

Mother Tongue: The Role of Vernacular Knowledge in Chronic Illness and Healthcare

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This work demonstrates how and why the expertise of non-medical actors, such as patients, caregivers, and patient advocacy groups, is essential for improving patient outcomes and quality of life. 'Vernacular' knowledge, including community beliefs, values, networks, and practices, both challenge and collaborate with institutional scientific knowledge. The value of this interaction of multiple kinds of knowledge is illuminated through a study of spinal muscular atrophy in Colombia, which explores how mother caregivers develop unique expertise, devices, and care practices, and use online social networks to share and learn both clinical and vernacular information. Supported by a broad body of evidence and theory, this paper makes a powerful case for elevating vernacular knowledge and the people and communities who practice it. It also showcases methods and channels that researchers and medical professionals can use to collaborate with caregivers in these non-institutional, but medically essential, spaces.

Introduction

There is an ongoing debate among scholars regarding the concept of the “vernacular”. In the field of architecture, anthropologists have discouraged its use, suggesting it has become just another concept to essentialize the Other, much like “primitive” or “folk” (Vellinga 2011). However, environmental studies have argued that expert science is “not enough” to make competent decisions (Turner 2004), and emphasize the importance of local knowledge to address ecological crises. In these studies, vernacular knowledge is defined as an integration of expert science with community beliefs and values, or a negotiation or collaboration between different forms of knowledge, rather than a dichotomy (Simpson et al. 2015).

In this case study, we apply the concept of the vernacular as *negotiation* to healthcare contexts, specifically to the knowledge developed and shared by chronic patients, caregivers, and patient advocacy groups. This concept is appropriate because this knowledge, rather than being in direct *opposition* to institutional medical knowledge, *negotiates* with it by embedding it in specific sociocultural contexts. Vernacular knowledge in healthcare, despite being non-institutional and sometimes non-scientific, is legitimate because it has the potential to achieve what is arguably the primary goal of medical knowledge: improving health outcomes and patients’ quality of life.

At A Piece of Pie, a global consulting firm with experience in medical anthropology and patient-centricity, we applied the concept of vernacular knowledge to a study on spinal muscular atrophy (SMA). SMA is a disorder that affects the cells controlling voluntary muscle movement, leading to muscle weakening and atrophy. Its most common type is typically evident before six months of age, meaning these children require permanent care, usually provided by their mothers. We saw an opportunity in SMA to understand the role of the vernacular knowledge displayed by these mother caregivers. After conducting an ethnographic study with five of them, we learned that their vernacular knowledge is negotiating three seemingly non-negotiable foundations in Western medicine. The first is the “know-it-all” doctor trope, which refers to society’s inability to acknowledge other kinds of expertise in medicine. The second is the rigid “hierarchy of evidence” within the current medical paradigm, where statistical evidence is considered more truthful and is preferred over ethnographic evidence. Finally, the third is the exclusive channels through which knowledge is exchanged, namely academic journals and medical conferences.

Negotiating these foundations entails having multiple ways to answer questions such as *who* talks in medicine (experts), *what* they talk about (evidence), and *how* they talk about it (channels). In the following sections, we will provide a general context on SMA, as well as the study’s objective and methodology. Afterwards, we delve into each of the negotiated foundations, demonstrating how ethnography (with its mindset and methods) enabled us to detect negotiation between bodies of knowledge rather than opposition. We close our case study arguing these negotiated foundations are not specific to SMA; they apply to chronic illnesses and conditions in general, in the sense that these patients and their caregivers are all developing their own bodies of knowledge.

Study Overview

Disease Context

Spinal muscular atrophy (SMA) is a genetic neuromuscular disorder that affects motor neurons, the cells that control all voluntary muscle movement, leading to muscle weakening and atrophy. There are several types of SMA, classified based on the age of onset, with type 1 being the most common and typically evident before six months of age. The incidence of SMA is calculated to be between 1 in 6,000 to 1 in 11,000 births (Cleveland Clinic, n.d.). Because it is such a rare disorder, diagnostic delay remains a significant challenge, especially when primary care physicians and pediatricians are not familiar with it (Cao 2021; Pera 2020).

