

Crafting an Amish biomedical landscape

Martha King

Abstract

Within their pluralistic system of health care, the Amish make medical decisions influenced by cultural practice: a call for adherents to separate themselves from the outside world and to yield to the group. Using ethnographic research, this article discusses one aspect of the relationship between Amish communities near Lancaster, Pennsylvania, and a pediatric genetics clinic that has reformed the ways it mobilizes biomedicine in order to engage this community. Despite local Amish reticence to participate in biomedical systems, three elements discussed here are among those that help shape successful relationships between Amish families and the clinic: a carefully crafted physical space, a conceptualization of genetic medicine as skilled work, and a consideration for culturally appropriate use of time. Amish spaces of practice open to incorporate the clinic as biomedical spaces labor to incorporate Amish practice. The result is an emergent therapeutic landscape developing as a response to group social practice.

Keywords

Amish, genetics, embodiment

Introduction

Elements of Amish society both attract and confound outsiders, including their fundamental religiosity, the nature of their modernity, the appearance of contradictions in their way of

life, and the differences between regional Amish groups. This attraction gets exploited as popular media flattens the multiplicities of Amish life through scripted ‘reality’ television, serialized fiction, video specials, tourist materials, and the national press. In contrast, recent work in Amish studies often focuses on the notable diversity of various Amish communities across North America (for example, Nolt and Meyers 2007; Hurst and McConnell 2010; Kraybill, Johnson-Weiner, and Nolt 2013). There is a balance to be found here in considering Amish identity and experience in the world. Amish do live in small groups that are notably different from one another; they are also stitched together across geographies, settlements, and districts by similarly holding themselves separate from the non-Amish around them. These communities have grown from a common history, and this background provides important context for understanding Amish society across their population as well as within local and regional groups.

Current Amish are extant members of the Anabaptist movement, which was part of the Radical Reformation in sixteenth-century Europe. Most early Anabaptists declared that religion should be fully separated from the state, require a life of pacifism in accordance with their biblical interpretations, and be entered into intentionally as a voluntary choice made by adults. These basic tenets remain in place within contemporary Anabaptist denominations, both conservative and progressive. During the Radical Reformation, many early Anabaptists joined under the leader Menno Simmons, taking on the name Mennonites. In the 1690s, the early Mennonite church suffered a schism under the provocation of a fiery young leader named Jacob Amman, whose followers were eventually referred to as the Amish. Due to their dedication to voluntary religious adherence, early Anabaptists began rebaptizing adults and were therefore considered heretics; around 2,500 were executed by state order over the course of about a century. After a period of political asylum in the Netherlands, the first Amish to arrive in North America landed in Pennsylvania thanks to William Penn’s promise of religious freedom.

Decades of continued religious intolerance, poor economic conditions, war, and unstable political atmospheres led most European and Russian Anabaptists to the New World¹. Among the waves of Anabaptist immigrants, a group of Amish came together to form the Lancaster settlement in southeastern Pennsylvania. In the early eighteenth century, this group consisted of approximately 128 adults (Lee et al. 2010, 9). Because the community has remained almost exclusively endogamous, those 128 adults formed both the cultural and the

1 For detailed histories of the early Anabaptists and Amish church, including details on their migration and expansion into North America, see Dyck 1981; Nolt 1992; Kraybill et al. 2013.

genetic foundation for Lancaster's current 35,070 members, about 11 percent of the world's Amish population (Young Center for Anabaptist and Pietist Studies 2016). While the Amish today may be perceived as a homogeneous cultural group, they practice within a spectrum of conservatism and maintain social diversity. For example, a study of Amish communities in upstate New York would be remarkably different than one in Lancaster County, PA, due to levels of conservatism, economic stability, relative wealth, and local history. These variations manifest in social, political, and liturgical ways, and in forms of practice both mundane and ritualistic.

The data for this article come from my fieldwork traveling to and living in the Lancaster County area over the course of three years. This produced a relatively standard set of ethnographic artifacts including participant observation notes as well as hundreds of hours of recorded interviews with Amish community members and the health care providers that serve them. Economic and social diversity exists even among the Lancaster districts, so I strove to meet with Amish families across the area to avoid essentializing the Amish as a monolithic group while simultaneously attempting to understand commonalities among health care practices within this area. Because my work focuses solely on the Lancaster settlement, for the remainder of this article I often use 'Amish' as shorthand for Lancaster Amish, with the understanding that my analyses may not fully resonate in another geographical area.

I studied the social, spatial, and material interactions of Amish and their health care providers, beginning from the center of their communities of practice: first, interactions between members of Amish communities; next, between Amish and their health care providers; and last, between Amish cultural worlds and cultures of biomedicine in general. Overall, I found that relationships between Amish and the various domains they access (such as technology, medicine, the state) involve conflicts that are resolved through constantly striving to enact and maintain a collective identity, regulated by their own body politic, and made manifest in the material of everyday life. From this larger body of ethnographic data, this article focuses on the Lancaster settlement's relationship with one specific biomedical organization: the Clinic for Special Children (CSC). In this article, I examine the therapeutic landscapes built in terms of space and time by the working relationship between the Amish and the modern genetic medicine of the CSC. These elements of practice not only break down a historical, cultural, and religious Amish reticence toward participation as biomedical subjects, they also illustrate shifts in the clinical praxis necessary to form such successful relationships.

