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Listening to Voices that are Challenging to Hear: Participatory Hermeneutics Ethnography with Children with Medical Complexity

Raíssa Passos dos Santos[1], PhD; **Mary Ellen Macdonald**, PhD[2], **Eliane Tatsch Neves**, PhD[3], **Franco Carnevale**, RN, PhD[4]
[1] CHU Sainte-Justine Research Center, Université de Montréal; [2] Dalhousie University;
[3] Universidade Federal de Santa Maria, Brazil; [4] McGill University

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Abstract

In this manuscript we explore the integration of participatory hermeneutic ethnography in research with children with complexity, particularly those who communicate differently. Traditional research methods often exclude these children, leading to a lack of representation of their unique experiences. The study employs a participatory approach that emphasizes ethical considerations, relational perspectives, and the inclusion of non-verbal communication methods to better capture the voices of these children. The research involved eight children with medical complexity, along with their families and healthcare professionals, providing a comprehensive understanding of their lived experiences. Data collection was conducted over seven months using methods such as participant observation, informal and structured interviews, and innovative techniques like drawing, storytelling, and play-based activities. The study highlighted the importance of respecting each child's unique communication style and ensuring their active participation in the research process. The findings reveal that traditional biomedical approaches often overlook the complex social and moral realities of children's experiences. By employing a hermeneutic framework, the research provided deeper insights into the children's expressions, both verbal and non-verbal, within their broader social contexts. This approach also underscored the significance of understanding children's voices through the lens of their relational and social environments. The study underscores the necessity of inclusive and participatory research methodologies for effectively capturing the varied experiences of children with medical complexity. It calls for a shift away from normalized expectations of verbal communication and emphasizes the need for continued development of methods that respect and validate the agency of all children, regardless of their communication abilities. The implications of this research extend to both academic inquiry and clinical practice, advocating for more ethically attuned and inclusive approaches in working with children who communicate differently. Future research should build on these findings, exploring innovative strategies to further empower these children and enhance our understanding of their experiences.

Keywords: Participatory Hermeneutic Ethnography, Children with Medical Complexity, Pediatric Nursing Ethics, Non-Verbal Communication, Social Justice in Healthcare

Corresponding Author: Raissa Passos dos Santos raissa.passos.dos.santos@umontreal.ca

Traditional research methods often fail to adequately include the voices of children, particularly those who communicate differently due to medical complexities. Drawing on literature from childhood studies and insights from our participatory research conducted with children, we critically reflect on the challenges of including children with medical complexity in research, focusing specifically on those who communicate differently. In nursing, understanding and respecting children's perspectives, especially in the context of complex care needs, is essential for developing child-centered approaches that support these children's interests and aspirations (Carnevale, 2022).

Children with medical complexity are defined as those with multiple care demands, including functional limitations, severe chronic health conditions, and significant use of health resources and services (Cohen et al., 2011; Millar et al., 2024). Many of these children have clinical diagnoses often labeled as "cognitive impairment," a term frequently used to justify their exclusion from research processes (Montreuil et al., 2019). This exclusion not only silences their voices but also overlooks their unique experiences and perspectives.

Several gaps exist in understanding the strengths and weaknesses of qualitative research methods in addressing the representation of children's voices and generating robust research (Facca et al., 2020; Montreuil et al., 2019; Pincock & Jones, 2020). This article presents an overview of a participatory ethnographic study conducted with children with medical complexity, aimed at better understanding their experiences and exploring the research question: What are the moral experiences of children with medical complexity? This approach suggests that participatory ethnography can effectively capture the social and relational aspects of children's voices while attending to them as ethical matters. The methodological perspectives discussed offer insights into how qualitative researchers can conduct studies with children who communicate differently, considering the multiple contexts surrounding this population and interpreting their experiences within an ethical framework. This article serves as a call to action for researchers to adopt more inclusive and participatory methods, thereby enriching our understanding of the diverse experiences of children with medical complexity.

