Towards a Praxiographic Approach to Patient-Reported Outcomes in the Context of Pediatric Cancer Treatment

Anthony gerard WRIGHT
Rutgers University, Camden, USA

DOI : https ://doi.org/10.17184/eac.9181

Résumé : Ces dernières décennies, la recherche sur les Patient-Reported Outcomes (PRO) en cancérologie est devenu une pratique commune aux États-Unis. Ces travaux ont permis d'améliorer les soins pour de nombreux patients. Cependant, certaines populations, en particulier les très jeunes enfants et les personnes ayant des handicapes, sont systématiquement exclues de ces recherches. Dans ce chapitre, je soutiens que ces exclusions sont en partie liées à la standardisation des méthodes d'enquête dans le domaine des PRO, qui s'appuient sur une conceptualisation logocentrique de la voix du patient. Sans nier la valeur de ces travaux sur les PRO, je suggère que les méthodes existantes peuvent être combinées à une approche praxiographique de l'étude de la voix du patient. Pour cela, mon propos s'appuie sur l'analyse d'un cas ; celui d'une jeune fille de 11 ans diagnostiquée avec une leucémie et une trisomie 21, rencontrée lors d'un travail de terrain à l'hôpital pour enfants de Californie.

Mots-clés : Patient-reported outcomes ; cancer pédiatrique ; voix du patient ; multimodalité ; praxiographie

Abstract: Research on patient-reported outcomes (PROs) in the context of cancer treatment has become increasingly common in the United States in the past several decades. This work has led to improvement in care and treatment outcomes for many patients. But there are also populations, particularly very young children and people with disabilities, who are systematically excluded. In this paper, I argue that these exclusions are partly driven by the standardized survey methods that dominate the field of PRO research, which is informed by a logocentric conceptualization of patient voice. Without denying the value of PRO research, I suggest that existing methods can be productively supplemented by a praxiographic approach to the study of patient voice, and I attempt to demonstrate this through analysis of the case of an 11-year-old girl diagnosed with leukemia and Down Syndrome, who I met via fieldwork at a children's hospital in California.

Keywords: Patient-reported outcomes; pediatric cancer; patient voice; multimodality; praxiography

1 Introduction

In recent decades in the United States, clinical researchers have called for increased attention to patient voices as a way of improving health care outcomes (Baumhauer, 2017). Since the 1990s, a vast literature on "patient-reported outcomes" (PROs) has emerged in many different areas of clinical research (Meadows, 2011 ; Snyder and Aaronson, 2009). The extent of this literature's growth can be cursorily demonstrated by a simple Google Scholar search. When the date range is set to 1970-1990, a search for the phrase "patient-reported outcomes" yields only 380 results but changing the range to 1990-2020 produces 313,000 results. Clearly, many physicians and clinical researchers have become invested in better understanding patients' experiences and trying to improve them.

In this paper, I focus specifically on PRO research in the context of pediatric cancer treatment. In general, pediatric biomedical specialties, including pediatric oncology, have been slower to incorporate PROs into their research and practice, although this seems to be changing. Still, there remain significant barriers to doing PRO research in pediatric contexts. Here I argue that one way to diminish these barriers is to supplement the survey methods commonly used in PRO research with the less prescriptive method of "praxiography," which I describe below (Mol, 2002). While I acknowledge the usefulness of survey methods in certain settings, I suggest that praxiography permits a more expansive conceptualization of patient voice that moves beyond the notion of voice as essentially linguistic—a notion which informs Western theories of rational selfhood. I then attempt to demonstrate this argument through analysis of a story that I co-produced with an 11-year-old girl, Gloria, who was diagnosed with acute myeloid leukemia and Down Syndrome, and her mother, Diana.[1] I show that, despite her limited linguistic capacities, Gloria used her voice in its various modalities. By paying attention to how she did this, I was able to better understand her feelings about the care she received.

2 Patient-Reported Outcomes

By the first decade of the 2000s, cancer researchers in the United States began to strongly advocate for the importance of documenting PROs (Lipscomb *et al.*, 2007). Within this literature, PROs are defined as "standardized reports of a patient's health condition directly from the patient" (Leahy & Steineck, 2020, p. 1). This approach is founded on the idea that patients "are the best reporters of their own experience" and that self-reports directly from patients therefore offer the most accurate representations of patient experience (Mack *et al.*, 2020, p. 2). According to Leahy & Steineck (2020, p. 1), "patient voice" is the "gold standard" for understanding experiences of biomedical diagnosis, treatment, and care.

[1] The study underwent an ethics review and was approved by the hospital's institutional review board (IRB). In line with IRB requirements, all names of people and places are pseudonyms. Given the highly person-specific nature of the data collected and the relatively small sample, it was not feasible to completely anonymize the data. Because of this, anyone familiar with Gloria's case will likely be able to identify her and her mother. While this presents certain risks, I believe them to be minimal in this case. Furthermore, Gloria's mother provided informed consent for her and Gloria to take part in the study, and Gloria provided assent.