Crafting clinical landscapes

The CSC is a nonprofit medical facility in Lancaster County specializing in the diagnosis, treatment, management, and research of genetic disorders. The clinic's staff provides services for more than 2,200 pediatric patients (Strauss and Puffenberger 2009). More than 90 percent of these patients are from the Plain communities with high relative incidences of genetic disorders, namely, the Amish and Old Order Mennonites in the Lancaster area. On-site lab work and clinical protocols have been developed with attention to two major factors: molecular diagnosis for all patients – including newborn screening programs – and systematic approaches to managing diagnoses in both symptomatic and asymptomatic patients. Over the last twenty-five years, the clinic has mapped more than 120 Mendelian disorders and created a number of novel and highly successful treatment protocols.

Unlike many biomedical outlets (local hospitals, general practitioners, pediatricians), this clinic is a biomedical facility that accesses and gets accessed by local Plain people at a regular rate with a remarkably high level of community satisfaction both within and between districts. They have utilized virtually no advertising in the past, yet they are known across the Plain populations with little discernable exception. As an anthropologist, this was one of the things that attracted me to this clinic in the first place. Virtually all of the Amish I spoke with told me about their refusal, reluctance, or ambivalence about utilizing biomedical services, yet they almost all spoke highly of the CSC through reputation or experience. Over the last thirty years, this clinic has established a remarkable relationship with the local Amish community and continues to deftly cross a divide between biomedicine and the Plain people it serves. Most of their patients come from the Lancaster area, but they also bring in patients from communities throughout neighboring states and the central part of Pennsylvania. Suspected cases of the diseases they treat caught by statewide newborn-screening programs are automatically forwarded to the clinic no matter the background of the child. Indeed, the CSC is partly responsible for creating acceptance of newborn screening among the Amish through including local midwives in the conversation about the importance of catching genetic abnormalities as early as possible.

The CSC's challenge has been to create an extension of everyday Amish life in the context of genetic medicine. These include tangible aspects of care as well as the kind of nonphysical dimensions of therapeutic landscapes that do not exist solely 'on the ground' but emanate from the belief and value systems of a cultural group (Wilson 2003, 85). An array of factors contribute to the successful relationship between the CSC and the Amish population it serves. Many of these factors go above and beyond the desire to understand Amish population genetics or the complexities of such a prolific founding population. These factors include: attention to Amish economic practices, engagement with the community history of

disease, incorporation of patient education, public health outreach, concern for continuity of care, and alteration of the clinic's spatial and temporal landscapes. Attention to some of these areas was carefully planned and some arose organically, but the staff at the CSC remains remarkably reflexive about even the subtlest experience of their patient population. Full analysis of these areas will appear in forthcoming publications, but here I turn to the last of these factors: alteration of the spatial and temporal landscapes through and in which Amish interact with biomedicine. It is no mistake that the CSC has built and fostered a space that attracts and retains their patient base, providing a remarkable example of biomedical landscapes as fruitful spaces of healing and community engagement across vast differences.

Researchers had been coming into Lancaster County to sample and study the genetics of the Amish for decades, but the clinic's founders, Dr. Holmes Morton and his wife Caroline, were the first to commit to developing screening and treatment protocols instead of simply using the community as a research population. Local Amish church districts recognized Morton's commitment to long-term care and his consideration of Plain religious cultures. A few short years after his arrival, an Amish grandfather of two young girls treated by Morton donated a small piece of rocky land that sloped off the end of a cornfield. Not long after, the Plain community raised the timber-frame building to house the clinic. When talking about the original plans for the structure and the community's involvement in raising the building, Caroline Morton acknowledged that 'the design as well as the way we built the clinic was really intended to invite the community to be a part of it'. Considerations of the built environment and material culture in the clinic started in this way and continue to manifest themselves on a day-to-day basis.

After driving down a long lane from a rural road, the clinic rises, built into the hillside with all three floors visible along the back. The driveway curves around and continues up the hill with the main entrance on the second, and main, floor in the front. This is not unlike the way many barns are built into hillsides or use earthen mounds, and it is not the only way the clinic resembles a farm building. With a simple façade of blue-gray wooden siding reminiscent of the area's Amish barns, and trimmed with deep red millwork and a matching red door, the structure is built on a massive post-and-beam skeleton with beautiful buttresses exposed along the front porch. Their sturdy beauty continues inside; cleanly milled, vertical beams meet wide posts, brought together by visible peg construction. Each wooden peg, having been inserted by hand, divulges a craft of skilled workmanship. At the end of the main hallway, the building opens up and the ceiling vaults to a windowed cupola. Gentle curvatures of wooden supports crisscross the air above. When the early morning light streams through the windows and quiet drapes the clinic like a winter blanket, the interior echoes the sacred silence of grand cathedrals. A cross-shaped nave with no altar, here stands a place where the knowledge of science and the sagacity of faith meet on a daily basis.

