Document generated on 08/10/2025 1:11 a.m.

Canadian Journal of Bioethics
Revue canadienne de bioéthique

The Asset of Subjectivity: Applying Mujerista Theology and Family Interest Assessment to Case Analysis

Rebecca Dawn Hood-Patterson

Volume 5, Number 1, 2022

URI: https://id.erudit.org/iderudit/1087215ar
DOI: https://doi.org/10.7202/1087215ar

See table of contents

Publisher(s)

Programmes de bioéthique, École de santé publique de l'Université de Montréal

ISSN

2561-4665 (digital)

Explore this journal

Cite this document

Hood-Patterson, R. D. (2022). The Asset of Subjectivity: Applying Mujerista Theology and Family Interest Assessment to Case Analysis. *Canadian Journal of Bioethics / Revue canadienne de bioéthique*, *5*(1), 146–148. https://doi.org/10.7202/1087215ar

Article abstract

Applying two theories to complex contexts results in a more well-rounded case analysis. This case, involving a Latinx family within pediatrics, requires a multi-faceted approach to better evaluate the culturally specific needs of the patient and the family system. A Mujerista theological approach highlights the subjective nature of family values and lived wisdom. This Mujerista approach adds another dimension, along with a Family Interest Model, for medical decision making.

© Rebecca Dawn Hood-Patterson, 2022

This document is protected by copyright law. Use of the services of Érudit (including reproduction) is subject to its terms and conditions, which can be viewed online.

https://apropos.erudit.org/en/users/policy-on-use/

This article is disseminated and preserved by Érudit.

Érudit is a non-profit inter-university consortium of the Université de Montréal, Université Laval, and the Université du Québec à Montréal. Its mission is to promote and disseminate research.

https://www.erudit.org/en/

Canadian Journal of Bioethics
Revue Canadienne de Bioéthique

RD Hood-Patterson. *Can J Bioeth / Rev Can Bioeth.* 2022;5(1):146-148

ÉTUDE DE CAS / CASE STUDY

The Asset of Subjectivity: Applying Mujerista Theology and Family Interest Assessment to Case Analysis

Rebecca Dawn Hood-Patterson[a]

Résumé
L'application de deux théories à des contextes complexes permet d'obtenir une analyse de cas plus complète. Ce cas, qui concerne une famille latino-américaine en pédiatrie, nécessite une approche multidimensionnelle pour mieux évaluer les besoins culturellement spécifiques du patient et du système familial. Une approche théologique Mujerista souligne la nature subjective des valeurs familiales et de la sagesse vécue. Cette approche Mujerista ajoute une autre dimension, ainsi qu'un modèle d'intérêt familial, pour la prise de décision médicale.

Mots-clés
théologie Mujerista, méthode théologique, prise de décision familiale, contextes latino-américains, pédiatrie

Abstract
Applying two theories to complex contexts results in a more well-rounded case analysis. This case, involving a Latinx family within pediatrics, requires a multi-faceted approach to better evaluate the culturally specific needs of the patient and the family system. A Mujerista theological approach highlights the subjective nature of family values and lived wisdom. This Mujerista approach adds another dimension, along with a Family Interest Model, for medical decision making.

Keywords
Mujerista theology, theological method, familial decision making, Latinx contexts, pediatrics

Affiliations
[a] The Center for Children's Health, Cook Children's Health Care System, Texas, USA

Correspondance / Correspondence: Dawn Hood-Patterson, dawn.hood-patterson@cookchildrens.org

INTRODUCTION

Applying two theories to complex contexts results in a more well-rounded case analysis. This case, involving a Latinx family within pediatrics, requires a multi-faceted approach to better evaluate the culturally specific needs of the patient and the family system. A Mujerista theological approach highlights the subjective nature of family values and lived wisdom. This Mujerista approach adds another dimension, along with a Family Interest Model, for medical decision making.

CASE

Lucas,[1] a Latino male, was born with Jarcho-Levin syndrome. He went from one Neonatal Intensive Care Unit (NICU) to a higher acuity NICU because he had trouble breathing. Lucas was discharged home after three months but remained at home only ten days before being readmitted for a respiratory infection. The initial goal was to help maintain Lucas' respiratory health and capacity until he was stable enough to have corrective surgery to expand his rib cage and correct his cervical vertebrae. As it was, his lungs could grow at pace with his body's need but because of his neck, Lucas could not safely maintain his airway.

Eventually, the healthcare team recommended a tracheostomy until they could get him to his corrective surgery. Lucas' mom, Sandra, agreed to the procedure and successfully completed trach-training. After several more months, a few stays in the Pediatric Intensive Care Unit, and never being able to wean Lucas to home-ventilator settings, the burden of caring for Lucas in the hospital while also caring for her other toddler, Leo, at home, Sandra recognized Lucas' diminished quality of life. Lucas was no longer playful, he acted agitated when being held, and he had several infections that kept him in intensive care. After each infection cleared, it seemed like Lucas had a lower base line than before the infection. Sandra asked the healthcare team to decannulate Lucas, allowing natural death, saying that he was "tired of fighting."