There is no cure for SMA, but recent treatment developments aim to stimulate the production of a specific protein that supports motor neurons. These therapies are extremely expensive and, in healthcare systems with limited resources, are typically approved only for patients with a timely diagnosis, whose motor neurons have not yet deteriorated. For those without access to these disease-modifying therapies, treatment focuses on managing symptoms and preventing complications. This usually includes breathing support (sometimes through tracheostomy), feeding tubes or gastrostomy, physical therapy, occupational therapy, and speech-language therapy. Children with type 1 SMA therefore require permanent care, which is most often provided by their mothers.

In contexts with limited access to disease-modifying therapies, as well as support devices, procedures, and therapies, mother caregivers and patient advocacy groups (PAGs) have become a strong, activist, and demanding force. In Latin America, they are widely using social media platforms, such as Instagram, to raise awareness about SMA, fundraise, sign petitions, pressure decision-makers, and illustrate the daily challenges faced by these patients. It is due to this dynamic context that we became motivated to conduct ethnographic research on SMA.

Study Objective and Methodology

The present study was conducted by A Piece of Pie (APoP), a global consulting firm that applies medical anthropology, design services, and innovation to help stakeholders address healthcare challenges. APoP became familiar with SMA due to a project for a pharma company that was interested in learning about the disorder's current situation in Colombia. For this previous project, we engaged with neurologists and other healthcare professionals (HCPs) that diagnose and treat SMA. Through these interactions and complementary desk research, we learned that mother caregivers and PAGs are empowered, self-organized, and well-informed, and that they have successfully used social media to increase their influence and reach. We therefore decided to conduct a study autonomously, this time focusing on mother caregivers and with the hopes of understanding how they came to assume this leadership role via social media. The study was focused on Latin American caregivers, because this was the region we were already familiar with in terms of SMA.

The research methods used were social listening and in-depth interviews. Social listening was conducted to learn what was being said online about SMA in Latin America. Although research teams can use tools such as Hootsuite Insights, on this occasion we conducted a more organic exercise by identifying opinion leaders (both medical and non-medical), searching news articles, blogs, and webinars, and

following specific hashtags on LinkedIn, Instagram, and X. An organic, as opposed to a tool-based, approach is adequate when the topic of interest is highly specific, such as SMA in Latin America. With this approach, we were able to find five robust Instagram accounts of Latin American mothers with children diagnosed with type 1 SMA: three were Colombian (but one of them lived in Florida), one was Brazilian, and one was Venezuelan.

With the social listening exercise, we gathered a broad understanding of common experiences and concerns among the five caregivers. We put this baseline knowledge to the test conducting in-depth interviews (IDIs) with three of them. The three IDIs were conducted remotely and included virtual home tours. We inquired about routines, early signs and diagnosis, access to treatment (including therapies, procedures, and support devices), and their goals and expectations using social media. The results obtained via social listening and IDIs are described in the following section.

Study Results: Negotiated Foundations

In this section, we present the study's results as negotiated foundations, or foundations of Western institutional medicine that, at first glance, appear non-negotiable. We focus on three: the first consists in the socially accepted idea or trope of the know-it-all doctor. The second refers to the rigid way in which different types of evidence are categorized in the current medical paradigm, which tags ethnographic evidence as the least desirable, and the third is the exclusivity of the institutional channels through which medical knowledge is shared (academic journals, medical congresses).