Hospitals and clinics can be understood as liminal spaces as they remove patients from the flows of everyday life into encapsulated environments. These spaces serve narrow functions and often actively attempt to remove their users from the outside world or larger contexts that may interrupt or complicate the goals within. Patients may be in between states of illness, diagnosis, and treatment, following protocols and dictates from unseen medical or administrative powers. Typical clinical spaces impact patients by becoming grounds for switching out major elements of individual identity, as someone moves from healthy person to cancer stricken, from immobile person to one with a new hip, etc. (Long, Hunter, and Van der Geest 2008, 73). Clinics and hospitals alike are ‘notable for the intensity and heterogeneity of the ongoing spatial ordering processes, both biomedical and other, that produce them’ (Street and Coleman 2012, 4). These liminal spaces often reflect symbolic and functional aspects of the clinic: sterility, interchangeability, universality, and hierarchy.

At the CSC, the liminal space of a standard medical clinic has been nearly negated, not simply scrubbed clean, but denied entry from its early construction. White linoleum floors, windowless exam rooms, melamine cabinetry, fluorescent overhead lights, and metal exam tables covered in plastic cushions have been passed over for warm wooden planking and bright twelve-pane windows, clean white walls with ivory trim, and the constant peek and exposure of thick wooden beams. Many of the exam tables are constructed from wood and each exam room is outfitted with wooden cabinets. Those timber beams erected, cabinets hung, coat pegs pounded in, and every wall painted by Amish and Mennonites who were touched in some way by the help their families received from the Mortons. The patient families feel this connection, even those who are not old enough to have taken part in the clinic-raising. ‘Our people built this place’, one father told me during a checkup with his son. ‘We feel each peg and board every time we walk over them. When new people come, this is a friendly place to walk into. It looks like if Amish made a doctors’ place up our people’s way!’ The concept of the CSC serving as more than a liminal area – as a therapeutic landscape – is amplified through the physicality of its crafted space.

This fine craftsmanship in a clinical landscape stands in contrast to traditional biomedical settings, and this divergence carries well into the laboratory. Virtually all of the testing and lab work is done on site at the CSC. The integration of the lab carries with it a number of benefits for patients and staff. Notable here are the ways the laboratory reveals medical genetics to be a type of craftsmanship. Just past the wooden coat pegs, open for straw hats or winter bonnets, the lab opens up off of the wide main hall of the clinic and sits directly across from two of the exam rooms. Windows across the front of the lab are mere feet away from the neighboring cornfield. The whirring of computer fans and centrifuges are accompanied by the jangle of horse-tack as horses tread by the windows while turning in the soil after harvest or hitching buggies in the parking lot. Sitting in an exam room with a child

screaming from a blood draw, her mother turns to me and says, 'You know where they take that blood? They take it right there [pointing across the hall]. It's the workshop of this whole place. Those in there are the workers. That whole outfit is the workshop, right here in this place'.

The lab is visually and physically available to Amish families coming through the clinic. They can see the work going on as they pass by. They can walk in if they wish to say hello or ask a question or stop to gaze on the equipment and busy labor of the lab's head, Dr. Eric Puffenberger, and his assistants. These patient families have the ability to peek far enough into the black box of molecular genetics to get a picture of the tactile work involved in decoding bodily mysteries. In interviews, patients and their families rarely mentioned the CSC's lab in relation to its cutting-edge science, despite the fact that the Lancaster Amish are some of the first communities worldwide receiving regular molecular diagnosis and genetically tailored treatment plans for some disorders. Instead, they see the labor itself being performed before them; most associated the lab with the 'work of doing medicine' or 'the dirty part of the job'. Just as a product gets crafted at a workbench by human hands, in the lab human hands operate state-of-the-art sequencing machines, pipettes, gene chips, filter papers, robust computers, and the like. The lab was referred to in metaphorical language, such as 'where they stitch all the pieces together' and 'the machine shop where they get it all going right!' The lab becomes a signal in the communal conversation around medical technology – spoken or not – where incorporating biomedical science becomes acceptable because it is crafted, built, felt, and fully integrated into the clinical culture at the CSC. Indeed, it is the only cornfield in the United States where you can get your whole exome sequenced.

Amish and medical pluralism

What of this communal conversation around medical technology? Amish social practice becomes visible through consideration of the use, avoidance, or alteration of various types of technology inside their communities. The Amish persist today as a headless, nonhierarchical grouping of church groups now spread as far west as Nevada, as far south as Florida, and well into Ontario and other parts of Canada. Most Amish live in a geographical settlement, further divided into church districts, or *die Gmay*. These groupings can be thought of as congregations, but *die Gmay* indicates much more. While church members do serve in leadership positions at the district and cross-district levels, Amish churches have no overseeing governing body and no centralized regulatory structures. What it means to be Amish is tied to the practices and discourses that are learned, dictated, and shaped at the district level. In other words, the Amish do not remain a separate and distinct people through conformity to a top-down chain of theological edicts. Through membership and

presence in their *Gmay*, collections of Amish individuals develop identities in conjunction with their participation in the cultural world of their district. As identities are built through Amish practice, the practice itself dictates that they fold those individual identities back into the whole, a true lamination of the self (Holland and Leander 2004, 6). This participation is both relative to and generative of their agency as well as their embodiment of activities, acts, and outcomes bounded by such a world. Involvement in a religious sect with group-enforced social rules that are in great contrast to the larger cultural milieu involves authoring collectively produced horizons of meaning against which action can be interpreted.