Published in : BESLE, Sylvain ; CAROF, Solenne ; DE MONTGOLFIER, Sandrine ; MURANO, Maria Cristina (dir.), *Cancers pédiatriques et génomique : un changement majeur ?. Regards croisés entre sciences sociales, médecine et associations*, Editions des archives contemporaines, ISBN : 9782813005496, doi : 10.17184/eac.9782813005496

By providing a discursive channel through which patients can construct and circulate reports of their experience, PROs carry the potential to amplify patient voices and thus increase their influence over the treatment and care process. Among adult patient populations, the use of PROs is associated with improved quality of life, decreased number of hospitalizations, and increased length of life (Basch *et al.*, 2016). Considering these positive trends, cancer researchers are calling for the expansion and increased systematization of PRO research, advocating particularly for the widespread use of patient-reported outcome measures (PROMs), or "questionnaires completed by patients to assess the effects of disease and treatment (or both) on symptoms, functioning, and health-related quality of life from their perspective" (Calvert *et al.*, 2019, p. 1).

While PRO research has gained a great deal of traction among adult patient populations, it has had less success in pediatric contexts. This is largely due to matters of efficiency and operationalizability, as there is "a limited array of developmentally appropriate, valid tools for child self-report" (Mack *et al.*, 2020, p. 2). In other words, PROMs are typically not designed in a way that is accessible to young children. Because of this, clinical researchers in pediatric settings often rely on proxy reports from adult caregivers. In these cases, the voices of parents or other adult guardians become surrogates for the patient's voice. In addition to their use among young children, proxy reports are also commonly used among patients with cognitive disabilities or other issues that prevent them from being able to complete a questionnaire (Mack *et al.*, 2020).

The use of proxy reports obviously compromises the "gold standard" of direct reportage from patients, and there does seem to be evidence that caregivers' and patients' perspectives may not always be in agreement. Multiple studies comparing patient and caregiver proxy reports show that accounts offered by parents and other adult caregivers do not necessarily align with patients' accounts of the same symptoms and functional issues (Varni *et al.*, 2015). For example, studies comparing reports of health-related quality of life (HRQOL) have shown that the correlation between parent and patient reports is moderate at best, as parents demonstrate a tendency to assign lower HRQOL ratings than patients (Chang & Yeh, 2005 ; Eiser *et al.*, 2003 ; Levi & Drotar, 1999). More recently, Mack *et al.* (2020) compared the reports of pediatric cancer patients and caregivers using the National Institutes of Health Patient-Reported Outcomes Measurement Information System (PROMIS), which includes patient self-report and caregiver proxy-report measures for the domains of mobility, pain interference, fatigue, depression, anxiety, and psychological stress (Irwin *et al.*, 2010). The study found that "caregivers consistently overestimated symptoms and underestimated mobility relative to the children themselves" (Mack *et al.*, 2020, p. 1).

Clearly, the exclusionary effects of PROMs and the limitations of proxy reporting present serious barriers to understanding the experiences of all patients. For this reason, it is important to consider alternatives to the standard survey-based approach. In the next section, I draw on linguistic anthropological theory to bring attention to several unexamined assumptions about "patient voice" that are contributing to the

Published in : BESLE, Sylvain ; CAROF, Solenne ; DE MONTGOLFIER, Sandrine ; MURANO, Maria Cristina (dir.), *Cancers pédiatriques et génomique : un changement majeur ?. Regards croisés entre sciences sociales, médecine et associations*, Editions des archives contemporaines, ISBN : 9782813005496, doi : 10.17184/eac.9782813005496

exclusionary effects of PRO research. I show that, by requiring the articulation of patient experiences in the linguistic and numeric terms of pre-established domains and measures, PRO research reproduces common Western assumptions about the relationship between language, voice, and rational selfhood. I then suggest that a "praxiographic" approach to the study of patient voice could be a useful way to supplement PRO research by expanding the range of voices deemed fit for inclusion (Mol, 2002).

3 Conceptualizing Voice

Although patient voice has been declared the "gold standard" in PRO research (Leahy & Steineck, 2020, p. 1), this literature pays relatively little attention to a seemingly fundamental question : How should patient voice be conceptualized ? For answers to this question, I turn to the field of linguistic anthropology, which, in the past several decades, has produced extensive meditations on voice. As Weidman (2014) points out in her useful review article, anthropologists have conceptualized and studied voice in several interrelated ways : 1) as a technologically mediated, sonic/material phenomenon, 2) as a culturally elaborated trope, and 3) as a locus of power. Here I will address these conceptualizations and explain how they shed light on the exclusionary ways in which voice is being operationalized in PRO research.