Foundation 1: The Know-It-All Doctor Trope

The speed at which medical knowledge is currently being generated is unprecedented, with estimates suggesting it doubles every 70 days (Densen 2011). In the field, we've seen that this has led HCPs to embrace what Microsoft CEO Satya Nadella calls a learn-it-all mindset, vs. a more traditional know-it-all one (Sweales 2019). And yet HCPs are still perceived as all-knowing, by most patients and by society as a whole. It is difficult to accept that HCPs also have cognitive biases that affect their decision-making process (Marino 2020), or that during patient consultations primary care physicians are asked questions they need to look up answers to (Kahane 2011). This know-it-all doctor trope is historical; it can be traced back to the nineteenth century, when "expert knowledge" embodied in the (male)

HCP disrupted previously “taken-for-granted practices” in Western modern societies (Escobar 2018). The knowledge possessed by these experts established itself as more objective and universal and thus more legitimate (Nieto 2019) and it still lingers in Western healthcare systems.

Our SMA study suggests there is a different kind of expert when it comes to chronic illness: that of the expert patient or caregiver, who has no choice but to become an expert to face daily challenges. One of the ways in which these experts differ from the know-it-all doctor trope is their fluid identity. They switch between knowing and learning, as seen in the case of mothers of patients with SMA. Just as they’re constantly learning from HCPs, they too have developed their own solutions out of necessity, which are validated and praised by HCPs. Mother1 described her own technique to remove mucus from her son’s airway walls, because her healthcare insurance wouldn’t cover vest therapy for patients with SMA. Mother2, while being grateful for the HCPs who advise her and care for her daughter, also shared do-it-yourself (DIY) solutions with us that demonstrate a deep understanding and analysis of the daily needs that patients with SMA have. Take, for example, an adapter that she and her husband attached to their daughter’s electric wheelchair, to secure the ventilator required for ventilatory support. Or how, instead of having special shoes made for her daughter’s insteps, she simply added platform shoe soles to her orthopedic boots, which has been more practical and cost-effective. Or, finally, a PVC pipe structure built over her daughter’s bed, to organize the “mess” caused by the cables of her life-support devices. HCPs might advise on all these devices, but ensuring they’re manageable and work together is certainly up to the caregiver expert.



Figure 1. PVC pipe structure built over the bed over a patient with SMA.
Credits: @princess_julieta Instagram account.

The ability to switch between knowing and learning makes these mothers well-suited for teamwork with HCPs. Much is being said in healthcare about the need for integrated care and for higher collaboration between stakeholders, an idea that clashes with the know-it-all doctor trope. In our study, we were pleased to witness mothers and nurses working together to define the best therapy routine for the patient (speech-language therapy, occupational therapy, respiratory therapy, etc.). As Mother1 put it, “What scares me the most is going somewhere when I’m not involved in the decision-making process.”

Besides this fluid identity, the patient/caregiver expert has other traits worth discussing. While HCPs are socially expected to super-specialize, the knowledge this kind of expert possesses grows in many directions. It is an organic, fragmented growth that comes from managing the multifaceted consequences of a chronic condition, which extend beyond just the clinical aspects. In our SMA study, we witnessed how these mothers inevitably delve into pedagogical debates, when considering the kind of education their children should receive. “I think, until what point is it relevant for my kid to know who conquered who”, Mother2 wonders, a sentiment also seen in Mother1 and Mother3, both interested in nurturing the skills their children will require to use future assistive communication technologies. Even

in SMA cases without cognitive impairment, standard education can be unsuitable for these patients; it may interfere with the patient's therapies, and in some contexts, transportation and school facilities are not disabled-friendly.

There are two final traits of the patient/caregiver expert we can appreciate in our study. The first is that they are much more relatable experts than HCPs; just as they use Instagram to share medical information on SMA, they discuss the emotional toll of the condition, and delve into mental health issues in a non-aspirational, non-influencer kind of way. Perhaps Instagram caregivers are where to look for alternatives to what scholars have called hedonic mental health, or mental health that is reduced to aesthetical healthy habits (Fischer 2009). The fact that they also share life “beyond SMA”, such as birthdays, holiday celebrations, and daily life, contributes to this relatability. As mentioned in an article about “heartland influencers” from *The New Indian Express*, “Influencers from small towns, with their modest backgrounds, are resonating with the average user in a way that is genuine and familiar.” (New Indian Express 2024). Second, these mothers are demonstrating how becoming an expert in a specific condition also includes normalizing it—not to make it less severe, but to let go of social stigma associated with it. As Mother2 puts it, “For me, my kid is a seven-year-old boy. I do not see him as sick, and I do not attend to his needs with this perception.”