Common histories across Amish populations help reveal these horizons of meaning. Early Anabaptist movements focused on individuals coming into practice with one another as a ‘priesthood of believers’ in order to defy or devalue the power of state-based religion. In line with their provenance, modern communities constantly work to set themselves apart from the surrounding world, from the state, the non-Amish, and many outside political, cultural, and religious influences. This is the first horizon of meaning produced in the community of practice. In the parlance of the Anabaptists, this is referred to as a ‘separation from worldliness’ (Kraybill et al. 2013, 26–33). The second horizon of meaning is the buttressing of the community via the yielding of individual selfhood (Kraybill 2001, 32). The reduction of individual autonomy both creates and maintains the pace of life inside the community while at the same time it strengthens the separation between Amish districts and the outside. It is the combination of these two horizons of meaning – separation from worldliness alongside yielding of selfhood – that propels members in Amish communities of practice.

The use, avoidance, or alteration of technologies provides examples in which these forms of social practice become visible. As an addition to biblical and confessional teachings, districts determine limitations on the use of various technologies, what kind of clothing should be worn, hairstyles, educational standards, acceptable vocational practices, and the like. Technology includes the material implements and implementation of a type of modernity understood as a ‘process of social separation that fragments and differentiates’ (Kraybill and Olshan 1994, 21). It is a misconception that the Amish do not participate in prevalent forms of consumer culture out of a fear of the modern or a religious principle that such things are inherently sinful. What drives many decisions – from not owning cars to wearing plain dress – are the effects that such technologies may have on the cohesion of the church district. Take the example of electricity. Founding church members envisioned that practices in a religious community should remain separate from the state and outside influences. Amish refrain from tapping their homes into the electrical grid in part because the grid is controlled, taxed, and regulated by state structures. Further, the refusal to use the grid builds domestic landscapes in ways that feed back into community intradependence. For example, dishes are washed by hand, as an electric dishwasher would weaken the ‘power of collective work’

(Kraybill et al. 2013, 314). An Amish woman told me she preferred her pulley line for drying laundry instead of a gas-powered clothes dryer. 'If it starts raining and I'm out', she said, 'one of the kids or a neighbor pulls in my laundry for me! Why wouldn't I want that?' After all the dishes and laundry are done, night activity is arranged around a modest flame or battery-powered lights; many times I saw how this brought household members together into smaller spaces, encouraged family discussion, and often kept households on a traditionally agrarian schedule of 'early to bed and early to rise' (even for nonfarming families). But Amish districts do not refuse electrical technology outright. Depending on the standards in a given church district, residential, farming, and shop work may incorporate non-grid power created by diesel generators or solar systems. And some rare districts may even allow the use of power from the electrical grid in business structures or barns. These practices are in a constant state of being built and maintained by the district's dual actions of group separation and self-yielding. These same complexities come into practice as Amish individuals and districts make decisions about health care.

Biomedical traditions often presume patients are autonomous subjects, or work to create them as such (Gordon 1988, 11), as disease is approached as a set of empirical symptoms, and medicines as biochemical reactions that may be tweaked in the research setting and then applied to bodies. Not only are lab and clinical medicine separated, clinician and patient are often reduced to low-functioning relationships where people are seen as complex but discoverable sets of machinery. This generates a real disconnect as church districts foster a culture that places primacy on the group (Kraybill 2001) and the church community guides knowledge production and the negotiation of technology. The study of health modalities, and biomedicine in particular, has to recognize a wide array of interests including local priorities concerning the well-being of both individual and community (Lock and Nguyen 2010, 2). The Amish work relentlessly to maintain separation, and are therefore faced with tough decisions about what approach or combination of approaches may be most suitable, most socially acceptable, and most effective in addressing the body's needs in relation to medical technologies and health care settings. In this area of Pennsylvania, I found that Amish pluralistic medicine can be divided into five distinct arms: chiropractic care; midwifery; medical tourism (primarily to Mexico); home care, including a variety of approaches from herbal medicine to the use of naturopaths; and local biomedical interventions including (but not limited to) genetic medicine. During my fieldwork in the Lancaster area, I observed and interviewed an array of health care providers to ascertain the provider viewpoint of Amish health practices including physicians, nurses, licensed chiropractors, unlicensed chiropractors, adjustors, naturopaths, herbalists, detox specialists, nurse midwives, other midwives, and the practitioners at the Clinic for Special Children.

When discussing Amish medical pluralism, I avoid the terms ‘alternative’ or ‘complementary’ medicine to reflect that, among the Amish, these arms are not considered secondary to biomedical approaches. Families tend to utilize branches of the pluralistic system for specific concerns in predictable patterns and combinations maintained by practice in their districts. As a general guideline, biomedical interventions are most typically used for emergency traumas, some ob-gyn care, long-term illnesses with high rates of morbidity, and genetic disorders or other birth defects. Rarely sought for preventative or regular care, a doctor may be a second, third, or even fourth line of defense against a condition that has lingered or worsened. Children do not typically have a pediatrician; adults rarely have a regular physician.