For many people, the word "voice" is likely to call to mind embodied acts of linguistic expression, such as speaking, singing, or writing. From this perspective, to use one's voice is to mobilize one's bodily capacities to generate sonic or material phenomena that are legible to others as language. This process is not only mediated by the body—which Marcel Mauss (1973, p. 75) famously described as the human's "first and most natural technical object, and at the same time technical means"—but it may also involve many other technical objects,[2] such as languages, microphones, pens, paper, keyboards, screens, etc. But beyond linguistic forms of voice, human bodies and the various objects they have at their disposal can also produce voice *via* imagistic, gestural, and other non-linguistic means. Linguistic anthropologists have begun to use the term "multimodality" as a way of signifying this fact (Nakassis, 2016 ; Shankar, 2017). Multimodality has also been taken up in sociocultural and visual anthropology, leading to a rethinking of the multiple modalities through which voices, representations, narratives, meanings, etc. are (re)produced and circulated in practice (Collins & Durington, 2018 ; Magaña, 2022 ; Wright & Velázquez Morales, 2021). This work has led to increased recognition of the wide variety of sonic/material forms that are constitutive of voice and thus moves us beyond the notion of voice as essentially linguistic—a notion which is firmly embedded in PRO research.

The common tendency to center linguistic modalities of voice, whether oral or written, is in part an effect of what anthropologists have called "semiotic ideologies" (Lambek, 2013). Webb Keane (2018, p. 65) defines "semiotic ideologies" as "people's underlying assumptions about what signs are, what functions signs do or do not serve, and what consequences they might or might not produce." Such assumptions play a profound

[2] In this paper, I take a cue from Mauss (1973) and Foucault (1988) in conceptualizing "technologies" broadly as the matrices of practical reason that shape how "technical objects" are produced and used in practice.

Published in : BESLE, Sylvain ; CAROF, Solenne ; DE MONTGOLFIER, Sandrine ; MURANO, Maria Cristina (dir.), *Cancers pédiatriques et génomique : un changement majeur ?. Regards croisés entre sciences sociales, médecine et associations*, Editions des archives contemporaines, ISBN : 9782813005496, doi : 10.17184/eac.9782813005496

role in structuring which sonic and material phenomena get recognized as voices, as well as how those voices are interpreted and evaluated. As Weidman (2014) points out, within the context of Western modernity, dominant semiotic ideologies have emphasized the idea that voices express linguistic signs that are indicative of self and identity. Bauman and Briggs (2003) show that one way in which subjects of the European Enlightenment identified themselves and others as properly enlightened was by producing distinct languages and modes of speaking and writing that they regarded as signs of rational knowledge, which they contrasted to the irrationality and superstition embedded in the language of lower-class and "primitive" folk, as well as to the non-linguistic vocality of non-human animals.

This cultural trope of the rational subject as one who embodies certain linguistic abilities has been seeded into various semiotic ideologies that shape life in contemporary Western societies, and it factors into the forms of power which shape the (non-)recognition of voice in everyday settings. People who do not have the capacity to generate what others would recognize as proper language are likely to be *devoiced*—that is, to be written off as either voiceless, or as having a voice that is deeply unreliable as a source of truth and rationality. In many cases, the experiences of devoiced people may simply be ignored or misrepresented.

Here I argue that PRO research runs the risk of devoicing certain patients by reproducing a semiotic ideology that frames patient voices as only epistemologically valuable insofar as they evince the socially competent use of language. The use of PROMs marks a reliable patient voice as one that can be represented and channeled in predictable ways—in other words, one that does not exceed established linguistic and numeric signs. Voices which do not obey these parameters become marked as interpretive problems, or perhaps as not really voices at all. This leads to reliance upon a proxy, who is called upon to speak *for* the devoiced patient, translating their experiences to meet the standardized demands of PRO surveys.

In the following section, I suggest that what Mol (2002) calls "praxiography" offers a useful way of expanding PRO research beyond the survey-based approach which currently dominates the field. While PRO surveys are appropriate for use with many patients, they clearly lead to the devoicing of people who, for developmental and other reasons, may lack the capacity to participate in them. Praxiographic methods, on the other hand, can be used to produce accounts of the technologically and socially mediated practices through which patient and caregiver voices emerge, although they are admittedly less amenable to standardization and thus do not permit the same ease of comparison across established domains. Still, I argue that these accounts are particularly useful for generating a more adequate conceptualization and recognition of the diverse modalities through which patient voices emerge. In this way, a praxiographic approach may be useful for improving the clinical care of patients whose voices are typically excluded from PRO research, such as young children and those who have speech or cognitive impairments that prevent them from completing a survey.