Background

Critical discourses challenge traditional power dynamics in research, emphasizing the need for equitable participation of all children, especially those marginalized due to communication differences (Musgrove et al., 2019). These discourses stress the importance of recognizing and dismantling systemic biases that hinder the inclusion of children's voices in research processes (Facca et al., 2020; Montreuil et al., 2019; Pincock & Jones, 2020).

Traditional conceptualizations of "voice" in research often assume participants can verbalize their experiences, thus excluding the perspectives of children who cannot communicate verbally (Pincock & Jones, 2020). To capture a diversity of voices, it is crucial to avoid methods based on adult-defined measures of competence that prioritize verbal communication. Instead, creating spaces for expressions through other means, such as visual or non-verbal communication, is essential (Pincock & Jones, 2020).

Adapting research methods to ensure meaningful participation of marginalized children, including those with disabilities, involves considering their unique ways of understanding and interacting with the world (Montreuil et al., 2019; Pincock & Jones, 2020). Including children with cognitive impairments in research challenges societal biases and stereotypes about their capabilities, instead viewing these children as active participants who can contribute valuable insights into their experiences and needs (Montreuil et al., 2019; Pincock & Jones, 2020).

Sociological studies of childhood highlight the significance of viewing children as active agents rather than passive subjects, capable of reasoning and interpreting their lived experiences (Bluebond-Langner & Korbin, 2007). Childhood studies literature suggests that research should illuminate how children comprehend their moral lives, preferences, and the influence of social contexts on their experiences (Carnevale et al., 2015; Esser et al., 2016). This perspective recognizes children's moral agency, defined as their capacity to act deliberately, express themselves, and reflect on their social worlds (Esser et al., 2016; Montreuil & Carnevale, 2016).

Engaging young people as active agents in a meaningful manner is crucial (Montreuil & Carnevale, 2016). Their communication extends beyond verbal interaction, enabling them to enact their agency without adult mediation or coercion (Teachman et al., 2018). This approach involves interpreting utterances, silences, and bodily expressions within the context of related expressions by others and the surrounding "webs of significance" (Carnevale, 2020). Moreover, understanding these children's experiences requires analyzing the relational contexts and processes around them, where their concerns and aspirations are intertwined with others' views (Carnevale et al., 2017; Teachman et al., 2018).

Participatory hermeneutic ethnography is essential for researching children with medical complexity, especially those who communicate differently (Montreuil & Carnevale, 2018). This child-focused approach combines hermeneutics, child agency, ethnography, and participatory research to produce relevant knowledge for the study participants (Montreuil & Carnevale, 2018). The collaborative nature of this methodology ensures that the voices of children, parents, and healthcare professionals are meaningfully considered (Cargo & Mercer, 2008). Other methodological approaches were considered, such as traditional ethnography and phenomenology, which are commonly used for exploring experiences and social contexts. However, traditional ethnography often lacks a participatory dimension, and phenomenology may not adequately address the relational and contextual nuances of children's voices, particularly those who communicate differently. Participatory hermeneutic ethnography was chosen for its ability to integrate interpretive analysis with participatory engagement, allowing for a deeper exploration of the moral and relational dimensions of children's experiences while actively involving them and their caregivers in the research process (Montreuil & Carnevale, 2018). This inclusivity is vital for marginalized groups, emphasizing research with people rather than about people (Bergold & Thomas, 2012). This approach promotes an ethical framework for researching this population, although there are limitations to operationalizing participatory research with these children that must be acknowledged and addressed (Montreuil & Carnevale, 2018).

This article presents a methodological discussion, offering an overview of the study findings to illustrate how participatory hermeneutic ethnography was operationalized and how this approach helped generate meaningful results. By integrating participatory hermeneutic ethnography with innovative qualitative data collection methods, we address the unique needs and perspectives of children who communicate differently. These adaptations include the use of non-verbal communication tools, flexible research designs that accommodate different communication styles, and collaborative approaches that actively involve children, parents, and caregivers in the research process. Our goal is to ensure that the research is inclusive and reflective of the experiences and perspectives of all children, regardless of their communication abilities.