Many Amish in the Lancaster area will utilize biomedicine at some point in their lives but it remains relatively disfavored. Even among those who utilize hospitals or doctors for some type of care, many of these Amish expressed deep social and cultural reasons for disliking biomedical intervention. The reasons expressed varied, including issues such as tradition, ‘My father never saw a doctor and lived to 97’; concern for continuity of care, ‘You never see the same doctor twice and each more confusing than the one before’; and time, ‘We wait and wait. After, I get a few minutes with the doctor and then he’s rushed off again’. And throughout my interview data, the issue of cost was consistently raised. Most biomedical care, particularly in private settings, remains unaffordable, and district rules dictate that individuals carry no outside health insurance nor subscribe to any type of government-based health assistance. Amish pay for visits in cash, and the district pools money to cover larger costs. Even as some local hospitals have recently begun changing their policies in order to charge Amish more reasonable rates as cash-paying patients, many services remain out of reach for most families to cover alone. Further, many Amish I spoke with argued against the regular use of biomedicine on the grounds that they refrain from indulging in practices that encourage or reward the ‘empires of man’: secularism, scientific authority, higher education, and economic excess. As one person put it, ‘Doctors are not men of God’. Instead, they seek to honor the ‘empire of God’ through their own bodily work in and around Amish landscapes.

In many ways, Amish plural medicine represents a kind of holism, similar to a non-Cartesian epistemology, where the body exists as a part in a larger, spiritual milieu. Spaces – both literal and symbolic – that are deemed suitable for Amish use gain therapeutic value. The therapeutic landscape made manifest in CSC’s built environment is one way to understand this intersection of identity, social practice, and health. Certainly, using skilled labor to craft the landscape of everyday life is revered for its ability to shape an Amish cultural world separate from the outside and for its ability to equalize individuals across space by crafting that life together. The value here is placed on the craft of Godly, bodily, Amish work.

Indeed, Amish health is determined by one's ability to perform labor, and illness is determined by one's inability to perform that same labor (Hostetler [1963] 1993, 322). Healthy bodies are seen as crafted by work. By the same token, medical care that makes visible the same spirit – a craft that signifies physical work – is valued. The nature of the spatial environment at the CSC opens up biomedicine in newly accessible forms for Amish patient families.

A clinic on 'Amish time'

The CSC provides a dynamic example of clinical practice shifting to operate effectively within a plural system where a biomedical culture and approach may not dominate. Earlier I mentioned how the alteration of the clinic's spatial and temporal arrangements are among the dimensions of the therapeutic landscape of the CSC that contribute to this successful relationship by extending everyday Amish life into the context of genetic medicine. They succeed, in part, by crafting an environment that accommodates local Amish communities in functional and ideological ways. I already discussed the build environment, but we can also consider the way Amish time is respected. The following example illustrates how consideration of Amish cultural values enables the practitioners and staff at the CSC to shift the way they practice medicine in order to improve patient outcomes. In an interview, I asked an Amish mother of five why she does not take her eldest son, who has chronic ear issues, to a doctor for regular pediatric care. She replies:

I would be able to find someone to watch the younger children and hire a driver, just so that someone I don't know much can look at my son for fifteen minutes, and they barely look at him at that? This is just not something for the time I spend. Then they charge \$200 to say he is sick? I know he is sick; that is why I brought him all the way there in the first place.

Before my fieldwork began, I was warned by a Mennonite friend that understanding 'Amish time' would be crucial for me as an ethnographer among the Amish. Busy from dawn to dusk, the time many of my Amish consultants take and the attention they pay to tasks is humble and deliberate. Traveling is constrained by the use of horse and buggy, and the lack of electricity puts certain temporal boundaries on the workday. Communication is never instant; with visits, circle letters, and phones outside the home, simple collaboration with others moves at a different speed than most of us are used to. This temporal notion is usually discussed as 'patience' by sociologists and historians in the Amish studies literature. Patience and deliberateness are seen as measures of a spiritual humility among many Amish communities. And the thoughtful time within which everyday tasks occur contributes to an overall disquiet with being rushed. This is the 'implicit, invisible message conveyed by every

Amish carriage that slowly makes its way along roadways as cars streak past it' (Kraybill et al. 2013, 67). While I agree that their experience of time is instructed by patience, their networks of technologies, craft, and social practice have also constructed this common sense of Amish time. Amish time became constantly apparent to me in the context of health care and integral in the therapeutic landscape of the clinic.

One afternoon, I sat with a family in the waiting room at Lancaster General Hospital. I watched as a mother fretted nervously with a young baby's socks, as two of her other kids played quietly nearby and she shot the occasional side glance at packs of white coats scurrying by. She shuffled her feet, dug through her bag for a baby toy, and took her glasses on and off multiple times. I did not think that it was the waiting itself that was causing her agitation, as we were there for an expected visit and knew her baby would be fine. So I asked her why she was so nervous. 'It makes me uncomfortable', she told me. 'Their jobs are to help people but it is unkindness the way they move so quickly, talk so fast, the way it took longer to get here than we will spend with the doctors. I'd rather stay home and get a visit' [from a chiropractor]'. The frenzied pace of 'hurry up and wait' in many biomedical settings, particularly hospitals, is considered inappropriate and unfriendly in the context of Amish time.