Published in : BESLE, Sylvain ; CAROF, Solenne ; DE MONTGOLFIER, Sandrine ; MURANO, Maria Cristina (dir.), *Cancers pédiatriques et génomique : un changement majeur ?. Regards croisés entre sciences sociales, médecine et associations*, Editions des archives contemporaines, ISBN : 9782813005496, doi : 10.17184/eac.9782813005496

4 Towards the Praxiographic Study of Patient Voices in Pediatric Settings

In her book, *The Body Multiple (2002),* Annemarie Mol offers the term "praxiography" to describe a form of research that critically engages with and builds upon longstanding ethnographic methodologies. While praxiography is deeply related to ethnography—Mol (2002, p. 119) even uses the hybrid term "ethnography/praxiography" at times—there is at least one important difference. In contrast to notions of ethnography as the study of cultures (signified by the prefix "ethno-"), praxiography is more interested in practices (Bueger, 2014). Of course, one may object that the neologism is unnecessary, as many ethnographers have already turned their attention to analyzing practices without seeing a need to rename their methodological approach. Various strains of "practice theory" have indeed circulated in ethnographic literature since at least the 1970s, and practice-oriented ethnographers have problematized the culture concept, some arguing for complete rejection and others for revision (Ortner, 2006 ; Abu-Lughod, 2008). One likely reason the label "ethnography" has persisted is that this latter group has continued to treat culture as a significant topic of inquiry. For these scholars, cultures are not stable wholes that can be defined in terms of their essential parts, but rather unfolding processes that enable and constrain human practices (Ortner, 2006).

In contrast to this work, my goal is not to focus on the relationship between culture and practice. The label "praxiography" therefore offers a more precise description of my methodological aims. Rather than fixing my attention on a specific cultural tradition, I follow Mol (2002, p.164) in focusing on the ways in which practices give rise to what she calls "ontological multiplicity." With this concept, Mol draws attention to the ways in which practices generate multiple realities—multiple in the sense that objects and processes which are viewed as "the same" can be enacted in more than one way, *via* more than one practical modality (Law & Singleton, 2014 ; Mol, 1999). Here I build on the work of Mol and others to show how praxiography can be used to explore the ontological multiplicity of "patient voice," which is not a single, unitary entity but a variable, ongoing process that emerges *via* a broad ensemble of practices and relations. In doing so, I show that patients' commentaries on treatment and care can emerge in multiple forms, some of which are non-linguistic and thus not amenable to the kinds of standardized survey approaches used in PRO research.[3]

At the same time, my proposal to supplement PRO research with praxiographic methods may raise eyebrows. The PRO approach is dedicated to documenting patient's perspectives, while Mol's (2002) articulation of praxiography explicitly rejects a perspectival approach on the grounds that a focus on meaning pushes practices, events, and objects into the background, rendering realities inaccessible, always shrouded behind veils of meaning. As she puts it : "In a world of meaning, nobody is in touch with the reality of diseases, everybody "merely" interprets them" (Mol, 2002, p. 11). While

[3]It is important to point out that this is not a gesture of "giving voice" to young people, as many scholars and activists have purported to do (Facca *et al.*, 2020 ; James, 2007). All the people who I met throughout my fieldwork already had voices. As such, my goal here is not to give anyone a capacity they already had, but rather to *pay attention to* and *take seriously* the precise ways in which they used their voices to comment on cancer treatment and caregiving practices.

Published in : BESLE, Sylvain ; CAROF, Solenne ; DE MONTGOLFIER, Sandrine ; MURANO, Maria Cristina (dir.), *Cancers pédiatriques et génomique : un changement majeur ?. Regards croisés entre sciences sociales, médecine et associations*, Editions des archives contemporaines, ISBN : 9782813005496, doi : 10.17184/eac.9782813005496

my research is thoroughly influenced by Mol's ideas, this is one point where I diverge. Rather than treating meanings/perspectives as metaphysical veils that obscure real objects, practices, and events, I instead see them as fundamental components of the physical world. "Meanings" do not float freely in some non-physical realm ; they are physically produced, manipulated, conveyed, and embodied by living persons with various technologies (including but not limited to language) at their disposal. By attending to the ontological multiplicity of "voice" as it emerges in everyday caregiving practices, I hope to show that the praxiographic approach need not shy away from matters of meaning or perspective. Instead, I see praxiography as presenting an opportunity to explore how meanings and perspectives are constructed and voiced in practice. This is distinct from an analysis of culture because my goal in this case is not to show how meanings and perspectives derive from and reproduce a historically consolidated tradition (i.e., a culture), even though this would be a perfectly reasonable goal. Still, it is not what I have in mind. Rather, my aim is to show how voices (broadly conceptualized) physically proliferate *via* and alongside practices.

While I invoke the term "praxiography" to emphasize my focus on practices and ontological multiplicities, my research nevertheless relied on the techniques of participant observation and interviewing, which have been most thoroughly developed by ethnographers. For 18 months from 2017-2018, I conducted research at a facility that I call California Children's Hospital (CCH).[4] This work included semi-structured interviews with 70 patients, parents, and health care professionals about their experiences of cancer diagnosis and treatment. All interviews were audio-recorded. In addition to interviewing, I also spent 2-3 days a week at the hospital observing and participating in patient-provider interactions in the clinic and the cancer ward. I gained access to these sites by "shadowing" oncologists during their clinic appointments and hospital rounds and by volunteering with the hospital's child life specialists and art and music therapists. My volunteer role involved helping to facilitate group art, music, and play sessions, as well as visiting individual patients at their bedsides to play games, make art, or just chat. I documented all my shadowing and volunteering activities in detailed fieldnotes.