THEORY EXPLAINED

Two theories can work in tandem to better understand the intricacies of this case. The first is a narrative theory that comes from Mujerista theology (a Latin@ feminist theology) – *la vida cotidiana* or "everyday life". The second is a theory comes from an ethical assessment framework. I begin by briefly defining these two theories and then describe, in greater detail, how each highlights different aspects of the case.

La vida cotidiana is a narrative theory (or a system of explaining how a narrative functions) that provides a culturally-specific manner to engage and evaluate lived wisdom. When narrating *la vida cotidiana* we are not simply telling a story to understand the ideas or meanings embedded within the story; instead, we begin to see how lived experience has the capacity to change

[1] All names have been changed, the family dynamics were altered, and a few details about the case were modified to better deidentify this case.

2022 RD Hood-Patterson. Creative Commons Attribution 4.0 International License
ISSN 2561-4665

or shape our theology, our values, our experiences, or the meanings we assign to those experiences. This narrative theory elevates lived experience in a way that puts it at the same level of importance as education, faith doctrines, values, or expert knowledge. It recognizes that, at times, the best course of action emerges through analysis of the seemingly mundane events of daily life, amplifying our learning-by-doing.

The second theory that can help shine light on this case emerges from an ethical assessment framework. The Family Interest Model takes into account the varied positions that a family may take when making choices about medical treatment and care (1). This model highlights how the centre of gravity (so to speak) is different for each family as they weigh the needs of each member of the family and/or as the family as a whole. It accounts for the fact that no family is alike when making a choice. Assessing different models of family decision-making and needs can strengthen the ability to offer a recommendation informed by the family's own constraints, contexts, and circumstances. Arguably, this model also highlights the many, sometimes opposing, needs that a family must grapple with when determining the best course of action for the family and for the patient.

Let me first examine in more detail what it means to narrate *la vida cotidiana*. In their work with Latin@ women, Ada María Isasi-Díaz (2) and Carmen Nanko-Fernandez (3) identified specialized knowledge emerging from *la vida cotidiana*, or common, everyday life.[2] *Lo cotidiano* is an intersectional, hermeneutical, and epistemological position encouraging subjective reflection on the "stuff" that makes up the "shared experience" within daily lives of Latina women (2, p.67). *Lo cotidiano* is a heuristic device used to understand and solve complex problems in a way that elevates lived experiences and learned expertise. In this framework, subjectivity is key. Subjectivity, within *lo cotidiano,* is not a detriment to this way of contextual evaluation or learned expertise. Embracing subjectivity is a way of extoling difference while simultaneously resisting individualizing ideals that often make humanity more isolated (2).

Nanko-Fernandez's (3) approach assumes that useful knowledge is embedded in *la vida cotidiana*.[3] Meanings given to life are constructed from doing the work of life – we know because we do. The subjective narratives and experiences of daily life agitate implied theories and social discourses about what it means to live with a "non-normal" body. Similarly, listening to the stories of daily life, as parents care for their children, can uncover broader concepts about familial and cultural values that might otherwise go unnoticed. The objective of narrating *la vida cotidiana* is to offer juxtapositions that "interrupt the norm and offer opportunities to entertain new ways" of thinking about our lives and the meanings that we give (3, p.xx).

Narrating *la vida cotidiana* is not simply telling a detailed life story; it is not a biography or medical history. Graham et al. (4) note that this form of narration extracts the embedded, implicit, values-laden constructs that materialize in the daily routines of parents caring for their children – those stories which might otherwise be overlooked. Asking about the "stuff" that makes up common, everyday life when caring for a child with a complex medical condition generates unique sets of knowledge. Oftentimes these experiences are so routine, write Holland and Ramazanoğlu (5), a "knowing in the doing," that they are "not yet discursively appropriated" (p.73). Healthcare providers and clinical ethicists must ask about the "common" and "routine" sources of knowledge that parents learn, simply because of the cares, tasks, and labour that is part and parcel to the close, every-day interaction with the body of their child.

I now turn to the second theory, one derived from assessing family interests within ethical decisions. In conjunction with knowledge gained from her daily lived experience, Sandra must also evaluate what is in the best interest for her family. This is where the four models described by Groll becomes helpful (1). Groll reminds us that not all families prioritize the same things when making decisions. Through Groll's perspective, taken with *la vida cotidiana*, we can see that some families may not even know to articulate the "common" or "mundane" things that happen as they care of their child(ren) or they may undervalue the beliefs embedded in the prosaic. Drawing conclusions using a Family Interest Model (1) we know that the right decision for a patient is never ascertained without considering the impact of the decision within a larger familial or societal framework. The Jarcho-Levin syndrome and respiratory infections were particular to Lucas' body but each member of the family, to varying degrees, shared an experience of that illness (6-7). In making a decision about Lucas' care, Sandra must consider all parties involved – her own, Leo, Lucas, their father, her extended family and her in-law's family (the extended families help with transportation, childcare, and spiritual and emotional support).

