

Beyond Autonomy: A Theological Anthropology for Pediatric Bioethics

By

Jessica Lynne Bratt Carle

Dissertation

Submitted to the Faculty of the

Graduate School of Vanderbilt University

in partial fulfillment of the requirements

for the degree of

DOCTOR OF PHILOSOPHY

in

Religion

September 30, 2019

Nashville, Tennessee

Approved:

Bonnie Miller-McLemore, Ph.D.

Jaco Hamman, Ph.D.

Larry Churchill, Ph.D.

Keith Meador, M.D.

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To Jonathan and Elliott, and to my parents, Ken and Laurel

Acknowledgments

My gratitude runs deep as I consider the many people who have contributed to this dissertation. You have inspired and encouraged me, prodded me towards bigger questions, shaped me into a more faithful Christian, and believed in my capabilities when my unbelief ran high. I thank my committee, first and foremost Bonnie Miller-McLemore, my advisor and an unparalleled source of wise theological scholarship on children and childhood. Jaco Hamman provided ample support not only for my studies in Religion, Psychology, and Culture, but also through his leadership of the Theology and Practice program. Keith Meador and Larry Churchill welcomed me to Vanderbilt's Center for Biomedical Ethics and Society and its robust interdisciplinary dialogue and relationships.

Camaraderie and commiseration among many fellow doctoral students buoyed my spirits in difficult seasons. Thanks especially to Yolanda Norton, Aimee Moiso, Courtney Bryant, Kyle Brooks, Stephanie Smith, Casey Sigmon, Lauren White, Richard Coble, Jon Stotts, Laine Walters Young, Peter Capretto, Bridgett Green, and Alan Murphy. I'm grateful for the courses I took at Vanderbilt with Barbara McClure, Evon Flesberg, and Bruce Rogers-Vaughn, and I count myself among the multitudes of Graduate Department of Religion students whose paths were kept smooth and straight by Karen Eardley's attention to endless administrative details.

Many others in Nashville became trusted friends and colleagues in study, ministry, and chaplaincy. Thanks to Raye Nell Dyer, Krister White, Cody Case, Matt Frierdich, Evelyn Graham, John Compton, Chris Benda, Denise Lillard, Katherine Smith, Guy Griffith, Michael Walters Young, and Nolan Huizenga. I'm grateful that the StoryCorps project came to Vanderbilt University Medical Center and allowed me the rich opportunity to interview Mildred Stahlman during the tenth decade of her inspiring life.

After three years in Nashville, my two years in Memphis brought enriching friendships that helped keep my academic pursuits alive while far from campus. I thank Janel and Laryn Kragt Bakker, Heidi and Dave Rupke, Rosie and Geoff Bakewell, Joelyn and Tom Drennan, Anne Apple, Amy George, Stacy Smith and Kevin Gallagher, the congregation of Trinity United Methodist Church, Glenn Ann Martin, and the nurses and chaplains at St. Jude Children's Research Hospital, especially Mark Brown and Brent Powell.

Both the roots and the branches of my experiences in theological education and chaplaincy are populated with those who have encouraged my studies and honed my pastoral skills, especially Wentzel VanHuyssteen, Rick Osmer, Deborah Hunsinger, Abigail Rian Evans, Donald Capps, Robert Dykstra, Gordon Mikoski, and Iain Torrance at Princeton Theological Seminary, my CPE supervisors Karen Morrow and Sue Asher, and Boston Children's Hospital colleagues Mary Robinson, Susan Harris, Peggy Bilotta, Bob Nee, and Michele Torres. Along with them I am grateful for Matt Flemming for first encouraging me to pursue an M.Div. and chart my own course, for the Pediatric Chaplains' Network and its vibrant pursuit of excellence and collegiality, for Joanne Wolfe and the Pediatric Advanced Care Team at Boston Children's and all the ways they are advancing pediatric palliative care, for Phoebe Chase Ramsey who is the best colleague-friend a hospital job could ever yield.

I thank dear friends Molly James, Sara VanderHaagen, Kezia Shirkey, and Joe Kuilema for being living proof when I needed it most that a PhD can be accomplished. Friends Rebekah, Vicky, and Bruce Menning, Daniel Meeter, Sharyl and Peyton Dixon, Jenn Graffius, Barb Boers, Sharon Hayes, Juel Grevenstuk, Jennifer VanderMolen, Jenny and Jared Knol, and Joshlyn Litzenberger have been steadfast gifts in my life for many years and carried me through the last seven in ways I cannot begin to repay.

This project would not have been possible without the countless patients and families who have allowed me to enter into profound moments in their lives. I am humbled by what I have witnessed and hope that my work honors the sacredness of their trust in me.

I give thanks for the patience, support, and profound example of lifelong learning I received from my parents, Ken and Laurel Bratt. My inner circle of family grew during these years of study and I am profoundly grateful for my husband Jonathan Bratt Carle and my one-year-old son Elliott, who have scaffolded my very being with joy and love and who no doubt are eager to see what life after my dissertation looks like. My siblings Christy and Justin and their families continue to shape my identity in ways that enrich my life deeply. I am grateful for my uncle Marvin Meyer, a prolific scholar of early Christianity who died from cancer in August 2012 during the very first week of my doctoral studies. He was a scholar whose curiosity and joy thoroughly animated his work, and in moments of academic tedium his memory has inspired me to persevere. I am grateful for my aunt Judy Strikwerda, whose profound developmental and physical disabilities have shaped her family members and so many others into more compassionate people. In my efforts to describe the full humanity of children in the midst of their less-developed cognitive skills, I often picture Judy, who likewise radiates the fullness of humanity that belongs to *all* of God's children.

Though I will gladly receive a diploma with my name on it, the names above are a constant reminder that pursuing this degree was by no means an autonomous effort. I recall the proverb, "If you want to walk fast, walk alone. If you want to walk far, walk together," and am so glad that I have shared this journey in the company of so many beloved ones.

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Introduction

“Anna,” a six-year-old girl on the pediatric intensive care unit, had arrived at the hospital by helicopter after sustaining extensive burns when her shirt caught fire as she played with a lighter. Her older sister’s hands were badly burned too when she tried to help extinguish the flames. The girl’s mother and I, their chaplain, stood at her bedside, observing the layers of bandages and the web of tubing and equipment that surrounded her small body, which was relying on a ventilator to breathe. This little girl faced weeks in intensive care and repeated trips to the operating room for painful dressing changes. A stay in a rehabilitation hospital would follow when she was medically ready for discharge from our facility.

Anna’s mother recounted an exchange she had with her just after the incident, before the girl’s breathing tube was inserted by first responders. “I tried to tell her it was an accident, that it wasn’t her fault,” her mother recalled. “Then she asked me a very adult question,” she continued. “She said, ‘How could it *not* be my fault?’”

This kindergartner’s question reveals her immediate grappling with the moral dimensions of her experience. It reflects her sense of culpability in her own and her sister’s injuries and her keen resistance to an adult’s quick effort to absolve her of such moral weight. Her mother’s framing of the question is also telling. Why is the girl’s question an “adult” one? This appraisal succinctly demonstrates a contemporary cultural tendency to regard children as merely innocent. At the same time, some nurses tending to this patient murmured warily whether the girl’s playing with fire evidenced a deviant personality, which evidenced the cultural notion of children as sinful creatures in need of discipline and instruction. I do not know whether others were self-aware of how larger assumptions about children were at play in Anna’s situation. What I do know is that there is a need for all of us who are caregivers in such settings to steadily improve

our capacity to attend and respond more fully to children when they grapple with both the joyful and painful realities of life around them. As long as a question like Anna's is an "adult" question, falling outside the constructed bounds of what we expect children to do or say, we will be ill-equipped to engage their full humanity in the midst of the pressing circumstances that require it the most.

Background

Since 2004, I have been a chaplain in numerous hospitals, beginning with my Clinical Pastoral Education training at the National Institutes of Health clinical center in Washington, D.C. and at Yale-New Haven Hospital in New Haven, CT. Subsequently, I have served at Boston Children's Hospital in Boston, MA; Monroe Carell, Jr. Children's Hospital at Vanderbilt in Nashville, TN; St. Thomas Health in Nashville, TN; St. Jude Children's Research Hospital in Memphis, TN; and currently at Helen DeVos Children's Hospital and Spectrum Health in Grand Rapids, MI. Hence, I come to this project with interests stirred by countless interactions with patients, families, and hospital staff. They have helped shape and refine my scholarly questions and my theological imagination as I follow my curiosities about how both medicine and theology regard children. My growing conviction that healthcare is fundamentally and problematically adult-centric prompted me to explore how theological resources could counteract this exclusion of children. This dissertation is an account of that exploration. I argue that theology and theological anthropology specifically can not only expand a limited view of children in healthcare, but also reinvigorate our limited views of what it means to be human at every age, beyond the cherished ideals of independence and self-sufficiency reflected in the concept of autonomy. While substantial theological contributions to bioethics have been made, theological

anthropology can aid in addressing the gaps that have resulted from the preoccupation with abstract norms and doctrinal directives that has marked much of theology's engagement with bioethics. Inherent in theological anthropology is a concern for engagement with the evolving accounts of human life proposed by other disciplines, and therefore it gives grounding and immediacy to theological interpretations of human life and human relationships with God. In contrast to theological discourse about children that focuses primarily on adults' responsibility for their religious education, theological anthropology invites greater appreciation of children as vital sources of illumination for a fuller understanding of what it means to be human. While I do not claim to set forth an exhaustive theological anthropology of children, I do propose key facets of such an anthropology that I believe are crucial in light of the limited articulations of children in the context of bioethics.

I write, then, from the perspective of a chaplain and an ordained minister in the Presbyterian Church (USA), as well as the perspective of a mother, a role that entered my life in the course of this project. I also write as an adult, which may go without saying, but which merits note. Complicated as it may be for any adult to write about children, or to write about how adults should think or act with respect to children, it is nonetheless true that children are a particular group for whom self-expression on a large scale is simply not feasible in the ways that it has become for other groups whose voices have been lifted from silence, obscurity, or misunderstanding, such as women, people of color, LGBT persons, and those living with disabilities. Children remain reliant on adults to deliberately consider and include them. An attempt like mine to speak of or speak for children must be accompanied by ample doses of humility and courage, and I hope I have honored that in my retelling of patient stories and the conclusions I draw.

A narrow approach to children

The problem of limited regard for children was readily visible one afternoon in a classroom at Vanderbilt Medical Center where I co-facilitated a clerkship session on pediatric ethics with a faculty member from Vanderbilt's Center for Biomedical Ethics and Society. We probed the second- and third-year medical students in the room for their perspectives and questions about children and medical ethics. At one point, we posed a question about the way a child figured into a hypothetical ethical dilemma. A young man quickly asserted that it really only involved the parents and the medical providers. When asked why, he replied flatly, "because the child doesn't have autonomy." Not only his words but also his body language communicated that this ought to be a sufficient answer. He leaned back in his chair and crossed his arms as if to say, *that's all you need to know*. Full stop, enough said. I wondered whether he was an archetype for many contemporary medical students. Are our future physicians being shaped with such a truncated view of autonomy that their view of children's place in ethics is limited to children's non-participant status?

While it is easy to portray this student's reply as merely simplistic and overly dismissive of children, it may be that his curt response also served to hide his discomfort with the entire subject of children. Perhaps he felt unequipped to articulate any other description of children beside their non-autonomous status. This encounter begins to reveal what is at stake in whether we measure children by anything more than their decision-making capacity or lack thereof. At stake, among other things, is the bearing of the provider towards the pediatric patient. If the child's identity is summed up as non-autonomous for the purposes of clinical interactions, what motive remains to prompt further curiosity about the child's experiences and perspectives? Defining children through the lens of the principle of respect for autonomy tolerates, nay, *invites*

an oversimplification of the youngest patients and allows an adult-centric demeanor to proceed without question.

Failure to appreciate children in more complex ways costs us the opportunity to provide the very sort of patient- and family-centered care that is now touted as standard in most hospitals. More expansive and appreciative understandings of children and their place in the healthcare environment are sorely needed. Adult-centric language and practice is particularly problematic in the healthcare setting, where it may function to obscure discomfort with facing the heartrending realities of caring for very sick children. Engaging with the emotionally difficult work of caring for seriously or terminally ill and dying babies, children, and adolescents confronts basic assumptions about childhood as a time of blissful innocence and growth. Hospitalized children are thus doubly in need of closer attention to their full humanity, lest they be avoided not only because they are children but also because they are sick children.

Problems with principles

Since its beginnings in the 1970s and 1980s, the young field of bioethics has grown rapidly, evolving in response to ever-advancing medical innovation and changing public opinion. Despite its progress, however, conventional bioethics continues to be overly preoccupied with autonomy, which became enshrined in research and clinical settings through what is often referred to as a principlist model of ethics, meaning the model articulated by medical ethicists Tom Beauchamp and James Childress in their *Principles of Biomedical Ethics*, first published in 1979 and now in its seventh edition (2012). “Respect for autonomy” was set forth as one of four key principles for medical ethics, along with beneficence, nonmaleficence, and justice. As I discuss further in chapter one, the principlist model casts autonomy in quite narrow terms,

specifically by focusing on its relation to informed consent, rendering it distinct from autonomy in wider moral and legal discourse and altering the more general bioethics concept of respect for persons that preceded Beauchamp and Childress' work.

Emphasis on autonomy in bioethics first emerged for understandable reasons. Appalling paternalism had been acceptable for far too long in clinical medicine, contributing to egregiously unethical practices and harmful experimentation. The impetus to define and preserve autonomy made sense in light of the circumstances to which bioethics was responding in its early years. Thus, it is reasonable that concern for autonomy should guide questions of decision-making capacity in hospitalized adults, along with the subsequent determination of appropriate surrogate decision-makers, two matters that arise with great frequency in clinical ethics consultations.

With autonomy and autonomous choice cast as primary concerns in healthcare decision making, however, children are automatically rendered peripheral stakeholders. Because children do not possess autonomous decision-making capacity, pediatric bioethics has largely focused on a "best interests" standard when parents or guardians must make decisions for children.¹ In most cases, parents are given the authority to act as a child's surrogate and the responsibility of making choices in the child's best interests, whereas in cases of adult surrogate decision making, "substituted judgment" is the guiding rationale.² That is, most adults have lived long enough and

¹ See especially Buchanan, Allen E, and Dan W Brock. *Deciding for Others: The Ethics of Surrogate Decision Making*. Cambridge, U.K.; New York, N.Y.: Cambridge University Press, 1989, and Diekema, Douglas S., Mark R. Mercurio, and Mary B. Adam, eds. *Clinical Ethics in Pediatrics: A Case-Based Textbook*. Cambridge: Cambridge University Press, 2011. Chapter one provides fuller discussion of this and other models.

² Beauchamp and Childress describe the best interests standard in this way:

Sometimes the patient's relevant preferences cannot be known. Under the best interests standard a surrogate decision maker must determine the highest net benefit among the available options, assigning different weights to interests the patient has in each option and discounting or subtracting inherent risks or costs. The term *best* is used because the surrogate's obligation is to maximize benefit through a comparative assessment that locates the highest net benefit. The best interests standard protects an incompetent person's well-being by requiring surrogates to assess the risks and benefits of various treatments and alternatives to treatment (*Principles of Biomedical Ethics*, 6th edition, 138).

in established patterns such that their loved ones can adequately make choices on their behalf in a way that approximates what the patient would choose if she or he had the capacity to do so.

With children, however, because patterns of personality, beliefs, and individual preferences are still emerging along with their developmental capacities for rational choice, adults are entrusted with decision-making power. This arrangement may be appropriate, but it fosters an approach in pediatric ethics that centers almost exclusively on matters of who gets to make decisions and how to establish which decisions are acceptable. Ethical discourse too often thus invites skipping right over the “incompetent” child in order to focus on the beliefs and preferences of the adult entrusted with power. This can leave much territory unexplored, such as the child’s own experience and the moral weight of relevant contextual factors in the family’s life.

When clinical ethics literature does try to address the ways in which children might be involved in their own healthcare experiences, it tends to focus narrowly on questions of the age at which a child could or should be asked to give assent to research participation, and the circumstances under which a minor might be allowed to give consent for his or her own decisions. While important, these investigations are often motivated by legal considerations, reflecting the litigious American healthcare culture more than a genuine concern for engaging children as developing persons with valuable perspectives, aims, and meaning-making capabilities. Additionally, these rubrics rely heavily on dominant stage theories of developmental psychology, which emphasize cognitive development without attending to other realms of development such as social and spiritual. Such theories focus on chronological stages and capacities in a way that can obscure the rich trajectory of spiritual development and maturation

among children and adolescents, as Bonnie Miller-McLemore has demonstrated.³ She identifies how dominant faith development theories build on these psychological theories and likewise neglect the important meaning-making capacities of children, focusing instead on matters of sin and grace, which are more reflective of adult concerns than the realities of children's lives.⁴ She rightly observes that "children's spirituality... defies conventional chronological categories of mature and immature," a truth which is obscured by linear interpretations of child development and evident in the fact that adulthood is certainly no guarantor of spiritual maturity.⁵ The inadequate interpretations of children produced by such developmental theories become all the more pronounced in a context like the hospital, where children may have marked limitations in their physical and cognitive capacities but nonetheless reflect patterns of thinking, behavior, affect, and spirituality that complicate or defy traditional stage-based models.

An exaggerated concern for autonomy reinforces an ideal of human flourishing marked by independent, unencumbered rational choice. This ideal categorically excludes children and ignores other understandings of human flourishing characterized by features like relationality and interdependence. Overemphasis on autonomy continues to feed a clinical imagination that envisions the default human being as one who can make his or her own decisions, whose informed consent can be properly obtained, and whose choices must not be unduly constrained by outside forces. Not only is this emphasis on autonomy generally problematic for the complex medical situations of adults and their widely varying capabilities and contexts, it is also particularly problematic for children because it is fundamentally skewed toward an adult-centric

³ Miller-McLemore, Bonnie. "Children's Voices, Spirituality, and Mature Faith." In *Children's Voices: Children's Perspectives in Ethics, Theology and Religious Education*, edited by Annemie Dillen and Didier Pollefeyt, 17–48. Leuven: Peeters, 2010.

⁴ Miller-McLemore, "Children's Voices, Spirituality, and Mature Faith," 32.

⁵ Miller-McLemore, "Children's Voices, Spirituality, and Mature Faith," 40.

ideal of persons. If autonomy is the hallmark of a fully capable person, then children automatically deemed non-autonomous are relegated to a separate category of persons from the outset. At first blush, this may seem straightforward and appropriate, due to children's very real needs for adult supervision, guidance, and protection. If this attitude characterizes the extent of regard for children in the medical milieu, however, it excuses any further need to appreciate and respond to children in their complexity, their full humanity, and their perspectives in the midst of their healthcare experiences.

Theological resources

Theology stands to inform clinical ethics by providing an anthropological framework in which to explore the textured fabric of human life, pursuing such questions as, What kind of creatures are we? What meaning is there in suffering? How do the relationships and systems in which we find ourselves shape our identity and our health? Pursuing theological anthropology can foster a more robust dialogue with bioethics, one which makes space for esteeming children more substantively alongside adults.

Theological work in clinical ethics has been heavily invested in articulating positions related to the very beginning and very end of life—namely, issues related to assisted reproduction and abortion and end of life topics such as physician aid in dying. These matters are worthy of attention, but they have commanded disproportionate attention at the expense of other pressing ethical matters across the lifespan.

Pastoral theology can speak into the gaps created by theology's previously narrow applications to bioethics. A branch of theology committed to theory and practice as mutually informing, pastoral theology has produced valuable theological perspectives on diversified

theories of human development, models of psychological and spiritual development, the impact of family systems and social structures, and the complex plight of those who are subject to varying forms of oppression and marginalization. It embraces the importance of lived experience and practices as sources worthy of serious engagement, and integrates these insights into approaches for ministries of care and healing.

In this context of pastoral theology, I suggest three areas of focus especially relevant for a theological anthropology of childhood reflecting the experience of hospitalized children: vulnerability, dependence, and agency. While these are by no means exhaustive in their description of hospitalized children or children in general, I chose them because they address, correct, and expand the most problematic features of autonomy. That is, vulnerability, dependence, and agency contradict and challenge interpretations of autonomy that overly prize ability, that presume independence as a baseline state, and that privilege rationality and reason as the chief, or only, means of expressing of agency.

The emergence of childhood studies

The field of childhood studies holds immense potential for challenging and expanding our views of children and can mobilize theological inquiry to do the same. Like bioethics, the field of childhood studies is only a few decades old. Stemming largely from sociological and anthropological study of children and childhood, it is steadily growing to incorporate more interdisciplinary conversation partners. Currently more robust in the United Kingdom and Europe than in the United States, childhood studies provides promising tools to better understand and address children in their lived realities. In order to develop an approach to medical ethics that has more to say about who children are than simply that they are non-autonomous,

incompetent decision makers, input from those who are aptly describing childhood can provide entirely different lenses. Allison James, a key British figure in the childhood studies literature, has nicely summarized the need for a different look at childhood, claiming that

an appreciation and understanding of children's own experience of the world must involve, first and most importantly, unpacking the ideas which shape the contextual practices and perceptions of childhood as it daily unfolds for children. Childhood cannot be regarded, simply and unproblematically, as the universal biological condition of immaturity which all children pass through. Instead, it must be critically depicted as embracing particular cultural perceptions and statements about that temporal biological condition. It is these which shape the life experiences of members of the social category “children” through providing a culturally specific rendering of the early years of life.⁶

James’ point is particularly relevant to the realms of healthcare and medical ethics, where children are certainly at risk of being defined simply by their temporal biological condition. If the need for seeing the ideas and cultural contexts that shape childhood is pressing in areas such as education, childrearing, and social policy, surely it is just as urgent with respect to health care, where biological reductionism looms large. Furthermore, with its dedication to identifying the variation in beliefs and practices with respect to children, childhood studies stands as a prime dialogue partner for both bioethics and theology in their efforts to describe and understand the positions and practices of children, families, and clinicians who may encounter misunderstandings and conflict.

Additionally, childhood studies can augment bioethics by providing a vital understanding of children as subjects in their own right, a move which scholars of religion have begun to engage more robustly.⁷ Whereas theology and ethics historically viewed children as recipients and objects of protection and care, childhood studies articulates how children are also agents and actors. As childhood studies scholar Jens Qvortrup and his colleagues note, the impetus for

⁶ James, Allison. *Childhood Identities: Self and Social Relationships in the Experience of the Child*. Edinburgh: Edinburgh University Press, 1993, 74.

⁷ I return to this topic in my discussion of agency in chapter 5.

childhood studies included a concern for the way that children “were largely appreciated as people who were on the receiving end in terms of provision and knowledge. Children were reduced to vulnerable people to be protected without being seen also as participants—in any case, not participants in the larger social fabric, which was an adult privilege and prerogative.”⁸

Adult privilege and prerogatives have dominated in religion and theology as well, but recent notable developments in childhood studies and religion scholarship have emerged to provide new perspective on children as producers of and participants in religious understandings and practice.

Children in religion

Though theological resources are well suited to the tasks of articulating the worth and interrelatedness of all people, scholarship in religion has been slow to lift up the subject of children as a legitimate endeavor alongside other areas of theological inquiry. Along with other childhood studies and religion scholars, John Wall has reflected on this lacuna, noting

Though the study of theology and children has come a long way in recent years, it still occupies a sequestered realm within larger theological inquiry. While no church leader or theologian today can fail to consider issues of gender, race, ethnicity, or culture, the same is not yet true for age.⁹

The neglect of age as a valid subject of inquiry, particularly when addressing those of very young age, also fits with pastoral theologian Bonnie Miller-McLemore’s observation that “Feminist analysis suggests that it is no accident that the closer one gets to practice, particular

⁸ Qvortrup, Jens, William A Corsaro, and Michael-Sebastian Honig. “Why Social Studies of Childhood? An Introduction to the Handbook.” In *The Palgrave Handbook of Childhood Studies*. Houndmills, Basingstoke, Hampshire; New York: Palgrave Macmillan, 2009, 5.

⁹ Wall, John. “Review of Jerome W. Berryman, *Children and the Theologians: Clearing the Way for Grace*.” *Journal of Childhood and Religion* 1 (2010), 1. See also Wall, John. “Childhood Studies, Hermeneutics, and Theological Ethics.” *The Journal of Religion* 86, no. 4 (October 2006): 523–48; Bunge, Marcia J. “The Child, Religion, and the Academy: Developing Robust Theological and Religious Understandings of Children and Childhood.” *The Journal of Religion* 86, no. 4 (October 2006): 549–79; and Miller-McLemore, Bonnie J. “Children and Religion in the Public Square: ‘Too Dangerous and Too Safe, Too Difficult and Too Silly.’” *Journal of Religion* 86, no. 3 (July 2006): 385–401.

experiences, personal faith, emotions, and subjectivity, the lower the academic status of the field.”¹⁰ Childhood studies scholar Lynne Vallone similarly reflects on the academy’s wariness toward children, asserting that in the context of what she sees as a deep ambivalence toward children in the United States, “the academy continues to be highly suspicious of any perceived ‘immaturity’ within the ivory tower. Even today it is not unusual for scholars from a wide array of disciplines to have to defend why they have placed children and childhood at the center of their research programs.”¹¹ Vallone laments that “[childhood studies’] potential as an urgent and relevant critical discourse that cuts across disciplines is as yet untapped—particularly in the United States,” but she remains optimistic for its potential to bridge divides between the humanities and social sciences based on the interdisciplinary efforts that continue to emerge within the field.¹²

In the past two decades more theologians have begun to address the place of children in the field. A Childhood Studies and Religion group was formed within the American Academy of Religion, influenced by the emergence of childhood studies as a formal discipline. The 2001 publication of *The Child in Christian Thought*, edited by Lutheran theologian Marcia Bunge, can be considered the “advent” of childhood studies literature in religion.¹³ In their foreword, Bunge and Wall note their hopes for the book: “We are bold enough to suggest that it launches a new

¹⁰ Miller-McLemore, Bonnie. “Feminist Theory in Pastoral Theology.” In *Feminist and Womanist Pastoral Theology*, edited by Bonnie J Miller-McLemore and Brita L Gill-Austern, 77–94. Nashville: Abingdon Press, 1999, 78.