In what follows, I offer a praxiographic story about working with Gloria, the aforementioned 11-year-old girl diagnosed with acute myeloid leukemia and Down Syndrome. I selected Gloria's case for analysis because she was the only verbally impaired patient with whom I worked as a volunteer, and my interactions with her required me to attend closely to non-linguistic manifestations of voice. In praxiographic terms, Gloria helped to attune me to the ontological multiplicity of voice. In addition to working with Gloria, I also interviewed her mother, Diana, a woman from El Salvador. Yet it is important to point out that I do not treat my conversations with Diana as a surrogate for Gloria's voice, as is common practice in PRO research. Instead, I analyze Diana's commentary as emerging in relation to Gloria's. Of course, like any mother, Diana could not literally speak for her daughter, but she nevertheless offered an informed account that I read alongside the various manifestations of Gloria's voice that I recorded in my fieldnotes.

[4]This project received funding from the National Science Foundation the Institute for the Study of Societal Issues at the University of California, Berkeley.

Published in : BESLE, Sylvain ; CAROF, Solenne ; DE MONTGOLFIER, Sandrine ; MURANO, Maria Cristina (dir.), *Cancers pédiatriques et génomique : un changement majeur ?. Regards croisés entre sciences sociales, médecine et associations*, Editions des archives contemporaines, ISBN : 9782813005496, doi : 10.17184/eac.9782813005496

5 Gloria's Commentary on Caregiving Practices

I was sitting at Gloria's bedside drawing a picture of an anthropomorphic cat lounging on a beach in Bermuda shorts when I heard her make a buzzing sound that, as I had learned from several months of volunteering with her, she often made when she wanted someone's attention. I looked up and saw her smiling and pointing at my drawing. "*Gato*!" she said, using the Spanish word for cat.[5] "Yep! That's a *gato*," I said. "He's not your typical *gato*, though. He loves to swim." She looked up at me and laughed, then continued coloring a picture of Pikachu, a character from the Pokémon series.

We worked on our art together in silence for a couple minutes before the door opened, and a nurse came in, wheeling a cart that held the various pieces of equipment used to take patients' temperature, blood oxygen level, pulse, and blood pressure—a routine practice often referred to as "taking vitals." Gloria shrieked in protest and began flailing her arms and legs. "Gloria, I know this is no fun" the nurse said in a comforting tone. "But it's really important for us to do it, and the sooner we do it, the sooner I'll leave you alone and you can get back to coloring." At this point, Gloria's mother, who had been down in the cafeteria eating lunch, returned and saw the familiar sight of Gloria resisting the taking of her vitals. She sat down next to Gloria on the bed, hugged her, and said "It's ok, baby. She won't hurt you. You gotta do this. Please, do it for me." At first, Gloria vigorously shook her head "no", but, after another minute or so of her mother's coaxing, she allowed her vitals to be taken.

Hospitalization was difficult for Gloria, as it is for virtually all young cancer patients. Being away from home for days on end, having to endure uncomfortable procedures and side effects, and being examined and talked about by various healthcare professionals contributed to these difficulties. In attempts to assuage these difficulties and foster as much comfort and well-being as possible, the hospital offered services and amenities for patients. In the cancer ward, there was a playroom stocked with toys, art supplies, a television, a video game console, and child-sized furniture. There were also a range of psychosocial professionals and volunteers (including me) who facilitated group and one-on-one art, music, and play sessions with patients.

Judging by how visibly excited she became when I would bring the "art cart" to her room, one of Gloria's favorite things to do at the hospital was draw, color, and paint, and she generally preferred to do this in the privacy of her room. She very rarely wanted to spend time in the common area or to join group sessions with other patients. As I witnessed on multiple occasions, when she did join group activities, she usually interacted minimally with other children and became disengaged from the activity within minutes. It seemed that one reason for this behavior was that Gloria had significant verbal impairments that made it difficult for her to express herself to other children. She would grow visibly frustrated when other children didn't understand her, and she therefore preferred doing activities that required minimal social interaction. Like many children with Down Syndrome, she also struggled with sensory issues that made it difficult for her to be in crowded, noisy environments, such as the playroom.

[5] Gloria used a mix of English and Spanish words, as she was raised in a bilingual household.

Published in : BESLE, Sylvain ; CAROF, Solenne ; DE MONTGOLFIER, Sandrine ; MURANO, Maria Cristina (dir.), *Cancers pédiatriques et génomique : un changement majeur ?. Regards croisés entre sciences sociales, médecine et associations*, Editions des archives contemporaines, ISBN : 9782813005496, doi : 10.17184/eac.9782813005496

By spending most of her time in her private room, Gloria was able to limit her exposure to these triggers somewhat, but not entirely. While she could avoid the noise and commotion of the crowded playroom, she still had to contend with the doctors and nurses who routinely visited her room, sometimes armed with technical objects, such as the vitals cart, which Gloria had learned to associate with discomfort. In addition to getting her vitals taken and enduring various routine procedures, she also had to regularly put up with large crowds of physicians, nurses, and trainees entering her room for rounds, a common practice where the medical team visits inpatients to check in on their status and review their treatment plan. CCH is a teaching hospital, and this meant that not only physicians and nurses regularly attended rounds, but also medical students who were training in oncology, not to mention researchers, such as myself, and undergraduate students who were shadowing doctors in preparation for medical school. It was not uncommon for six to eight people to be present on rounds. For Gloria, this meant six to eight uninvited people and voices suddenly entering her space, asking questions, and examining her body.