With this description of the patient/caregiver expert (in SMA, but in general too), our intention is not to discredit HCPs or institutional medicine. We simply wish to demonstrate it's possible to negotiate seemingly unalterable foundations in Western medicine, by recognizing there can be multiple ways to accumulate and exhibit expertise in this field. This is particularly relevant when we're focusing on knowledge that is exhibited not for personal recognition or prestige, but to improve patients' quality of life. Also worth mentioning is that it is precisely the ethnography's open-mindedness what enables us to see expertise where (according to institutional standards) there shouldn't be.

Foundation 2: Rigid Hierarchy of Evidence

As ethnographers working in healthcare contexts, we have witnessed the rise of evidence-based medicine or EBM. EBM can be described as the current paradigm in medicine, one which prioritizes evidence from biostatistics, engineering, and epidemiology, and questions the reliability and truthfulness of testimonies and anecdotes (Adams 2013). “...For evidence to say anything valid about “how to prevent or treat a known health problem” it must speak the language of statistics and epidemiology [...] In this ordering of priorities, one finds a simultaneous discrediting

of other forms of knowledge and evidence and other ways of conveying truth...” (Adams 2013, 57).

It is provocative to conduct ethnographic research under this paradigm. Rather than discrediting statistical evidence, our interest lies in negotiating this rigid hierarchy of knowledges and highlighting the value of ethnographic evidence as powerful in its own right, not as something complementary or secondary. This value is easy to see in our SMA study: Mother3 described how measuring her daughter’s heart rate, in addition to its clinical benefits, has also become a way of communicating with her daughter. “Her heart rate increases when she doesn’t like something. If her heart rate is elevated, we see her face and we can understand something is upsetting her, like she wants a diaper change. It has enabled us to understand how she is filling.” To understand the communication properties of heart rate measurements, something unconventional and yet real, is beyond the scope of clinical trials, the evidence type that scores highest in EBM.

Mother3’s extensive work with kinesiology tape also highlights the value of ethnographic evidence. She describes how she has used this tape for muscle support in her daughter’s hands and feet, and adds she is “not going according to any literature”. And yet, with her daughter’s visible improvements, she has “proof that it works and could work in more patients as well.”



Figure 2. Kinesiology tape use in patient with SMA. Credits: @unidosporluciana Instagram account.

In our SMA study we have two more examples of evidence that, while generated unconventionally according to EBM standards, are still powerful. First, Mother1 told us she used videos provided by Mother2 to “fight” for nebulization. Her health insurance didn’t cover nebulization therapy for patients with SMA, but with this video of Mother2’s daughter and how she had improved, Mother1 obtained the therapy for her son. We should therefore acknowledge that videos casually posted on social media can impact decision-making in healthcare systems. As Mother1 expressed, “With the video, we are imparting knowledge to others. If they ever tell me there’s nothing to do, I now know what I could show them.” Second, Mother1 described how a group of pedagogy students reached out to conduct a project with her son and his educational therapies. This way, evidence was generated in the form of a student project, a learning-by-doing space was organically created, and non-medical students were able to work closely with a rare disease that most HCPs such as primary care physicians never see.

As ethnographers working in healthcare contexts, supported by medical anthropology theory, our job is to visualize illness as a phenomenon embedded in specific sociocultural contexts. This requires an exploration of illness not only in its clinical dimension, but in others as well. And because non-clinical dimensions are equally important, so are the types of evidence that inform us about these.