Sandra had to evaluate her values with regard to determining what it means for Lucas to "be alive" and what it means to be an attentive and well-bonded parent to her son Leo. Sandra also had to consider the contextual constraints of remaining in the hospital with Lucas, far from home, and with limited transportation. Each family member, her values, the values of her family, and the contextual constraints, when examined together, highlight conflicting priorities and points of agreement. Yet, when reading the conflicting priorities and points of agreement through the lens of *la vida cotidiana*, it becomes possible to see how Sandra and her family prioritize their values.

APPLICATION

First, ethicists must pay attention to the cultural-contextual. The Western-centric training that many clinicians receive can undervalue the lived knowledge gained from daily life. Clinicians should become accustomed to helping families and caregivers

[2] One must proceed with trepidation and awareness, however, and not usurp a methodology particularly tied to a cultural *lucha* (fight) for identity and survival. When White clinicians and researchers use a method from a people group outside of their own, they must pay attention to the historical function of that method.
[3] The knowledge generated, particularly for Nanko-Fernandez, is for theological reflection but the method is transferable to other disciplines and contexts of practice.

articulate the wisdom that they have gained through the daily acts of caring for their child. This wisdom is revelatory in unmasking family values, cultural resources, or religious beliefs that foster decision-making. Understanding the "why" of what a family does can help both clinicians and families. Investigating *la vida cotidiana* is achievable with humble curiosity about daily practice and cares.

Second, clinicians must consider the multiple ways that families weigh varying interests when deciding if procedures, like a tracheostomy, are "manageable." This same weighing of interests is also applicable when a family is making end of life decisions. Clinicians cannot presume that they understand a family's cultural and contextual constraints. Nor should clinicians assume to understand why or how a family evaluates the needs of each member as a part of the whole. Sandra, having cared for both Lucas and Leo, had conducted a months-long comparative case analysis. She recognized the impact of Lucas' illness on both sons and their respective qualities of life. Sandra began to detect the toll that the extended hospitalization was taking on Lucas. She noted how little bonding she had been able to do with Leo since most of her time was in the hospital with Lucas.

Over months of paying attention to the common, everyday struggle for Lucas to breathe and his multiple attempts to overcome respiratory infections, Sandra observed that his ability to play, to eat, to be held, and move were all hindered by his vent dependence and his bone structure. When Sandra began to realize that "*sus luzes*" or "his lights" from his baby soother, which danced on the hospital room ceiling, were Lucas' primary source of joy, Sandra questioned if the repeated respiratory infections and Jarcho-Levin syndrome were manageable or survivable, and to what end.

RECOMMENDATIONS

1. Ethicists must learn to ask parents and caregivers about the emerging knowledge that comes from the daily care of a child. Ask questions like, "What has changed for you as you learn to care for your child?" This knowledge is valuable in revealing learned wisdom about the manageability of diseases as well as family values.

2. Ethicists must ask about how the illness affects the parents and caregivers as well as other members of the family. Questions like, "How has your child's sickness changed the way your family works?" This vein of question demonstrates how the family is negotiating the various interests among affected parties.

Reçu/Received: 16/04/2021
Publié/Published: 01/03/2022

Remerciements
Je tiens à remercier le Dr Nico Nortjé pour avoir encouragé la réflexion sur les études de cas.

Acknowledgements
I would like to thank Dr. Nico Nortjé for encouraging case study reflection.

Conflits d'intérêts
Aucun à déclarer

Conflicts of Interest
None to declare

Édition/Editors: Vanessa Chenel & Aliya Affdal

Les éditeurs suivent les recommandations et les procédures décrites dans le Code of Conduct and Best Practice Guidelines for Journal Editors de COPE. Plus précisément, ils travaillent pour s'assurer des plus hautes normes éthiques de la publication, y compris l'identification et la gestion des conflits d'intérêts (pour les éditeurs et pour les auteurs), la juste évaluation des manuscrits et la publication de manuscrits qui répondent aux normes d'excellence de la revue.

The editors follow the recommendations and procedures outlined in the COPE Code of Conduct and Best Practice Guidelines for Journal Editors. Specifically, the editors will work to ensure the highest ethical standards of publication, including: the identification and management of conflicts of interest (for editors and for authors), the fair evaluation of manuscripts, and the publication of manuscripts that meet the journal's standards of excellence.

REFERENCES

1. Groll D. Four models of family interests. Pediatrics. 2014;134(2):S83-4.
2. Isasi-Díaz AM. Mujerista Theology. Maryknoll, NY: Orbis Books; 1996.
3. Nanko-Fernandez C. Theologizing en Espanglish. Maryknoll, NY: Orbis Books; 2010.
4. Graham E, Walton H, Ward F. Theological Reflection: Methods. London: SCM Press; 2005.
5. Holland J, Ramazanoğlu C. Feminist methodology: Challenges and choices. Thousand Oaks, CA: SAGE Publications; 2008.
6. McFadden SH, McFadden JT. Aging Together: Dementia, Friendship, and Flourishing Communities. Baltimore, MD: Johns Hopkins University Press; 2011.
7. Frank A. At the Will of the Body: Reflections on Illness. New York, NY: Mariner Books; 2002.