While rounds and vitals were emotionally triggering situations that were brought directly into Gloria's room, there were also plenty of instances when she was forced to leave her room and spend time in less familiar spaces that were also loaded with triggering potential. For example, she had to regularly be transported from her room to other parts of the hospital to have routine procedures, which she did not enjoy. Not only did these procedures require her to pass through strange environments and interact with unfamiliar people, but they also often subjected her to painful experiences, such as having large needles inserted into her spine for regular "lumbar punctures," which are commonly used to test for the presence of cancer cells in the cerebrospinal fluid. And even when routine procedures were not physically painful, they could still be emotional and sensory stressors for her. For example, going through CT scans and other imaging procedures required her to sit still inside or next to huge machines that made strange noises.

One condition that seemed to make some of these situations less unsettling for Gloria was advance warning. Gloria did not appreciate abrupt interruptions or activity transitions. For this reason, her mother asked nurses to let her know 10 to 15 minutes before they were coming to do vitals or any other procedure (although not all nurses remembered to do so). This gave her more time to prepare Gloria for the interruption, making her more willing to tolerate it when it happened. Another condition that seemed to make a significant difference in Gloria's distress level was familiarity with the people entering her room. Unsurprisingly, she generally responded more negatively to professionals and volunteers she did not know well—a dynamic I watched unfold in the context of my relationship with her. When I first began visiting Gloria as a volunteer, she was extremely reserved and would not directly engage with me. Over time, however, I became more familiar, and she began to express obvious excitement when I would show up with my art supplies, which, unlike the vitals cart, she associated with fun.

Published in : BESLE, Sylvain ; CAROF, Solenne ; DE MONTGOLFIER, Sandrine ; MURANO, Maria Cristina (dir.), *Cancers pédiatriques et génomique : un changement majeur ?. Regards croisés entre sciences sociales, médecine et associations*, Editions des archives contemporaines, ISBN : 9782813005496, doi : 10.17184/eac.9782813005496

6 The Multiple Modalities of Gloria's Voice

In pointing out the routine treatment and caregiving practices that Gloria found upsetting or otherwise triggering, I want to emphasize that I am aware of her emotions because she used her voice in its multiple modalities to express them. Although her linguistic capacities were limited, it would be a mistake to equate voice with its linguistic manifestations. As the aforementioned linguistic anthropologists have emphasized, voice is also constructed through gestures, facial expressions, non-linguistic utterances, meaningful silences, and other non-linguistic modalities.

If I were to have only paid attention to the literal words Gloria uttered, I would have missed a great deal of her voice and the way she used it to comment on the care she was receiving at the hospital. While she did not articulate her evaluations of treatment and care in complete sentences or in ways that could be easily captured by the standardized methodologies of PRO research, she nevertheless offered socially forceful evaluations and responses to her treatment and care. These evaluations emerged in a range of ways that signaled her approval or disapproval of the cancer treatment and caregiving practices she was experiencing or was about to experience. When a practice caused Gloria distress, it was not uncommon for her to scream, vigorously shake her head "no", refuse to look at her caregivers, or flail her arms and legs.

In addition to paying attention to bodily gestures, silences, and other factors that constituted Gloria's voice, I also learned a great deal about how to interpret her voice from conducting interviews with her mother, who knew her better than anyone at the hospital and who was extremely well-sensitized to even the most subtle evaluative cues that Gloria expressed. Of course, to rely on interviews with parents or other caregivers is to raise the problems of proxy reporting discussed above. But unlike in the context of PRO research, which is most often entirely survey-based, praxiography involves the combination, or "triangulation," of interviews with methods of participant observation that involve direct and ongoing interactions with patients and parents. This allows the researcher to gauge the distance between parental voices and patient voices. For example, in my interviews with Gloria's mother, she pointed out that Gloria had a difficult time interacting with other children at the hospital because of her verbal and other impairments. I was able to confirm this with my own observations, as I witnessed multiple instances in which Gloria attempted to join a group activity in the playroom only to grow frustrated by other children's inability to understand her. Gloria's mother also told me about her dislike for having her vitals taken unannounced, which I witnessed firsthand many times when making art with her in her room.