¹¹ Vallone, Lynne. “Doing Childhood Studies.” In *The Children’s Table: Childhood Studies and the Humanities*, edited by Anna Mae Duane, 238–54. Athens: University of Georgia Press, 2013, 239.

¹² Vallone, “Doing Childhood Studies,” 239-240.

¹³ Miller-McLemore, Bonnie J. “Childhood Studies and Pastoral Counseling.” In *Understanding Pastoral Counseling*, edited by Elizabeth A Maynard and Jill Lynnae Snodgrass, 413–33. New York: Springer, 2015, 413.

field of inquiry: the study of Christian theological approaches to children and the responsibilities of families and society toward them.”¹⁴

In a special issue on Religion and Childhood Studies, the *Journal of Religion* lifted up scholars whose work joined that of childhood studies scholars in exploring questions of “how we define childhood, how childhood has changed over time, and how children experience the world.”¹⁵ Bunge’s contribution in the issue begins by articulating the backdrop against which this surge of religious scholarship on children began. She notes that many other disciplines such as law, philosophy, and anthropology have shown new attention to children and childhood, and that global concern for children’s welfare has also drawn more public focus. Alongside this pair of academic and public attention, religious perspectives have been slow to emerge. Bunge describes the resistance in this way:

Despite the rising concern for and curiosity about children, scholars of religion, theologians, and ethicists across religious lines have had little to say about children, and they have had little to contribute to the growing political and academic debates about children or our obligations to them. Many have not treated childhood as a topic meriting serious attention, and they have not sought to articulate robust religious understandings of children themselves.¹⁶

While religious scholars have often focused on issues that relate to children, such as abortion, reproductive technology, marriage, and family, they have neglected questions about the nature and status of children themselves, relegating views of children to overly narrow and simplistic understandings that diminish the “complexity and integrity” of children and fail to account for how children also have a role in shaping adults and adult spirituality.¹⁷

¹⁴ Bunge, Marcia J., ed. *The Child in Christian Thought*. Religion, Marriage, and Family Series. Grand Rapids, Mich: W.B. Eerdmans, 2001, xi.

¹⁵ Catherine A. Brekus, “Special Issue: Religion and Childhood Studies,” *The Journal of Religion* 86, no. 4 (October 2006): 521.

¹⁶ Marcia J. Bunge, “The Child, Religion, and the Academy: Developing Robust Theological and Religious Understandings of Children and Childhood,” *The Journal of Religion* 86, no. 4 (October 2006): 551.

¹⁷ Marcia J. Bunge, “The Child, Religion, and the Academy,” 552.

Until recently, Bunge remarks, attention to children in religion came mostly from religious educators and practitioners whose interests were often limited to children's spirituality and faith development. Broadening this scope with greater attention to religious and theological understandings of children in general, says Bunge, has the potential to inform and strengthen the involvement of faith communities with children, to deepen understanding of religious traditions, and to equip theologians for interdisciplinary discussions and policy debates in order to advance the well-being of children both nationally and internationally.¹⁸ Bunge identifies a clear and urgent need for new theological understandings of children that will account for the ways that children can be seen as more than simply in need of instruction and discipline, but also as teachers, bearers of revelation, and models of faith.

Rather than simply focusing on children's spirituality or religious education, theologies of childhood actually make use of the child as a lens to assess the beliefs and practices of Christian traditions even with respect to aspects that are not typically associated with children. Within the fields of practical and pastoral theology, Pamela Couture's *Seeing Children, Seeing God: A Practical Theology of Children and Poverty*, Bonnie Miller-McLemore's *Let the Children Come: Reimagining Childhood from a Christian Perspective*, and Joyce Mercer's *Welcoming Children: A Practical Theology of Childhood* in particular made significant contributions which additionally incorporated the kind of robust interdisciplinary engagement common to practical theological approaches.¹⁹ These three represent a groundswell of new insight produced around the same time as Bunge's *The Child in Christian Thought*. Couture uses

¹⁸ Marcia J. Bunge, "The Child, Religion, and the Academy," 553.

¹⁹ Couture, Pamela D. *Seeing Children, Seeing God: A Practical Theology of Children and Poverty*. Nashville, TN: Abingdon Press, 2000.; Miller-McLemore, Bonnie J. *Let the Children Come: Reimagining Childhood from a Christian Perspective*. San Francisco, CA: Jossey-Bass, 2003; Mercer, Joyce. *Welcoming Children: A Practical Theology of Childhood*. St. Louis, Mo: Chalice Press, 2005.

the framework of children's rights and what she calls children's social ecology, examining not only the material poverty that besets many children but also the poverty of "tenuous connections" brought about by the failure of adults to take on shared responsibilities for children. Couture assesses the consequences of these shirked duties: "We have not so ordered our lives that children may grow in love and grace, much less have their basic needs met for shelter, food, multiple stable adult relationships, medical care, and education."²⁰ With an eye to how practical theology conceptualizes care of children and to the ways in which gendered divisions of labor have constricted modes of care, Couture advocates that churches and theological schools ought to strengthen the existing tenuous connections with vulnerable children in their contexts.²¹ She calls for pastoral theologians to move beyond child development in their research and instruction and branch out to strategies that will buffer children against the many risks of harm that they face.²² Despite the general cultural emphasis on children and families that appears to be well-established, says Couture, this work of addressing children's various poverties remains urgent because the United States has failed to develop permanent policies where concern for children is paramount.²³

In *Let the Children Come: Reimagining Childhood from a Christian Perspective*, which I draw on throughout this project, Bonnie Miller-McLemore undertakes the descriptive task of exploring how adults think about children and the prescriptive task of directing how adults *should* think about children.²⁴ She describes historical and cultural trends in how children have been regarded and indicates that in light of current theological understandings, "children must be

²⁰ Couture, *Seeing Children, Seeing God*, 14, 16.

²¹ Couture, *Seeing Children, Seeing God*, 47.

²² Couture, *Seeing Children, Seeing God*, 96.

²³ Couture, *Seeing Children, Seeing God*, 112.

²⁴ Miller-McLemore, *Let the Children Come*, xxv.

fully respected as persons, valued as gifts, and viewed as agents.”²⁵ In this formulation, Miller-McLemore counters dominant competing views of children as entirely innocent or depraved and also transcends the problematic views of children that surfaced with the shift to an industrialized society, where children are no longer economic assets but burdens whose value in a market culture must reside in being emotionally priceless.²⁶

Along with Couture and Miller-McLemore, Joyce Mercer advances the theological conversation regarding children. She specifically seeks a “child-affirming theology and church,” attending to cultural and systemic influences that inhibit faith communities from fully welcoming children.²⁷ Among these influences, Mercer names market culture as a particularly harmful culprit, and in response she esteems the deeply formative nature of Christian faith, asserting that “Christian identity has the power to oppose the destructive identities consumer culture offers today.”²⁸ Mercer’s focus on welcoming children more fully through congregational practices of education and liturgy is buttressed by strong theoretical footings for children’s full inclusion, including a thorough exploration of the place of children in the gospel of Mark. Furthermore, Mercer explores adult responsibilities in light of how children are marginalized and oppressed by globalized capitalism, but she also lifts up the importance of adults recognizing the divine in children. She explains,

when we look to children, when we know them well enough and care for them deeply enough to welcome them, then we get the chance to know some things about God and to come to know God differently than might otherwise occur. If welcoming a child is a way to welcome God, then perhaps there is something about God that is as messy, playful, noisy, active, spontaneous, restless and unpredictable as that which one encounters in welcoming a child.²⁹

²⁵ Miller-McLemore, *Let the Children Come*, xxiii.

²⁶ Miller-McLemore, *Let the Children Come*, 6.

²⁷ Mercer, *Welcoming Children*, x.

²⁸ Mercer, *Welcoming Children*, ix-x.

²⁹ Mercer, *Welcoming Children*, 262.

Mercer's conclusions about the vital place of children in the life of faith leads her to bafflement over theology's slow pace of change—she admits, “I cannot imagine what is keeping all theologians of every ilk in this country from locating children and their welcome in a very prominent location within their theologies.”³⁰ With respect to bioethics, I too puzzle with Mercer over why the adult-centric premises and practices of principlist ethics have not been more swiftly and thoroughly altered to better reflect and accommodate children. With Couture and Miller-McLemore, I likewise yearn to see a more fully developed understanding of children and the material and social poverties that shape their interactions with healthcare, and I hope that a more honest reckoning with the way that adults currently think about children in the hospital context will yield attitudes and practices that respect their subjectivity and agency.

The limitations and resistance seen in religious studies with regard to children resonate with the limitations that persist in bioethics as well. Pediatrician and ethicist Margaret Mohrmann laments, “Not only bioethics but ethics in general, Christian ethics in particular, has long avoided—or perhaps, considered unnecessary—the hard work of looking clearly at who our children are and who they are not.”³¹ Noting Bunge's edited volume as an important recent exception, Mohrmann asserts that it would not be too much of an exaggeration to say that until recently, Christian thought on children was based on fourth-century theologian Gregory of Nyssa's writing on infants' early deaths. Mohrmann notes that from then on, focus on children has revolved around three areas: baptism, Christian education, and children's duties toward parents.³² Furthermore, she observes that pediatric medical ethics specifically has made the

³⁰ Mercer, *Welcoming Children*, 262.

³¹ Mohrmann, Margaret E. “Whose Interests Are They, Anyway?” *Journal of Religious Ethics* 34, no. 1 (March 1, 2006), 141.

³² Mohrmann, “Whose Interests Are They, Anyway?,” 142.

“erroneous claim ... that one can reason well about the care of children by thinking of them, ethically, as though they were adults writ small, whose primary claim on us is for representation or protection of their nascent autonomy.”³³

Religion and childhood studies scholar Susan Ridgely Bales stands as one vital example of focusing on children’s experiences directly rather than casting them as adults writ small or relying on adult recollections of childhood experiences. After immersing herself with young Catholic children from two parishes as they prepared for their First Communion, Bales found stark differences between the meanings adults attributed to the ritual and those that the children articulated for themselves. She remarks on how adults often reflect on their own such childhood experiences and tend to describe them “using primarily abstract reasoning and prescribed doctrine ... whereas the children mediated their understanding of religion through their senses (taste, sight, and touch) as well as their emotions (excitement, anxiety, and joy).”³⁴ Bales adeptly describes how developmental assumptions can constrict adult views of children, creating narrow boundaries for their expected behaviors and perspectives. Echoing the same problem I identify with the emphasis on (adult) autonomy in bioethics, Bales notes that “Having children’s limitations as the starting point for adults’ work necessarily restricts understanding of children’s perceptions to a rather narrow set of possibilities.”³⁵ Her dedication to child-centered research stands in contrast to the persistence of religious scholarship that largely overlooks children. Bales laments this stubborn problem and the assumption it reflects, namely, that children are simply not capable of serious thought about their participation in religious life.³⁶

³³ Mohrmann, “Whose Interests Are They, Anyway?,” 142.

³⁴ Bales, Susan R. *When I Was a Child: Children’s Interpretations of First Communion*. Chapel Hill: University of North Carolina Press, 2005, 181.

³⁵ Bales, *When I Was a Child*, 9.

³⁶ Bales, *When I Was a Child*, 13.

Children's hospitals too are places where children's physical senses are immediately engaged as they undergo medical treatment, and where emotions of anxiety and joy can run high. They are also sites where vibrant spirituality and its practices can get overlooked in the presence of assumptions that religious belief deals primarily with denominational affiliations, doctrines and authoritative injunctions about healthcare decisions. Bioethics discourse that remains preoccupied with cognitive abilities and discrete quandaries further sidelines the more nuanced ways in which children meaningfully experience and participate in their medical care, making it difficult to ascribe importance to actual children and not just abstractions *about* children. Though my work does not entail a systematic ethnographic study, it nonetheless reflects Bales' style of close observation and immersion as I draw on firsthand experiences with patients and families. The authoritative sources from which I draw consist not only of scholarly texts but also the insights gained from countless hours of proximity and close attention to the pastoral, ethical, and medical contours of everyday clinical encounters among patients, family members, doctors, nurses, and other assorted hospital staff.

Children's hospitals – a fraught history

I have chosen to situate my proposed theological anthropology not in abstract relation to pediatric bioethics but to the site of children in hospitals. Today, most pediatric hospital patients are in hospitals designated for children, and the history of children's hospitals in the US reveals that they have been a locus of competing views of children from the start. Prevailing understandings of children and the relative roles of parents, doctors, and social reformers were readily apparent in early children's hospitals such as those in Boston, as described by physician and historian Helen Hughes Evans. She locates children's hospitals at the intersection of medical

history and societal approaches to children and families, as places that reveal functional definitions of children and what adults ought to do with and for them. Early children's hospitals, founded in response to high infant and child morbidity and mortality, were a magnet for social reformers eager to promote Christian and middle-class values in the midst of industrialization and growing immigrant populations. Children, notes Evans, "personified the dependent patient ripe for charitable and therapeutic melioration."³⁷

Historian David Sloane recounts similar interpretations of the origins of children's hospitals, remarking that "The hospital was not simply a place for the physically ill; it was also a place for normative training and moral education."³⁸ Children's hospitals reflected a new space where physicians and social reformers could

domesticate parents, educate and cure children, and socialize families. The social reform mission meshed with the medical purpose, albeit sometimes uneasily, to create a fictional parentless home managed by professionals for the purpose of saving children physically and spiritually. ...

Through the giving of the charity, the women hoped to reform and mold their young charges into healthy and respectable citizens. With new intellects, refined manners, and softened hearts they would influence their families, and therefore improve their society.³⁹

The first US children's hospital was established in Philadelphia in 1855. By 1890, there were about 30 independent children's hospitals in North America and their number grew rapidly—between 1890 and 1920, the number of children's hospitals in US and Canada tripled.⁴⁰

The physical space of children's hospitals evolved to reflect changing priorities. In the earliest children's hospitals, women reformers bent on social mission worked to make hospitals

³⁷ Evans, Helen Hughes. "Hospital Waifs: The Hospital Care of Children in Boston, 1860-1920." Ph.D. dissertation, Harvard University, 1995, 5.

³⁸ Sloane, David C. "A (Better) Home Away from Home." In *Designing Modern Childhoods: History, Space, and the Material Culture of Children*, edited by Marta Gutman and Ning De Coninck-Smith, 42–60. New Brunswick, N.J.: Rutgers University Press, 2008, 54.

³⁹ Sloane, "A (Better) Home Away from Home," 43, 47.

⁴⁰ Sloane, "A (Better) Home Away from Home," 42, 47.

replicate a home environment as closely as possible. They advocated for the inclusion of porches, a feature seldom present in adult hospitals but which evoked stately middle-class homes.⁴¹ Sloane writes, “The porches were physical manifestations of the children's hospital as a fictional home in which parents gave up their children to the scientific expertise and moral superiority of hospital physicians and managers.”⁴² Gradually, however, hospitals transitioned from a homelike environment to one shaped by the medical needs that dominated.⁴³ As Evans puts it, the “rising scientific ethos subsumed the nurturing role of the hospital.”⁴⁴

One of these perceived medical needs was the separation of parents from their hospitalized children. Physician and medical historian Howard Markel notes that because many children’s hospitals focused primarily on the correction of orthopedic problems and congenital malformations, pediatric patients often required months of hospitalization, making hospitals “ideal places to remodel children morally as well as physically.”⁴⁵ Visiting hours for parents were kept to a strict minimum in the name of science or perhaps physicians’ convenience.

Markel recounts the extremely restricted parental visiting hours at Boston Children’s Hospital in 1894, when parents were allowed to visit only two days a week—from 11 am to noon on Wednesdays and 3 to 4pm on Sundays.⁴⁶ Such enforced parental absence is the extreme opposite of the family-centered nature of today’s children’s hospitals, where private rooms are expected and parents are usually present without restriction. At the time, however, “Most physicians practicing in this era considered childhood diseases to be caused by unhealthy

⁴¹ Sloane, “A (Better) Home Away from Home,” 51.

⁴² Sloane, “A (Better) Home Away from Home,” 51.

⁴³ Sloane, “A (Better) Home Away from Home,” 50-51.

⁴⁴ Evans, “Hospital Waifs,” iii.

⁴⁵ Markel, Howard. “When Hospitals Kept Children From Parents.” *The New York Times*, January 1, 2008, quoting Harvard medical historian Charles Rosenberg.

⁴⁶ Markel, Howard. “When Hospitals Kept Children From Parents.”

environments and improper parenting ... Removing children from deleterious home environments was considered therapeutic.”⁴⁷ Well into the 1950s, parental visitation remained extremely limited. Though much progress has been made in accommodating the supportive presence of parents and other family members, much ground still needs to be covered in order to accommodate the need for children’s perspectives and experiences to be more roundly recognized in the hospital setting. Fostering the physical presence of families is a step in the right direction, reflecting the importance of preserving key attachments, but this change alone does not mitigate the larger narratives about children that dominate in the medical setting and the wider culture.

Methodology

In their introduction to *Theological Reflection: Methods*, theologians Elaine Graham, Heather Walton, and Frances Ward consider the history of doctrine and summarize “that theology has always been contextual and is best understood as possessing a practical function: to nurture, to inform identity, to communicate.”⁴⁸ The history of medical ethics reflects a heavy use of theology to address narrowly defined dilemmas, but this contrasting description of theology’s functional identity legitimates the kind of re-engagement through theological anthropology that I propose for pediatric bioethics. Thus, my methodology for this project embraces what Graham et al. call “theology in the vernacular,” which they describe as

based upon the conviction that the Christian gospel does not exist in abstract form but is most authentically encountered when it is incarnated within specific cultural contexts. it will assume diverse shapes according to the local environment in which it is embodied and speak in the vernacular using the idioms, symbols and narrative forms employed in

⁴⁷ Markel, Howard. “When Hospitals Kept Children From Parents,” quoting Helen Hughes Evans.

⁴⁸ Graham, Elaine L, Heather Walton, and Frances Ward. *Theological Reflection: Sources*. London: SCM Press, 2007, 10.

everyday life. Those who advocate this understanding of theology see the work of theological reflection as being akin to that of learning a language.⁴⁹

Graham et al. describe how a grasp of such vernacular language equips theologians with technical proficiency, but more importantly, it forms a worldview that in turn deeply shapes their own understanding. “[W]hen theologians seek to communicate in a way that is relevant within a particular cultural context, they will find their own understanding of the gospel challenged, enriched and transformed through this process,” Graham et al. summarize, conveying the transformative power of communicating not in abstract universals but in the richness of specific contextually mediated language.⁵⁰

The authors also note that theology carried out in this vernacular model draws extensively on the work of anthropologist Clifford Geertz, who distinguished between “thick” and “thin” description, where thin descriptions are preoccupied with determining the ontological status of what is observed, and thick descriptions focus on their import.⁵¹ In a comment that resonates with my aim of thick description within the context of children’s hospitals and pediatric ethics, Geertz asserts “the essential task of theory building here is not to codify abstract regularities but to make thick description possible, not to generalize across cases but to generalize within them.”⁵² Principlist medical ethics and its preoccupation with autonomy has enshrined a description of children that is all too thin. Theological anthropology can broaden our regard for children, providing a much thicker rendering of who they are, what they experience, and what their needs rightly ought to evoke from us.

⁴⁹ Graham et al., *Theological Reflection: Sources*. London: SCM Press, 2007, 370.

⁵⁰ Graham et al., *Theological Reflection: Sources*. London: SCM Press, 2007, 370.

⁵¹ Geertz, Clifford. *The Interpretation of Cultures: Selected Essays*. New York: Basic Books, 1973, 10.

⁵² Geertz, *The Interpretation of Cultures*, 26.

As Miller-McLemore describes, pastoral theology embraces thick description as a methodological tool for “seeking a multilayered analysis of human strife, including detailed, intricately woven, ‘experience-near’ rather than ‘experience-distant’ readings of the ‘living human document.’”⁵³ My “experience-near” methodological style in this project fosters close analysis of how practice and theory are mutually informing in the spheres of theology and pediatric bioethics. These insights drawn from the vernacular raise renewed possibilities for critical engagement to enrich practices of care for hospitalized children.

Chapter summaries and development of the argument

Narrow and undeveloped views of children animate the contemporary landscape of hospitals and healthcare. The dominant principlist bioethics approach has reinforced those constrained views, fostering a regard for children as merely non-autonomous, incompetent patients, as I argue in chapter one. Though the principlist approach emerged with ample justification, its accompanying models of surrogate decision-making render the approach to decision-making most often used in pediatric clinic ethics, namely, the best interests standard, at the bottom of the hierarchy. While alternatives to the best interests standard have been proposed, the prominence of principlist surrogate decision-making models have enduring problematic implications for children.

In chapter two, I explore the limitations of theology’s historically truncated role in bioethics, and propose an altered and expanded role. Despite the widespread influence of theologians in the early development of bioethics, the field subsequently secularized as efforts

⁵³ Miller-McLemore, Bonnie J. “The Living Human Web: Pastoral Theology at the Turn of the Century.” In *Through the Eyes of Women: Insights for Pastoral Care*, edited by Jeanne Stevenson Moessner, 9–26. Minneapolis, MN: Fortress Press, 1996, 24.

grew to find a universally applicable articulation of moral norms. I contend that theological anthropology represents an approach for effectively re-engaging theology and bioethics. To this end, I identify four features of pastoral theology that render it a fitting discipline for such theological anthropological engagement both in content and method. Finally, I consider pastoral theology's engagement with children thus far and suggest future work to more robustly address children in the healthcare context, situating my own project as one response to such needs.

Chapter three places vulnerability as the first of three features of my proposed theological anthropology of hospitalized children. I discuss limitations of vulnerability as it is cast in the principlist model and argue that multiple additional facets of vulnerability pertain to hospitalized children. Children are vulnerable in how they are defined both overtly and operationally and vulnerable in a marketplace model of healthcare. Lastly, children are situated within a divine affirmation of vulnerability underscored by theological themes such as incarnation and the image of God.

Chapter four asserts dependence as a second vital aspect of the proposed theological anthropology. Though some theories of medical ethics such as feminist approaches have addressed dependence, these approaches fail to capture how the dependence of children entails more than immediate basic reliance and also encompasses complex relational realities in a matrix of social and systemic dynamics. Dependence, in my view, describes the social makeup of the self and the need for communities who would seek to be inclusive to recognize their own dependence on the neediest among them. These additional features of dependence thus create imperatives for healthcare that responds more fully to children and their needs.

In chapter five I argue that agency is a third feature of a theological anthropology of hospitalized children. I distinguish agency from the concept of assent that has functioned as

medical ethics' primary attempt to acknowledge and engage children, and note the limitations of assent and the advantages of agency for describing how children engage in their medical care. As agency has been a key concept in the growing field of childhood studies, I suggest its evolving meanings are conducive to greater use in the realm of pediatric medical care as well. These connections are further strengthened by considering vocation as a manifestation of theological agency in children, and by engaging spirituality as a lens for recognizing and affirming agency in the hospital setting.

The theological anthropology I propose bears the potential to nurture a greater regard for children in the midst of a bioethics that has oversimplified who they are. I argue that this greater regard is possible with respect to adults as well, as the three features of vulnerability, dependence, and agency not only illuminate childhood more fully but also shed light on the human situation far beyond our early years. My sixth and final chapter thus pulls back to look at childhood in the context of the human lifespan and at the enduring nature of vulnerability, dependence, and agency. I assert that the task of de-centering adulthood is vital for the flourishing of both children and adults, and theological resources can equip such de-centering to foster greater appreciation of childhood's ongoing place in human life. I identify recent research connecting adverse childhood experiences and adult health as a focal point where theological perspectives can deftly affirm the crucial need to expand theoretical approaches to childhood in order to foster well-being at all ages.

As pediatric medical care expands and refines its capabilities toward a future no doubt filled with tremendous possibilities, so must we who care for children in such settings also continue to expand and refine our grasp of children as full persons whose standing and experience matters greatly. We must insist on a bioethical discourse that engages the complex

realities of children and childhood and refrain from settling for simplistic renderings of children that measure them and their capacities only in relation to the adults we hope they will one day become. Though theological resources did shape the founding of bioethics, crucial untapped contributions remain that can help to describe what kind of people children are and to equip caregivers who wish to more effectively honor the fullness of their humanity in the midst of ethical complexity. I believe we are obligated to children like Anna, whose story began this introduction and whose experience beckons us to delve deeply into the contours of moral experience that are all too easily overlooked when the patient happens to be a child.

Chapter 1

Situating the pediatric patient in clinical ethics

Pediatrician and bioethicist Margaret Mohrmann has observed that “bioethics speaks to the doers of medicine, the practitioners and policymakers, but rarely, if at all, to the ‘done-to.’”⁵⁴ Children are a particular group of the “done-to” whose place in healthcare and bioethics has yet to receive adequate attention.⁵⁵ I thought of Mohrmann’s words recently as I watched the situation of a very young infant whose cardiac surgery had been complicated by an anatomical difference that had gone undetected pre-operatively. Complications after surgery unfortunately led to the need for extensive resuscitation measures, including several days on the most sophisticated life support technology, ECMO (extracorporeal membrane oxygenation). Testing after this event tragically revealed that the baby boy had suffered irreversible brain damage to every area of his brain except for some minimal brainstem activity. As his body and his brain atrophied over the coming weeks, the attending physicians that rotated through his care recommended withdrawal of life-sustaining therapies but honored his parents’ wishes to continue aggressive treatment. His parents and extended family were steadfast in believing that God would heal their baby, and made it extremely clear that under no circumstances would they consent to allow their son to die.

Along with many other staff, I grew distressed at the baby’s condition, the seemingly futile interventions being done to him, and the specter of litigation that seemed to prevent any physician from curtailing the situation. I had a strong rapport of trust with the baby’s parents yet

⁵⁴ Mohrmann, Margaret E. “On Being True to Form.” In *Health and Human Flourishing: Religion, Medicine, and Moral Anthropology*, edited by Carol Taylor and Roberto Dell’Oro. Washington, D.C: Georgetown University Press, 2006, 90.

