and disorders. This information is otherwise harder to obtain in much detail. These books are a way of sharing information about certain medical issues. Informally, they also provide a way so that authors do not have to tell the same story over and over to community members who ask. On the other hand, these written accounts create a space where like-
conditions are normalized and the afflicted person no longer feels different in that space.

Particularly within writings about people with special needs, readers will get an insider’s perspective on the ambition and energy provided to support those special individuals. They will learn that armies of capable single young women volunteer respite and therapy to relieve mothers. Account authors share their perspectives, their love for the work, and how they perceive clients as blessings (even on rough days). Readers will also see that individuals with special needs participate in the community like other members. Woven within these accounts are plain people’s feelings about each other, the emotional well-being of those involved, and their value of the infirm.

People who have experienced similar challenges will often show compassion to unknown people by traveling many miles to show up at a funeral of a special child (for example) or a similar farm accident. These “been there” networks provide support even if it crosses Anabaptist denominations. Writers often include contact information for readers in their books as a way of reaching out to someone facing a similar situation.

**PLAIN STORIES AS TOOLS FOR CULTURAL INTERPRETATION**

Healthcare professionals can extract various cultural beliefs, practices, and meaning from books written by plain authors to build their own knowledge and caring competency of plain peoples. From plain authors’ writings, healthcare professionals will be exposed to support networks among plain peoples including: therapies (such as equine riding), school/care centers, mental health facilities, and at-risk or addiction centers. Readers will be introduced to plain settlements’ culture for funding methods and staffing, including volunteerism.

Similarly, for healthcare providers interested in working with plain people, bedside writings give insight into how plain people interpret the medical system, treatments, what they appreciate in the services they receive and what they don’t. Plain writers’ frankness and details reveal the depth to which plain people understand medical issues, what they are willing to do, and how they interpret death, hardship, or their loved ones’ sufferings.

Bedside diaries provide healthcare professionals with a plethora of information about patients’ medical experiences. They can also be used by professionals to examine and guide treatment choices and procedures. Given cultural contexts and language differences, these accounts provide a window into plain people’s own (home) medical world and their understanding of it. Treatments and resources, unknown by professionals, may provide valuable answers and worthwhile options to try. Resources within the community may be viable options for treatment. Clues to population-specific disorders may be found within plain authors’ books, and healthcare providers could extract this valuable information to reach out to other professionals or caregivers more familiar with the condition.

For example, when Esther Smucker, a Lancaster County Amish woman, wrote about the death of their son who was hit by an automobile, her journal was a way to process her grief and mourn her loss. Later, she was encouraged to publish her writing and did so as the book, *Good Night, My Son*. Readers outside of plain circles found the work (a first of its time) to be a unique glimpse into the mind of a plain person going through grief. *Pull Through Blessings* is a compilation of stories from families with Hirschsprung’s Disease, including the more specific Mennonite-type Hirschsprung’s. Medical providers can learn patients’ frustrations while searching for answers with the medical world and this condition. *Braces and Blessings* is Sadie Byler’s personal experience with clubfoot and cloaca, a rare congenital malformation. Healthcare personnel can learn from her about resilience. The author of *I’ll Leave My All to Him* (Figure 1), Rosene Zimmerman, describes a severe accident along with the family’s hospital experiences. She also describes the role plain people played in having members on the EMT squad. *One Step at a Time*, featuring Cockayne syndrome, gives details about this rare genetic disorder and also provides a first-person narrative of the raw struggles of a mother with multiple children with the disorder and their family’s place in the community. Healthcare professionals can learn of the cultural importance of family and community as support networks when facing such challenges. In her book, *Beyond the White Cross*, Elaine Yoder

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7 See review in this issue, page 238.
writes of her spiritual struggles with survivor’s guilt and recovery as a young girl from an auto accident. Providers can come to comprehend that spiritual care is a vital component to healing.