That being said, even Gloria's mother could not flawlessly read her mind, and there were plenty of times when Gloria was distressed for reasons that her mother could not discern. There is no level of intimacy in human relationships that could render one voice perpetually transparent to another, and it is arguably the case that even individual human beings may embody and express voices in ways that are not entirely transparent to themselves. Still, we cannot let this inevitable opacity, no matter the degree, prevent us from paying attention to what patients and caregivers are trying to express. To do so would be to drastically limit the scope of our studies, and, more

Published in : BESLE, Sylvain ; CAROF, Solenne ; DE MONTGOLFIER, Sandrine ; MURANO, Maria Cristina (dir.), *Cancers pédiatriques et génomique : un changement majeur ?. Regards croisés entre sciences sociales, médecine et associations*, Editions des archives contemporaines, ISBN : 9782813005496, doi : 10.17184/eac.9782813005496

importantly, to engage in an ableist and ageist form of exclusion that could lead us to systematically ignore the voices of patients who are disabled and/or very young.

7 Conclusion

As I have shown here, a praxiographic approach to the study of patient voices can provide detailed narratives focused on the embodied relationships and practices through which patient voices are expressed. While existing survey-based studies of PROs have fruitfully drawn attention to the importance of documenting patient voices in research, their reliance on established measures that require respondents to express their voices in purely linguistic or numeric formats limit the researcher's ability to document non-linguistic forms of voice and specific contextual factors that shape them. Praxiography can help here, supplementing the data provided by PROs with detailed descriptions of the ontological multiplicity of patients' voices as they emerge in everyday practices. This will not only result in more detailed accounts of patient-reported outcomes, but it will also make it possible for clinical researchers to document non-linguistic voices that are not amenable to survey methods.

At the same time, a praxiographic approach has limitations of its own. While it enables detailed descriptions of voices as they emerge in the context of everyday practices, it is not easily conducive to statistical analysis or controlled comparison. Yet this does not mean that it is opposed to questions of broader significance. What Mol calls "praxiographic stories" (2002, p. 156), such as the one I have just shared, do attend to highly specific situations, but the potential significance of these stories is never limited to the situations or locations described. Rather, issues of general significance can be identified by tracing connections across praxiographic stories—in other words, by looking for embodied conditions, activities, and objects that commonly emerge in a field of practice, or across related fields of practice. While this is an important aspect of praxiography, drawing such connections has not been my goal in this paper, which is more focused on showing how the praxiographic approach is useful for documenting the voices and commentaries of cancer patients, such as Gloria, who are often excluded from PRO research.

Published in : BESLE, Sylvain ; CAROF, Solenne ; DE MONTGOLFIER, Sandrine ; MURANO, Maria Cristina (dir.), *Cancers pédiatriques et génomique : un changement majeur ?. Regards croisés entre sciences sociales, médecine et associations*, Editions des archives contemporaines, ISBN : 9782813005496, doi : 10.17184/eac.9782813005496

References

Abu-Lughod, L. (2008). Writing against culture. In *The cultural geography reader* (p. 62-71). Routledge.

Basch, E., Deal, A. M., Kris, M. G., Scher, H. I., Hudis, C. A., Sabbatini, P., Rogak, L., Bennett, A.V., Dueck, A.C., Atkinson, T.M., Chou, J.F., Dulko, D., Sit, L., Barz, A., Novotny, P., Fruscione, M., Sloan, J.A., & Schrag, D. (2016). Symptom monitoring with patient-reported outcomes during routine cancer treatment : a randomized controlled trial. *Journal of Clinical Oncology*, *34*(6), 557-565.

Bauman, R., & Briggs, C.L. (2003). *Voices of modernity : Language ideologies and the politics of inequality.* Cambridge University Press.

Baumhauer, J. F. (2017). Patient-reported outcomes—are they living up to their potential ? *New England Journal of Medicine*, *377*(1), 6-9.

Bueger, C. (2014). Pathways to practice : Praxiography and international politics. *European Political Science Review*, *6*(3), 383-406.

Calvert, M., Kyte, D., Price, G., Valderas, J. M., & Hjollund, N. H. (2019). Maximising the impact of patient reported outcome assessment for patients and society. *BMJ 364*(8184). doi : 10.1136/bmj.k5267

Chang, P.C., & Yeh, C.H. (2005). Agreement between child self-report and parent proxy-report to evaluate quality of life in children with cancer. *Psychooncology 14*(2), 125-134. doi :10.1002/pon.828

Collins, S. G., & Durington, M. S. (2018). Multimodality. In H. Callan and S. Coleman (Eds.), *The international encyclopedia of anthropology* (p. 1-7). Wiley.

Eiser, C., Vance, Y.H., Horne, B., Glaser, A., & Galvin, H. (2003). The value of the PedsQLTM in assessing quality of life in survivors of childhood cancer. *Child : Care, Health, and Development 29*(2), 95-102. doi :10.1046/j.1365-2214.2003.00318.x

Facca, D., Gladstone, B., & Teachman, G. (2020). Working the limits of "giving voice" to children : A critical conceptual review. *International Journal of Qualitative Methods*, *19* (January-December), 1-10.

Foucault, M. (1988). *Technologies of the self : A seminar with Michel Foucault.* (L.H. Martin, H. Gutman, & P.H. Hutton, Eds.) University of Massachussetts Press.