⁵⁵ Unless otherwise specified, “children” in this project refers to minors; thus, children and adolescents ages 18 and under.

felt at an impasse. I and many others felt that the baby was suffering on some level, even if he couldn't cognitively register pain or discomfort. But the parents felt that he wasn't suffering because "God would step in if he were suffering." They awaited what they believed would be a clear sign from God—either the child's miraculous healing or his death, the latter of which they felt would only be a clear sign from God if it occurred despite heroic lifesaving efforts from the baby's medical caregivers. The prospect of allowing the child to die from the biological sequelae of his injuries was unconscionable to this couple, and the mother repeatedly expressed her belief that to discontinue life support would be "taking a life" and equivalent to abortion.

In one of the many instances where a code blue was called, summoning a dozen staff to the baby's bedside to resuscitate him, I gently asked the parents if they were sure they wanted the efforts to proceed, especially as they had been reminded that chest compressions during CPR could break his sternum or ribs and that reinserting the repeatedly dislodged breathing tube in his mouth could cause bleeding in his airway. I tried once again to convey that it was permissible for them to ask the resuscitative efforts to be stopped. They indicated they wanted the staff to continue. The baby did finally succumb to death when yet another resuscitation effort became unsuccessful. I continue to wrestle with this baby's story, as I find it illustrative of the shortcomings of principlist ethics when it comes to pediatric patients. For better or worse, the parents were within their rights to assert the choices they did, and although the medical team struggled with those choices, they did not see any benefit to the patient or to the parents in overriding them, especially because doing so might have caused profound distress to the family or created legal or media havoc. At the same time, they saw no benefit to the patient in continuing their extensive medical interventions. Many staff tried to find consolation in the low likelihood that the baby could experience any physical pain or discomfort. Trying even to follow

a principle of avoiding harm to this patient felt like an unattainable theoretical reach, and determining whether decisions were made in his best interests (or even what those interests consisted of) seemed subjective and elusive. A more capacious bioethics is needed in order to respond to the complexities of such patients, and a better understanding of children in the clinical realm will bolster the efficacy of such advances.

Against the backdrop of the overall development of the field of bioethics in the past few decades, this chapter traces the emergence of what is commonly referred to as the principlist model of bioethics. I consider the place of respect for autonomy within that model, then explore the best interests standard as the pediatric decision-making model which stems from the emphasis on autonomy in the principlist model. Subsequently, I describe what I see as problematic implications for children that arise from this model.

In the larger arc of this project, this chapter serves to illustrate that the current dominant medical ethics stance sorely lacks a more robust appreciation for the kind of people that children are and for their experiences in the health care system. This stance also obscures the particular features of their lives that ought to have more import on how they are regarded. Hence, this chapter lays groundwork for the ways in which pastoral theology and childhood studies can inform a theological anthropology of hospitalized children in which vulnerability, dependence, and agency are better appreciated as significant moral features of hospitalized children's lives.

The birth of bioethics and the emergence of the principlist model

In response to egregious abuses of human subjects in biomedical research, in such cases as the Nazi concentration camps of World War II and the Tuskegee syphilis study in the United States beginning in the 1930s, the US government articulated guidelines for research, focusing

on the ethical recruitment of research subjects, obtaining informed consent, and protecting subject who were at greater risk of harm.⁵⁶ These guidelines are described in the 1979 Belmont Report, which was produced by the United States' National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research and adopted as a policy document of the US Department of Health, Education, and Welfare. The document was modeled after other codes, such as the Nuremberg Code, that had emerged in response to unethical human experimentation. In focusing on the three ethical principles consisting of respect for persons, beneficence, and justice, the Belmont Report exerted great influence on the subsequent development of the field of bioethics and the weight of the principlist approach.

The Belmont report's first principle states that "Respect for Persons" consists of two distinct moral requirements: "the requirement to acknowledge autonomy and the requirement to protect those with diminished autonomy."⁵⁷ The Belmont Report defines an autonomous person as "an individual capable of deliberation about personal goals and of acting under the direction of such deliberation" and asserts that "to respect autonomy is to give weight to autonomous persons' considered opinions and choices while refraining from obstructing their actions unless they are clearly detrimental to others."⁵⁸ It acknowledges that self-determination is a capacity that matures over the course of the lifespan and one that can be lost due to illness or disability,

⁵⁶ At least seventy projects involving medical research and "cruel and often lethal experimentation on human subjects" were carried out in the Nazi concentration camps between 1939 and 1946. See "Medical Experiments," United States Holocaust Memorial Museum. Accessed July 17, 2019.

<https://www.ushmm.org/collections/bibliography/medical-experiments>.

The "Tuskegee Study of Untreated Syphilis in the Negro Male" began in 1932 and lasted forty years. Not only were subjects enrolled without informed consent, those affected by syphilis were not given treatment even after penicillin was found to be effective. See "Tuskegee Study - Timeline," The Centers for Disease Control and Prevention,

<https://www.cdc.gov/tuskegee/timeline.htm>. Accessed July 17, 2019.

⁵⁷ The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. "The Belmont Report," 1979. <http://www.hhs.gov/ohrp/humansubjects/guidance/belmont.html>.

⁵⁸ "The Belmont Report."

and also that competing claims for liberty and protection can often be a challenging aspect of respect for autonomy.

The Belmont Report makes an important distinction between research and practice, one which ought to be stressed more frequently in bioethics given how extensively its research-oriented imperatives have been adopted as sufficient for the realm of clinical practice despite significant differences in the way research and clinical practice differ in their aims and potential benefits. In its research focus, the Report states that it aims to go beyond setting forth the kinds of specific rules seen in the Nuremberg Code and instead to articulate broad ethical principles that can be “comprehensive” in the sense of providing researchers and subjects with the ethical norms inherent in human subjects research. The Report thus seeks “to provide an analytical framework that will guide the resolution of ethical problems arising from research involving human subjects.”⁵⁹ While the Report attempts to distinguish the sometimes-murky boundaries between research and practice, it does not discuss whether or how the ethical principles ought to relate to clinical practice. In general, the Report defines practice as “interventions that are designed solely to enhance the well-being of an individual patient or client and that have a reasonable expectation of success” whose purpose is “to provide diagnosis, preventive treatment or therapy.”⁶⁰ Research, by contrast, is usually “described in a formal protocol” and is “designed to test an hypothesis, permit conclusions to be drawn, and thereby to develop or contribute to generalizable knowledge.”⁶¹ Although the Report makes an effort to call for review in cases where practice tends toward the experimental to an extent that is more characteristic of research, it does not offer guidelines for applying the principles to matters of everyday practice.

⁵⁹ “The Belmont Report.”

⁶⁰ “The Belmont Report.”

⁶¹ “The Belmont Report.”

This omission remains significant given the contrast between research and clinical practice and the enduring use of principlist approaches in both settings. Conceiving of respect for autonomy as a way to ensure that a research subject has given informed consent in order to contribute data towards an aggregate outcome that may or may not yield any personal benefit is a very different matter than trying to ensure respect for a specific hospitalized patient's autonomy and all the very personal outcomes immediately at stake. Such a critical foray into the salient distinctions between research and practice may have been beyond the scope of the Belmont Report, yet the question remains: what gets overlooked when principles for ethical research with human subjects get applied to the general practice of medicine? A consideration of what the Belmont Report would have added, were it to have addressed the implementation of the principles for practice, should be an important feature of any assessment of the usefulness and fit of the principlist approach to clinical ethics.⁶² While the principles may be relevant and useful to a certain extent in the clinical setting, it is woefully insufficient to assume that they provide comprehensive guidance for idiosyncratic clinical scenarios that sharply contrast with the standardized format of most research endeavors.

This limitation is particularly significant for pediatrics, I would assert, because there are many treatment protocols for infants and children which are novel enough that they are experimental for quite some time; that is, the distinction between therapeutic treatment and experimentation is often very difficult to make. Indeed, in a case-based pediatric ethics textbook, pediatric bioethicist John Lantos notes that in a sense, everything in pediatrics is experimental, and acknowledges how “innovation without careful study has been the norm in much of

⁶² I am grateful to Larry Churchill for pointing out this feature of the Belmont Report and raising the question of whether clinical ethics has generally adopted research ethics wholesale without such an examination.

pediatrics.”⁶³ This gray area creates difficulties in weighing the relative importance of proposed treatments for individual patients in the midst of the benefits that may result for future patients based on knowledge gained, especially when desperate parents are willing to try just about anything for their seriously ill child. I have met many parents who sign on to—or insist on—interventions and therapies that have very low likelihood of benefit and high likelihood of great burdens for their own child. Their reasoning for this is typically an understandable desire to try absolutely anything that might save their child’s life, and a willingness to expose their child to potential suffering in hopes that the benefits might outweigh the burdens, if not ultimately for their own child then perhaps for other children who might reap future benefits of treatments that move from experimental to established status. In these situations, pediatric providers must weigh the benefits and burdens of withholding or offering such treatment to desperate parents and patients. Certainly, the various incentives of innovation may make it easier for a clinician who is eager to make new advances to acquiesce to parental requests even when an intervention might not be medically prudent. Because new technologies continue to create interventions for treating life-limiting diseases and conditions in childhood, pediatric patients are often unwitting pioneers on the frontier of medical innovation, and their parents as surrogate decision makers face high degrees of uncertainty and unprecedented outcomes. The ethical significance of medical innovation is felt across the lifespan, to be sure, but one can imagine that the weight of it may rest differently on an adult patient considering a novel, experimental treatment for him- or herself, as opposed to parents acting as decision makers confronted with options for their child that may range from well-established to completely experimental, any of which comes with

⁶³ Lantos, John D. “The Introduction of Innovative Technology into Practice.” In *Clinical Ethics in Pediatrics: a Case-Based Textbook*, edited by Douglas S. Diekema, Mark R. Mercurio, and Mary B. Adam, 186–93. Cambridge: Cambridge University Press, 2011, 189.

complicated deliberation when chosen on behalf of a patient who is one's own child and whose values and preferences have yet to materialize and be articulated.

The principlist model's rise to prominence

The Belmont Report carried significant weight for bioethics and paved the way for new articulations of ethical principles. It emerged at a time when bioethics literature was ripe for gravitating toward this kind of organized approach set forth by authoritative voices endorsed at the federal level. The Belmont report's approach offered what appeared to be a cohesive and thorough approach for addressing the most concerning bioethics issues of the time, namely, promoting and protecting informed consent in relation to experimentation. As insightful and applicable as the model was, its rise to prominence in bioethics was not due to demonstrated superiority over other models but instead emerged from a combination of social and political factors that effectively made it the only viable option.

Sociologist John Evans describes how the principles developed into the widely accepted parameters of argumentation in public bioethical debates.⁶⁴ He writes,

The institutionalization of the Belmont principles was due to several converging events. The most important was acceptance of the [National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research]'s advice, when the Department of Health, Education, and Welfare made the Belmont Report public law governing the research activities of federally funded scientists. This meant that every IRB [Institutional Review Board] at an institution that received federal money had to apply these principles. Since journals refuse to publish results from research not reviewed by IRBs, the principles became the standard not only for federally funded research, but for privately sponsored research as well. This was a huge resource given to the new profession of bioethics in its competition with other professions: the government was essentially requiring researchers at every research university and hospital in the nation to learn its form of argumentation.⁶⁵

⁶⁴ Evans, John Hyde. *Playing God?: Human Genetic Engineering and the Rationalization of Public Bioethical Debate*. Chicago: University of Chicago Press, 2002, 88-89.

⁶⁵ Evans, *Playing God?*, 88-89.

Along with this financial incentive for both government-funded and private researchers to adopt the principles in order to retain eligibility for federal money, there was also the reality that the principles were the most comprehensive approach to bioethics because of how extensively they were articulated in *Principles of Biomedical Ethics*.⁶⁶ Evans remarks that the widespread adoption of the principles quickly expanded beyond research ethics to include many other topics in science, medicine, and society, such as abortion, medical rationing, and euthanasia. He notes, “Once the form of argumentation of bioethics had been enshrined in public law for human experimentation, and embodied in a popular textbook, it began to spread rapidly.”⁶⁷ Consequently, demand grew for training in the principlist model, leading to a situation where, according to Evans, the principles “are all that the average bioethicist attends to.”⁶⁸ With these larger historical and economic factors influencing the prominence of principlist bioethics in mind, I turn now to a discussion of the word that has loomed large in the vernacular of medical ethics ever since: autonomy.

Autonomy in the principlist model

The etymology of what is cursorily often referred to as autonomy in bioethics is itself noteworthy. As Catholic bioethicist M. Therese Lysaught highlights, the principle of “respect for persons” was established by the mid-1970s as a central theme of the emerging field of bioethics.⁶⁹ Such respect was the footing on which informed consent rested, and on which safeguards for protection were established. Lysaught traces the shifts in nomenclature that later

⁶⁶ Beauchamp, Tom L, and James F Childress. *Principles of Biomedical Ethics*. First edition. New York: Oxford University Press, 1979.

⁶⁷ Evans, *Playing God?*, 90.

⁶⁸ Evans, *Playing God?*, 91.

⁶⁹ Lysaught, M. Therese. “Respect: Or, How Respect for Persons Became Respect for Autonomy.” *Journal of Medicine & Philosophy* 29, no. 6 (December 2004), 671.

evolved with the Belmont Report and subsequently with the *Principles of Biomedical Ethics*. The Belmont report, she notes, used the term “respect for persons,” while the *Principles* described a principle of “respect for autonomy” of which respect for persons is one aspect.⁷⁰ She critiques this move as reductionist, summarizing:

Thus, although for Beauchamp and Childress the principle of autonomy appeared to map the same ground as the principle of respect for persons, they introduced three key changes. First, as both the name of the principle and their discussion noted, it is not persons as such but autonomy that is to be respected. . . . Second, and somewhat tautologically, the world of persons is delimited to those who are autonomous. The principle of autonomy, by definition, applies only to the autonomous.⁷¹

Lysaught identifies a third change in that respect for autonomy calls for non-interference and an obligation not to constrain autonomy, which she feels lacks the fulness of what respect for persons entailed.

The enshrining of autonomy thus coincides with the first edition of *Principles of Biomedical Ethics*, published in 1979 by bioethicists Tom Beauchamp and James Childress. Their focus on the four principles of respect for autonomy, nonmaleficence, beneficence, and justice has evolved over several editions of the book. In the preface to the sixth edition (2009) they acknowledge critiques of their model, including the critique that their focus on autonomy overrides other moral considerations and reflects a distinctly American bias.⁷² They contend, however, that “In a properly structured theory, respect for autonomy is not an excessively individualistic, absolutistic, or overriding notion that emphasizes individual rights to the neglect or exclusion of social responsibilities.”⁷³ They further assert that autonomy’s order in the listing of principles does not set it first in priority among the four principles.

⁷⁰ Lysaught, “Respect: Or, How Respect for Persons Became Respect for Autonomy,” 675.

⁷¹ Lysaught, “Respect: Or, How Respect for Persons Became Respect for Autonomy,” 675-76.

⁷² Beauchamp, Tom L, and James F Childress. *Principles of Biomedical Ethics*. 6th ed. New York: Oxford University Press, 2009, viii.

⁷³ Beauchamp and Childress, *Principles of Biomedical Ethics*, 6th ed., viii.

Beauchamp and Childress establish the following definition of autonomy:

Personal autonomy encompasses, at a minimum, self-rule that is free from both controlling interference by others and from certain limitations such as an inadequate understanding that prevents meaningful choice. The autonomous individual acts freely in accordance with a self-chosen plan... A person of diminished autonomy, by contrast, is in some respect controlled by others or incapable of deliberating or acting on the basis of his or her desires and plans.⁷⁴

Perhaps because of their critics who have lamented the “triumph of autonomy” in medical ethics, Beauchamp and Childress choose not to focus on the traits and abilities of autonomous *persons*, but instead to describe the features and protections of autonomous *choice*.⁷⁵ Autonomous choice is characterized by choosers who act 1) intentionally, 2) with understanding, and 3) without controlling influences that determine their action.⁷⁶ They acknowledge that the ideal of complete freedom from outside influence may be unattainable in reality, but emphasize the preservation of autonomous choice as a professional obligation prompted by the patient’s right, not duty, of autonomous choice.⁷⁷

Moreover, say Beauchamp and Childress, respect for autonomy and autonomous choice must be regarded as both a negative and a positive obligation; that is, negative in the sense of being free from constraint, and positive in the sense of fostering autonomous decision making through providing adequate disclosure of information and ensuring voluntariness.⁷⁸ To some degree these obligations reflect the influences of John Stuart Mill and Immanuel Kant, respectively. Mill, a nineteenth-century British philosopher, was focused on protecting persons

⁷⁴ Beauchamp and Childress, *Principles of Biomedical Ethics*, 6th ed., 99.

⁷⁵ Beauchamp and Childress, *Principles of Biomedical Ethics*, 6th ed., 100, 105. While the first section of the chapter on autonomy in the first edition (1979) is “The autonomous person,” by the sixth edition Beauchamp and Childress are careful to note their emphasis on decision making which leads them to “concentrate on *autonomous choice* rather than on general capacities for governance and self-management,” (100, emphasis in original).

⁷⁶ Beauchamp and Childress, *Principles of Biomedical Ethics*, 6th ed., 101.

⁷⁷ Beauchamp and Childress, *Principles of Biomedical Ethics*, 6th ed., 107.

⁷⁸ Beauchamp and Childress, *Principles of Biomedical Ethics*, 6th ed., 104.

from outside interference with individual liberty. Kant, an eighteenth-century German philosopher, emphasized the importance of treating persons as inherently worthy and thus as ends, not means to an end, so as to foster their fullest capacities and abilities.⁷⁹ Both reflect Western modern ideals of Enlightenment thinking that continue to shape bioethics by underscoring human freedom and rights. However, they also reflect a lack of attunement to human diversity, especially developmental and cultural diversity, which has contributed to entrenching dominant bioethics discourse in a problematic pattern of narrowly-conceived normative visions of who constitutes “persons” in research and practice.

Surrogate decision-making

The principlist articulation of autonomy serves to scaffold the definition of informed consent, in which autonomous choice is expressed by a patient or surrogate decision maker. Beauchamp and Childress note that in the few decades since informed consent began receiving attention, emphasis has shifted from the physician’s obligation to disclose information toward a focus on the patient’s capacity to understand and consent voluntarily.⁸⁰ Capacity and competence, related concepts in medical settings and legal decisions, are used to describe the ability of a patient to make an autonomous choice as defined above. For those patients who are seen as lacking capacity for whatever reason, whether temporarily or permanently, surrogate decision makers are relied upon to make choices on the patient’s behalf. As the authors put it, “Surrogate decision makers are authorized to reach decisions for doubtfully autonomous or nonautonomous patients.”⁸¹ Building on the framework of autonomy as they define it,

⁷⁹ Beauchamp and Childress, *Principles of Biomedical Ethics*, 6th ed., 103.

⁸⁰ Beauchamp and Childress, *Principles of Biomedical Ethics*, 6th ed., 118.

⁸¹ Beauchamp and Childress, *Principles of Biomedical Ethics*, 6th ed., 135.

Beauchamp and Childress describe substituted judgment, precedent autonomy, and best interests as three guidance models for surrogate decision making, each of which is invoked based on an assessment of whether and to what degree the patient has previously expressed his or her own wishes regarding healthcare decisions. Their ordering of the three reflects their assessment of optimal choices. That is, the second and third options are meant to be used when the patient's condition renders the first option untenable. Here I briefly describe each of these in order to highlight the distinct features of the third model, the best interests standard, which is the guidance model for surrogate decision makers in pediatric settings.

Substituted judgment

Substituted judgment, the first model of surrogate decision making, is meant to be put in place when a decision maker is reasonably able to make a judgment in the way the patient would have made it. This assumes that “the surrogate should have such a deep and relevant familiarity with the patient that the particular judgment made reflects the patient's views and values.”⁸² Beauchamp and Childress admit the limitations of this view, noting the importance of making a decision that the patient himself or herself would want, not a decision that the *surrogate* wants for the patient. Moreover, substituted judgment is not meant to be used in cases where patients have never been competent autonomous decision makers, since such patients provide no basis on which surrogate decision makers could infer the patient's preferences. Thus, it is not intended to apply in cases where the patient is a child.

⁸² Beauchamp and Childress, *Principles of Biomedical Ethics*, 6th ed., 137.

Precedent autonomy

The second model of surrogate decision making is called precedent or pure autonomy, and it relies on a patient having previously expressed an autonomous choice or preference which then forms the basis of the surrogate decision maker's deliberation. Unlike substituted judgment, which Beauchamp and Childress claim is a weak standard of preserving autonomy, the precedent autonomy model rests on what a patient has actually expressed, not on a preference expressed by a surrogate who has tried to don the "mental mantle" of the patient.⁸³ The challenges that arise in the precedent autonomy model, however, often relate to whether the decision at hand is still subject to the patient's previously expressed preferences. It can be difficult to provide evidence that the patient's choice would be consistent under a new set of circumstances, and a surrogate may be biased toward particular values the patient held, regardless of their immediate relevance to the new choice.⁸⁴

The best interests standard

The third model of surrogate decision making is the best interests standard, in which the surrogate must attempt to make a decision that maximizes benefit to the patient by assessing the benefit among the available options and the patient's interests in each one, and subtracting the attendant risks and costs of each option. This model, say Beauchamp and Childress, is used when quality of life is a key consideration and when a previously autonomous patient's preferences may not adequately have addressed the future circumstances that now render the patient in worse, or perhaps better, condition than they anticipated when previously expressing their

⁸³ Beauchamp and Childress, *Principles of Biomedical Ethics*, 6th ed., 136-137.

⁸⁴ Beauchamp and Childress, *Principles of Biomedical Ethics*, 6th ed., 138.

wishes.⁸⁵ As with their discussion of the first two models, Beauchamp and Childress focus largely on those circumstances in which a previously competent person made decisions, such as writing an advance directive, which are meant to be carried out by a surrogate. Beauchamp and Childress contend that the principle of respect for autonomy undergirds the first and second models of decision making, both of which essentially carry equal weight in cases where preferences have been expressed. This leaves the third model, the best interests standard, as a less preferable option to be used when “the previously competent person left no reliable traces of his or her preferences.”⁸⁶ Using the description of a patient who once was competent to make medical decisions, but is no longer, Beauchamp and Childress predicate the best interests model on assumptions about idealized autonomous decision making capacity.

I turn now to an evaluation of the problems that arise from this stance. Because the three models of surrogate decision making have been established as a hierarchy that bioethicist Daniel Sulmasy notes is “canonical” in bioethics textbooks and professional codes, and because the third model is already the least preferable choice yet the most applicable to children, the starting point for this approach to pediatric ethics is already fraught with limitations and deserves careful analysis.⁸⁷

Models for pediatric decision making

The best interests standard has serious limitations as a model for surrogate decision making with pediatric patients that deserve further explanation. It is telling that Beauchamp and

⁸⁵ Beauchamp and Childress, *Principles of Biomedical Ethics*, 6th ed., 139.

⁸⁶ Beauchamp and Childress, *Principles of Biomedical Ethics*, 6th ed., 140.

⁸⁷ Sulmasy, Daniel P. “Research in Medical Ethics: Scholarship in ‘Substituted Judgment.’” In *Methods in Medical Ethics*, edited by Jeremy Sugarman and Daniel P. Sulmasy, Second edition. Georgetown University Press, 2010, 299.

Childress hardly mention minors in their discussion of surrogate decision making, despite the fact that surrogate decision-making is the standard, not the exception, when it comes to medical decisions for minors. The adult-centric nature of the principlist model is abundantly evident here, in that surrogate decision making is situated as an exception to a norm in which persons are presumed to be capable of autonomous choice. In contrast, children are an entire population of patients whose need for surrogate decision makers is presumed from the start, and yet the decision-making model best suited to them is the one of last resort in the overall hierarchy of surrogate decision-making models. Beauchamp and Childress end their section on surrogate decision making with the assertion that “If the previously competent person left no reliable traces of his or her preferences, surrogate decision makers should adhere only to the best interests standard,”⁸⁸ thus underscoring their envisioned use of the best interests standard for those “previously competent” rather than registering it as central to the multitudes of minors for whom such baseline competence has not yet emerged.

Beauchamp and Childress thus continuously envision the adult patient when discussing issues such as respect for autonomy. This presumption is certainly not unique to their text but is commonly present in medical ethics literature wherever surrogate decision-making is cast primarily as a second order option to be employed when the patient’s previous level of capacity is temporarily or permanently compromised. These scenarios contrast markedly from the routine scenarios with pediatric patients where capacity is lacking not because it has been lost temporarily or permanently but because it is still emerging. Whether or not Beauchamp and Childress intentionally left out a greater discussion of how pediatric surrogate decision-making

⁸⁸ Beauchamp and Childress, *Principles of Biomedical Ethics*, 6th ed., 140.

takes place, the absence of such a discussion further underscores the degree to which their model is predicated on adult patients.

Given the adult premises of surrogate decision-making guidelines in general, it is not surprising that attempts to apply the best interests standard in decision making for children have met with difficulty. As I discuss below, some writers such as bioethicists and philosophers Allen Buchanan and Dan Brock maintain that it is the most fitting model of surrogate decision making for children. Others, such as physician and pediatric ethicist Douglas Diekema, contend that the best interests model is so fraught with problems that it ought to be replaced by a different standard altogether. I explore this debate to show how the best interests standard is commonly understood and how it has created problems and received important critique in pediatric ethics.

Buchanan and Brock: the best interests standard

In their book *Deciding for Others: The Ethics of Surrogate Decision Making*, Buchanan and Brock attempt to provide a more systematic treatment of decision making for incompetent patients, noting that until their own contribution to the literature, bioethicists had been preoccupied with justifying and articulating the right of self-determination of competent patients.⁸⁹ In this way, they build on the work of Beauchamp and Childress, seeking to flesh out the principlist surrogate models by offering both a theoretical framework and extensive application to the needs of three classes of incompetent patients: the elderly, minors, and psychiatric patients. Their discussion of the best interests standard as applied to minors is representative of the ways in which the best interest standard has animated pediatric clinical

⁸⁹ Buchanan, Allen E, and Dan W Brock. *Deciding for Others: The Ethics of Surrogate Decision Making*. Cambridge, U.K.; New York: Cambridge University Press, 1989, xi.

ethics, as evidenced by the ongoing reference to their work in other pediatric ethics literature.⁹⁰ Therefore, in light of this project's goal of enhancing pediatric ethics with a theological anthropology, it is important here to lay out the features of how minor children are portrayed in the larger realm of medical decision making. Doing so helps to illustrate the operative assumptions and limitations concerning pediatric patients.