A consideration for cultural constructions of time runs deep through the clinical set-up at the CSC. This is one of the many ways that the clinic shifts the shape of the environment of clinical genetics in order to meet its patient population. The day is designed so that families spend as much time as they need to with their physicians – and a portion of that time goes toward continuing important social relationships. Many visits last between forty-five and sixty minutes, but it was not unheard of during my time there for visits to go on for two hours or more. This stands in stark contrast to a pediatric visit at a standard clinic, which is typically scheduled for fifteen or thirty minutes, with a single physician seeing twenty to thirty patients a day. The pace of work at the CSC not only aids in incredible continuity of care (something we may all like but the Amish are particularly sensitive to) but also provides a natural forum for integrating essential patient education and building social relationships between patient families and practitioners that carry into the Amish community at large.

The spatial and temporal boundaries in this landscape are tied together at multiple nodes, but the place with the most impact is right back there in the lab. As mentioned earlier, lab work (screening, testing, biobanking) is fluidly incorporated into clinical care due in part to the lab's close proximity to the physical space of patient care. Just as Amish individuals only need to peek across the hall to discover the machinery of modern genomics, their samples make the same short journey. For example, the amino acid levels of a baby with an inborn error in metabolism may be checked in real time at a fraction of the cost charged at most

commercial labs or tertiary care centers. Due to the incorporation of the clinic and lab setting, a test like this will be back in about 45 minutes – often while the family is still in the building. Critical adjustments to the diet and supplements can be made in real-time reaction to the body's levels. This is not only scientifically and medically more appropriate, it has the potential to save Amish parents and, by extension, their entire church district thousands of dollars in medical costs over the infancy of a single child. By slowing down the pace of clinical care, the CSC is actually able to speed up their own reaction time and keep more Amish kids healthy as a result.

A blend of tradition and innovation

As clinicians and researchers, the goals of practitioners at the CSC include identifying genetic causes of disabilities, improving diagnoses, and implementing novel therapies to create a cohesive strategy for improving pediatric health outcomes while reducing medical costs. Simultaneously, the clinic aims to achieve these goals by attending to the cultural interpretations of its patient population and has achieved notable success in this endeavor. These physicians and researchers have taken on a mission to make advanced medical technologies accessible, affordable, and culturally acceptable to the Plain folk in central Pennsylvania. Screening and treatments performed at the CSC have been long regarded as pioneering and considered harbingers of a medical future based in new genetic understandings. The *New York Times* called the clinic 'a model and a test of medicine as it eventually will be' (Belkin 2005). This prediction rings true as the CSC continues to push the forefront of translational genomics in ways that are unique. Unlike tertiary care centers or major research hospitals, the clinic operates at the community level. Yet it brings the unmistakable benefits of these closed-study populations to bear on the nascent field of medical genomics, while also bringing complex and highly technological biomedical science to a community with children who suffer from genetic complications at astoundingly high frequencies. The CSC stands as a bridge between the lessons buried deep in the genetic code of Lancaster County's Amish and the ability of modern science to help, comfort, and even heal. Like the population it serves, the clinic stands as a dynamic blend of tradition and innovation.

But the CSC does not remove Amish families and patients from their otherwise plural medical system or somehow convert these individuals to faith in allopathic treatments based on biomedical science. Amish families with children treated at the CSC might understand a bit more about metabolic disorders or congenital malformations than other Amish families, but they still utilize the other arms of their plural system with typical regularity. One child in a family may be seen at the CSC on a monthly basis, but his brothers and sisters are likely to have no interaction with a physician (although a number of CSC families get siblings

vaccinated at the clinic in part to help protect the child most at risk). The physicians have to remain constantly aware of what other modalities a family might be utilizing for their sick child. As long as these treatments are not contraindicated, the CSC staff does not generally advocate against them. But there are tragic stories of families that have, in retrospect, made the wrong decisions when faced with choices between taking up protocols at the clinic or following the advice of their chiropractor, herbalist, or naturopath. These disastrous outcomes are not common, but do stand out. In this context, the CSC has emerged as a space with the flexibility to accommodate aspects of local Amish society, and these accommodations have resulted in a long-term interchange between Amish patient families and biomedical practitioners in the clinical setting.

I depict this interchange as dialogic: it moves in both directions. Although none of the physicians come from Amish or Mennonite backgrounds, in order to serve these communities, they began to resist ways that the state typically structures and participates in biomedical enterprise. For example, the CSC does not run their facility or research using federal or state grants. The clinic's founder and former medical director explained, 'The ways patient care and genetic research are currently funded and linked are symptoms of our broken medical system'. The CSC is kept open using private funds, modest service fees, and money generated by fundraisers put on by the Amish and Mennonite communities they serve. Clinicians are well aware that their education levels are higher than those of their patient population. And while their scientific knowledge enables them to help the community in new and significant ways, they also recognize that their authoritative knowledge does not function the same way it would in most other clinical settings. Medical authority rests in the patient's reliance on the physician's competence and on claims that compel trust (Starr 1983, 15–17). Physicians and nurses at the CSC temper some of the authority they were trained to exert in medical school, recognizing that they are working with people who value the authority of God and the authority of community.