Materials and Methods: Study Overview

Study Design

The study employed a participatory hermeneutic ethnographic design using an advisory committee composed of children, family members, and healthcare professionals to explore the lived experiences of children with medical complexity who communicate differently.

Sample

The sample consisted of eight children with medical complexity along with their families, resulting in a total of 25 participants. Additionally, a team of 15 study advisors—comprised of four children with medical complexity, four family members, four healthcare professionals, two managers, and one decision-maker—played a critical role in shaping the research process. These advisors were involved both as participants and as consultants, meaning their insights informed the development of the study while they also contributed as key informants.

Study advisors actively engaged in shared decision-making with the researcher, guiding various aspects of the research process. This collaboration included identifying additional study participants, determining the criteria for participant inclusion, and selecting the best times and locations for participant observations. Advisors also provided input on the methods of data collection and contributed to data generation, interpretation, and analysis. Preliminary consultations were held to discuss these aspects, ensuring that decisions were co-constructed and aligned with the advisors' knowledge and experiences.

Nurses, physicians, and managers contributed specific expertise regarding the social and medical contexts that children with medical complexity navigate. Inclusion criteria focused on children with significant healthcare needs and varying communication abilities to ensure a diverse representation of experiences. The recruitment process involved close collaboration with healthcare professionals and families to identify suitable participants while maintaining inclusivity and ethical rigor.

By integrating these advisors as key contributors throughout the data generation and interpretation processes, the study ensured a rich and nuanced understanding of the experiences of children with medical complexity alongside actionable insights to inform practice.

Data Generation

Data collection occurred in 2019-2020 over a period of seven months, providing ample time to build trust and gather comprehensive insights into the children's daily lives and interactions. Children and families suggested data collection times and places, emphasizing when they preferred the researcher's presence.

Data generation involved several key strategies. Participant observation was a central approach, enabling the researcher to immerse herself in the children's social environments. During these observation sessions, informal interviews were conducted with both the children and their families to gather additional insights. Additionally, individual structured interviews were carried out with key informants, including parents and healthcare professionals, to obtain more detailed information. To facilitate communication with children who had limited verbal abilities, innovative methods such as visual aids and play-based techniques were also employed.

Data Analysis

The data analysis was conducted using a participatory hermeneutical interpretation process, which involved several key steps. Initially, interpretive comments were generated from transcriptions of interviews and field notes. These comments served as the foundation for the subsequent narrative synthesis, where multiple data sources were merged to create comprehensive accounts of each participant's experiences. The preliminary interpretations were then reviewed collaboratively with study advisors, including both children and parents, in individual meetings to gather their insights and validate the findings. Finally, the interpretations were clarified and refined based on the feedback from the advisors, ensuring that the final accounts accurately reflected the participants' experiences.

Rigour

To ensure the rigour of the study, several measures were implemented. Triangulation was employed by using multiple data sources and methods to cross-verify findings, thereby enhancing the study's credibility. Collaboration with participants was integral, as they were involved in reviewing and validating the interpretations to ensure the accuracy and authenticity of the findings. This participatory validation process contributed to the trustworthiness of the data and interpretations.

Ethical Considerations

Ethical considerations were central to the study's design and implementation. An ongoing consent/assent process was maintained, ensuring that children's willingness to participate was continuously reaffirmed throughout the study. This approach prioritized respect for children's autonomy and their right to withdraw at any time without consequence. Confidentiality was strictly upheld, with participants' identities protected during data collection and analysis. Specific measures included anonymizing sensitive details, such as medical diagnoses and names of healthcare providers, and securely storing all research data to prevent unauthorized access.

The study received ethical approval from the institution’s Research Ethics Board, adhering to ethical guidelines for conducting research with human participants. The collaborative approach also enhanced ethical integrity by involving participants in decisions about the research process, ensuring that their input shaped the methods and interpretations in a way that honored their voices and agency. These steps reflect a commitment to fostering a respectful and inclusive research environment.