Buchanan and Brock's intent is to explore minors' ability to participate in treatment; their interest is not geared toward participation in research. Noting that the doctrine of informed consent includes the legal presumption that minors are not competent to make their own medical decisions, Buchanan and Brock parse out the factors that can nonetheless influence case-by-case determinations of minors' capacity to consent to or refuse medical treatment. Drawing such a non-arbitrary threshold is difficult, they admit, but they draw on dominant developmental psychology models such as Jean Piaget's stage theory of cognitive development in order to explore the weight of a child's emerging ability to reason, to articulate a vision of the good for one's life, and to experience an internal locus of control.⁹¹

Buchanan and Brock describe three types of interests that are at stake for minors. The first two interests, well-being and self-determination, are shared by patients of any age, but carry less weight with children. Well-being, they explain, is usually determined by settled aims and values, as with adults; in the case of children, well-being is predicated "less on their current individual preferences and more on the objective conditions necessary to foster their development and opportunities."⁹² Involving children in their own care can foster greater compliance with medical treatment, they remark, and in this way the child's present preferences

⁹⁰ See for example Ross, Lainie Friedman. "Theory and Practice of Pediatric Bioethics." *Perspectives in Biology and Medicine* 58, no. 3 (2016): 267–80.

⁹¹ Buchanan and Brock, *Deciding for Others*, 219-223.

⁹² Buchanan and Brock, *Deciding for Others*, 228.

can align with the future interest in well-being.⁹³ Self-determination, the second type of interest, also has a weaker basis with children than with adults, say Buchanan and Brock. Self-determination “involves the capacities to form, revise over time, and pursue a plan of life or conception of the good,” they note, and although such plans may have biological or environmental limitations, “[i]t is through the ongoing exercise of the capacity for self-determination that persons become and are active as responsible agents, shaping their lives and controlling their destinies.”⁹⁴ Brock and Buchanan take care to note that the self-determination interests of children are found more squarely in children’s future interests in developing the capacities to become self-determining adults, rather than in their present interests in making self-determined decisions.⁹⁵ Self-determination is thus best understood as a future interest for children.

The third interest at stake, say Buchanan and Brock, is particular to pediatrics and is vital regardless of the extent to which a child is competent to provide consent. This third value is the interests of the parent, meaning the parent’s prerogative in protecting the welfare of the child according to the parent’s values and standards. This interest might more frequently give rise to overriding a child’s expressed preferences, say Buchanan and Brock, more so than an adult’s preferences might be overridden by another adult decision maker.⁹⁶ This rationale is based on the belief that the parent is ordinarily best suited and more concerned to protect the child’s interests than any other party. Of course, a parent’s right to make decisions is not absolute, and many ethical dilemmas are characterized by disagreement over whether parents or health care

⁹³ Buchanan and Brock, *Deciding for Others*, 229.

⁹⁴ Buchanan and Brock, *Deciding for Others*, 229-230.

⁹⁵ Buchanan and Brock, *Deciding for Others*, 231.

⁹⁶ Buchanan and Brock, *Deciding for Others*, 233.

professionals are advocating for a child's best interests. Buchanan and Brock rightly point out a few limitations of the best interests standard in order to clarify their position. They assert that the best interests standard only applies in cases where an infant or child has "morally considerable interests;" this might rule out infants who are born without a brain, for example, and who have no potential for improvement or survival.

The best interests standard also does not mean that parental failure to fully optimize the benefits to the child should merit immediate intervention by a third party, or even prompt a challenge to the parents' decision.⁹⁷ By this assertion, Buchanan and Brock indicate that the best interests standard is intended to be a guide, not a set of criteria for identifying one permissible or obligatory option. Because of the factors of parents' own interests and their interests related to their other children, there may be ample leeway for the parents to make a decision that does not fully optimize the isolated interests of the ill child.

The specific considerations of these issues in cases involving newborns bear similarities to cases with older children, but with some significant differences, say Buchanan and Brock. Because the gradual acquisition of competence to make decisions is not yet underway in infancy, the infants' interests in developing the capacities necessary to exercise agency and preferences are even more future-oriented. The interests lie with future states of affairs, but are nonetheless present in infancy along with the infant's current interests related to pleasure, pain and discomfort.⁹⁸ In contrast to theories which hold that a subject can only possess an interest in the future if she can picture herself in that future state, Buchanan and Brock maintain that infants nonetheless possess future interests. Moreover, they are careful to note that future interests

⁹⁷ Buchanan and Brock, *Deciding for Others*, 235-236.

⁹⁸ Buchanan and Brock, *Deciding for Others*, 248.

should not override present interests as they relate to the infant's current pain and suffering. The danger of considerations of suffering being overridden by therapeutic goals is a real concern, they note, citing the dearth of scientific understandings about infants' capacity to feel pain and the longstanding history of procedures that were done on infants without anesthesia.⁹⁹

Buchanan and Brock spell out two critical conditions that operate in the midst of decisions made for infants. These conditions are most fully articulated by formal decision theory, which says that uncertainty and risk are the two conditions of ignorance in the face of decisions. Risk is involved when the decision maker can identify the potential consequences and their probabilities and make a decision that attempts to maximize benefits over harms. Uncertainty, however, entails a greater level of ignorance. When there are no probabilities to weigh but only a very unclear range of outcomes, the decision maker may be drawn in various directions based on something other than a principle that can reasonably maximize benefit. Furthermore, even in situations where risks are identifiable and uncertainty is minimized, decision makers may make vastly different choices as they try to decide not on what they would choose for themselves but on what they would choose for another. Buchanan and Brock note how challenging this is, admitting that the "element of subjectivity is therefore irreducible. No advances in prognostic skills, physiology, or even in individual psychology can be expected to eliminate it."¹⁰⁰ They stress the importance of establishing institutional practices and resources that can safeguard against the tendency to overtreat and to underappreciate pain and suffering.¹⁰¹ At the same time, undertreatment can be a dangerous option in cases where parents' interests are being elevated at the expense of the infant's. For instance, regarding the Baby Doe case in the 1980s in which

⁹⁹ Buchanan and Brock, *Deciding for Others*, 250. I discuss this history further in chapter 3.

¹⁰⁰ Buchanan and Brock, *Deciding for Others*, 252.

¹⁰¹ Buchanan and Brock, *Deciding for Others*, 257.

parents refused surgical intervention for their infant with Down Syndrome, resulting in the child's death, Buchanan and Brock remark on the crucial difference between the parents' right to terminate their parental responsibilities and their right, or what ought to have been a lack thereof, to disregard the child's fundamental interests.¹⁰²

Buchanan and Brock reveal the complexities of fitting the ideals of the best interests standard to the myriad realities of minor patients, who vary widely in their developmental situatedness and related capabilities. Their work goes to great and detailed lengths in order to articulate the application of the best interests standard among diverse subpopulations of minors, from newborns to adolescents. In my view, this further underscores the adult premises of the origins of the best interests standard, for surely a decision-making model built from the ground up on the nuanced and ever-changing capacities of minors would result in a more nimble approach. Such efforts are discernible in the approaches described below.

Diekema: the harm principle

Building on Buchanan and Brock's treatment of the best interests standard, physician and pediatric ethicist Douglas Diekema suggests that the best interests standard is not only insufficient for parental decision making, but that it is also not reflective of the actual practice carried out by medical professionals or the legal system. Diekema claims that the best interests standard is actually a misnomer because of how it is actually practiced. He describes, for instance, the way bioethicist Loretta Kopelman defends the merits of the best interests standard and argues that she is actually describing something other than a best interests model.¹⁰³

¹⁰² Buchanan and Brock, *Deciding for Others*, 260.

¹⁰³ See Kopelman, Loretta M. "The Best-Interests Standard as Threshold, Ideal, and Standard of Reasonableness." *Journal of Medicine and Philosophy* 22, no. 3 (June 1, 1997): 271–89.

Kopelman holds that the best interests standard, as used in clinical and legal settings, serves to establish a “threshold for intervention and judgment” as well as a means of setting policy and articulating a “standard of reasonableness.”¹⁰⁴ In response, Diekema asserts that such merits still do not function as a guideline for actually articulating a child’s best interests; he thus echoes Kopelman in valuing a decision-making model that sets a threshold for intervention but insists on more specific nomenclature. Diekema proposes that what he calls the “harm principle” ought to serve as the threshold for invoking third party intervention in cases where parental decision making is questioned.¹⁰⁵ He writes, “The real question is not so much about identifying which medical alternative represents the best interest of the child, but rather about identifying a harm threshold below which parental decisions will not be tolerated.”¹⁰⁶ Diekema summarizes this approach, noting that

The harm principle provides a foundation for interfering with parental freedom that more accurately describes an appropriate standard for interfering with parents who refuse to consent to medical treatment on behalf of a child. State intervention is justified not when a parental refusal is contrary to a child's best interest, but when the parental refusal places the child at significant risk of serious preventable harm.¹⁰⁷

Diekema does reiterate the important place of parents and that informed consent is crucial; without it, treatment is battery.¹⁰⁸ Thus, for patients such as children who are not assumed to be able to provide informed consent, the right to accept or refuse treatment must be exercised on their behalf. Diekema concurs that there are several reasons why it makes sense to defer to parents’ preferences in decision making for children – parents are generally best suited to weigh the potentially competing interests among family members and ought to have ample

¹⁰⁴ Kopelman, “The Best-Interests Standard as Threshold, Ideal, and Standard of Reasonableness,” 271.

¹⁰⁵ Diekema, Douglas. “Parental Refusals of Medical Treatment: The Harm Principle as Threshold for State Intervention.” *Theoretical Medicine and Bioethics* 25, no. 4 (2004): 243–264.

¹⁰⁶ Diekema, “Parental Refusals of Medical Treatment,” 249.

¹⁰⁷ Diekema, “Parental Refusals of Medical Treatment,” 258.

¹⁰⁸ Diekema, “Parental Refusals of Medical Treatment,” 243.

freedom from outside intrusion in order to raise their children according to their own standards and values.¹⁰⁹ In cases where parental decisions would place a child's health or life in jeopardy, however, the state's power to act as a surrogate is often invoked.

Diekema's take on the best interests standards echoes the rationale that Buchanan and Brock also assert, but he offers a fourfold critique of the best interests standard as he builds his case for a harm-based intervention approach instead. He argues that the best interests standard is not ultimately suited to help decide whether and when state authority should override parental authority. First, he notes that best interests can be quite difficult to define. Secondly, he argues that the concept of best interests is inherently a question of values; most parents believe they are making decisions in the best interests of their child, so the conflict that arises lies in the tension between the parents' values about what is in their child's best interests and whatever the state or health care professionals believe is in the child's best interests. Thirdly, he asserts that interests are not only value laden but also complex, and that there can be an unfortunate tendency to reduce the child's interests to medical interests alone, thereby underappreciating interests that pertain to emotional, physical, and other aspects of undergoing treatment.

Finally, Diekema remarks that the best interests standard is not imposed on parents in other aspects of their children's lives—that is, in very few aspects of parenting and family life would the state mandate that parents make choices based singularly on harms and benefits to their children. He offers examples such as how the state does not mandate that parents provide a college education for their children even though it would be beneficial, nor does the state require parents to avoid driving because of the potential for harm inherent in doing so. Requiring parents to always act in a way that optimizes benefit for their children, to the exclusion of other values

¹⁰⁹ Diekema, "Parental Refusals of Medical Treatment," 244.

and consideration of the interests of others, may not be realistic in healthcare decision-making either, says Diekema. Because the interests of children are neither unambiguous nor absolute, our decision-making guidance models need to account for the complexity and subjectivity therein.¹¹⁰

Diekema proposes that the harm principle is a more accommodating model than the best interests standard, and he believes that the model is already operative in practice because of how, currently, the courts generally give leeway for parental preference when the child's life is not imminently in danger but tend to give less discretion to parents when the child's life is imminently in jeopardy. To continue to appeal to a best interests standard, he writes, "simply confuses physicians and others who must determine when parental refusals of consent should be tolerated and when state intervention should be sought."¹¹¹ Diekema contends that the courts tend to override parents' wishes not simply when the best interests of the child fail to be optimized, but when the child is actually in danger of harm because of the parents' wishes.¹¹² That is, a range of options are often acceptable, regardless of whether they meet an idealized best interests standard; instead, it is when a threshold of harm is reached that state intervention is usually sought.

As for how to specify the harm threshold for limiting parental authority, Diekema suggests eight conditions for justifying state intervention when parents have refused medical treatment for their child. These include, for instance, "Is the harm imminent, requiring immediate action to prevent it?," "Is the intervention that has been refused of proven efficacy, and therefore, likely to prevent the harm?," and "Can the state intervention be generalized to all other similar

¹¹⁰ Diekema, "Parental Refusals of Medical Treatment," 246-248.

¹¹¹ Diekema, "Parental Refusals of Medical Treatment," 248.

¹¹² Diekema, "Parental Refusals of Medical Treatment," 249.

situations?”¹¹³ He offers a few illustrations of how those conditions are met in cases where intervention is typically favored.¹¹⁴ For instance, if parents in the Jehovah’s Witness tradition refuse to consent for a blood transfusion for their child, or if parents who practice Christian Science refuse to provide insulin to a child with diabetes, the threshold of harm is met on a number of counts, such as the fact that the treatment in question is of proven efficacy and the risk of harm is imminent. This is an important distinction especially when considering cases of parental refusal of treatments that are of doubtful or unproven efficacy, where “therapy itself poses grave risks or limited likelihood of success.”¹¹⁵ For instance, when oncologists might recommend that a child undergo a bone marrow transplant after other cancer therapies have been unsuccessful, state intervention is less likely if parents refuse on the basis of consideration for what may be marginal success rates and high likelihood of suffering and death. In these and other cases where treatment is less uniformly efficacious and carries significant burdens, greater acceptance of parent preference may prevail.

Overall, Diekema argues that the best interests standard as it is typically construed tends to further confusion and upholds an unattainable ideal. He advocates for the harm principle based on what he sees are the practices already in place when health care professionals and the courts try to navigate the need to preserve both parental liberties and child well-being. While the harm principle may be useful for establishing a threshold for intervention when parents or guardians refuse recommended medical care, it does not adequately explore a ceiling for the kind of limits in question when parents and providers may push for treatment whose benefits and burdens are ambiguous and render questions of best interests and harm very difficult to untangle.

¹¹³ Diekema, “Parental Refusals of Medical Treatment,” 252.

¹¹⁴ Diekema, “Parental Refusals of Medical Treatment,” 255.

¹¹⁵ Diekema, “Parental Refusals of Medical Treatment,” 257.

Miller: basic interests

Another modification to the best interests standard is articulated by religious ethicist Richard Miller in his book *Children, Ethics, and Modern Medicine*.¹¹⁶ Miller's book is a rare publication in that it is entirely focused on pediatric medical ethics; his work includes extensive case material drawn from several months of observational work in a children's hospital.¹¹⁷ Miller argues for using the concept of "basic interests" instead of best interests, precisely because of the way that a child's interests cannot be considered in a vacuum apart from the other duties and interests that parents and caregivers must consider.¹¹⁸ Thus, parents cannot be required to make decisions that are always in the child's best interests, but they can be required to decide in ways that uphold a child's basic interests. Intervention is justified when those basic interests are not met but not justified simply when best interests are not upheld. The impetus for Miller's position therefore seems closely aligned with Diekema's rationale for the harm principle.

The above description of the best interests standard, the harm principle, and the basic interests argument only scratches the surface of what could be discussed here regarding clinical ethics in pediatrics. However, although these concepts are not exhaustive, they are nonetheless representative of the approach generally taken with pediatric ethics, an approach rooted in the emphasis on autonomy in medical ethics. Questions of who may provide informed consent for a minor, and under what conditions, continue to hold deep importance, and rightly so to some extent. What has been underappreciated, however, is the extent to which this emphasis on

¹¹⁶ Miller, Richard B. *Children, Ethics, and Modern Medicine*. Bloomington, IN: Indiana University Press, 2003.

¹¹⁷ Other noteworthy pediatric-focused ethics texts include Diekema, Douglas S., Mark R. Mercurio, and Mary B. Adam, eds. *Clinical Ethics in Pediatrics: A Case-Based Textbook*. Cambridge: Cambridge University Press, 2011; Kodish, Eric, ed. *Ethics and Research with Children a Case-Based Approach*. Oxford; New York: Oxford University Press, 2005; and Frankel, Lorry R, Amnon Goldworth, Mary V. Rorty, and William A. Silverman, eds. *Ethical Dilemmas in Pediatrics Cases and Commentaries*. Cambridge: Cambridge Univ. Press, 2005.

¹¹⁸ Miller, *Children, Ethics, and Modern Medicine*, 121.

autonomous decision-making has eclipsed other important aspects of clinical ethics for both pediatric and adult patients. The theological anthropology that I propose in this project can offer a more robust picture of the kind of people hospitalized children are, and of what their particular needs and contributions might be. Preoccupation with the legalities and philosophical foundations of informed consent only takes us so far in our efforts to realize a health care system in which the robust realities of human persons, no matter their age or cognitive capacities, are appreciated and attended to. While not denying the importance of informed consent and the weighty matters of decision making, those who work with ill children need to consider more closely the problematic implications for pediatric bioethics that arise from autonomy's dominance, the subject to which I now turn.

Autonomy's problematic implications for children

Narrow regard

First and foremost, the principlist model defines children too narrowly. Adult patients and adult health care professionals are regarded as choosers and actors; their decisions and caregiving are described as integral to the tensions and conflicts that arise in health care as they seek to sort out the principles of respect for autonomy, beneficence, nonmaleficence, and justice. Their preferences and experiences are given ample moral weight and consideration. Children, by contrast, are cast entirely as persons who lack the capacity to make autonomous decisions. While it may be true and wholly appropriate to assert that children need others to deliberate and decide on their behalf, such a narrow regard for children overlooks their embeddedness in the complicated realities of health and illness and in the power structures of an adult-run health care system. As long as medical ethics continues to place value primarily, or almost exclusively, on a

patient's capacity to make decisions, other morally significant features of a patient's identity and experience remain ignored. There has certainly been a push toward obtaining assent from young children who may be too young to consent but whose ability to understand and comply with medical treatment should be acknowledged.¹¹⁹ The point remains, however, that this push is still rooted in the preoccupation with decision-making, and it is geared more toward concerns with research ethics than with the clinical ethics that shape everyday practice in health care settings.

What is lost then, in this narrow regard? Overall, the fixation on decision-making competence deals with only a fragment of the fuller scope of children's experience as hospital patients. The widespread emphasis on considering the future interests of children when we make present medical decisions for them echoes the common view of children as primarily adults in the making, whose future interests are to be prioritized first and foremost. While this assumption may be limiting for children under any circumstances, it is especially limiting when we consider the context of hospitalized children, particularly those who are living with acute or chronic illnesses and conditions that may very well shorten their lifespans. When a realistic time horizon for a child's life does not reach into adulthood, it may be unhelpful and inappropriate to weigh decisions based primarily on the future interests of a child, particularly when our theories have described those future interests based on a supposed trajectory for achieving self-determination. Hospitalized children are thus a population who can poignantly reveal how cultural assumptions about children as adults in the making are often poorly fitted to the realities of children's lived experience.

These assumptions about children are reflected in pediatric ethics literature, as pediatrician and ethicist Margaret Mohrmann has noted. Most of these works, she argues, have

¹¹⁹ See for instance the *American Journal of Bioethics* v. 3 (4), 2003, for a number of articles on assent, a topic I discuss further in chapter 5.

made the “erroneous claim...that one can reason well about the care of children by thinking of them, ethically, as though they were adults writ small, whose primary claim on us is for representation or protection of their nascent autonomy.”¹²⁰ Though considerations of autonomy may be important, by no means do they exhaust the considerations that are vital to appreciating the identity and needs of children in the medical environment. Mohrmann rightly points out that adult preoccupation with a child’s future attainment of an adult state of autonomy leads to a medical gaze focused exclusively on representing and protecting. These foci are worthwhile, but insufficient for appreciating other salient features of who children are and what they contribute to their own experience and to the experiences of the adults who care for them. Traditional emphases on autonomy thus contain adult-centric assumptions and adult-centric operative definitions of children and childhood.

Presuming simplistic parental autonomy

A second set of concerns arising out of the principlist model and its restrictive regard for children emerges from the way that the principle of respect for autonomy overly simplifies the notion that autonomous decisions can be made for a child by his or her parents. I am not referring to how problematic this can be when parents’ preferences are controversial; instead, I am suggesting that it can be risky to generally assume that surrogates possess the kind of autonomous decision making that is uncoerced and unfettered by outside constraints.

The problem with presuming autonomous choice in pediatric surrogate decision makers, usually parents, is embedded in the working definition of autonomy that Beauchamp and Childress offered. If personal autonomy entails acting freely with “a self-chosen plan” and being

¹²⁰ Mohrmann, Margaret E. “Whose Interests Are They, Anyway?” *Journal of Religious Ethics* 34, no. 1 (March 1, 2006), 142.

“free from both controlling interference by others and from certain limitations such as an inadequate understanding that prevents meaningful choice,”¹²¹ I would argue that the everyday situations in which those conditions are actually met for parents may not be as easily guaranteed as the principlist model envisions. It is far too tempting to assume that the ethical issues which arise in pediatric healthcare are adequately addressed once a reassuringly appropriate surrogate is identified. But to situate ethical dilemmas as though they primarily reside in the nexus of the options from which decision makers choose, and not to acknowledge the salient moral issues that shape the availability or recommendation of certain options presented to parents in the first place, is to ignore the wider framework of medical care and its attendant power dynamics, incentives, and biases.

Particularly because physicians may be biased toward treatment even in cases when an option to forgo treatment is morally permissible, they have immense power to shape the range of options from which parents or other surrogates can choose. This power to portray various treatment options in more or less favorable lights should give pause to anyone who would too quickly assume that parents are free from interference and limitations when they consider medical decisions for their children. Moreover, the influences of market-driven healthcare are not benign when it comes to the pressures to advance new technological interventions, and because pediatrics continues to be a medical horizon on which many new innovations are unfolding, there is often an implicit push to attempt aggressive treatment interventions rather than opt for a palliative approach to care.

¹²¹ Beauchamp and Childress, *Principles of Biomedical Ethics*, 6th ed., 99.

The case of hypoplastic left heart syndrome

Let me pause in my analysis of the concerns to discuss one example of innovation that I believe illustrates the complexity of parental autonomous decision making: the diagnosis and treatment of hypoplastic left heart syndrome (HLHS), a congenital heart defect which is fatal without intervention and for which surgical interventions have been developed only in the last few decades.¹²² Many infants with HLHS ultimately do not survive, and even when successful, treatment for HLHS involves multiple major surgeries over the course of the child's first two years of life. In many cases infants ultimately require a heart transplant. Surgical innovation has drastically changed the conversation around whether it is permissible to opt for non-intervention, and therefore allow death, in infants with this diagnosis. While that palliative option was once the only option, it is now one of multiple options, and pediatric ethicists and cardiologists debate whether it is obligatory to recommend treatment, or whether opting out of intervention is still permissible. Thus, a cardiologist's or surgeon's power to offer either treatment or palliative care, and how she or he assesses and represents those options, clearly shapes the parents' deliberations. With more and more families opting for surgical intervention, surgical outcomes are improving, creating a high likelihood that choosing non-intervention will become less and less common.¹²³

Pediatricians and bioethicists Erin Flanagan-Klygis and Joel Frader discuss the ethical complexities of decision-making related to HLHS and the difficulties of conducting the kind of systematic research that would result in resolving the inconsistency and controversy that persists

¹²² "Facts about Hypoplastic Left Heart Syndrome." <https://www.cdc.gov/ncbddd/heartdefects/hlhs.html>

¹²³ A study of incidence and death rates of HLHS in California from 1990-2004 found consistent incidence of diagnosis but drastic change in surgical intervention, with the number of babies undergoing surgery more than doubling in that time period, from 23.2% to 53.7%. Gordon, Brent M., Sandra Rodriguez, Maggie Lee, and Ruey-Kang Chang. "Decreasing Number of Deaths of Infants with Hypoplastic Left Heart Syndrome." *The Journal of Pediatrics* 153, no. 3 (2008): 354-58.

about appropriate or recommended treatment options. They explore the confusion understandably experienced by parents faced with making life-or-death decisions for their children in a context where “doctors know relatively little about the quality of life experienced by survivors of palliative surgery for HLHS.”¹²⁴ What constitutes an assurance of having achieved “informed consent” from parents or acting in the “best interests” of a child when such uncertainty persists and when the prevailing trends in medical recommendations are driven not by carefully conducted research but often by the excitement of innovative possibilities? Flanagan-Klygis and Frader elaborate on the drivers of innovation and the drawbacks that make it difficult to assess whether putting children through surgeries is “worth it.”¹²⁵ They note:

In circumstances, as with HLHS, where death will occur without an intervention, surgeons and parents understandably try new ideas to affect a rescue. Such desperation encourages creativity and innovation. Once a surgeon appears to have promising success with an innovative technique, word gets out, creating interest, excitement, and promise. Pressure builds for other surgeons to reproduce the results. No one wants to take the time or make the effort to initiate clinical trials... Indeed, to the extent that an innovation dramatically and plainly succeeds, formal research makes little sense—it might even be inappropriate. This raises an interesting set of questions about what counts as success. Is it survival alone? Does success mean survival for a certain number of weeks, months, or years? Does survival with high rates of complications or residual disability spell success? Who should judge the degree of success?