For example, the clinic does not do preconception screening for Amish patients, and prenatal screening is rare. But over many years, families across the area have learned that early intervention can help seemingly normal newborns, so some parents who know they are already at high risk will undergo prenatal testing purely so they will be prepared to take action when the baby is born. The CSC does not push or encourage these technologies. They might, however, encourage a family to utilize a computer-based communication device for a child confined to a wheelchair and unable to communicate beyond a few basic signals. Some families may jump at this chance, some in a more conservative district may refuse such technology, and still others may want it but their district may be unable or unwilling to pool the costs to purchase and maintain such a system. As I watched the negotiation of medical technology, one area continued to recur as a key element to understanding how these worlds

come together in one therapeutic landscape: the space and time of the clinic. Incorporating state-of-the-art biomedical science becomes acceptable among Amish because it is crafted, built, felt, and fully integrated into the clinical culture at the CSC.

There is certainly sample bias of a sort here: the CSC is not a general practice. Most of these families have children with mild to profound issues stemming from deleterious genetic variants both known and unknown. Some of these patients die young with untreatable disorders, some live with complex but manageable health issues, and some benefit from treatment protocols that lead to productive adult lives. Before the CSC existed, some Amish children were tested, researched, and treated in nearby tertiary care centers at high cost with relatively low success in alleviating their medical challenges. But the presence of the CSC as a medical home for these families, and eventually as a part of an Amish health system, has brought new trust and interest in the biomedical approaches used there. Even beyond the direct impact made on the two thousand-plus patients and their families, the settlement as a whole has benefited from this relationship, including through the CSC's vaccination clinics, its foundational role in helping to implement newborn screening by way of local midwives, and other public health outreach programs run by the clinic's staff.

Genes alone don't determine outcomes; expression and phenotypes are mitigated by the landscapes where they interact. These are health landscapes populated by human and nonhuman actors; these are the cultural worlds that people interact in and create through their interactions. With this consideration, biomedical culture itself becomes part of the environment that shapes manifestations of disease and thereby influences health outcomes and phenotypes in patient populations. The data from this project reveal that recognizing and adjusting for this concept has been key to the construction of the CSC as a therapeutic landscape that shifts the ways both medicine and research are conducted. In other words, the physicians at this clinic recognized that it is not just the 'outside' environments of the patients that are important in the interplay of genetics and environment; it's not just what patients are doing when they go home but how they experience the whole of their environment, including the clinic.

Concluding thoughts

As Amish families engage with genetic medicine, they experience both an anatomical and a molecular body. Constituted at these different levels, genetic bodies and genetic diseases are often seen as knowable objects through the lens of scientific understanding, a type of knowledge typically outside of the realm of experience for most Lancaster Amish. But both genetic bodies and genetic disease are also unpredictable and shaped by their environments. Amish social forces work on these environments as well. I've described here how Amish

cultural practices form a five-armed plural medical system that typically marginalizes biomedical care, and how one biomedical institution has become fully part of the Amish therapeutic landscape. The sedimented cultural practices of Amish delineate the social and physical dimensions of their therapeutic landscape. In turn, the willingness of practitioners at the CSC to (re)shape the culture of biomedicine reinforces that landscape in symbolically significant ways.

Anthropology offers us the opportunity to investigate the experiences of bodily action and affliction, and to understand them as a space where ‘nature, society, and culture speak simultaneously’ (Scheper-Hughes and Lock 1987, 31); we can bring these together under the category of therapeutic landscape and allow a medical anthropology lens to look across conceptualizations of landscape. Gesler (1992, 473) alludes to this idea by imagining therapeutic landscapes as products of social and material circumstances that ‘reflect both human intentions and actions and the constraints and structures imposed by society’.

In many ways, the CSC’s unspoken mission has been to create both a literal and ideological extension of everyday Amish landscapes in the biomedical realm. First, the space of practice where Amish collective identities are built also shapes the suitability of health technologies. The CSC was planted and has grown into an acceptable and effective biomedical home for many Amish families in the area due in part to its ability to become a therapeutic landscape that is repeatedly ‘molded by the interplay, the negotiation between physical, individual, and social factors’ (Gesler 1992, 743). Second, collective practice has a distinct effect on how Amish bodies move through and experience space in and out of the clinic. Paying attention to craft and practice as a dialogic interchange allows us to combine explicit and tacit knowledges of work with aesthetics and materiality. In this sense, the crafts of carpentry, quilting, doctoring, parenting, networking, storytelling, and others all point us back to enacting cultural worlds through the body. An array of factors contributes to the successful relationship between the CSC and the Amish population it serves, including the crafting of spatial experiences. Providing a space for expression of Amish craft and space in the context of biomedicine enables the CSC staff to move beyond simply providing medical care, bringing education modules into the clinic, or providing outreach. They are able to shift the way they practice medicine in order to improve patient outcomes. We might think about the CSC as a biomedical space that has been incorporated into Amish therapeutic landscapes, but we can also conceive of the reverse: that these Amish spaces are incorporated into biomedical landscapes. It is in both of these, and in this dialogic space that is built between the two, where the true therapeutic landscape resides.

Acknowledgements

Preliminary research for this project was funded by the Graduate School at the University of North Carolina at Chapel Hill and by the Center for Genomics and Society at the University of North Carolina at Chapel Hill (funded by the NHGRI/NIH under Award Number 2P50HG004488). The primary research for this project was funded by the National Science Foundation. The content and analysis here are solely the responsibility of the author. Thanks to M. Stoltzfus, an Amish reader, for her thoughtful comments on an early draft of this paper.