Operationalization of Participatory Hermeneutic Ethnographic Methods with Children with Medical Complexity

Participant Observation: Reactions, Expressions, and Interactions

Participant observation is a key strategy for data generation with children with medical complexity, offering valuable insights into “how our organizations and institutions work, how we make our living, and how we grow and develop to be a member of our various social groups” (Guest et al., 2013, p. 271). This method is particularly powerful for researching children’s experiences, especially those who communicate differently, as it allows for the capture of phenomena that might elude structured interviews and quantitative methods (Carnevale et al., 2008).

Because participant observation is rooted in the actions and context of a social setting, the researcher should go where the action is, meaning the location of the human experience explored (Guest et al., 2013). In our study, the researcher conducted observations over seven months across various settings, including hospitals, participants’ homes, and other locations identified as significant by the participants themselves. This extensive period of data generation provided the researcher with multiple opportunities to engage deeply with the actions, interactions, and social situations of the participants, fostering trusting relationships and a richer understanding of their lived experiences (Knoblauch, 2005).

The timing and locations for observations were carefully pre-arranged with participants, ensuring that the researcher was present during moments they considered meaningful. Participants were asked to identify, during their everyday lives, the moments they considered most significant—for instance, feelings of distress, satisfaction, or gratification. The researcher followed families through various situations, including medical appointments, school activities, rehabilitation sessions, birthday parties, religious rituals, hospitalizations, and even journeys to different cities for medical appointments at specialized clinics. This strategy of involving the researcher in such a wide range of settings provided an intimate view of the participants’ preferences, concerns, and encounters with health services and local practices, offering a comprehensive understanding of their experiences.

Observation sessions varied in length, ranging from one to five hours, depending on the specific circumstances of the child, the family, and the situation. The number of participant observation sessions also varied across the sample, with each child participating in anywhere from 10 to 19 sessions. These observations were particularly instrumental in capturing the diverse forms of communication used by children and how they navigate their social worlds, interact with others, and understand their lived experiences (Carnevale et al., 2008; Greene & Hogan, 2005).

Notably, in this context, the term “observe” goes beyond merely “registering” events—it involves active participation. The researcher did not just observe from the sidelines but engaged directly with the participants, conducting informal interviews and participating in activities alongside them. This approach enriched the data collected, providing a deeper insight into the children’s experiences by allowing the researcher to contextualize the observations within the broader social and moral realities of the children’s lives (Montreuil & Carnevale, 2018). These informal interactions were crucial for understanding the complex and nuanced experiences of the children, offering a broader picture than could be achieved through observation alone.

For children who communicate differently, observation strategies are particularly relevant. These children's voices are often mediated through others, such as parents or caregivers, who serve as interlocutors. The role of the interlocutor is vital—they are individuals who can interpret and express the child's experiences, making them essential partners in the research process (Teachman et al., 2018). In our study, many children expressed their views through relational perspectives, where their voices were mediated and interpreted by those around them. Mothers and sisters, in particular, played crucial roles as interlocutors, acting as the child's voice when necessary. The interlocutor, therefore, is someone deeply connected to the child, able to understand their expressions and concerns, and ultimately a person with whom the child feels confident sharing their experiences.

Interactions between children, family members, and healthcare professionals were meticulously observed, providing valuable insights into the dialogical processes, practices, events, and attitudes embedded in the everyday lives of children with medical complexity. The researcher constantly observed the children's *reactions* and *responses* to specific situations, including *expressions* of happiness, contentment, discomfort, distress, and dissatisfaction, as well as their interactions with family members and healthcare professionals during everyday situations and clinical encounters. These varied forms of expression were viewed not merely as physio-psychological indicators but as expressions deeply connected to the children's moral and social realities within their local environments. This broader context was essential for interpreting the children's experiences, particularly in understanding how they navigate the complex social dynamics of their lives.