Innovating surgeons will likely have considerable enthusiasm for their accomplishments, especially when it involves saving a child’s life. The understandable bias of the surgeon can prevent recognition of unintended negative consequences arising from the new operation. The history of surgery contains many such stories.¹²⁶

I have spent ample time with many HLHS patients and their families on pediatric cardiac intensive care units, following their ups and downs through surgeries, recoveries, setbacks, and

¹²⁴ Flanagan-Klygis, Erin, and Joel E. Frader. “Research and Innovation in Pediatric Surgery: The Problem of Hypoplastic Left-Heart Syndrome.” In *Ethics and Research with Children: a Case-Based Approach*, ed. Eric Kodish, 262–73. Oxford; New York: Oxford University Press, 2005, 264.

¹²⁵ Flanagan-Klygis and Frader, “Research and Innovation in Pediatric Surgery: The Problem of Hypoplastic Left-Heart Syndrome,” 264.

¹²⁶ Flanagan-Klygis and Frader, “Research and Innovation in Pediatric Surgery: The Problem of Hypoplastic Left-Heart Syndrome,” 265.

successes, usually over the course of a months-long hospitalization. However, I only recently for the first time met a family who had opted for non-intervention for their newborn diagnosed prenatally with HLHS. The baby boy was rooming-in with his mother in her postpartum room, a stark contrast to the NICU isolette where he would have immediately been transferred after birth if the family had chosen the surgical intervention. The parents were devastated by their son's impending death, as they had been since learning of his diagnosis, but they felt steadfast in their choice to take him home if time would allow, rather than subject their son to what would probably be an entire first year of his life spent in the hospital if he did survive his first surgeries. The family lived far from the hospital and had two older children.

These parents made the decision to forego what they felt would be excessive burdens for their son and their entire family, and instead chose to cherish time together as a family while sparing their son from pain. While they were prepared for the possibility that he might die within hours of birth at the hospital, they were ultimately able to take him home on hospice and he died two weeks later. The image in my mind of this baby, clothed and nestled in his mother's arms, now gives me pause whenever I see another tiny infant with HLHS in the cardiac ICU, perhaps sedated or paralyzed with an open chest after another surgery, able to be held only occasionally, spending month after month in the hospital while his or her family juggles the many life stressors that accompany such a harrowing journey. It may be true that parents are still supported in their determination of their child's best interests, whatever decision that may translate into for each family. Likewise, given the only gradually emerging efficacy of surgical approaches, the state is unlikely to intervene anytime soon for parents who decline surgical interventions in this kind of scenario—there is certainly no consensus that to refuse surgical intervention constitutes harm. Yet, I am also struck by the kind of moral courage required by families like the one I recently

met, who knew they might be criticized for their choice by hospital staff accustomed to aggressive efforts to “save” babies or by a wider culture infused with “the social expectation that one must ‘do something’ for any sick child.”¹²⁷

Protecting and empowering autonomous parental decisions must take more into account than simply the parents’ beliefs and values, especially when pressure mounts to opt for aggressive and high-stakes treatment options for one’s child even when positive outcomes are highly unlikely. Any theory of parental autonomous decision making that does not admit to how such pressures shape the nuances of what constitutes interference and coercion will remain limited in its account for the complexities of decision-making in pediatrics.

Inattention to context

In addition to an overly narrow regard for children and an overly simplistic portrayal of autonomy in parental decision making for children, principlist models also foster a disregard for the particularities of context in pediatric decision-making. If values, beliefs, and other preferences play vital roles in health care scenarios involving children, then theories and frameworks of pediatric clinical ethics ought to attend closely to the way in which cultural contexts shape those values and beliefs. Principlist approaches, however, operate on implicit assumptions of common morality, building on the Western liberal notions of the rational self and the good life; this shortcoming is identified by theorists who seek to engage a more robust and context-driven understanding of the self and morality.¹²⁸ Attention to context is vital for clinical ethics regarding patients of any age; however, it ought to figure especially prominently when

¹²⁷ Flanagan-Klygis and Frader, “Research and Innovation in Pediatric Surgery: The Problem of Hypoplastic Left-Heart Syndrome,” 269.

¹²⁸ See for example Traphagan, John W. *Rethinking Autonomy: A Critique of Principlism in Biomedical Ethics*. Albany: SUNY Press, 2013.

discussing pediatric ethics because of the extent to which beliefs about childrearing and family life are shaped by cultural contexts and because of the generous latitude in choice given to parents.

Two facets of the theoretical approaches discussed above, for example, become particularly problematic when considering cultural variation. First, the idea that there are “objective conditions” which can account for the optimal development of children into self-determined adults is suspect. Buchanan and Brock assert, however, that

In contrast to adults, there is more room in an account of children’s good for appeal to the objective conditions necessary for the development and preservation of the abilities and opportunities that will enable them later, as adults, to be self-determining agents with choices from among a reasonable array of life plans.¹²⁹

Because Buchanan and Brock are silent on what constitutes such objective conditions, their assertion vaguely implies that the needs of children are somehow more straightforward because they do not yet have the complex makeup of adult values and preferences. I would contend, however, that those complex factors are already present in their parents and other adult decision makers. That is, even when it comes to an abstract ideal of objectivity regarding the needs of children, there would likely be major variation among culturally diverse groups of parents. Even the premise of childhood as being a time for prioritizing the development of adult independence and self-determination is culturally constructed and would carry very different weight among parents from various contexts.

The second problem arising from a failure to account for contextual and cultural diversity is located in the common use of the “reasonable person” standard, which suggests interrogating difficult ethical situations with the hypothetical question of whether a reasonable or rational

¹²⁹ Buchanan and Brock, *Deciding for Others*, 238.

person would prefer to live with the consequences of a particular decision, or perhaps would prefer to terminate life in order to end its pain and suffering. Rationality, however, is an inadequate way to account for the permissible range of preferred decisions that patients and surrogate decision makers might make. Rational people might still differ drastically in their choices, and on the converse, a choice outside of what some would consider a rational approach does not necessarily entail an unethical choice. The rational person standard not only implies that rationality trumps other influences on decision-making, it also implies that widely diverse people might choose similarly, on account of their shared rationality, rather than choose based on the nuances of their life experiences, cultural and spiritual beliefs, and the relationships they share with those around them.

Moreover, to talk about the reasonable person standard with respect to pediatrics is to somehow suggest that parents' decisions can be assessed based on rational criteria, without accounting for the significance of the emotional connection and investment they have with their children. To pit rationality against other legitimate factors that shape a given person's stance is to reinforce a Western intellectual tradition that prizes abstraction and distance over particularity and proximity. Elevating culture or other influences besides those narrowly defined as rational ones with respect to decision makers' stances may not necessarily produce clearer answers or pathways when it comes to pediatric surrogate decision-making. Nonetheless, the need remains for more robust treatment of how and why certain stances emerge.

Contrary to what Buchanan and Brock contend, the obstacles to judging whether a life is worth living do not simply "vanish" when we employ the lens of the reasonable person in pediatric decision making.¹³⁰ And when matters pertain, for instance, to a set of parents who are

¹³⁰ Buchanan and Brock, *Deciding for Others*, 253.

desperately advocating for aggressive medical care for their critically ill child, a child whom the health care team members feel quite certain will not survive, it is easy for those parents to be cast as being out of touch, in denial, or unreasonable in their insistence on continued aggressive interventions. In these scenarios—and they are unfortunately commonplace in children’s hospitals—the reasonable person standard backfires. A reasonable person could conclude that the patient’s life can justifiably be allowed to end in order to relieve suffering; however, the converse position does not necessarily indicate irrationality, particularly when the scenario centers around parental love for a child. Common cultural assumptions about parents’ role as tireless advocates for their children can come in conflict with the notion that a parent could ever deign to allow a child’s life to end, particularly when parents perceive medical heroics as holding out the possibility of healing. In sum, reliance on the reasonable person standard only underscores the insufficiencies of focusing on autonomy for decision makers in pediatric cases.

Reliance on developmental psychology

Lastly, an implication of medical ethics’ preoccupation with autonomy is that it echoes and reinforces the way in which dominant theories of human development prize abstract thinking and reason and focus on chronological step-wise growth, as in the models of cognitive and moral development posited by Sigmund Freud, Jean Piaget, Erik Erikson, and Lawrence Kohlberg. The credence given to these stage-based theories seems to be nearly unquestioned in the medical realm, and thus notions of autonomy and competence have built upon commonly held tenets regarding the ages and stages at which children can think abstractly, make altruistic decisions, delay gratification, consider their future interests, and so on. Principlist ethics builds unselfcritically on such developmental psychology theories, missing the opportunity to

investigate whether and how such theories apply to the range of children whose lives are profoundly shaped by their medical conditions. Stage theories are problematic in general because of their assumed universality, and they are particularly problematic when we consider children whose development follows a less predictable course due to their health status. Some hospitalized and chronically ill children, for instance, may not exhibit the kind of cognitive stage theory development that dominant theories presume, but these children may nonetheless display tremendous maturity in other aspects of their development such as relational, emotional, and spiritual.

Dominant medical ethics theories and dominant developmental psychology theories often share a bias toward the value of rational and intellectual prowess over against other kinds of astute capacities. These theories leave us wanting in our efforts to account for the children who perhaps will never attain the physical or intellectual stature cast as the ideal zenith of human development and who thus do not share the assumed telos of what the human life course ought to look like. Operating on assumptions about what it means to be “normal” or “mature” becomes all the more fraught with problems when considering populations such as medically complicated children and their caregiving family members.

In the above critique of medical ethics’ emphasis on autonomy, my intention is to highlight how adult-centric models of medical ethics are poorly suited to offer a robust approach to children in the healthcare setting. However, I by no means intend to ignore other approaches to medical ethics such as virtue theories, feminist approaches including an ethics of care, and narrative based models, several of which raise critiques of the principlist approach similar to those I have articulated above. It is striking to me, however, that many of the critiques of autonomy that have been articulated by these other approaches still do not identify how

problematic this is for children in particular. Autonomy is critiqued for its rootedness in Western thought, in American individualism, and in a principle-preoccupied medical ethics, but there seems to remain an underlying assumption that children's non-autonomous status is simply a given, regardless of the reasons autonomy may be troubling or insufficient. This leaves unanswered any questions about the place of those—*all those* ages 18 and younger—who are presumed non-autonomous regardless of the operative definition of autonomy. If respect for autonomy remains paramount in clinical ethics, on what basis and in what manner do we respect those we deem to lack autonomy?

Conclusion

The emphasis on autonomy in the principlist approach to medical ethics casts children to the periphery by focusing on adult capacities and responsibilities. Children are thus defined primarily by what they are lacking, namely, autonomous choice and the capacity for reasoned thought that underlies it, leaving no impetus for inquiry about what they do possess, or whether their identity as persons has any moral significance other than what adult decision makers assign to it.

In the following chapter, I turn to theology and its resources for describing children and their identity. I consider the primary ways that theology has contributed to medical ethics heretofore, and I suggest that theology has been underutilized in the wider need to humanize medical ethics. Beyond doctrinal stances and moral philosophy, theology can also shape an anthropology that can bolster efforts to situate and appreciate children in the midst of the medical environment. Where the principlist approach risks regarding children based on their deficits

alone, theological approaches can speak into the void, envisioning engagement with the full humanity children possess.

Chapter 2

Pastoral theology responds to secularized bioethics

Having described how the emphasis on autonomy in the principlist medical ethics model results in a restricted regard for children, I now consider the ways that theology can be a resource to more robustly understand and appreciate children. The problems posed by excessive emphasis on the principles, and especially the principle of respect for autonomy, expose the need for greater attention to children and their status within a medical context that persists in esteeming a normative vision of rational, independent adult decision makers, where all others are cast as anomalous patients in need of accommodation. I suggest that reclaiming theology, and theological anthropology specifically, can broaden and elevate our regard for children as vital sources in the ongoing necessary quest to consider questions such as: What kind of people are we? What does it mean to be in need of constant care from others? What are the sources of our distress and suffering? Toward this end, I explore three areas of emphasis.

First, I consider theology's place in the origins of bioethics and the secularization of bioethics that has ensued. I contend that engaging a richer theological anthropology could revive theological bioethics. In the second section, I argue that theological anthropology is a vital means to help us better account for children in the healthcare context and to develop a more humane bioethics, and that pastoral theology is best equipped to do so by building on more traditional theological perspectives in a way that refines, corrects, and advances our understanding of children's lived realities. In the third section, I explain why the field of pastoral theology is well suited with respect to both method and content to provide a bridge between theology and medical ethics as they each relate to children. The fourth section of this chapter focuses broadly on how pastoral theology has thus far addressed issues related to children and childhood. I identify the

strengths of this literature as well as the gaps and possibilities that remain, particularly in relation to matters of children's place in the healthcare context.

Theology and bioethics

The relationship between theology and bioethics has evolved over time, and the secularization of bioethics has left us with a greater, not lesser, need for theological contributions to bioethics. While this subtopic could consume an entire project of its own, here I will focus in broad strokes on the ways in which theology has contributed to bioethics. Rather than delving into the particulars of how any given theorist has argued about discrete bioethical conundrums, I trace some key arguments regarding the arc of theology's involvement with bioethics. I suggest that theology has been underutilized with respect to bioethics, and that there is ample warrant for renewed attention to the potential contributions of theology. This section situates the project theologically, asking in what ways and for what reasons a theological anthropology of hospitalized children might enhance and expand pediatric bioethics.

From early on in the development of bioethics, theologians were prominent voices in the literature. This history is recounted by several ethicists in a special supplement called "Theology, Religious Traditions, and Bioethics" in the July/August 1990 issue of *The Hastings Center Report*.¹³¹ In his article, "Religion and the Secularization of Bioethics," Daniel Callahan, a founder in 1969 of the Hastings Center, a bioethics institute, explains why it made sense that theologians weighed in early as key voices in the field. Up to that point, religious traditions had done the most sustained reflection on issues of life, death, and suffering, making them most engaged in the very issues that bioethics sought to address. Theologians were attuned to the ways

¹³¹The Hastings Center is the world's first bioethics research institute. It is a nonpartisan, nonprofit organization - see <http://www.thehastingscenter.org/>

that moral teachings embedded in religious traditions could speak to the emerging tensions created by new technologies, and they could aptly articulate how research abuses had violated the rights and dignity of research subjects.

Some key theologians in the early developments of bioethics included Protestant ethicists like Paul Ramsey, a Methodist, whose 1970 book *The Patient as Person*¹³² can be considered “the first major contribution to bioethics as a discipline,” according to a history of the field written by bioethicist Albert Jonsen, who himself was a Jesuit priest early in his vocation.¹³³ My own present aims cohere with Ramsey’s in that he was concerned with articulating not just guidelines for medical decision-making but also grounding respect for the sweeping nature of human experiences and needs and the correlating commitments required of physicians and researchers. For Ramsey, the explicitly theological theme of covenant guides much of this investigation. He sums the scope of his book’s chief aim:

simply to explore the meaning of *care*, to find the actions and abstentions that come from adherence to *covenant*, to ask the meaning of the *sanctity* of life, to articulate the requirements of steadfast *faithfulness* to a fellow man. We shall ask, What are the moral claims upon us in crucial medical situations and human relations in which some decision must be made about how to show respect for, protect, preserve, and honor the life of fellow man?¹³⁴

Interestingly, Ramsey’s first chapter addresses the subject of consent in relation to research involving children, reflecting his commitment to illuminate the personhood of those who might otherwise be treated as a means to an end in the eager momentum of medical progress. He writes,

The individual child is to be tended in illness or in dying, since he himself is not able to donate his illness or his dying to be studied and worked upon solely for the advancement of medicine. . . . future experience may tell us more about the meaning of this particular

¹³² Ramsey, Paul. *The Patient as Person*. New Haven: Yale University Press, 1970.

¹³³ Albert R. Jonsen, “A History of Religion and Bioethics,” in *Handbook of Bioethics and Religion*, ed. David E. Guinn (Oxford; New York: Oxford University Press, 2006), 29.

¹³⁴ Ramsey, *The Patient as Person*, xiii, emphasis in original.

rule expressive of loyalty to a human child, and we may learn a great deal more about how to apply it in new situations with greater sensitivity and refinement—or we may learn more and more how to practice violations of it.¹³⁵

In keeping with his wider claims about respect for persons, Ramsey thus emphatically asserts a “canon of faithfulness to the child” grounded in the theological convictions of covenantal responsibility.¹³⁶ His words strike me as prescient as I reflect on the ongoing tensions related to ethically appropriate ways to conduct research with children, especially when patients themselves have a low likelihood of benefitting from the knowledge gained for future practice.

Prior to Ramsey’s work, earlier interest in medical ethics had been captured in Joseph Fletcher’s 1954 book *Morals and Medicine*,¹³⁷ but Callahan notes that despite Fletcher’s Episcopalian tradition, the book and its “situation ethics” bore little that was distinctly theological, and that Fletcher was actually aiming to overturn some traditional religious values by emphasizing the situatedness of moral choices over against binding moral principles.¹³⁸ Catholic theologians like Richard McCormick, a Jesuit, were also influential in the rise of bioethics. McCormick used natural law theory, as did many Catholics, in hopes of making arguments that would make sense and appeal to any rational person. In this way Catholic bioethics aimed early on at articulating not only a theologically coherent approach but a universal ethics.

Theologians were well-represented not only in early bioethics publications but also in representative and institutional roles. For instance, theologians like Ramsey and McCormick, along with theological ethicists James Gustafson and Karen Lebacqz, had key seats at the table

¹³⁵ Ramsey, *The Patient as Person*, 12.

¹³⁶ Ramsey, *The Patient as Person*, 13.

¹³⁷ Fletcher, Joseph F. *Morals and Medicine*. Princeton, N.J.: Princeton University Press, 1954.

¹³⁸ Daniel Callahan, “Religion and the Secularization of Bioethics,” *The Hastings Center Report* 20, no. 4 (1990): 3.

for important policy-making bodies such as the National Commission on the Protection of Human Subjects of Biomedical and Behavioral Research (1974) and the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (1979).¹³⁹ Furthermore, as Jonsen describes in his historical summary, the primary guild of bioethics began in 1965 as the Committee on Medical Education and Theology. At the time, it was a collaboration of Methodist and Presbyterian churches seeking to explore religious ministry in medical education. Jonsen notes that at the time "Its goal was to counter the 'depersonalization' of medical students and the 'mechanistic way' in which medicine was being taught."¹⁴⁰ This committee evolved into the Committee on Health and Human Values, and then into the Society of Health and Human Values, which gradually emphasized religion less, merging with other groups and becoming in 1998 the American Society for Bioethics and the Humanities, the current primary guild of bioethicists. As Jonsen puts it, "Beginning as a collectivity of ministers and theologians, it had evolved into a community of nondenominational, largely non-religiously affiliated bioethicists."¹⁴¹ What Jonsen summarizes in these organizational moves reflects a deeper shift as theological voices gave way to a more secular bioethics.

Secularization in bioethics

Despite the significant early contributions of theologians in bioethics, Callahan says that the move toward greater secularization in bioethics constituted the largest change in the field in the 1970s and 1980s. Bioethics became shaped less by religious traditions and more by

¹³⁹ Lisa Sowle Cahill, "Religion and Theology," in *Methods in Medical Ethics*, ed. Jeremy Sugarman and Daniel P. Sulmasy, Second ed., (Georgetown University Press, 2010), 75.

¹⁴⁰ Jonsen, "A History of Religion and Bioethics," 32.

¹⁴¹ Jonsen, "A History of Religion and Bioethics," 32.

philosophical and legal concepts, resulting in a discourse built on secular themes such as “universal rights, individual self-direction, procedural justice, and a systematic denial of either a common good or a transcendent individual good.”¹⁴² The emergence of these themes, says Callahan, drew momentum from the growing public interest in bioethics. As the legal system, media, and professional societies became engaged in bioethics, there was pressure to adopt a common secular mode. Where theologians had once led, philosophers and lawyers now took the lead, seeking a way of framing and discussing issues that “would bypass religious struggles.”¹⁴³ While there was not necessarily outright hostility toward religion, there was a presumption that religion was more often the source of deep conflict than a resource for public policy.

Not only did pressure from external changes prompt greater secularization in bioethics, so did the internal motivation of some theological bioethicists. Those who hoped for a wider audience and wanted to remain in the mix of bioethical voices sought to avoid alienating non-religious participants, and thus they adopted language that would cohere with a pluralistic public discourse. Bonnie Miller-McLemore summarizes this multidimensional shift well, noting that in bioethics, “those wearing non-theological hats defined the problems and left little room for theological types of answers. Theologians who entered the discussion failed to do so specifically as theologians.”¹⁴⁴ Tom Beauchamp and James Childress themselves can be counted among those with theological training who entered the field without overt theological approaches; both held degrees from Yale Divinity School, yet their supposedly universal ethical principles of

¹⁴² Callahan, “Religion and the Secularization of Bioethics,” 2.

¹⁴³ Callahan, “Religion and the Secularization of Bioethics,” 3.

¹⁴⁴ Bonnie J. Miller-McLemore, “Thinking Theologically about Modern Medicine,” *Journal of Religion and Health* 30, no. 4 (December 1991), 291. Miller-McLemore’s own career began with part-time work in the 1980s at the Park Ridge Center for the Study of Health, Faith, and Ethics, which was funded by a Chicago hospital system from 1985-2000 and was instrumental in producing a number of publications under the series title “Health and Medicine in the Faith Traditions” (personal correspondence, June 2019).

respect for autonomy, beneficence, nonmaleficence, and justice became well-established in “the foundational text in secular bioethics,” *The Principles of Biomedical Ethics*. Both Callahan and ethicist Lisa Sowle Cahill note that the emergence of the principles model, and the president’s commission reports it stemmed from, reflect the locus at which theology gave way to a predominantly secular discourse in bioethics.¹⁴⁵ Cahill describes how theologians “became marginalized in a field that increasingly relied on universal, rational, and secular principles, and they sought decision-making and policy resolutions that could be squared with U.S. legal traditions and command public support.”¹⁴⁶ Although there have been different responses among theologians to that marginalization, the principlist model remains emblematic of bioethics’ attempt to transcend the perceived limits of theological input.¹⁴⁷

However, as theologians sought to maximize relevance and intelligibility in their approaches to bioethics, they were inattentive to the way in which this shift left their work susceptible to differing moral visions that had little theological footing. Miller-McLemore notes, quoting practical theologian Don Browning, that the well-intended bent toward interdisciplinary engagement has often unfortunately led theologians to appropriate “not only scientific information and therapeutic techniques but various normative visions of human fulfillment which are often neither philosophically sound nor theologically defensible.”¹⁴⁸

¹⁴⁵ Callahan, “Religion and the Secularization of Bioethics,” 3; Cahill, “Religion and Theology,” 75.

¹⁴⁶ Cahill, “Religion and Theology,” 75.

¹⁴⁷ For further description and categorization of theological approaches to bioethics see Cahill, “Religion and Theology,” 77-86.

¹⁴⁸ Miller-McLemore, “Thinking Theologically about Modern Medicine,” 294, quoting Browning, Don S. “Practical Theology in a Pluralistic Age.” In *Practical Theology*, edited by Don S Browning. San Francisco: Harper & Row, 1983, 188.

The cost of preoccupation with dilemmas

The byproducts of this secularization include a narrowed focus. Instead of attending to the wider worldviews and visions of human flourishing that accompany religious traditions, bioethics honed in on the rules and norms that operate best in response to specific dilemmas. As religious ethicist Courtney Campbell notes in another contribution to the *Hastings Center* supplement, the “quandary-centered concerns” that have evolved in bioethics have the unfortunate consequence of sending other crucial issues to the periphery, such as the nature and purpose of life, the place of health, medicine, suffering, and death.¹⁴⁹ I concur with Campbell’s point, as I find that the narrowing of bioethics to preoccupations with specific dilemmas has impoverished mainstream bioethics by largely dismissing the general wisdom of religious traditions.

Callahan echoes this point as well, admitting that despite his own distance from a personal commitment to religion, something valuable is lost when bioethics becomes secularized. Religious perspectives, he notes, “have provided a way of looking at the world and understanding one’s own life that has a fecundity and uniqueness not matched by philosophy, law, or political theory.”¹⁵⁰ Moreover, he identifies how this shift creates both a fear of the law and a dependency on the law, even though the law can only describe what is forbidden and acceptable, not what is commendable or right. The visions of what is commendable and right are embedded in actual human communities, he writes, but the particularities of these communities

¹⁴⁹ Courtney S. Campbell, “Religion and Moral Meaning in Bioethics,” *The Hastings Center Report* 20, no. 4 (1990): 8.

¹⁵⁰ Callahan, “Religion and the Secularization of Bioethics,” 2.

become suspect in light of secularization and the way it values detached neutrality and a culture-free rationalistic universalism.¹⁵¹

Moreover, Callahan remarks that religion not only moved from being considered a primary resource to being downplayed in the interest of universals, but that it also came to be regarded as a source of struggle, a locus of deep and unresolvable moral conflict. Callahan observes, “ours is a society extraordinarily wary of provoking fundamental debates about basic worldviews and ethical premises. Such debates are seen as more likely to produce destructive battles than illuminating social insights.”¹⁵² Removing religion from the public arena of bioethical debate meant relegating it more firmly to the private sphere. “Whatever place it might have in the private lives of individuals, it simply did not count as one of the available common resources for setting public policy,” Callahan says of religion’s place in secularized bioethics.¹⁵³

Above all other consequences, however, Callahan maintains that the worst failing of such secularized bioethics is its “enormous reluctance to question the conventional ends and goals of medicine, thereby running a constant risk of simply legitimating, by way of ethical tinkering and casuistical fussiness, the way things are.”¹⁵⁴ With an increased focus on applying abstract norms to specific dilemmas, bioethics distanced itself from the richness of wider worldviews and with

¹⁵¹ Related to this growing secularization is the rise of what is referred to as “biopower,” a concept denoting the power exerted over bodies and their meanings which was articulated by French philosopher Michel Foucault. While an extensive discussion of this concept exceeds the parameters of this project, it is important to note here as it contributes to the momentum of stripping medical care down to supposedly morally neutral aims. Pastoral theologian Richard Coble describes biopower and its impact on the provision of spiritual care by chaplains in clinical settings. He identifies three distinct trends of biopower: first, the promotion of life, in which the hospital plays a key role as it represents healing and the fight against death; second, the production of knowledge, which equips institutions with the power to name health and decline in the lives of individuals; and third, the division of people, such as the filtering of sick and healthy, patient and staff, and other distinctions that convey hierarchy and economic power. (Coble, Richard. *The Chaplain’s Presence and Medical Power: Rethinking Loss in the Hospital System*. Lexington Books, 2018, 5-6).