Professionals who take the time to read some of these accounts show that they care about the people they serve. When plain clients see something of “our people” within an unfamiliar setting (such as a medical clinic), they see this as kinship connection. They appreciate accommodations such as a children’s hospital that investigated and then provided acceptable reading materials for plain children that frequented that hospital; or seeing *Life’s Special Sunbeams* in the waiting room at the clinic which indirectly helped them connect with other people with the same challenges. Plain individuals appreciate healthcare providers who see the human side of people, valuing compassion, care, and mercy. Connections through literature help foster positive relationships.

Healthcare professionals will not agree with everything written by plain authors in these accounts, so professionals’ attitudes will be challenged. However, learning about different medical practices and perspectives in these books is insightful and, per chance, may lead to clarification of misconceptions. Language differences, for example, occasionally surface which cause knee-jerk reactions over how a person sees a loved one. The word *retarded*, for example, has strong negative responses in the medical and special needs world. However when a plain author uses the word to describe their child, it does not mean the same thing. The word means slower, a condition, and nothing more. Plain people are not necessarily behind the times in political correctness, but simply, they do not use the word in that way. In this case, a reader needs to consider translation issues or cultural distinctions of English language usage before reacting quickly with assumptions.

Accounts written by plain people may provide answers to healthcare professionals’ frustrations, such as, why a certain plain group refuses to comply with a certain practice. Stories could help professionals be sensitive to potential value conflicts. In a culture where one is hesitant to declare that he refuses to do a certain practice, these books can provide background information to anticipate potential red flags or uncomfortable mannerisms. Reading these authors can help professionals avoid medical frustrations, problems, and unhealthy relationships. Some plain clients will find it difficult to articulate the reason why they refuse a type of treatment (often falling back on “tradition” or “it’s not Amish” [defined as: it’s not the same way of thinking]). Sometimes it is a language issue; other times, the belief is so embedded within the culture that it is hard to explain as a separate entity.

Given the too-frequent depiction of plain people as “old-fashioned,” it may be tempting for healthcare professionals to perceive plain people’s home or self-care practices as backward or folksy. Gleaning home practices from books written by plain authors will give providers insights into what clients are doing at home and suggest questions to ask in case certain herbs or remedies conflict with

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*8 A monthly sharing forum magazine containing diary-like entries from individuals working with special needs.*

**Figure 1: I’ll Leave It All to Him and Other Tragedy-Related Book Covers**
prescription medications.\(^9\)Localized home remedy books\(^10\) give community-specific practices that are helpful for medical professionals. These books do not only address local practices but frequently list addresses of medicinal suppliers and educators (albeit mostly product-promotional education). Medical professionals and researchers can solicit these catalogs and gain a perspective of what types of medicines/herbs communities use for what condition and also from where they are getting their health information.

Clients need to be able to feel safe in order to be honest to communicate with professionals.\(^11\) There have been times when plain people and professionals have combined knowledge to successfully find solutions and relief for the infirm. Clients who know that professionals are uncritical of home practices are more likely to share openly what they tried at home. This helps avoid problematic treatment complications. Occasionally, there have been instances when home health products have been sold to plain people that contain illegal or harmful substances. Healthcare professionals can help identify these products and get them off the market if they see reoccurring problems with users. Basic knowledge of these products is useful.

While plain people respect healthcare professionals’ knowledge, they do not feel that the medical world has the answers to all medical questions; it is better to learn from each other. Plain people seek help from professionals when they recognize their limitations to provide adequate care for their loved ones. In their mind, they are \textit{not} handing over care; they are learning from the professional to improve the care they can give. As professionals read personal accounts written by plain authors, they should note the role of the professional as a \textit{helper} providing knowledge and expertise to the family caregiver. The professional provider should be an instructor or teacher. Plain people like to learn, especially about how the body works. Providers should educate and warn plain patients of potentially harmful practices by explaining why or how it may hurt the body.