Multiple observations and informal interviews were essential in capturing the experiences of children who communicate differently, enabling the collection of both verbal and nonverbal data. Given the varied forms of communication, these children's voices are often filtered through the interpretations of others. This underscores the critical importance of relational perspectives in understanding their experiences. The social dynamics and interactions with others were not just influential but central to uncovering the true nature of these children's lived experiences. These relational contexts provided crucial insights that would have been missed if only traditional communication methods were relied upon. Additionally, informal conversations are essential to understanding the context related to different aspects of people's experiences, such as attitudes and how local norms and structures are navigated (Hammersley & Atkinson, 2019).

When studying children's experiences, researchers can significantly enrich their understanding by using strategies that are naturally integrated into the children's everyday lives. This approach allows for a deeper exploration of how children navigate complex situations in their clinical encounters and beyond (Greene & Hogan, 2005; Montreuil et al., 2021). For example, during an observation moment with a child receiving intravenous medication, the researcher used dolls, puzzles, and coloring books to engage with child. The child, in turn, used her dolls to represent herself and significant others, describing her experiences through play. This strategy provided the researcher with a unique insight into the child's feelings and perceptions, which might not have been articulated in a traditional interview setting. Such strategies not only allow children to express their experiences in their own way but also reduce the power differential between researcher and participant, making the child an active participant in the research process (Teachman et al., 2018).

Individual Interviews and Recognition of Children's Diversity

When possible, individual structured interviews with key informants can be conducted to deepen the understanding of the phenomenon under study (Montreuil & Carnevale, 2018). Key informants are those with substantial experience and knowledge about the subject, such as individuals familiar with the care and experiences of children with medical complexity. This strategy is particularly useful for collecting data on complex issues that may arise during participant observation, creating an iterative process where formal interviews and participant observation continually inform one another (Montreuil & Carnevale, 2018).

In our study, parents were included as key informants, with interviews emphasizing the importance of relational aspects and the children's relational voices. To gain deeper insights into the children's expressions during observations, parents were asked how their child felt in specific situations and how the child conveyed their understanding of positive and negative experiences. Additionally, formal interviews with mothers were focused on capturing the child's lived encounters with healthcare services, particularly understanding the child's voice as mediated through the mother's perspective.

Interviews were also conducted with children who had some verbal speech capacity, usually in the presence of their mothers. Strategies for facilitating interviews with children, such as drawing, play, and storytelling, have been described as particularly effective in elucidating children's interpretations, choices, and preferences (Kirk, 2007). Innovative and flexible methods, tailored to the abilities and preferences of children with cognitive impairments—such as visual aids, storytelling, and play-based techniques—allow children to express themselves comfortably and naturally (Montreuil et al., 2019). These methods not only enhance communication but also empower children by validating their modes of expression and acknowledging their agency (Montreuil et al., 2019).

In our study, some children were comfortable with drawing, while others were not. For those who did not engage in drawing activities, alternative activities were developed based on the participants' suggestions. For example, one child asked the researcher to prepare a list of questions. While answering these questions, the child was actively involved in sharing interpretations of his experiences with rehabilitation, challenges at school, and everyday life with his family. Another child preferred playing and was more comfortable when his older sister was present. Consequently, interviews were conducted while playing with cars, dolls, and drawing, with the sister actively participating in the conversations. Respecting each child's uniqueness and preferences was crucial for the researcher to engage with the particularities of each child's world. These particularities were then contrasted with the broader social contexts—such as interviews with families and healthcare professionals, as well as analysis of key documents—in which the children are embedded, promoting a deeper understanding of the background perceptions surrounding their experiences.

In line with a participatory commitment, children participating in formal interviews were given the choice to conduct the interviews alone or with their primary caregiver. All the children requested that their mothers be present during the interviews. This decision was considered data-enhancing, as it drew on relational perspectives to better understand the children's views. The children's choice to have their mothers present was respected, and their voices were explored and understood within these relational contexts. Additionally, mothers often facilitated the conversation when the researcher encountered difficulties in understanding the children, creating a complex web of interaction that ultimately enriched the understanding of the children's experiences.