¹⁵² Callahan, “Religion and the Secularization of Bioethics,” 3-4.

¹⁵³ Callahan, “Religion and the Secularization of Bioethics,” 3.

¹⁵⁴ Callahan, “Religion and the Secularization of Bioethics,” 4.

this move came a corollary tendency to “tinker” with specific human problems, to borrow Callahan’s word, rather than to engage with the complex fabric of human life. When theologians have tried to accommodate the push for common ground in moral reasoning within bioethics discourse, what gets lost in the search for a shared vernacular is the distinct *telos* of a particular view of human flourishing animated by longstanding theological visions, which are always embedded in particular practices, communities, and historical traditions.

Re-engaging theology and bioethics: Lisa Cahill

In light of secularization, re-articulating the aims of theology in relationship to bioethics thus remains a vital task. Catholic ethicist Lisa Cahill has articulated a helpful perspective that calls for the robust involvement of theology with bioethics. While recognizing the marginalization of religious voices that others have described, she nonetheless calls for a prophetic re-engagement of theology and bioethics. She has written extensively about theology and bioethics and the potential for theology’s re-engagement, and several of her publications investigate whether and how religious claims can be considered in light of secular claims.¹⁵⁵ Echoing Callahan and others, Cahill admits that bioethics grew to great cultural credibility when religious voices were set aside, and that theologians lost their prophetic voice when they stopping speaking in a distinctly religious manner and when they considered their voices to have integrity only when speaking within their religious communities.¹⁵⁶ She laments, “As a result of

¹⁵⁵ Cahill, Lisa Sowle. “Can Theology Have a Role in ‘Public’ Bioethical Discourse?” *The Hastings Center Report* 20, no. 4 (1990): 10–14; “Bioethics, Theology, and Social Change.” *The Journal of Religious Ethics* 31, no. 3 (2003): 363–98; *Theological Bioethics: Participation, Justice, and Change*. Washington, D.C.: Georgetown University Press, 2005.

¹⁵⁶ Cahill, “Bioethics, Theology, and Social Change,” 368.

theologians' infatuation with public influence, it would seem, they capitulated to a procedural bioethics that reduced all substantive moral values to autonomy and informed consent."¹⁵⁷

Cahill critiques theologians, however, who base such capitulation on the ascendancy of a supposedly "thin" secular discourse over against the "thick" discourse of religion.

Cahill's key contribution here is the way she identifies how, rather than existing as a thick discourse in the face of a thin secular discourse, religion is actually one of *many* thick discourses that animate bioethics. She urges,

Theologians searching for a new model of thinking bioethically should recall postmodernism's insight that even abstract and supposedly universal principles always come to be articulated out of particular and historical communities of practice and discernment. Every political value system or agenda has a past, a context, and a set of investments, whether it be liberal democracy, the scientific research imperative, free market economics, communitarianism, or socialism.¹⁵⁸

Consequently, none who would contribute to bioethics with supposedly neutral vocabulary can actually engage in public policy debates on the basis of an "objective, traditionless, secular version of philosophical reasoning" with regard to ideas such as autonomy, rights, and liberty.¹⁵⁹

All such ideas, Cahill contends, emerge from complex political, legal, philosophical, moral, and religious traditions which are far from universal but have come to be constitutive of a broadly shared North American perspective. Cahill asserts therefore that there simply is no privileged view "above the fray," as in the words of religion scholar Jeffrey Stout.¹⁶⁰ Any attempts to whittle bioethics down to a universal view from nowhere stubbornly ignore the situatedness of all theoretical influences that contribute to social, moral, and religious realities.

¹⁵⁷ Cahill, *Theological Bioethics: Participation, Justice, and Change*, 18.

¹⁵⁸ Cahill, *Theological Bioethics: Participation, Justice, and Change*, 19.

¹⁵⁹ Cahill, "Can Theology Have a Role in 'Public' Bioethical Discourse?," 11.

¹⁶⁰ Cahill, "Can Theology Have a Role in 'Public' Bioethical Discourse?," 11, quoting Jeffrey Stout, *Ethics After Babel: The Languages of Morals and their Discontents* (Boston: Beacon Press, 1988), 282.

Cahill therefore insists that theology ought to enter unapologetically into the discourse of bioethics without shedding its norms, claims, and traditions. She writes, “The narrative of the exclusion of ‘religion’ helps conceal the fact that ‘secular’ bioethics is in fact deeply and extensively tradition-based and ‘thick’ with the imagery and language of transcendent meaning.”¹⁶¹ That is, rather than shirking in the face of a supposedly neutral secular discourse, theological bioethics ought to seek robust engagement between the established worldviews and aims of religion and those of other discourses.

Cahill identifies three such additional discourses that shape “secular” bioethics: science, market capitalism, and liberal individualism. She notes that each one, far from being objective and value-free, rests on worldviews that promote particular ideas of human nature, the ends of human life, and the good society. All of these, she remarks, “invoke symbols of ultimacy that capture the imagination, convert desires, direct practical reason, and motivate action.”¹⁶² Because religious voices likewise attend to worldviews and symbols of ultimacy, it is thus unnecessary for theology to shy away from engaging with these other perspectives, says Cahill; instead, they should enter into dialogue and mutual critique with one another. Cahill identifies the tension remaining as theologians navigate participation in the discourses of bioethics, claiming that

Theologians today seek to reassert their religious identity while not giving up public credibility. This is not just about a theological identity crisis. It is also about dissatisfaction with the recent tradition of principled, secular medical ethics that prizes autonomy (and its structural protection, informed consent). Theology's search for a new model corresponds to a simultaneous philosophical development—post-modernism—and its insight that even abstract and supposedly universal principles are formulated in historical communities.¹⁶³

¹⁶¹ Cahill, "Bioethics, Theology, and Social Change," 371.

¹⁶² Cahill, "Bioethics, Theology, and Social Change," 376.

¹⁶³ Cahill, "Religion and Theology," 76.

Cahill deftly identifies the possibilities inherent in the alignment of three factors—first, the latent resources of theological contributions to bioethical discourse; second, the need for a new expression in light of the shortcomings of the established dominant principlist model of bioethics; and third, the inherent receptivity toward “thick” discourses like those of religion in an era that admits no one universal expression can prevail.

Though children are not a primary focus for Cahill, her work nonetheless supports efforts to enhance their visibility and their participation in more just social structures. She asserts that theological bioethics must counteract the individualism pervasive in Western culture and in bioethics. This too coheres with the pressing needs of children, whose place in dilemma-focused bioethics is overshadowed by the presumption that what really matters are the individual preferences of their parents. Cahill envisions a more socially engaged theological bioethics that can undergird an overall bioethics discourse where the presence and needs of children can be better recognized, and which can make use of their developmental status to point towards matters of equity and justice, not just situational quandaries and decision-makers’ personal choices. My project aligns with this kind of effort to re-engage theological discourse with bioethics, not with the intent to prescribe guidance in the face of specific pediatric dilemmas, but to animate a greater regard for children and their needs and experiences in the medical context. I now explore why articulating a theological anthropology is a means conducive to this aim.

Turning to theological anthropology

Theology’s gradual capitulation to a principles- and dilemma-focused approach to bioethics reinforced an artificially narrow view of human experience, one centered on rational deliberation and choice. This trend toward a restrictive account of what it means for humans to

flourish represents a stilted theological anthropology, one devoid of the texture, layers, and complexity of the lived realities of humans in every age.

In the persistence of this dilemma-focused culture in bioethics, pediatric clinical ethics is particularly susceptible to this narrow regard, precisely because the need for an appropriate surrogate decision-maker is built in from the start as the grounding salient feature in pediatric ethics. Children are disproportionately impacted by this dilemma-focused trend and the meager account of human life that accompanies it, however, because they are envisioned from the outset to be excluded from engagement with deliberation and choice. Dilemmas are the stuff of adult action. Children are excused from and expected to be spared of the difficulties of such dilemmas. But does that leave any place for children as actors in the realm of clinical ethics? Presuming children's lack of autonomy produces a strikingly sparse telling of who they are as people, leaving them defined primarily by the responsibilities of care and protection that adults carry for them. To an even greater degree than for adults, there remains a need to describe who children are, not just how they choose or should be chosen for.

By concentrating on questions of human nature and goals, theological anthropology can speak into bioethics and widen views of adults and children alike, offering a lens to inform the prior questions of identity, meaning, and suffering that shape not only dilemmas but social and systemic responses as well. Contributing a case for theology and bioethics in the same Hastings Center supplement as Campbell and Callahan, James Wind¹⁶⁴ also elucidates why theological anthropology represents a vital resource. He reflects on how theology ought first and foremost to provide a more accurate view of the people we encounter in the secular realms of the academy, health care, and public policy, claiming that “Attending to religion requires us both to be honest

¹⁶⁴ At the time, Wind was program director for the Religion Division of the Lilly Endowment, Inc.

about who we are as a people and to be more responsive to the full humanity with which we deal in bioethics.”¹⁶⁵ Doing so, says Wind, prevents the kind of fragmentation and alienation that result when secular language of rights and duties is solely employed to describe human beings; religious perspectives rightly also consider things like limits, finitude, and fallenness. Religious communities and traditions, says Wind, can contribute to a “more variegated or motley view of humanity, helping us see more of the full marvel present in each human being. Instead of a restrictive or reductionist view they can suggest more expansive one, ones that remind us of mystery and possibility.”¹⁶⁶ Embracing these theological contributions opens the door to complexity, Wind admits, and requires engagement beyond dilemmas with the hermeneutical, interpretive dimensions of bioethics.¹⁶⁷

More recently, Catholic bioethicist Roberto Dell’Oro similarly urged further attention to exploring theological anthropology, which he summarizes as “the understanding of the human as disclosed by Christian revelation.”¹⁶⁸ Dell’Oro finds theological anthropology particularly valuable because it interacts with the historical nature of revelation and thus remains open to new interpretations both in form and content. This openness offers a crucial counterpoint to the marginalization of theology he observes in bioethics: “At present, the field of bioethics seems to exhibit a certain resistance to the integration of theological voices, a methodological ‘closure’ of sorts that might appear as both unexpected and startling to an attentive observer of the field’s beginnings.”¹⁶⁹ With Cahill, he too identifies the danger of marginalizing theology on the premise that its “thick” interpretations are at odds with a widely accessible bioethics. He asserts,

¹⁶⁵ Wind, James P. “What Can Religion Offer Bioethics?” *The Hastings Center Report* 20, no. 4 (1990), 18.

¹⁶⁶ Wind, “What Can Religion Offer Bioethics?” 19.

¹⁶⁷ Wind, “What Can Religion Offer Bioethics?” 19.

¹⁶⁸ Dell’Oro, “Theological Anthropology and Bioethics,” 19.

¹⁶⁹ Dell’Oro, “Theological Anthropology and Bioethics,” 14.

Viewing moral pluralism as an obstacle toward the sharing of any “thick” notion of the good within society, bioethics expunges as philosophically uninteresting any attempts to ground such notions on a coherent anthropological basis. In so doing, it replaces questions of moral meaning with questions of procedure and reduces the task of ethics to a logical analysis of moral argumentation, one that functions meaningfully as long as it remains within the framework of a “thin” common morality.¹⁷⁰

One consequence of this methodological closure as Dell’Oro sees it is that ethics becomes focused on the rightness of actions without assessing the goodness of the ends implicitly sought after by those actions.¹⁷¹ Dell’Oro suggests that theological ethics, in turn, has failed to make a case for its own relevance in public discourse, thus stifling the moral wisdom rooted in religious traditions that could have wider relevance. He specifies why theological anthropology reopens a route toward robust engagement and relevance in the public realm:

The contribution of theological anthropology to bioethics represents an expression of the publicness of theology and, moreover, an expression of theology's responsibility in serving the intelligence of faith (*intellectus fidei*) and the vision of the good that it entails. Such a responsibility is relative to the momentous significance of the ethical challenges confronting humankind. Are the intuitions of the good, which define the moral treasure of every great religious tradition, to be dismissed from the public debate as fundamentally irrational, or will they be looked at as a reservoir of meaning and wisdom on what it means to be human?¹⁷²

Furthermore, Dell’Oro contends that because Christian theological anthropology is informed by the historically-situated nature of revelation, it thus remains open over time to new interpretations both in form and in content.¹⁷³

Building on his case for such new interpretations and applications, Dell’Oro calls for an “anthropological system of coordinates,” by which he means areas of human experience that form the horizon of meaning for human life.¹⁷⁴ These anthropological coordinates require

¹⁷⁰ Dell’Oro, “Theological Anthropology and Bioethics,” 14.

¹⁷¹ Dell’Oro, “Theological Anthropology and Bioethics,” 14.

¹⁷² Dell’Oro, “Theological Anthropology and Bioethics,” 19.

¹⁷³ Dell’Oro, “Theological Anthropology and Bioethics,” 19.

¹⁷⁴ Dell’Oro, “Theological Anthropology and Bioethics,” 26-27.

practical reasoning and moral experience in order to be translated into practices and norms, he says, and they can then mediate between theological affirmations and moral norms.¹⁷⁵ Dell’Oro mentions some of these coordinates, such as humans being made in the image of God, and the inherent dignity of humans as grounded in God’s historical participation in human history through the incarnation. These and other theological affirmations underscore for Dell’Oro that God’s sharing in human history indicates that no element of human experience can be rejected as meaningless.¹⁷⁶

There remains a need to traverse more deeply into theological anthropology in regard to children, whose experience and significance has been threatened with meaninglessness in the shadow of adult-focused theological and ethical inquiry. Questions about the goodness of ends being pursued are highly relevant in matters that involve determining a medical course of action for a child, and yet the engagement with such questions can easily get sidelined when discussions defer to weighing the merits of immediate actions, accommodating the preferences of parents, and succumbing to the heady momentum of scientific progress.

When focusing specifically on the population of children who find themselves patients in hospitals, moreover, theological anthropology can bring features to the fore that can easily get overlooked when attending to people in general or even children in general. Theological exploration of how hospitalized children reflect full humanity can yield important insights that can upend our assumptions about what it means to engage in both the everyday and extraordinary matters of caregiving and clinical ethics. Using Dell’Oro’s language of coordinates as a way of describing theological anthropology, I suggest in this project that vulnerability,

¹⁷⁵ Dell’Oro, “Theological Anthropology and Bioethics,” 27.

¹⁷⁶ Dell’Oro, “Theological Anthropology and Bioethics,” 26-27.

dependence, and agency serve as significant coordinates for hospitalized children as we continue to map the connection points between theology and clinical ethics.

Pastoral theology's resources for bioethics

As a discipline grounded by close attention to human experience and relationships, pastoral theology is particularly well-suited to inform a theological anthropology of childhood in the service of enriching bioethics. It can navigate through the kind of coordinates Dell'Oro envisions, identifying the sources and the wider implications of various accounts of human life. Pastoral theological inquiry is inherently anthropological in that it draws on the material of everyday human life in order to inform what would otherwise be abstractions. Through its areas of focus and its inherent methodological emphases, pastoral theology addresses and builds on the shortcomings of existing theological approaches to bioethics. Despite limited formal input from pastoral theology into bioethics, great potential remains for implementing pastoral theology at what pastoral theologian Nathan Carlin identifies as both the macro and micro levels of bioethics discourse.¹⁷⁷ That is, the need for greater attention not only to individuals but to social justice concerns in bioethics merits further contributions from just such a discipline that has focused on both. In the following, I briefly describe practical theology as a discipline, tracing the way it has been incorporated into the landscape of theological education and the wider academic study of theology. I then describe the particular area of pastoral theology within practical theology and lift up four features of pastoral theology that render it particularly helpful to the task of developing the theological anthropology I have proposed.

¹⁷⁷ Carlin, "Bioethics and Pastoral Concern: Some Possible New Directions in Pastoral Theology." *Pastoral Psychology* 62, no. 2 (May 15, 2012), 135.

Practical theology and pastoral theology have been variously defined and distinguished from one another. In this project, I align with the view that pastoral theology is a subset of practical theology. In contrast to British and some American (particularly Roman Catholic) perspectives that may use these terms interchangeably, I find it helpful to see practical theology as a wider umbrella under which pastoral theology is situated. Where practical theology is most often defined as the branch of theology that addresses ministerial practice and includes fields such as homiletics and Christian education, pastoral theology can best be understood as a subset of practical theology. Larry Graham specifies, “Pastoral theology is the branch of theology which develops theoretical understandings of and practical guidelines for the ministry of care.”¹⁷⁸ Pastoral theological method, likewise, focuses not just on the activities of care but on “critical evaluation” of practice and “evaluation of the sources, norms, and procedures of theological judgments,” as pastoral theologian T.W. Jennings explains.¹⁷⁹

Pastoral theology’s disciplinary identity emerges from the wider historical evolution of practical theology. Nineteenth-century German theologian Friedrich Schleiermacher was a key figure in the development of practical theology generally by arguing for its place as a worthy discipline in the modern university. Schleiermacher esteemed practical theology because it incorporated other areas of theological study such as systematic and historical theology, and thus he wanted the modern university to regard it as a subject area on equal footing with other areas of theological study. Attuned to the need for a compelling argument for theological study in the university, Schleiermacher wanted to make the case for an educated clergy who were skilled at coordinating the functions of the church in a theologically astute manner. He felt that, in addition

¹⁷⁸ Graham, Larry Kent. *Care of Persons, Care of Worlds: A Psychosystems Approach to Pastoral Care and Counseling*. Nashville: Abingdon Press, 1992, 20.

¹⁷⁹ Jennings, T.W. “Pastoral Theological Methodology.” In *Dictionary of Pastoral Care and Counseling*, edited by Rodney Hunter. Nashville: Abingdon Press, 1990, 862.

to encompassing all areas of theological study, practical theology also called for more complex intellectual judgments than other areas of theology. He argued that practical theology was concerned not only with practice itself but also with the *theory* of practice. That is, he insisted that the endeavors of practical theology were not limited to the exercises of pastoral ministry, but also with cultivating sound theoretical footing for those actions. This interplay between theory and practice continues as a key feature of the field of practical theology today.¹⁸⁰

However, although the legacy of focusing on practice has carried through to the present, it has also met with some misperceptions in recent decades which have caused practical theology to be construed as a discipline consisting of “hints and helps” for ministry rather than as a field of inquiry alongside other areas of theology, as Schleiermacher had originally envisioned.¹⁸¹ Conflating practical theology with these activities has resulted in what is often disparagingly referred to as the clerical paradigm. As Miller-McLemore describes, the clerical paradigm has become the shorthand way of implying that practical theology is only focused on skills for individual ministers, and that practical theology is to blame for what is wrong with theological education overall.¹⁸²

Miller-McLemore goes on, however, to illustrate that the clerical paradigm and its detractors may actually represent a misunderstanding of the clerical paradigm in the first place. Its focus on practice, she says, is not meant to exclude theoretical knowledge. Rather than disdaining the wisdom of pastoral know-how, she suggests, we need to see that the focus on pastoral practice is perhaps a symptom and not the cause of what ails theological education—that

¹⁸⁰ See González, Justo L. *The History of Theological Education*. Nashville: Abingdon Press, 2015, 105-108.

¹⁸¹ Browning, Don S. “Toward a Practical Theology of Care.” *Union Seminary Quarterly Review* 36, no. 2 & 3 (Winter/Spring 1981), 166.

¹⁸² Miller-McLemore, Bonnie J. “The ‘Clerical Paradigm’: A Fallacy of Misplaced Concreteness?” *International Journal of Practical Theology* 11, no. 1 (January 19, 2007), 22.

perhaps an overly academic paradigm of theological education has led to a dismissive stance toward practice.¹⁸³ Such neglect of the importance of practice also entails a denial that theory itself is shaped by practice. Early pastoral theologian Seward Hiltner had insisted that “the proper study of practice would illuminate theological understanding itself,”¹⁸⁴ aiming to solidify the inseparable importance of both theory and practice.

This discussion is important because although this project may inform practice, it is not primarily about how to improve pastoral care to children in the hospital. It describes a theological orientation in order to shape more attentive and dignifying care for children, not only on the part of spiritual caregivers but also on the part of physicians, nurses, ethicists, and so many other healthcare workers who are involved in the complex scenarios that arise in pediatric healthcare. In the same way that it is important not to reduce practical theology to know-how, it is important not to limit the contributions of pastoral theology for attending to the needs of hospitalized children. What is needed is not just practice, but robust theories of practice that draw on ancient wisdom and speak to the realities of the contemporary context. Stemming from this distinction, there are several reasons why pastoral theology is well suited to inform a theological anthropology of hospitalized children. I see at least four reasons why pastoral theology aligns well with the aim of this project.

Person- and pathos-centered

Miller-McLemore distinguishes pastoral from practical theology in this way: “Whereas practical theology is integrative, concerned about broader issues of ministry, discipleship, and

¹⁸³ Miller-McLemore, “The ‘Clerical Paradigm,’” 24-25.

¹⁸⁴ Miller-McLemore, “Also a Pastoral Theologian,” 816, reference to Hiltner, Seward. *Preface to Pastoral Theology*. New York, Abingdon Press, 1958, 47.

formation, pastoral theology is person- and pathos-centered.”¹⁸⁵ As it narrows in from the concerns of practical theology which often lie at the level of congregational activities, pastoral theology attends closely to the suffering and flourishing that emerge from examining person and pathos, and this invites foregrounding interpersonal relationships of care such as those constantly at work in an environment like the hospital.

Furthermore, because pastoral theology is located at “the point where human suffering evokes or calls for a religious response,”¹⁸⁶ it is well suited to examine the needs that arise for children in the hospital. While hospitalization by no means precludes flourishing, it also entails some injury or illness that represents a threat or impediment to flourishing and an intrusive deviation from the established caregiving relationships familiar to the child outside the hospital. The many challenges to flourishing that present themselves in the midst of the healthcare environment come from the embodied realities of physical threats but also from moral conflicts about how best to envision and pursue a child’s possibilities for well-being. Attending to both the intrapersonal and the interpersonal, pastoral theology is attuned to the sources of suffering and meaning that emerge both from within and without, offering a lens for looking at the physical, emotional, and spiritual challenges hospitalized children face as well as the dynamic relationships with family and healthcare providers that come to bear on those challenges.

In terms of pastoral theology’s potential for enriching bioethics, Carlin adds further emphasis to pastoral theology’s close attentiveness to person and pathos. In his recent book

¹⁸⁵ Miller-McLemore, Bonnie J. “Five Misunderstandings about Practical Theology.” *International Journal of Practical Theology* 16, no. 1 (January 2012), 17.

¹⁸⁶ Miller-McLemore, Bonnie J. “The Subject and Practice of Pastoral Theology as a Practical Theological Discipline.” In *Liberating Faith Practices: Feminist Practical Theologies in Context*, edited by Denise Ackermann and Riet Bons-Storm, 175–98. Leuven: Peeters, 1998, 179.

Pastoral Aesthetics: A Theological Perspective on Principlist Bioethics,¹⁸⁷ Carlin acknowledges Beauchamp and Childress' assertion that critiques of their use of autonomy have been largely misguided. He sympathizes with their view to some extent, but maintains that some of these critiques do have "considerable merit," and his book takes up one of those critiques in particular: "*principlist bioethics pays insufficient attention to experience and to context.*"¹⁸⁸ Carlin thus advocates for deepening the approach to principlist ethics by expanding otherwise abstract moral norms in response to the varied and complex realities of human life.

Interdisciplinary engagement

Pastoral theology is inherently nimble with multiple thick discourses such as those pertinent to moral deliberation in bioethics. Pastoral theology's interdisciplinary identity is thus a second characteristic that informs a theological anthropology in conversation with bioethics. Understandings of the relationships between theology and its various "cognate secular disciplines"¹⁸⁹ such as psychology and sociology may differ greatly on questions of precedence and power given to each contributing discipline. Regardless of the particulars in these relationships, pastoral theology engages robustly with the knowledge yielded by other disciplines in order to produce an informed but critically engaged understanding. Pastoral theology has long reflected an eager openness to other fields, rather than shielding itself as though outside theoretical input could only represent competition or threat to a theological vantage point. As

¹⁸⁷ Carlin, Nathan. *Pastoral Aesthetics: A Theological Perspective on Principlist Bioethics*. New York: Oxford University Press, 2019.

¹⁸⁸ Carlin, *Pastoral Aesthetics*, 15, emphasis original.

¹⁸⁹ Graham, *Care of Persons, Care of Worlds*, 20-23. Such disciplines constitute one of five sources of pastoral theological knowledge Graham identifies, the others being: the actual practice of the ministry of care, the social and cultural context in which ministry occurs, the living religious tradition contextualizing the ministry of care, and the personhood of the caretaker and pastoral theologian.

Bonnie Miller-McLemore recounts, pastoral theology has drawn extensively on the “correlational” and “revised critical correlational” methodologies of twentieth-century theologians Paul Tillich and David Tracy, respectively, which sought to connect wider inquiries and theological responses. She describes,

For Tillich, the questions raised by human existence, often helpfully named and analyzed by the human sciences, must be correlated with the answers of the Christian tradition. Tracy revises Tillich’s one-directional juxtapositioning of “situation” and “message” by asserting that both the human sciences and theology suggest questions and answers; hence the dialogue is multidirectional. The human sciences not only provide answers, they may qualify those of religion.¹⁹⁰

This interdisciplinary inclination at the heart of pastoral theology has meant that pastoral theology continuously engages with the insights yielded from dialogue partners. This engagement has also held pastoral theology accountable for sharpening its own self-understanding within that dialogue by asking what it means to have a distinctly theological perspective—and how that response might be changed—in relation to the findings of other disciplines’ inquiries, especially those of psychology.