At the end of this article is a bibliography of select titles that can give professionals inside perspectives on medical issues. When choosing to learn from various books about plain people, it is important to note that not all plain people are the same. Try to choose materials that feature populations close to (in values of technology level or dress) the population with whom professionals are working. They might not be the same group, but they will generally have similar values and beliefs. Health practices, especially if it touches spiritual areas,\(^12\) can be very controversial, even within the group. To provide additional resources, several reference books are included in the bibliography that plain people use for their health choices and some views on alternative health, natural, or herbal practices. Healthcare professionals can glean varying beliefs and practices of plain Anabaptist culture from these texts.

\section*{CREATE LIBRARIES OF PLAIN AUTHORS’ WRITINGS}

Cultural competency is too often only taught through textbooks and guest speakers. However, textbooks hardly do justice, and a speaker provides only one perspective. Both negate variety or the individual within the group. It would be advantageous for medical facilities to have libraries containing materials written by plain authors for staff reference. Researchers could collect medicinal catalogs and paraphernalia from these books to understand where plain populations get their health information and what they use for particular ailments. From there, handy reference books can be created for professionals. Books on experiences with rare disorders not only create great case studies, but also provide links to already existing networks among plain people and to doctors or population-specific clinics working on similar cases.

Partnerships between plain authors and community libraries would be a benefit to the local

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\(^9\) For example. St. John’s wort and some anti-depressants—both used for depression issues.

\(^10\) Such as the Conewango Valley home remedy book. (See bibliography.)

\(^11\) Plain people are intimidated by the professional world, especially as there have been many cases where their children or their family have been harassed, intimidated, or turned in for possible neglect or abuse because of different opinions about medicine. Having their children taken from them is their greatest fear when dealing with the medical world. Consider educating, if concerns of harm are raised; not if there is a difference in opinion.

\(^12\) Such as faith healing, Eastern, or New Age medicine, brauche, or pain drawing
community. With some coordination, it could be expanded to clients or caregivers who may be experiencing similar medical issues or reaching out to others for knowledge and support (Figure 2).

CONCLUSION

The nonfiction accounts, written by plain authors, described in this article, and in the bibliography following, should not be dismissed as unprofessional or lacking in scholarliness or social scientific analysis. They should be recognized and used because they tell of experiences, feelings, knowledge, faith, and humanity. Through these publications, the plain population gets to tell their stories, from their perspective, which has long been neglected. These books provide a deeper understanding of the minds, abilities, and perspectives of plain people. They are valuable in increasing healthcare professionals’ competency to serve them.

ANNOTATED BIBLIOGRAPHY OF SELECT RESOURCES

Evangelical Medical Dramas or Inspirational Stories

Titles in this category are organized at the discretion of the author, by presentation as well as stylistic elements within the stories explained above. Some titles include elements of fiction in order to add more to the telling of the account.


**Biographies and Autobiographies.**

These true stories combine medical, family, and community, with personal inner thoughts and feelings surrounding the medical experience.


Bontrager, Ervin, Jeffery Miller, and Carolyn Sue Miller. 2014. *Beyond the Sunset*. Manton, MI: Rainbow Hollow Press. A compilation of a family and a youth group’s memories of a fellow youth in a fatal buggy accident. Illustrates grieving and peer group bonds. [Amish].


High, Mary. 2014. *A Purple Rose*. Waterloo, NY: Self-published. An album-style picture book offering a personal look at a daughter with pretzel syndrome and her family’s life through pictures of family, school, and community relationships. [Conservative Mennonite; Eastern].


Nisley, Clara. No date. *Safe in the Arms of Jesus*. Millersburg, OH: Self-published. This is a midwife’s compilation of experiences parents had dealing with stillbirths and deaths of infants.


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13 Old Order Mennonite refers to Old Order of service. Thus, churches such as Groffdale Mennonites (horse and buggy) and Weaverland Mennonites (automobile group) are both considered Old Order Mennonites.