Participatory Data Analysis and Interpretation with Children with Medical Complexity

The data analysis process for participatory hermeneutic ethnography is conducted through a process of hermeneutical interpretation (Montreuil & Carnevale, 2018), applying the analytical steps proposed by Benner (1994) and Crist and Tanner (2003). Following this process, the understanding of deep meanings underlying human experience is achieved by examining the part-whole relations, in which parts are contrasted between other parts and the whole in a hermeneutical circle (Benner, 1994; Crist & Tanner, 2003). By contrasting individual experiences (part) and the broader social context (whole), this hermeneutical process of analysis "continuously relates what is meaningful to the context, and also examines the collective moral experiences of certain groups" (e.g., children, nurses, and families) (Montreuil & Carnevale, 2018, p. 7).

From a participatory view, interpretation of data should be developed in collaboration with people involved with the research process, resulting in interpretive accounts that conform to the children's experiences (Montreuil & Carnevale, 2018). In our study, the collaborative process of interpretation involved presenting and discussing interpretations with study advisors, including children and parents, during individual meetings with participants, and their insights and thoughts on these interpretations were sought. Particularly for children who communicate differently, their parents' insights were needed as the researcher presented preliminary interpretations based on multiple moments of participant observation and informal interviews.

In addition to this collaborative interpretive process, data from documents and interviews with healthcare professionals and other collaborators can be used to provide contextual data and deepen the understanding of the moral context in which children's experiences are lived (Montreuil & Carnevale, 2018). Following interpretations conducted with study advisors, complete documents with information from participant observations and interviews were created for each participant. A descriptive synthesis of each case, including the child and the family, was created. Syntheses were then used to identify study exemplars, where similarities and differences were highlighted and contrasted to better understand participants' lived experiences (Benner, 1994).

Consent and Assent as an Ongoing Process: Beyond Procedural Steps

Given that participants' consent should be accessed in a processual rather than episodic manner (TCPS-2, 2014), when conducting participant observation with children, their assent, that is, the "child's willful agreement (not the simple absence of objection) to participation in a study" should be reaffirmed throughout the research process (Carnevale et al., 2008, p. 25). For instance, parents were asked to provide consent for their children's participation and children were asked to provide verbal and written assent, when possible. The inclusion of children who communicate differently may further complicate the process of consent/assent, and this issue were tackled by continuously observing the children's expressions and reactions to detect possible discomfort during the data generation process. As a processual matter, these assessments were made during each encounter with the child, ensuring that they understood and engaged with the research process.

When conducting research with children, strategies should be developed to ascertain their right to withdraw from the study at any time (Carnevale et al., 2008). In our study, children were allowed to ask the researcher to leave when they felt they wanted to stop the data generation process. Another strategy was making sure that children did not feel "obligated" to answer questions. For instance, during interviews or when the researcher asked children questions and they responded with silence, mothers would sometimes encourage children to answer as a form of compliance with adults' requests. The researcher would then emphasize to the children and mothers that they did not need to answer the question if they did not want to and that not answering was acceptable for the research process. These strategies also gave children a better sense of "ownership" with the study, creating a space where they felt "in control" of their involvement with the study. For instance, when asked about how they felt about having a 'non-treatable' disease, one child said he preferred not to answer. The mother told the child that I was there to "speak with him" and he should answer. I then highlighted to her and the child that it was ok not to answer and moved on to another question.

Discussion

Listening to Children's Voices Through Hermeneutics: Research Exemplar

A case exemplar will be presented to illustrate the methodological and interpretive processes employed in this study. Through this exemplar, we aim to equip researchers with tools and strategies for conducting observational methods that integrate the social and relational dimensions of children who communicate differently. The story of one child from the study will be described, detailing how their experiences were interpreted. Observations were conducted by a trained researcher with expertise in participatory hermeneutic ethnography, alongside clinically qualified healthcare professionals who were present to provide insight into the potential causes of the child's distress. No other interventions were proposed or taken in the context of this study, as our goal was to avoid altering the environment where data were being generated. This exemplar is not intended to present research findings; rather, it demonstrates how the methods outlined in this article enabled a deeper understanding of the voices of children who communicate differently. All names and identifying details have been altered to ensure anonymity and confidentiality.