Foundation 3: Exclusive Information Channels

Years of global fieldwork in healthcare contexts have taught us that academic journals and medical congresses are always among HCPs’ preferred information sources. Because it’s where to find the most up-to-date information, as well as the key opinion leaders of every medical field, it is understandable that these two sources have become the institutional (foundational) way in which medical knowledge is shared. However, approaching HCPs ethnographically has also enabled us to see these sources can be exclusive in many ways. This is best seen in the following barriers:

- Not all HCPs are able to attend medical congresses due to budget or time constraints.
- There can be language barriers for HCPs not completely fluent in English (this applies to academic journals and congresses).
- The most up-to-date information shared in journals and at congresses is often derived from studies and trials conducted on specific regions (Western Europe, North America) and with specific patient profiles.

- HCPs struggle to find time to read all the academic papers available, and to filter or curate those which could be most relevant to them.

By acknowledging these barriers, one becomes motivated to explore alternative channels in which knowledge could be exchanged in healthcare contexts. This was possible in our SMA study: in our social media exercise, we observed how these mothers are successfully using social media—and specifically Instagram—to share both clinical and vernacular information. Clinical, because they are sharing general information about SMA in a more relatable (but not less scientific!) way. Many posts are focused on early symptoms and diagnosis, to inform followers about babies’ developmental milestones and warning signs. Vernacular, because they use Instagram to exhibit their DIY solutions previously mentioned (a result of their caregiver expertise), and are constantly recommending how to manage SMA beyond its strictly clinical dimension. This includes detailed descriptions of their children’s morning and night routines, therapies that can be effectively done without using specialized equipment, room layout, tips to leave the house and attend public places, etc.



Figure 3. Occupational therapy for SMA patients using household items.
Credits: @unidosporluciana Instagram account.

These examples suggest social media used by patient/caregiver experts should be recognized as a valid channel in which knowledge is exchanged in healthcare. In the table below, we show how the Instagram profiles of our study’s mothers, by being less exclusive, are not susceptible to the barriers just mentioned, that we’ve identified in the field.

Table 1. Susceptibility of Social Media to Exclusivity Barriers

Barrier	Social media (Instagram)
Inability to attend medical congresses due to budget or time constraints	Social media posts are completely available to anyone with a smartphone.
Language barriers for HCPs not completely fluent in English	Social media posts are made in the local language and even include colloquial and slang terms. Mother1, for example, posts in Spanglish, appealing to her followers in Miami and Orlando, without disconnecting from Colombian or American populations. In other words, these channels can take advantage of the less formal and rigid relation they have with language.
Lack of patient representation/diversity in most up-to-date and relevant studies and trials	Social media posts, as shown in our SMA study, have a local focus. They talk about the challenges of the local healthcare system and, when there is a new development regarding a disease and its treatments, they discuss the implications of this for their local contexts. Additionally, patient/caregiver experts are providing the exact information their local followers need in their Instagram profiles: they do this by answering questions via stories or during lives.
Lack of time to filter/curate and read the right papers	Social media content can be consumed and can be informative in just a few seconds. On Instagram, this is possible because content in diverse formats beyond text: carousels, reels, stories, infographics, etc.

With this comparison, we are certainly not discrediting academic journals and medical congresses. After all, the peer-review process required for journal publication is what ensures the quality, veracity, and progress of medical research. Our intention is for HCPs and other healthcare stakeholders to consider the possibility of knowledge channels beyond the foundational/institutional. One could argue that these alternative channels like social media are not targeting HCPs at all, but we can think of at least three reasons why this isn’t true: first, they allow HCPs to learn what “real” patients, caregivers, and their families are asking and commenting on regarding a disease or condition. This can inform them on what topics they

should prioritize during consultations. Second, our fieldwork shows that referring patients to “official” online sources (patient associations’ social media accounts) is more useful and significant than handing them printed brochures during consultations—especially when a patient has just been informed about their diagnosis.