Showalter, Velina. (No date). Wheels and Wings for Lester. No publication information. An example of the innovative creativity among plain people to overcome medical limitations. [Old Order Mennonite]


Spiritual Background of Death and Grieving

These books are theological and therapeutic; written for plain audiences about death.


Plain People’s Reference Materials

Reference books used by plain people and writings on health issues, some expressing or representing internal debates. Not all plain people agree on what should be practiced—sometimes with very strong opinions that can develop into heated debates.


Byler, Dr. Tony Lee. 2014. Holding out Hope. Morgantown, PA: Masthoff Press. Focused
on educating Conservative and Old Order settings, this book is a primer for plain people in understanding mental illness and options for treatment.

_Home Remedies from the Horse and Buggy Country of Conewango Valley, New York._ 2009. Sugarcreek, OH: Carlisle Printing. This is one example of a local collection of home remedies for symptoms of various illnesses as well as a Heloise-type collection of household advice, such as what to do about ants. The book supports medical professions and advises to use them. In combination, it gives useful advice for illnesses normally vaccinated (such as, keeping the person in the dark to protect the eyes for measles). Includes addresses for medical suppliers and histories of some treatments. [Amish; Troyer].

Weaver, Paul. 2014. _Gripped by a Dark Hand._ Stoneboro, PA: Ridgeway Publishing. Cautions on the spiritual dangers of alternative health practices. 14

Weaver, Rachel. 2010. _Be Your Own Doctor I & II._ Reinholds, PA: Share-A-Care Press. The widely used at-home encyclopedia for herbal and home remedies largely based on Dr. Christopher’s herb program. Her other titles include, _Be Your Child’s Pediatrician_ and _Backyard Pharmacy._ [Remnant Church].

**Periodicals**

_Life’s Special Sunbeams_ is an affordable magazine where parents, relatives, and teachers of special needs children share their experiences in a diary form. Contributors are from mainly horse and buggy or Old Order Amish and Mennonite homes. [Amish, Lancaster County].

_Lemonade Magazine_ [“If life gives you lemons, make lemonade”] has contributors with critical or long term illnesses from a variety of churches who have conversations about ongoing health issues, perspectives on health, and home healthcare. This homegrown magazine is designed to help others remain positive about their condition and to offer help by sharing what works for them. Contributors are generally from lower tech churches.

**How to Acquire These Books**

Some of these books are available by visiting local stores. Availability may be limited to how these texts (or people) are directly connected to that specific community. Amish and Mennonite publishers and book distributors do mail orders and carry a larger variety of titles than local shops. Some discounts may be offered if it is made known that the order is for a public/school library.

Christian Light Publications (VA), TGS International (OH), Faith View Bookstore (Fredericksburg, OH), and Living Waters (Elmira, ON) have websites. Ridgeway Books (155 Haun Rd. Jamestown PA 16134. PH: 833.690.1260) and Grace Press (2175 Division Hwy. Ephrata, PA 17522) have catalogs. Clay Bookstore has one of the most diverse collections: 2450 W Main St Ephrata, PA 17522; (717) 733-7253.

Ridgeway Books offers a wide selection of books. Grace Press offers more conservative Mennonite publications and is ambitious in providing good special education materials. A few publishers offer E-books and MP3 titles. Mennonite colleges such as Goshen (Indiana) or Bluffton (Ohio) have many titles available. Clients from the population, whom you may get to know, may also be willing to help acquire titles. They will appreciate your interest.

To inquire about:

_Lemonade._ Write to Lemonade 11387A SW CR 2007, Rich Hill, MO 64779

_Life’s Special Sunbeams._ Write to LSS 1022 Rabbit Hill Road, Lititz, PA 17543

**REFERENCES**


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14 Note that there is some difference in natural, alternative, herbal, and New Age/Eastern medicine; however, definitions among plain groups can blur with acceptance or rejection within the group.