About the author

Martha King is an anthropologist working at the intersections of health, medicine, belief, genetics, community, practice, and the body. She holds an MA in folklore/American studies and a PhD in anthropology. Her research considers the bodily care employed by the Amish and their relationships with biomedicine. She currently works as a lecturer in the Department of Anthropology at the University of North Carolina at Chapel Hill.

References

- Belkin, Lisa. 2005. 'A Doctor for the Future'. *The New York Times Magazine*. 6 November, 65–115. <https://nyti.ms/1fJQqOa>
- Dyck, Cornelius J. 1981. *An Introduction to Mennonite History: A Popular History of the Anabaptists and the Mennonites*. Scottdale, PA: Herald Press.
- Gesler, Wilbert M. 1992. 'Therapeutic Landscapes: Medical Issues in Light of the New Cultural Geography'. *Social Science and Medicine* 34, no. 7: 735–46. [https://doi.org/10.1016/0277-9536\(92\)90360-3](https://doi.org/10.1016/0277-9536(92)90360-3).
- Gordon, Deborah R. 1988. 'Tenacious Assumptions in Western Medicine'. In *Biomedicine Examined*, edited by Margaret Lock and Deborah R. Gordon, 19–56. Dordrecht: Kluwer Academic Publishers.
- Holland, Dorothy, and Kevin Leander. 2004. 'Ethnographic Studies of Positioning and Subjectivity: An Introduction'. *Ethos* 32, no. 2: 127–39. <http://www.jstor.org/stable/3651830>.
- Hostetler, John Andrew. (1963) 1993. *Amish Society*. Baltimore, MD: Johns Hopkins University Press.
- Hurst, Charles E., and David L. McConnell. 2010. *An Amish Paradox: Diversity and Change in the World's Largest Amish Community*. Baltimore, MD: Johns Hopkins University Press.
- Kraybill, Donald B. 2001. *The Riddle of Amish Culture*. Baltimore, MD: Johns Hopkins University Press.

- Kraybill, Donald B., Karen Johnson-Weiner, and Steven M. Nolt. 2013. *The Amish*. Baltimore, MD: Johns Hopkins University Press.
- Kraybill, Donald B., and Marc Alan Olshan, eds. 1994. *The Amish Struggle with Modernity*. Hanover, NH: University Press of New England.
- Lee, Woei-Jyh, Toni Pollin, Jeffrey O'Connell, Richa Agarwala, and Alejandro Schaffer. 2010. 'PedHunter 2.0 and its Usage to Characterize the Founder Structure of the Old Order Amish of Lancaster County'. *BMC Medical Genetics* 11, no.1: 68. <https://doi.org/10.1186/1471-2350-11-68>.
- Lock, Margaret M., and Vinh-Kim Nguyen. 2010. *An Anthropology of Biomedicine*. Malden, MA: Wiley-Blackwell.
- Long, Debbi, Cynthia L. Hunter, and Sjaak van der Geest. 2008. 'When the Field Is a Ward or Clinic: Hospital Ethnography'. *Anthropology and Medicine* 15, no. 2: 71–78. <https://doi.org/10.1080/13648470802121844>.
- Nolt, Steven M. 1992. *A History of the Amish*. Intercourse, PA: Good Books.
- Nolt, Steven, and Thomas J. Meyers. 2007. *Plain Diversity: Amish Cultures and Identities*. Baltimore, MD: Johns Hopkins University Press.
- Scheper-Hughes, Nancy, and Margaret M. Lock. 1987. 'The Mindful Body: A Prolegomenon to Future Work in Medical Anthropology'. *Medical Anthropology Quarterly* 1, no. 1: 6–41. <http://www.jstor.org/stable/648769>.
- Starr, Paul. 1982. *The Social Transformation of American Medicine*. New York: Basic Books.
- Strauss, K. A., and Eric Puffenberger. 2009. 'Genetics, Medicine, and the Plain People'. *Annual Review of Genomics and Human Genetics* 10: 513–36.
- Street, Alice, and Simon Coleman. 2012. 'Introduction: Real and Imagined Spaces'. *Space and Culture* 15, no. 1: 4–17.
- Young Center for Anabaptist and Pietist Studies. 2016. *Amish Population Trends*. Young Center for Anabaptist and Pietist Studies, Elizabethtown College. <http://groups.etown.edu/amishstudies/statistics/population-trends-2011-2016>.
- Young Center for Anabaptist and Pietist Studies. 2016. *The Twelve Largest Amish Settlements 2016*. Young Center for Anabaptist and Pietist Studies, Elizabethtown College. <http://groups.etown.edu/amishstudies/statistics/largest-settlements>.
- Williams, Allison. 1998. 'Therapeutic Landscapes in Holistic Medicine'. *Social Science & Medicine* 46, no. 9: 1193–203. [https://dx.doi.org/10.1016/S0277-9536\(97\)10048-X](https://dx.doi.org/10.1016/S0277-9536(97)10048-X).
- Wilson, Kathleen. 2003. 'Therapeutic Landscapes and First Nations Peoples: An Exploration of Culture, Health and Place'. *Health & Place* 9, no. 2: 83–93. [https://doi.org/10.1016/S1353-8292\(02\)00016-3](https://doi.org/10.1016/S1353-8292(02)00016-3).