Third, HCPs have to accept that people are using many sources to inform themselves, beyond the medical consultation. We still encounter HCPs that look down upon patients doing research on “Dr. Google”—a derogatory way to refer to online search—when the attitude they should adopt is instructing patients how to do this responsibly. A study conducted in the UK about vernacular knowledge in contraception concluded that patients “...make sense of a lot of information from different sources, and that different sources of information served different functions. Medical information was gained from the National Health Service (NHS) website, or conversations with clinicians, whereas the more embodied types of knowledge—what a contraceptive might actually be like—was provided by friends and family.” (Newton 2024, 1).

A final comment on social media and alternative knowledge channels: they enable patients and caregivers to connect with each other, which is especially relevant in rare diseases such as SMA. These organic communities provide clinical information, but also emotional support. In our study, Mother1 met Mother2 on Instagram and now calls her “my doctor”: “If I have a question, I don’t call the doctor, I call her.”

Discussion

The three negotiated foundations presented here are not specific to our SMA study. We have observed similar dynamics while conducting ethnographic research in diverse regions and with various chronic illnesses and conditions. For instance, in a recent study on hereditary angioedema (HAE) with US patients, we found that patients are not given explicit instructions regarding “trigger” foods they should avoid to prevent the unexplained swelling caused by HAE. Consequently, they become experts through an empirical, trial-and-error process, and are keen to share this feedback with their HCPs. This mirrors the agency demonstrated by SMA caregiver experts and exemplifies vernacular knowledge that leads to significant improvements in quality of life. As Newton (2024) states, “Studying such knowledge can reveal how people conventionally understand the ways in which medical interventions act on the body.” (Newton 2024, 1).

Likewise, in a study on atopic dermatitis (AD) in Europe and Asia, our research team encountered a mother caregiver who, after struggling for months to get her toddler to sit still while she applied an ointment, created a nursery rhyme to actively involve him in the treatment routine. As seen on SMA, while the HCP advises on treatment, the caregiver expert finds a way to do it, even if it's an unconventional way from a clinical point of view. In this AD study, we also witnessed how mothers and their teenage daughters with AD are exchanging makeup tips on social media. Makeup isn't saving anyone's lives, but it is an example of vernacular knowledge that improves the quality of life of a teenage girl, and grants her a sense of "normalcy".

These two brief examples, plus decades of fieldwork with chronic patients and caregivers conducted by APoP, demonstrate the value of our SMA study: shining light on vernacular knowledge in healthcare contexts, as alternative knowledge that is improving quality of life, yielding better health outcomes, and empowering patient communities. In this sense, is it knowledge that shouldn't be overlooked by HCPs, considering it can improve the patient-HCP relationship and optimize medical consultations. As expressed by Simpson et al. (2015), building partnerships with vernacular actors is essential to tackle complex problems.

Two final reflections related to vernacular knowledge, which we do not explore in depth in our SMA study but find provocative for further research in alternative knowledges: the first is Chilean sociologist Martín Tironi's argument that the most radical innovation lies within local and ancestral wisdom and practices (Tironi 2023). This is relevant to ethnographers and designers working in industry (in healthcare and beyond), considering business organizations are thirsty for innovation and often expect us to fulfill this. The second is Ehrenreich and English's observation on the historic role women have played in medicine as autonomous, non-institutional healers, or healers of the poor and vulnerable (Ehrenreich and English 2010). This can definitely be used as a starting point to conduct further research on women as carriers of vernacular knowledge.

About the Author

Juliana Saldarriaga is a Colombian anthropologist with experience in business consulting, particularly in healthcare consulting in LATAM and the US. She has a growing interest in medical anthropology and is conducting research on health inequalities and the digital transformation and AI in healthcare. As a project manager at A Piece of Pie, she applies ethnography, systems thinking, and feminist frameworks to work with health insurance companies, hospitals, and the pharmaceutical industry.

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