Precisely because hospitalized children are situated in an environment dominated by medical perspectives and their component specialties, and because ethically challenging situations invite bioethical analysis that draws on decades of scholarship in philosophy, law, theology, psychology, and health sciences, a conversation between disciplines is always already underway in pediatric clinical ethics. Pastoral theology’s receptivity to engage with such a plurality of perspectives positions it well to contribute a vital affirmation of children as subjects within such situations, and to advocate for theological analysis alongside biological, legal, and philosophical considerations. Carlin too weighs in on the dormant possibilities for engagement

¹⁹⁰ Miller-McLemore, Bonnie J. “The Living Human Web: Pastoral Theology at the Turn of the Century.” In *Through the Eyes of Women: Insights for Pastoral Care*, edited by Jeanne Stevenson Moessner, 9–26. Minneapolis, MN: Fortress Press, 1996, 11.

between pastoral theology and bioethics. A central claim of his book is that “pastoral theology can contribute to bioethics and that bioethics can contribute to pastoral theology. Pastoral theology and bioethics, when cross-fertilized, can yield new crops. . . . They offer each other an expansion of territory.”¹⁹¹ He suggests that bioethics can offer pastoral theology new areas of focus, and that pastoral theology can offer new methods of inquiry to bioethics.¹⁹²

Pastoral theology has delved more deeply into other disciplinary accounts of human experience, particularly those of psychology, than has practical theology generally. In light of how practical and pastoral theology are often referred to interchangeably in other contexts, Miller-McLemore summarizes this more established distinction in the American context: “In using psychology, pastoral theology has sought a specificity of focus on particular persons and pain—the visceral and interior life of human beings—that is often absent from practical theology.”¹⁹³ This assertion reiterates pastoral theology’s priority of seeking well-informed theories to shape practice, lest practice be inadequately informed by religious perspectives in isolation.

Systems-focused

Thirdly, pastoral theology is poised to speak insightfully into the situations of hospitalized children because it attends to individuals in the context of the systemic realities that shape them and their experiences. Despite ongoing deep influences from psychoanalytic theories positing that individual suffering resulted from internal drives and conflicts, pastoral theology has grown to encompass a greater focus on the interpersonal and wider systemic influences on

¹⁹¹ Carlin, *Pastoral Aesthetics*, 143.

¹⁹² Carlin, *Pastoral Aesthetics*, 143.

¹⁹³ Miller-McLemore, Bonnie J. “Five Misunderstandings about Practical Theology.” *International Journal of Practical Theology* 16, no. 1 (January 2012), 17.

suffering and flourishing. Pastoral theologian Larry Graham calls this approach a “psychosystemic” one, where the interplay between individual psyches and systemic factors is reciprocal and ever-present.¹⁹⁴ The individual’s healing is caught up with social, cultural, and natural factors, says Graham, and the fulfillment or suffering of any individual cannot be understood apart from those systemic factors. Graham coined the phrase for this approach after failing to identify existing theories that effectively transcended the polarities between care of persons and responses to the larger social order. Miller-McLemore names Graham’s work as one example of the impact caused by an “emphasis on confronting systems of domination,” which created a “shift in pastoral theology from care narrowly defined as counseling to care understood as part of a wide cultural, social, and religious context.”¹⁹⁵ Miller-McLemore identifies feminist commitments in pastoral theology as the impetus for this shift, as feminist perspectives call for analyzing and addressing “structures and ideologies that rank people as inferior or superior according to various traits of human nature, whether gender, sexual orientation, color, age, physical ability, and so forth.”¹⁹⁶ Interdisciplinary engagement thus undergirds the transformative and prophetic tasks of pastoral theology as it calls for care and change on a systemic level, seeking to foster healing not just among sufferers but from the sources of suffering themselves.

Chapter four discusses dependence in the setting of systems and the individual’s embeddedness within them, but it is worth noting here the methodological significance of pastoral theology’s capacity to attend carefully to both the individual and the system. A child admitted to a hospital is automatically caught up, along with his or her immediate family or

¹⁹⁴ Graham, *Care of Persons, Care of Worlds*, 13, 39.

¹⁹⁵ Miller-McLemore, “The Living Human Web,” 16.

¹⁹⁶ Miller-McLemore, “The Living Human Web,” 16.

caregivers, within the larger system of medical authority, Western beliefs about health and illness, insurance and billing systems, and the complex interprofessional relationships among disciplines that are present in the hospital, such as attending physicians, physician fellows and residents, medical students, physician assistants, nurse practitioners, nurses, nursing care assistants, social workers, physical and occupational therapists, respiratory and speech therapists, child life specialists, psychologists, chaplains, and administrators. To be a patient in the hospital is to enter into a complex system whose language, values, norms, and objectives may be difficult to discern for the uninitiated, and sometimes difficult to align with even for those who are well acquainted with them. Additionally, when the patient is a child, the ability to navigate those systems is mediated through adult caregivers with widely varying capacities. While many adult patients might also be overwhelmed by the medical system, every pediatric patient automatically faces the additional limitations, whether actual or constructed, that his or her younger age imposes on the capacity and authority to engage with those systems.

Moreover, the adult-centric nature of the hospital environment all too often reifies the child's place as an object of care and not a participating subject in the decisions and plans that unfold on a daily basis.¹⁹⁷ A child's need for an adult voice, whether to be a spokesperson, advocate, questioner, or executor of plans, renders children further removed from the power to influence the systems around themselves. Pastoral theology is well suited to investigate the way care is understood and carried out in the midst of such systems, and to examine how individuals interact with and understand those expressions of care.

¹⁹⁷ I discuss this further in the context of agency in chapter 5.

Attention to marginalization and oppression

Pastoral theology equips a theological anthropology of hospitalized children in a fourth way through focusing on the needs and experiences of the marginalized and oppressed. Owing to its more person- and pathos-centered approach when compared to practical theology in general, pastoral theology aims to identify those whose voices are overlooked or silenced in submission to dominant ones. Because it engages with both practice and theory, pastoral theology ensures that abstractions about human flourishing cannot become idealized in ways that ignore the lived realities of those who struggle to embody them. Closely attending to the experiences of those who are disproportionately kept from flourishing—the marginalized and oppressed—invariably leads to discoveries of the constraints and forces that limit potential human flourishing. As Miller-McLemore succinctly puts it, “If knowledge depends upon power, then power must be given to the silenced.” She traces this conviction to the influence of Anton Boisen (1876-1965) who was instrumental in the development of pastoral counseling and clinical pastoral education: “Boisen, having suffered an emotional breakdown and finding himself inside a mental hospital, refused the marginalized, ostracized status of the mentally ill patient. He claimed the importance of what he learned about health, spirituality, and theology as learning that could occur from nowhere else than inside the experience of illness and suffering.”¹⁹⁸ Boisen thus elevated the place of knowledge gained from within oppressed identities, subverting the typical tendency whereby voices of those in power shape such perceptions from the outside. This shift still awaits progress when it comes to validating the knowledge *of* children and not just adult knowledge *about* children.

¹⁹⁸ Miller-McLemore, “The Living Human Web,” 21-22.

Pastoral theology thus seeks to move quickly beyond abstract constructions of care and seeks to incorporate how practices of care might respond to the specific needs of those who struggle from discrimination of all kinds based on their demographics, their physical limitations, their experiences of abuse, addiction and violence, and from the vagaries of the criminal justice system and political power systems on every scale. Efforts to care for and heal individuals beset by a kaleidoscope of systemic influences around and within them must name, expose, and address the factors that limit healing and which often cause suffering in the first place.

Hospitalized children can certainly be regarded through this lens of pastoral theology's attention to the marginalized and oppressed. Oppression often does not manifest as overtly in their situations as it does in many egregious circumstances elsewhere, and hospitals are certainly places of care on the whole. And yet, there are unquestioned adult-centric norms that prevail in the hospital, leaving children to the margins with respect to visibility and power. Their status as minors limits their ability to legally participate in their care decisions, and their varying cognitive or relational capacities based on age and other situational or chronic factors renders them often unable to understand or influence what is happening to them from a medical perspective. On top of their status as children, their admission to a hospital means that some significant bodily need has placed them in the position of needing physical care beyond whatever their immediate family or caregivers can provide. For those who are seriously, chronically, or terminally ill, the challenges of being a child in the medical system are often additionally encumbered with the weight of being a sick or disabled person in a society that sets able-bodiedness as normative. Children's "otherness" as non-adult is compounded when layered with the otherness of illness or disability, and the adult impulse to protect and to speak for them often becomes anxious and amplified in the midst of a child's hospitalization.

Whatever marginalization children experience with respect to simply being children is complicated and nuanced when combined with the circumstances and identity markers of being a patient in the hospital, and raises the importance of gleaning knowledge through their experience from within their own context. Again, Carlin connects pastoral theology and bioethics on this theme as well, suggesting that pastoral theology can deepen the principlist notion of justice by “attending to local manifestations of systemic sin” and “by listening to the voices of oppressed individuals.”¹⁹⁹ As I aim to show in this project, bioethics stands to be enriched by further encounters with pastoral theology—or perhaps more precisely, the *people* about whom bioethics speaks, whether practitioners or patients or others in the constellation of caregiving, all stand to be enriched by the theoretical and practical growth that might emerge from further engagement between pastoral theology and bioethics.

Children and pastoral theology

Despite its commitment to those whose voices have been marginalized, pastoral theology has not always attended closely to children as a marginalized group, and its focus on children has largely centered on children in crisis, including those affected by poverty or abuse.²⁰⁰ Practical and pastoral theological texts on children have not delved deeply into theories of children and childhood, with Miller-McLemore’s work being an exception and thus a significant resource for

¹⁹⁹ Carlin, *Pastoral Aesthetics*, 144.

²⁰⁰ See Lester, Andrew D. *Pastoral Care with Children in Crisis*. Philadelphia: Westminster Press, 1985, and *When Children Suffer: A Sourcebook for Ministry with Children in Crisis*. Philadelphia: Westminster Press, 1987, along with Couture, Pamela D. *Child Poverty: Love, Justice, and Social Responsibility*. St. Louis, Mo.: Chalice Press, 2007, and *Seeing Children, Seeing God: A Practical Theology of Children and Poverty*. Nashville, TN: Abingdon Press, 2000.

this project.²⁰¹ More often, such literature has sought primarily to help clergy feel more comfortable with pastoral care to children in hospitals, without offering a theoretical approach to understanding the voices and status of children in general and in settings like the hospital in particular.²⁰² In this respect, pastoral theology's contributions to children in the medical setting thus far unfortunately resembles the tendency to focus on "hints and helps" apart from deep theoretical reflection on the ideas that shape practice in the first place. A theological anthropology of hospitalized children can more deeply inform practice by formulating a richer view of children that insists on taking contemporary scientific and social realities seriously. A vibrant theological anthropology specifically describing children in the health care context will confront blithe cultural assumptions about children as adults-in-process, and will likewise insist on more incisive religious reflection on the role and aims of adult relationships with and responsibilities to children particularly in regard to illness and suffering.

Pastoral theology's sluggishness in attending more fully to children also reflects how the discipline has looked less at age than at gender and race and ethnicity when analyzing the power dynamics that contribute to systemic oppression. This tendency reflects the wider trend in Western theology which "has largely cast the mature adult Caucasian male as primary actor," as Miller-McLemore summarizes, noting that "While questions about the need for greater inclusivity have led to fresh consideration of gender, race, ethnicity, and class, the adult-centered proclivity of theology has become even more entrenched in recent centuries," with recent

²⁰¹ Theoretical approaches to children and childhood are central in Miller-McLemore's *Let the Children Come: Reimagining Childhood from a Christian Perspective* (San Francisco, CA: Jossey-Bass, 2003) and *In the Midst of Chaos: Caring for Children as Spiritual Practice* (San Francisco, CA: Jossey-Bass, 2007).

²⁰² See for example Hesch, John B. *Clinical Pastoral Care for Hospitalized Children and Their Families*. New York: Paulist Press, 1987, Grossoehme, Daniel H. *The Pastoral Care of Children*. New York: Haworth Pastoral Press, 1999, and Kilgore, James E. *Pastoral Care of the Hospitalized Child*. New York, Exposition Press, 1968.

exceptions consisting primarily of material focused on religious education.²⁰³ Miller-McLemore attributes the presence of this trend in pastoral theology in part to the way in which feminist pastoral theologians were concentrating primarily on gender, wanting first to esteem the status of women. Along with secular feminist theorists, they may have regarded greater esteem of children as a threat to such work and its efforts to decouple women and motherhood. Now, says Miller-McLemore, in the midst of a society that continues to evolve with benign neglect of children's perceptions and needs, there is a new urgency to revise "truncated and harmful understandings" of children just as was true with respect to women.²⁰⁴

Elsewhere, Miller-McLemore describes how few scholars of religion have taken on the challenge of studying the interrelated concerns of both women *and* children; most have focused on one or the other, reinforcing the fallacy that attention to children must come at the expense of attention to mothers, and vice versa.²⁰⁵ She traces this dichotomized approach to the ways in which portrayals of the relational connections between women and children have too often been detrimental to both groups. Deliberate efforts have been made toward fresh joint appraisals, such that now "Seeing women and children as full and separate subjects apart from their familial connections is one of the key advances of both women's and children's studies."²⁰⁶ Miller-McLemore underscores the ongoing harm done to women and children when scholarly work neglects the interconnections between the welfare of children and women.²⁰⁷ However, she

²⁰³ Miller-McLemore, Bonnie J. "Whither the Children? Childhood in Religious Education." *The Journal of Religion* 86, no. 4 (2006), 635.

²⁰⁴ Miller-McLemore, Bonnie J. "'Let the Children Come' Revisited: Contemporary Feminist Theologians on Children." In *The Child in Christian Thought*, edited by Marcia J. Bunge. Grand Rapids, Mich: W.B. Eerdmans, 2001, 451, 465.

²⁰⁵ Miller-McLemore, Bonnie J. "Feminism, Children, and Mothering." *Journal of Childhood and Religion* 2, no. 1 (January 2011), 17-18.

²⁰⁶ Miller-McLemore, "Feminism, Children, and Mothering," 19.

²⁰⁷ Miller-McLemore, "Feminism, Children, and Mothering," 26.

suggests that effective efforts to engage those interconnections ought to start by acknowledging that the varying needs and interests of women and children *do* often conflict, a recognition that can foreground subsequent important questions about the needs they do have in common and how their rights might be understood in relationship to one another.²⁰⁸ Even as I presently advocate for greater attention to children as subjects in medical settings, I do not intend to separate their voices from those of the adults who care for them, especially mothers who often are expected to bear the brunt of responding to the immediate needs of their hospitalized children.

Dedicating focus to children in the hospital setting without lapsing into adult-centric priorities can be as challenging as focusing on children in any context, however. Miller-McLemore describes the pervasive tendency of adult concerns to overshadow children even in the most well-intentioned religious and theological sources, noting “how easily the child as a central subject slips into the background, just as happens in the wider public sphere, and serves as a means to some other equally important and certainly related, but still primarily adult, agenda.”²⁰⁹ The same is largely true when medical ethics ventures into pediatric concerns—perhaps pediatric clinical ethics should be referred to more honestly as parental medical ethics.

Persistence in taking children seriously as central subjects, says Miller-McLemore, “requires a movement from an exploration of dilemmas to an investigation of Christian resources back to a renewed practice.”²¹⁰ Her assertion echoes the current need to expand bioethical preoccupation with dilemmas by critically engaging with a resource like theological anthropology. And yet, as she contends, even this resource has heretofore been woefully

²⁰⁸ Miller-McLemore, “Feminism, Children, and Mothering,” 30.

²⁰⁹ Miller-McLemore, Bonnie J. “Children and Religion in the Public Square: ‘Too Dangerous and Too Safe, Too Difficult and Too Silly.’” *Journal of Religion* 86, no. 3 (July 2006), 395.

²¹⁰ Miller-McLemore, “Children and Religion in the Public Square,” 396.

predicated on adults: “Modern theological anthropology, centered largely on adult cognition and volition, has become a hollow, narrow rendition of the lively unpredictability of human life with children.”²¹¹

The interdisciplinary work of pastoral theology requires forward momentum as dialogue partners advance their own insights. Childhood studies, for instance, as a recent academic enterprise incorporating sociology and anthropology and foregrounding children as subjects and social actors, continues to examine new perspectives on the needs and experiences of children. So too should pastoral theology develop and incorporate new insights that build on children as a central focus rather than as peripheral exceptions. Additionally, the forward momentum of the sciences and the accompanying medical advances that result in new possibilities for children and their families also invite fresh responses from pastoral theology. As Miller-McLemore observes,

Ultimately, pastoral theologians are more aware than many scholars in religion and theology that if we do not answer questions of anguish and flourishing out of the wealth of knowledge found within religious traditions, plenty of secular professionals and new age pundits stand by ready to step in. Doctors, therapists, public educators, brain scientists, and corporate leaders are eager to include “spirituality” as a concern and expertise.²¹²

To Miller-McLemore’s point, I would add that the bulk of literature addressing children’s spiritual needs in the healthcare setting in recent years has come from the nursing profession, not from religious figures.²¹³ Theological renderings of who children are as people and as patients ought to keep pace with our understanding of what we can provide for them medically.

²¹¹ Miller-McLemore, “‘Let the Children Come’ Revisited,” 447.

²¹² Miller-McLemore, Bonnie J. “Also a Pastoral Theologian: In Pursuit of Dynamic Theology (Or: Meditations from a Recalcitrant Heart).” *Pastoral Psychology* 59, no. 6 (March 9, 2010), 826.

²¹³ Examples authored by nurses or published in nursing journals include: Davies, Betty, Paul Brenner, Stacy Orloff, Liz Sumner, and William Worden. “Addressing Spirituality in Pediatric Hospice and Palliative Care.” *Journal of Palliative Care* 18, no. 1 (2002): 59–67. Kamper, RosaLee, Lois Van Cleve, and Marilyn Savedra. “Children With Advanced Cancer: Responses to a Spiritual Quality of Life Interview.” *Journal for Specialists in Pediatric Nursing* 15, no. 4 (2010): 301–6. Elkins, Maureen, and Roberta Cavendish. “Developing a Plan for Pediatric Spiritual Care.” *Holistic Nursing Practice* 18, no. 4 (2004): 179–86. McSherry, Wilfred, and Joanna Smith. “How Do Children Express Their Spiritual Needs?” *Paediatric Nursing* 19, no. 3 (2007): 17–20. Mueller, Carolyn

Conclusion

Despite early robust engagement between the fledging discipline of bioethics and the longstanding insights of religious traditions, subsequent secularization in bioethics confined theological insights in hopes of putting forth universally applicable moral tenets. This sidelining of theology has been counterproductive, obscuring the reality that bioethical discourse continues to reflect the same kinds of situatedness and particularity in its values and assumptions, and thus unnecessarily dismissing vital engagement with those particularities represented by theological perspectives. Productive engagement between theology and bioethics can be recovered, I argue, by connecting a fuller theological anthropology with the pressing questions of contemporary medical practice. Beyond applying doctrines to specific dilemmas, theology holds the possibility of equipping us to engage the ever-deeper questions of meaning, possibility, and equity that arise in the face of the uncharted technological territory that healthcare continues to traverse. Theological anthropology invites reconsidering how the range of human life, including childhood, illumines the fullness of what it means to be human. Likewise, pastoral theology bears latent potential for articulating how an often-overlooked population such as children can enrich not only theological understandings but also the practice that emerges from theology's engagement with other disciplines. Using pastoral theology as a vantage point to inform a theological anthropology of children in the hospital context thus activates new connections for the sake of pediatric patients, their families and medical caregivers, and the ethicists that bear responsibility for continuing to depict ethically salient issues and provide guidance in morally fraught circumstances.

R. "Spirituality in Children: Understanding And Developing Interventions." *Pediatric Nursing* 36, no. 4 (2010): 197–203, 208. Fina, Doris K. "The Spiritual Needs of Pediatric Patients and Their Families." *AORN Journal* 62, no. 4 (1995): 556-564.

In my own analysis, at least three facets of a theological anthropology of children in the hospital setting have the potential to augment the limited portrayal of children created by the principlist approach to clinical ethics. These three features are vulnerability, dependence, and agency, and each offers an urgent and necessary response to the enduring prominence of autonomy in medical ethics and the associations that come with it which detract from a respectful regard for the full humanity of children. These three counteract the ideals prized by operative understandings of autonomy that that overly value being in control, being isolated from relational constraints, and exercising rational choice. These three are certainly not exhaustive when considering all that might be said theologically about who children are, but they pinpoint important sites of existing misunderstandings and offer deeper and richer alternatives going forward.

Chapter 3

Vulnerability: multivalent susceptibilities and possibilities

Following the previous chapters' discussions of the place of children in clinical ethics and the place of theology in the development of the field of bioethics, this chapter examines vulnerability as the first of three vital aspects of a theological anthropology for pediatric bioethics. I discuss vulnerability first because it provides a starting place that aligns with the characterization of children under the umbrella term of "vulnerable populations" in much of bioethical discourse. This abbreviated way of referencing children deserves investigation because the reality of what it means to say that children are vulnerable is anything but straightforward. A distinctly theological articulation of vulnerability can expand more basic definitions of vulnerability that usually operate with respect to healthcare and to children generally. Theologically unpacking what vulnerability consists of and how it is augmented or mitigated can thus foster greater insight into children and how we might understand and respond to them more fully in the medical context. I explore the multivalent character of vulnerability, in that it is manifest in the physical realities of children's lives and also derived from the constructed ways in which they are defined and treated in familial, social, religious, educational, and medical environments. As I write this, in my mind's eye I envision children I have met who were vulnerable not only because they are smaller than adults or less able to advocate for themselves, but also because they were entangled in circumstances and relationships that augmented their vulnerability. The infant who was sleeping in her swing as her caregiver fell asleep on the couch with a lit cigarette, causing a housefire and extensive burns. The twelve-year-old girl who died from carbon monoxide poisoning caused by the space heater her impoverished family was using to heat their trailer. The three-year-old who fell out of a second-

story window because the landlord didn't secure the screen. The numerous Amish boys and girls I have met who were injured when inattentive drivers of powerful motor vehicles struck their families' buggies—societal respect for a religious and cultural minority's way of life unfortunately does not confer much physical protection when a distracted driver is behind the wheel. I think too of all the children who must carry EpiPens with them wherever they go because of severe, life-threatening allergic reactions. In their basic need for this cheap drug delivered in a straightforward, portable treatment device, they are vulnerable to the vicissitudes of pharmaceutical companies and the incentives and competition that shape prices with little regard for the financial means of the actual people who will use their product.²¹⁴ They are likewise vulnerable to the variations among insurance companies and to the larger legislative influences that could advocate more effectively for patient access to these much-needed drugs if only more adults would become informed and involved and do with their power what children cannot do to exercise their voice about such things: vote. Suffice to say, as a background feature of childhood, vulnerability in its varied forms sets the stage for how children and childhood are regarded, and sets in bold relief both the beneficial and harmful actions carried out on their behalf by adults.

In the following, I begin by examining characterizations of vulnerability in medical ethics and popular social psychology, showing how adult-centric framings of vulnerability underappreciate the situations of children. I also consider how the material and social vulnerabilities of children in the United States deserve more attention in the medical realm. In the second section I consider how vulnerability is perpetuated and exacerbated by the various ways that children are defined culturally, politically, and philosophically. Because these

²¹⁴ Carroll, Aaron E. "The EpiPen, a Case Study in Health System Dysfunction." *The New York Times*, August 23, 2016. <http://www.nytimes.com/2016/08/24/upshot/the-epipen-a-case-study-in-health-care-system-dysfunction.html>.

definitions are often implicit, they do not always get assessed as they should, and we fail to grapple with the implications of our operative definitions, especially in settings like the hospital. I turn to historical theologian Barbara Pitkin, in particular, because she offers theological insight and rationale for thinking and acting in ways that reflect the full humanity of children, and to philosopher Thomas Attig whose work on the existential suffering of children also provides a compelling picture of what is at stake in the definitions by which we operate. Yet, children's vulnerability is shaped not only by how people regard and define children, but also by the dominant consumer model of health care in America and the market forces that shape healthcare settings. In the third section, Catholic ethicist Todd Whitmore's work on the anthropological implications of a market culture guides an analysis of the particular challenges of children in the marketplace and offers a constructive theological alternative. He does not consider, however, the feature of vulnerability specifically, nor the nature of children as vulnerable or vulnerability's place as a human and even Christian characteristic. In order to grapple with these important considerations, in the fourth section I draw on Protestant systematic theologian David Jensen who casts vulnerability in a new light in relation to the divine. Jensen's alignment of vulnerability with the image of God creates renewed appreciation for vulnerability and for the pressing importance of the caring responses it evokes. I find in the convergence of these layers of vulnerability a new way of reckoning with the frailty of bodily human life so readily apparent in children. Theologically speaking, vulnerability beckons for more than just added protection from harm. It also reveals the shared vulnerability among all who are impacted by the circumstances that render some persons particularly vulnerable, underscoring a solidarity that is further bolstered by recognizing such vulnerability embraced in the very nature of the Divine.

Vulnerability in medical ethics

In his introduction to *Health and Human Flourishing: Religion, Medicine, and Moral Anthropology*, Roberto Dell’Oro notes that vulnerability is an obvious and intrinsic part of the human condition, whether caused by universal physical vulnerabilities or by the fluctuating power differentials among human beings.²¹⁵ Despite this reality, however, the history of Western moral philosophy and of bioethics too demonstrates very little attention to human vulnerability. Dell’Oro maintains that this reflects rationalistic understandings of moral events and anthropological presuppositions where moral subjects are “autonomous, individualistic, and self-sufficient.”²¹⁶ Dell’Oro finds further evidence of this trend in the fact that the first edition of Beauchamp and Childress’ *Principles of Biomedical Ethics* (1979), despite being the most widely recognized approach to bioethics in America, did not even mention vulnerability in its index.²¹⁷

In more recent editions of *Principles of Biomedical Ethics*, vulnerability and vulnerable populations are addressed in the context of their moral status. In the sixth edition of the *Principles* (2009), Beauchamp and Childress discuss various vulnerable populations, specifying that “Vulnerable persons in biomedical contexts are incapable of protecting their own interests because of sickness, debilitation, mental illness, immaturity, cognitive impairment, and the like.”²¹⁸ In the context of the principlist approach, vulnerability primarily functions to heighten the importance of ensuring that one’s interests are protected from threats to autonomous choice and the other elements of informed consent. This characterization of vulnerable populations does

²¹⁵ Carol Taylor and Roberto Dell’Oro, eds., *Health and Human Flourishing: Religion, Medicine, and Moral Anthropology* (Washington, D.C: Georgetown University Press, 2006), 2.