Irwin, D.E., Stucky, B.D., Thissen, D., DeWitt, E.M., Lai, J.S., Yeatts, K., Varni, J.W., DeWalt, D.A. (2010). Sampling plan and patient characteristics of the PROMIS pediatrics large-scale survey. *Quality of Life Research 19*(4), 585-594. doi :10.1007/s11136-010-9618-4

James, A. (2007). Giving voice to children's voices : Practices and problems, pitfalls and potentials. *American anthropologist*, *109*(2), 261-272.

Keane, W. (2018). On semiotic ideology. *Signs and society 6*(1), 64-87.

Lambek, M. (2013). Varieties of semiotic ideology in the interpretation of religion. In J. Boddy & M. Lambek (Eds.), *A companion to the anthropology of religion* (p. 137-153). Wiley.

Law, J., & Singleton, V. (2014). ANT, multiplicity and policy. *Critical Policy Studies 8*(4), 379-396.

Leahy, A.B., & Steineck, A. (2020). Patient-reported outcomes in pediatric oncology : The patient voice as a gold standard. *JAMA Pediatrics 174*(11). doi : 10.1001/jamapediatrics.2020.2868.

Levi R.B., & Drotar, D. (1999). Health-related quality of life in childhood cancer : discrepancy in parent-child reports. *International Journal of Cancer 83*(S12), 58-64.

Lipscomb, J., Gotay, C. C., & Snyder, C. F. (2007). Patient-reported outcomes in cancer : a review of recent research and policy initiatives. *CA : a cancer journal for clinicians*, *57*(5), 278-300.

Mack, J.W., McFatrich, M., Withycombe, J.S., Maurer, S.H., Jacobs, S.S., Lin, L., Lucas, N.R., Baker, J.N., Mann, C.M., Sung, L., Tomlinson, D., Hinds, P.S., & Reeve, B.B. (2020). Agreement Between Child Self-Report and Caregiver-Proxy Report for Symptoms and Functioning of Children Undergoing Cancer Treatment. *JAMA Pediatrics 174*(11). doi : 10.1001/jamapediatrics.2020.2861.

Magaña, M. R. (2022). Multimodal archives of transborder belonging : Murals, social media, and racialized geographies in Los Angeles. *American Anthropologist 124*(4), 703-720.

Mauss, M. (1973). Techniques of the body. *Economy and Society 2*(1), 70–88. doi : 10.1080/03085147300000003.

Meadows, K. A. (2011). Patient-reported outcome measures : an overview. *British Journal of Community Nursing*, *16*(3), 146-151.

Mol, A. (2002). *The body multiple : Ontology in medical practice.* Duke University Press.

Published in : BESLE, Sylvain ; CAROF, Solenne ; DE MONTGOLFIER, Sandrine ; MURANO, Maria Cristina (dir.), *Cancers pédiatriques et génomique : un changement majeur ?. Regards croisés entre sciences sociales, médecine et associations*, Editions des archives contemporaines, ISBN : 9782813005496, doi : 10.17184/eac.9782813005496

Mol, A. (1999). Ontological politics. A word and some questions. *The Sociological Review*, *47*(S1), 74-89.

Nakassis, C. V. (2016). Linguistic anthropology in 2015 : Not the study of language. *American Anthropologist*, *118*(2), 330-345.

Ortner, S. B. (2006). *Anthropology and Social Theory : Culture, Power, and the Acting Subject*. Duke University Press.

Shankar, S. (2017). Linguistic anthropology in 2016 : Now what ?. *American Anthropologist*, *119*(2), 319-332.

Snyder, C. F., & Aaronson, N. K. (2009). Use of patient-reported outcomes in clinical practice. *The Lancet*, *374*(9687), 369-370.

Weidman, A. (2014). Anthropology and voice. *Annual Review of Anthropology 43*(1), 37–51. doi:10.1146/annurev-anthro-102313-030050.

Wright, A.G., & Velázquez Morales, J.J. (2021). 'Where your voice burns like fire' : Visual art and radio broadcasting as semiotic practices of intergenerational political socialization among the Purépecha of Cherán, México. *Global Studies of Childhood 11*(2), 179-194. doi :10.1177/20436106211008647.

Varni J.W., Thissen, D., Stucky, B.D., Liu, Y., Magnus, B., He, J., DeWitt, E.M., Irwin, D.E., Lai, J., Amtmann, D., & DeWalt, D.A. (2015). Item-level informant discrepancies between children and their parents on the PROMIS pediatric scales. *Quality of Life Research* 24(8), 1921-1937. doi : 10.1007/s11136-014-0914-2

Published in : BESLE, Sylvain ; CAROF, Solenne ; DE MONTGOLFIER, Sandrine ; MURANO, Maria Cristina (dir.), *Cancers pédiatriques et génomique : un changement majeur ?. Regards croisés entre sciences sociales, médecine et associations*, Editions des archives contemporaines, ISBN : 9782813005496, doi : 10.17184/eac.9782813005496