The researcher first met Angelica, a 12-year-old with severe cerebral palsy, in February 2019 when she was hospitalized for severe malnutrition. Unable to swallow enough food, she was prescribed a nasogastric tube, with plans for a gastrostomy. After discharge, every time Angelica pulled the tube out, she and her mother had to travel 17 km to the hospital for reinsertion. The journey was difficult—especially when it rained, turning the streets near their home to mud. They had no car or money for a taxi, and public transportation wasn't wheelchair accessible. Local primary care services refused to help, saying, "the hospital staff knows better how to care for a child with complex clinical conditions like Angelica." Despite making a total of 25 trips to the hospital for the same reason over five months, the surgery was repeatedly delayed. Healthcare professionals would wonder, "Oh my God! Why hasn't this surgery been done yet?" Finally, in August, when Angelica and her mother returned once more, the head nurse in charge recognized them and expressed her tremendous discomfort in doing the procedure again. She escalated the situation to hospital management, leading to the surgery being scheduled for the next day, which brought much-needed relief to Angelica.

Building upon ontological views of children as moral agents, who are constantly interacting with their social surroundings and able to express interpretations of their different lived encounters, expressions of discomfort and crying in the case described above were not only understood to be physical or emotional expressions. In light of the broader social context in which the experiences of Angelica were embedded, significant challenges are involved to endure her lived experiences. This means that, by crying, Angelica was telling us that what was happening with her was wrong. Her constant crying at home and the hospital was considered an expression that the social contexts encircling her could not alleviate her suffering.

During the multiple visits to the hospital, healthcare professionals would emphasize the need for replacing the tube instead of Angelica's communication of discomfort. During these visits, the paradigm of the biomedical model was predominant. The biomedical model has its focus on the medical procedure, where clinicians need to identify malfunctions in human bodies and fix them by using care that is cure-focused (Rocca & Anjum, 2020). While the phenomenon involving Angelica's discomfort with regards to the nasogastric tube was complex, the focus of conducting a medical procedure provided a reductionist view, where clinicians isolated the physical discomfort from the multiple contextual perspectives involved.

In this scenario, healthcare practices may be harmful when they do not consider the complex nature of children's voices. When recognizing the multiple challenges and limitations of modern medical practices, Angelica's crying can be understood as a form of asking healthcare professionals to act beyond the biomedical model of performing procedures. Having her nasogastric tube replaced was not enough to provide her comfort and foster her experiences. However, when healthcare professionals were engaged with the caring situation and able to enact their moral agency, moved by the feelings of distress regarding Angelica's suffering, the search for a solution enabled care that was better committed to meeting children's needs in a comprehensive way.

Particularly, this research exemplar describes how the understanding of multiple forms of children's voices and expressions of moral agency can be achieved through multiple attentive participant observations. These attentive moments of participant observations required the taken-for-granted notions to be separated from suffering, where expectations of Angelica not crying anymore were not only understood from a biomedical perspective (e.g., acceptance of the discomfort caused by the medical procedure and consequent crying of the child). This methodological process is in line with what Carnevale (2009) defines as an *empathic attunement*. In this process, the understanding of a patient's emotions goes beyond conventional notions of suffering. Rather, they should be understood through a hermeneutical process of interpretation, which ultimately shapes how things matter to people within particular social contexts (Carnevale, 2009). This genuine interest in understanding children's experiences, which is particularly important for children who communicate differently, leads to a mutual understanding or a *rapprochement* (Carnevale, 2019). As an implication for clinical practice, Carnevale (2019) defines *rapprochement* as follows:

> Hermeneutical rapprochement recognizes that there is no pre-existing consensus on the ultimate goods that should be pursued; seeking a rapprochement of the various moral outlooks regarding the case, including those held by the patient, family members, physicians, nurses, other HCPs, the institution, the state, as well as recognized norms and standards. (p. 9)

In the understanding of Angelica's expressions of pain, there were significant conflicts between her experiences and the social context in which she was embedded that needed to be considered in order to provide a better understanding of her lived experiences. Moreover, from a researcher's perspective, the in-depth understanding of her crying was only possible by presumed conceptualizations of suffering and emotions and giving space to *empathic attunement* (Carnevale, 2020). The *empathic attunement* here was necessary to include the perspectives of children who communicate differently beyond the dominant views of these children as incapable of participating in discussions involving them, providing a significant advancement in the examination of their preferences and experiences.

Strengths and Limitations of Conducting Research with Children with Medical Complexity who Communicate Differently

Problems with "Normalized" Views of Communication and Children's Differences

A significant methodological challenge in understanding the voices of children who communicate differently lies in the conventional reliance on "normalized" forms of communication, which inherently creates an expectation of verbal responses. This expectation can lead researchers away from empathic attunement, as the absence of verbal answers may be perceived as a failure in the research process. This was a challenge faced by the researcher at the outset of fieldwork. The initial inability to conduct verbal interviews with the children led to frustration and hindered the observation of broader aspects of the children's experiences. During early participant observation, the focus was primarily on questioning the children and awaiting their responses. However, as the researcher recognized and addressed her own expectations, she became more attuned to the implicit aspects of the children's voices, such as the impact of using a nasogastric tube within the context of low-income families, caregivers with limited education, and geographical challenges in accessing hospital services. It was only by acknowledging these relational and social dimensions, as seen in Angelica's case, that the researcher could gain a deeper understanding of the children's experiences.

While participatory hermeneutic ethnography is a fitting method for investigating the experiences of children who communicate differently, it is important to note that this framework does not aim to provide a complete and objective account of participants' perspectives. Rather, it offers a comprehensive research orientation and interpretive approach that illuminates children's experiences through their diverse perspectives (Montreuil & Carnevale, 2018, p.5). Therefore, further research is needed to better understand the voices of children who communicate differently, as new methods may enhance our ability to include and understand this often-marginalized population.

Conclusion

This study highlights the importance of adopting inclusive and participatory research methodologies to adequately capture the voices of children with medical complexity, particularly those who communicate differently. By employing participatory hermeneutic ethnography, we were able to uncover the rich, multifaceted experiences of these children, offering a deeper understanding that transcends traditional research approaches. For nursing, this approach is particularly valuable as it informs child-centered care practices, enhances relational engagement, and supports evidence-based interventions tailored to the unique interests of children with medical complexity. The findings demonstrate that methods grounded in empathy, relational understanding, and ethical sensitivity are crucial for engaging with children who are often marginalized in research due to their communication abilities.

Our research underscores the need to move beyond the normalized expectations of verbal communication, recognizing that children's voices can be expressed through various non-verbal means, which are equally valid and meaningful. The study exemplifies how participatory approaches, when applied rigorously, can illuminate the lived experiences of children within their social and relational contexts, challenging the conventional assumptions that often silence these voices in research. For nurses, this highlights the importance of recognizing and interpreting non-verbal communication as a vital aspect of care, particularly when working with children who have complex medical needs.

Moreover, this work calls for continued efforts to refine and expand methodologies that are sensitive to the unique needs of children with medical complexity. By fostering a more inclusive research environment, we not only enhance the validity and richness of our findings but also affirm the agency of all children, ensuring their perspectives are represented and respected in the research process. Future studies should build on this foundation, exploring innovative methods that further empower children who communicate differently, thereby contributing to a more just and comprehensive understanding of their experiences. This continued methodological innovation will also help advance nursing practices, providing insights that support holistic and ethically sound care for children with diverse communication needs.

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