²¹⁶ Taylor and Dell’Oro, *Health and Human Flourishing*, 3.

²¹⁷ Taylor and Dell’Oro, *Health and Human Flourishing*, 3.

²¹⁸ Tom L Beauchamp and James F Childress, *Principles of Biomedical Ethics*, Sixth edition (New York: Oxford University Press, 2009), 89.

not do justice to children, for whom vulnerability is not an aberration from an autonomous norm, as it might be considered in certain adults, but instead is an presumed baseline state for the entire population.

The principlist model tends to assess vulnerability only insofar as it has implications for autonomy. Put simply, someone whose autonomous decision-making capacity is considered intact is not thought of as being particularly vulnerable, and someone who does not have autonomous capacity is generally lumped in the vulnerable category. However, this binary obscures the multivalent character of vulnerability and the way its presence can certainly persist even in adults considered fully autonomous who find themselves in a health crisis. Vulnerability lives in many places beside our cognitive capacities. Autonomy is not the antidote to vulnerability.

Children are vulnerable for more reasons than because they need adults to make decisions on their behalf. Such minimal rendering of their vulnerability in the principlist approach reflects the adult-focused preoccupation with determining the conditions for self-governance or for investing authority in a surrogate decision-maker. It is neither realistic nor developmentally appropriate to expect that children should somehow be responsible for their medical decisions, but focusing almost exclusively on who makes the decisions only ensconces us further in definitions of vulnerability that reflect ideals of rationality and individuality.

A contrasting account of vulnerability: Brené Brown

The above account of vulnerability contrasts markedly with the version of vulnerability currently receiving widespread popular attention in the work of social psychologist Brené

Brown, whose video “The Power of Vulnerability” has been viewed over 40 million times.²¹⁹

Brown’s work merits attention here because although it differs in focus from vulnerability in medical ethics, it too reflects underlying adult-centric assumptions. She champions a version of vulnerability that is chosen and lived out deliberately, in defiance of a culture that values invulnerability. Brown urges her audience to embrace their own vulnerability in order to more fully engage and connect with themselves and others. As she describes it,

Vulnerability is not weakness, and the uncertainty, risk, and emotional exposure we face every day are not optional. Our only choice is a question of engagement. Our willingness to own and engage with our vulnerability determines the depth of our courage and the clarity of our purpose; the level to which we protect ourselves from being vulnerable is a measure of our fear and disconnection.²²⁰

While Beauchamp and Childress characterize vulnerability as a liability or deficit, with vulnerable persons being unable to protect their own interests, Brown casts vulnerability as an asset that, when chosen and accepted, can be used in the service of one’s own interests, in order to foster honest connection and closer relationships.

Brown’s view of vulnerability is predicated on adults in that it envisions a freedom to choose vulnerability in engaging with the outside world. While there may be comparable benefits for that sort of chosen vulnerability for children, too, I want to focus more intently on the vulnerability that is not freely chosen but which automatically accompanies childhood. While Brown touts a vulnerability that can reclaim and recast notions of weakness and strength, children are subject to the unchosen vulnerability that comes with the baseline territory of being a smaller, younger human being, and all the cultural conventions which accompany such status.

²¹⁹ Brené Brown, *The Power of Vulnerability*, accessed February 23, 2017, http://www.ted.com/talks/brene_brown_on_vulnerability.

²²⁰ Brené Brown, *Daring Greatly: How the Courage to Be Vulnerable Transforms the Way We Live, Love, Parent, and Lead*. New York: Gotham, 2012, 2.

Rather than dismissing Brown's rendering of vulnerability as irrelevant for children, however, I find within it revealing of the way in which childhood vulnerability is disdained as a form of weakness meant to get left behind in the process of maturation. Perhaps Brown's version of vulnerability is at once both compelling and difficult for adults to embrace because it evokes a freedom from the adult pressures of conformity to an image of invulnerability, but also because it smacks of feelings of weakness and susceptibility associated with the more immediate and apparent childhood forms of vulnerability. Such vulnerability reminds adults of the precarious vulnerabilities of childhood that were imposed instead of chosen, and perhaps Brown's work is widely popular in part because it invites an empowering reconsideration and reclaiming of that vulnerability.

Pastoral theologian Herbert Anderson and pastor Susan Johnson mention this association in a discussion of adult indifference toward children in their book *Regarding Children: A New Respect for Childhood and Families*. Noting many observations of indifference toward children in American culture, they gravitate toward the work of attorney and religious educator Janet Pais who theorizes "that adults have contempt for children precisely because they are small, weak, and needful."²²¹ Adult desire for strength, power, and control relegates childhood vulnerability to a realm where it is more likely to evoke pity than respect. In Pais' view, such contempt emerges from adults' own avoidance of vulnerability and contributes to the physical, sexual, and psychological abuse of children.²²² Despite the significance of this claim, Anderson and Johnson do not delve further into the psychodynamics of adult indifference, but instead focus on what is needed to elevate the status of children, claiming that "*The transformation of our attitude toward*

²²¹ Anderson, Herbert, and Susan B. W. Johnson. *Regarding Children: A New Respect for Childhood and Families*. Louisville, Ky.: Westminster John Knox Press, 1994, 17.

²²² Anderson and Johnson, *Regarding Children*, 17.

being a child is one of the fundamental and urgent agendas for our time.”²²³ They contend that along with greater respect, legislation is also needed to facilitate well-being for children and the families that seek to nurture them.

Hospitalized children in various states of illness or injury cast vulnerability in even bolder relief—a deeper challenge that Anderson and Johnson do not consider. Medical ethics literature often focuses on the narratives of otherwise healthy adults who are faced with adjusting to the sudden onset of new vulnerability posed by a diagnosis or health event that represents an interruption to life as they knew it. These accounts depict persons who were accustomed to having their full capacities, and who must adapt to the changes in their ability to protect their own interests or enact their own wishes. For children, in contrast, such added vulnerability due to illness is not an *interruption* of an established capacity to protect their interests, but rather builds on their baseline vulnerability, heightening the conditions they have known from birth.

Layers of Vulnerability in pediatric patients

Vulnerability is multivalent in pediatric hospital patients. They are physically vulnerable due to their smaller size, which renders them more susceptible to harm from things like medication dosage errors or imprecise sizing of medical equipment, along with their susceptibility to harm from violence, abuse, and neglect, which may take a larger toll on their bodies compared with adults. Physical characteristics resulting from their illness, injuries, or treatment may make them vulnerable to stigma or scrutiny—for instance, a child bald from chemotherapy, or a child with a prosthetic limb, or a child whose genetic condition causes facial deformities. Those whose bodies do not align with what they are expected to look like at a

²²³ Anderson and Johnson, *Regarding Children*, 18, emphasis original.

particular age might be treated as much younger than they are—I picture an eight-year-old girl I visited recently whose rare disorder has caused her physical growth to stop at such a small size that she still wears infant-sized clothing. It took great intentionality to interact with her not as I would with an infant but as I would with any school age child.

Socioeconomic and racial considerations and disparities in health also highlight the vulnerability of hospitalized children. A 2016 report by the American Academy of Pediatrics notes that child poverty persists at higher rates in the US than in comparable developed countries. According to 2014 census data, approximately one in five children were living at or below 100% of the federal poverty level, or \$24,230 of annual income for a family of four, with the percentage rising to over 40% of children living in “poor, near poor, or low income” households as measured by 200% of the federal poverty level.²²⁴ African American, Hispanic, and Native American children are three times more likely to live in poverty compared to white and Asian children, with infants and toddlers also being more likely to suffer poverty than older children. The report warns,

Children who experience poverty, particular during early life or for an extended period, are at risk of a host of adverse health and developmental outcomes throughout their life course. Poverty has a profound effect on specific circumstances, such as birth weight, infant mortality, language development, chronic illness, environmental exposure, nutrition, and injury. Child poverty also influence genomic function and brain development by exposure to toxic stress, a condition characterized by “excessive or prolonged activation of the physiologic stress response systems in the absence of the buffering protection afforded by stable, responsive relationships.”²²⁵

Decisions that may or may not happen in the “best interests” of a child happen not only between pediatric medical providers and parents, but also at countless loci of policy and legislative action that shape the conditions under which children enter into the healthcare setting. This means that

²²⁴ AAP Council on Community Pediatrics. “Poverty and Child Health in the United States.” *Pediatrics*, April 1, 2016, 1.

²²⁵ AAP Council on Community Pediatrics. “Poverty and Child Health,” 1.

the many hospitalized children whose families are already stressed economically are disproportionately burdened by additional stressors such as the loss of income from a parent missing work in order to be in the hospital with a child. Transportation, stable housing, and food security are concerns I encounter daily with families in the hospital, especially when a child's admission is anticipated to be lengthy or when the family is a long distance from home.

Recent studies demonstrate that the impact of these socioeconomic realities is magnified by the burdens of treatment for childhood cancer specifically, in ways that one can easily imagine being relevant for other diagnoses as well. While this magnified impact seems plausible and significant, it is nonetheless true that until very recently, no research was being done about how socioeconomic variables interacted with pediatric cancer treatment protocols, which are extensively studied and standardized across children's hospitals nationwide. Pediatric oncologist Kira Bona has led the charge in insisting that these protocols and clinical trials begin collecting data regarding families' socioeconomic status, especially since childhood cancer treatment is already associated with increased levels of poverty for families in the first six months of treatment. She and her colleagues have hypothesized that higher levels of poverty are associated with delays in cancer treatment and with increased emotional stress for patients and parents. Along with other comorbidities that are vital to recognize in treatment plans for particular patients, poverty should be given its due as a significant interacting factor. By looking at initial data gathered in this line of inquiry, Bona and colleagues were able to identify a trend in which, of those children who experienced relapse in their cancer, those in the most impoverished group relapsed sooner than others.²²⁶ Because early relapse is more difficult to treat than later relapse,

²²⁶ Bona, Kira. "Poverty in Pediatric Oncology: Time to Integrate Socioeconomic Measures into Clinical Trials." St Jude Children's Research Hospital, January 19, 2017. See also Bona, Kira, Wendy B. London, Dongjing Guo, Deborah A. Frank, and Joanne Wolfe. "Trajectory of Material Hardship and Income Poverty in Families of Children Undergoing Chemotherapy: A Prospective Cohort Study." *Pediatric Blood & Cancer* 63, no. 1 (January 1, 2016):

this economically-driven difference bears sobering implications for the well-being and ultimate survival of those children who were already grappling with the burdens of poverty before being diagnosed with cancer.

Furthermore, children and adolescents are vulnerable not only from harm externally imposed by individuals or systemic factors such as socioeconomic status but also from the harm they too often impose on themselves. Nationwide, children's hospital admissions for suicidal thoughts or behaviors doubled from 2008-2015.²²⁷ Youth who identify as LGBT or who are questioning their sexual identity or orientation have twice the rate of suicidal ideation compared to their peers, and remain at greater risk for attempting or completing suicide, along with those who are bullied or beset with mental health problems. Suicide remains the second leading cause of death among 15-19 -year-olds.²²⁸ In the hospital where I currently work as a chaplain, it is not uncommon for patients admitted following suicidal ideation or attempt to wait for days if not weeks for placement and transfer to one of the few area residential psychiatric centers that accepts minors.

Children's basic access to quality and consistent health care may be mitigated by their parental resources beyond finances such as health insurance, transportation, proficiency with English, family support, and health literacy. Their access is also shaped by the systemic bureaucracies of hospital administration and insurance companies. At all levels of access, children are vulnerable to limits in their care determined well outside of their control by adults who may or may not take initiative to advocate on their behalf.

105–11, and Pelletier, Wendy, and Kira Bona. "Assessment of Financial Burden as a Standard of Care in Pediatric Oncology." *Pediatric Blood & Cancer* 62, no. S5 (December 1, 2015): S619–31.

²²⁷ "Children's Hospitals Admissions for Suicidal Thoughts, Actions Double during Past Decade." *AAP News*, September 22, 2017.

²²⁸ Shain, Benjamin, and Committee on Adolescence. "Suicide and Suicide Attempts in Adolescents." *Pediatrics*, June 27, 2016, e1-2.

A good example of factors beyond children's control is the lack of support for parents in politics and public policy. Economist Sylvia Hewlett describes the layers of vulnerability that led to the death of her twins, who were born at 23 weeks' gestation when Hewlett's water broke. At the time, she was approaching tenure review at Barnard and had considered taking time off, but there was no maternity or parental leave policy and she would have lost her job. Only 18 months away from tenure and having spent 12 years in the academic track, she decided to stick it out. She describes the larger forces that contributed to her babies' demise, noting "The right to parental leave would have made an enormous difference to the life chances of those twins, as would a set of colleagues who understood the value of parenthood."²²⁹ The lack of social supports for parenthood thus trickles down swiftly into stark vulnerability for people like Hewlett's twins. Almost daily in my work I see children whose parents struggle mightily with what they feel is their minimal presence with their child in the hospital—if they are the parent who carries the health insurance, they are often caught in a heart-wrenching bind between remaining present with their child, or going to work to preserve the child's health insurance. Not surprisingly, a lot depends on the level of support from parents' employers, and those in jobs that allow working remotely tend to be present at the bedside much more than those whose labor cannot accommodate their physical absence.

A stark vulnerability manifests at the end of life as well, as care for dying children receives much less attention and resources than for adults in their final years and days. In my experience, for instance, it can be very difficult for families to find a hospice company that works with pediatric patients, especially if a family is from a more rural area. I met a family recently whose daughter was near death due to cancer, and she was in the hospital for the first

²²⁹ Hewlett, Sylvia Ann, and Cornel West. *The War against Parents: What We Can Do for America's Beleaguered Moms and Dads*. Boston: Houghton Mifflin, 1998, 20.

time in the course of her treatment, which had otherwise been outpatient. When the social worker and I broached the topic of whether the family would want to take her home to die if possible, they indicated that they might like an inpatient hospice option, because as with many families in that situation, they were unsure as to whether they could withstand having their daughter die in their own home. The social worker and I sadly had to explain that there are less than a handful of such pediatric hospice houses in the United States currently, and none within hundreds of miles of our location. A recent *New York Times Magazine* article highlights the opening of just the third such facility in the US designed specifically for children, noting that “by some estimates, around half a million children have serious medical conditions that are expected to shorten their lives. For too many of them, death will most likely happen amid the fluorescence and thrumming machinery of an intensive-care unit.”²³⁰ The article indicates more generally that despite the rise in hospice providers, pediatric patients have not benefitted accordingly: “Hospice organizations, thriving on Medicare’s payments [since the 1986 Medicare Hospice Benefit Act], have proliferated to number more than 4,500, but only something like 10 percent of them will care for children.”²³¹ These findings echo those of the comprehensive Institute of Medicine report “When Children Die,” which summarized that “Too often, children who die and their families fail to receive competent, compassionate, and consistent care that meets their physical, emotional, and spiritual needs.”²³² The report notes that although child death is much rarer than adult death, over 50,000 children die each year, and their end of life experience merits vast improvements in provision of support. Noting that most literature specifically on spiritual concerns at end of life is

²³⁰ Ouyang, Helen. “Where Should a Child Die? Hospice Homes Help Families With the Unimaginable.” *The New York Times Magazine*, May 15, 2019.

²³¹ Ouyang, Helen. “Where Should a Child Die?”

²³² Committee on Palliative and End-of-Life Care for Children and Their Families. “When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families.” Institute of Medicine. 2002.

likewise focused on adults, the report laments that “little research has investigated the spiritual concerns of children with life-threatening medical problems and ways of responding to these concerns.”²³³ Though the death of children is far rarer than it used to be, and far rarer than the deaths of older adults, children are nonetheless deserving of the same access to comprehensive and dignified care that we would aspire to provide for those who happen to have lived longer lives.

Definitional vulnerability

Beyond the layers of vulnerability present in children’s physical and social realities, the ways in which they are generally defined as a class of people also yields vulnerability, for much is at stake especially for sick or disabled children in how they are regarded. Overt and latent beliefs and attitudes about who children are, what they need, what their childhood should look like in relation to an envisioned adulthood, and about who is responsible for their nurture, protection, and well-being all contribute to vulnerability in that they render children starkly at the mercy of adults who get to choose how to manage the power differential between them. The vulnerability of hospitalized children thus far exceeds both the cursory portrayal in medical ethics literature and the physical and demographic vulnerabilities common to children across other contexts. Subject not only to the adult conceptions of childhood that operate in wider cultural trends, hospitalized children are also subject to adult interpretations of their suffering and quality of life, and to assumptions about how children experience themselves and their care. A recent book authored by a pediatric surgeon and CEO of a leading children’s hospital

²³³ Committee on Palliative and End-of-Life Care for Children and Their Families. “When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families.” Institute of Medicine. 2002, 165.

references children as “adults to be,”²³⁴ reflecting just how customary and acceptable it is, even when focused on the *present* care of patients who happen to be children, to refer to them chiefly in terms of their expected future status as though, by extension, the main idea in pediatrics is to grow adults. Theological perspectives can describe what is at stake in such operative definitions. Barbara Pitkin’s work does just that.

The fundamental humanity of children

Historical theologian Barbara Pitkin is a scholar of the sixteenth-century Protestant Reformer John Calvin whose contributions to religion and childhood studies began with her inclusion in Bunge’s edited volume, *The Child in Christian Thought*, where Bunge deliberately included women scholars with historical expertise of major Christian thinkers.²³⁵ In her chapter, Pitkin explores Calvin’s views of sin and election in relationship to children, drawing on what little he wrote directly about children.²³⁶ She finds significance in his interpretation of children as “gifts of God” as it shapes an ethic of both parental and societal responsibility and mitigates otherwise harsh responses to perceived sinfulness in children.²³⁷ Pitkin also locates Calvin’s theology of infant baptism as a paradigmatic validation of children’s full humanity and their right to inclusion in the church. In contrast to other reformers who emphasized the need for baptism on the basis of sin, Pitkin remarks that Calvin’s “primary justification for infant baptism is not the sinfulness of children, nor even their need for faith or perhaps their latent possession of it, but

²³⁴ Newman, Kurt, M.D. *Healing Children: A Surgeon’s Stories from the Frontiers of Pediatric Medicine*. New York: Penguin Books, 2018.

²³⁵ Bunge, Marcia J., ed. *The Child in Christian Thought*. Grand Rapids, Mich: W.B. Eerdmans, 2001.

²³⁶ Pitkin, Barbara. “‘The Heritage of the Lord’: Children in the Theology of John Calvin.” In *The Child in Christian Thought*, edited by Marcia J. Bunge, 160–93. Grand Rapids, Mich: W.B. Eerdmans, 2001.

²³⁷ Pitkin, “‘The Heritage of the Lord’: Children in the Theology of John Calvin,” 170-74.

the fact that God has commanded it *because they are already members of the covenant.*²³⁸ Thus, Calvin affirms children's own claim to this sacramental participation apart from any adult evaluations of their worthiness or depravity.

Contemporaneously, in "Are Children Human?," an address given in honor of the Presbyterian Church (USA)'s "Year of the Child," Pitkin poses a superficially silly question in order to highlight the implications of failing to see children as fully human.²³⁹ Pitkin argues that this failure lies at the root of many of the global crises that children face today. She rightly notes that although a shift in our mentality towards children will not be sufficient to address the problems they face, we will nonetheless be frustrated in our efforts to address those problems unless we do achieve a shift our thinking about who they are. Theology provides key resources for making this shift, says Pitkin, by offering a critical view of how childhood has been viewed in the past and forming the basis for challenging the dominant adult-centric culture.

Pitkin describes the two dominant but contradictory underlying views of childhood that have shaped our approach to children. On the one hand is the concept of children as idealized and utterly innocent, having natural potential that simply needs to unfold properly; this view emerges from the thought of eighteenth-century French philosopher Jean-Jacques Rousseau. The downside of this view is that it can undermine our capacity to appreciate the moral accountability of children. On the other hand, says Pitkin, is a view of children as needing correction and restraint in order to overcome their natural dangerous impulses. This view carries the drawbacks

²³⁸ Pitkin, "The Heritage of the Lord": Children in the Theology of John Calvin," 185.

²³⁹ Pitkin, Barbara. "Are Children Human?" Occasional Paper, Theology and Worship. Presbyterian Church (USA), 2000.

of having inspired harsh corporal punishment and psychological domination aimed at restraining the child's self-will and conforming the child's will to that of adults.²⁴⁰

Pitkin identifies the commonality of these two views: both manifest an assumption that "children are incomplete human beings," and that childhood "is not an end in itself but something to be gotten through, whether through the unfolding of natural potential with minimal adult interference or through a domestication of an unruly or disordered self through strict control and guidance."²⁴¹ Both views of children lead to disadvantages for them in a culture where adult fulfillment is prized over the nurture of children, asserts Pitkin, and where growing up as fast as possible is prioritized. Both views promote a view of childhood as a temporary and less valuable part of human life.²⁴² The ensuing adult-centric culture, further reinforced in workplaces and in the marketplace, leads to policies and practices that reflect an indifference or outright contempt toward children, as also mentioned above in Anderson and Johnson's work.

Pitkin argues that the resources of Christian theological anthropology, when critically examined and reinterpreted, provide a way to uphold the full humanity of children while also appreciating the specific needs presented by childhood as a stage in human life. She notes that the Christian tradition has itself carried contradictory views of children, regarding them as image bearers of God but also as sinful. Unlike the culturally positive and negative views of children, however, theological understandings of children as both saints and sinners underscore a theological anthropology applicable to humans of every age. She writes that in this theological tension, children are

²⁴⁰ Pitkin, "Are Children Human?," 3. Bonnie Miller-McLemore traces similar definitional tensions and historical shifts in *Let the Children Come*, which I also address in chapter 5.

²⁴¹ Pitkin, "Are Children Human?," 4.

²⁴² Pitkin, "Are Children Human?," 4.

assumed to be complete human beings and are included in a theological anthropology that is universal: all humans are in the image of God and all humans are fallen. In contrast to the idealized image, children are no more innocent than anyone else. And in contrast to the negative image, children are no more depraved than anyone else.²⁴³

Christian theology can hold these views of humanity in paradoxical tension, rather than pitting childhood and adulthood against each another. At the same time, notes Pitkin, this theological anthropology does not gloss over the differences between children and adults, but instead promotes ways of viewing their human wholeness at every stage. The aim of nurturing children, then, is not to rush them to the next developmental stage but to recognize their full humanity at every stage, along with the ramifications of sin that likewise affect humans across the lifespan.²⁴⁴

This theological framework offers at least four ways to mitigate the vulnerability caused by seeing children as incomplete human beings. First, says Pitkin, children ought to be affirmed as gifts, rather than seen as property. The sacrament of infant baptism upholds the view of children as gifts, entrusted as such not only to parents but also to a church and the wider community. Second, children are esteemed as full members of the church. Reformed theology in particular includes children as part of covenant membership in the church; this affirmation too is evident in the baptism of infants. Third, Pitkin notes that the church is meant to nurture the spiritual, emotional, physical, and social growth and well-being of children, especially in light of their vulnerable status in an adult-centric culture. The Christian community's obligation to care for the children in its midst is a reminder of the inherent value of children and counteracts any attribution of lower status. Lastly, Christian tradition affirms the complete humanity of children

²⁴³ Pitkin, "Are Children Human?," 8.

²⁴⁴ Pitkin, "Are Children Human?," 8–9.

by seeing them not simply as passive recipients but as active agents of Christian faith and service.²⁴⁵

Pitkin specifies that this latter injunction to see children as active agents is not merely a sentimental valuing of the faith of children, often seen as simple and trusting, but rather an invitation to model the spiritual maturity of children evident in their questions, wrestling, and openness related to faith. Seeing children as contributors to and not just recipients of the communal life of faith can help uphold a theologically robust affirmation of children as full human beings, and this theological foundation can provide a vital alternative to a cultural conception of children as less than complete humans.²⁴⁶

Pitkin's view of children is particularly relevant in the healthcare environment as well. Hospitalized children are more vulnerable from the outset beyond the baseline vulnerability of childhood because of their illness or injury, which poses some degree of additional threat to their well-being, development, and social relationships. Their need for medical care also reflects the vulnerability of children who are at the mercy of a complex bureaucratic medical system, with the degree to which they have access determined by an array of power brokers including their parents, providers, insurance companies, and pharmaceutical manufacturers.

Additionally, as Pitkin remarks elsewhere, children's bodily vulnerability can be augmented by adults who remain preoccupied with moral and psychological aspects of child development. She contends, "We do not honor children's bodies when [we] decry their physical suffering but at the same time omit or downplay their physical nature in our understandings of who they are."²⁴⁷ Because hospitalization brings matters of the body to the foreground,

²⁴⁵ Pitkin, "Are Children Human?," 12-14.

²⁴⁶ Pitkin, "Are Children Human?," 14. I discuss theological perspectives on the agency of children further in chapter 5.

²⁴⁷ Pitkin, Barbara. "Honoring Children's Bodies." *Journal of Lutheran Ethics* 4, no. 1 (January 2004).

definitional vulnerability also relates to adult interpretations of children's suffering and pain. Nowhere is this more evident than in the sobering truth that into the late 1980s, it was standard practice to operate on newborns without anesthesia or pain medicine, based on the assumption that they could not feel pain. Pediatric anesthesiologist Sunny Anand, renowned for his now decades long work in advocating for newborn pain management, recounts the "traditional views" that "led to a widespread belief in the medical community that the human neonate or fetus may not be capable of perceiving pain."²⁴⁸ These views held that because newborns are unlikely to interpret or have memories of painful experiences, they may not experience what was assumed to be the largely subjective experience of pain. Writing in 1988, he observes

One result of the pervasive view of neonatal pain is that newborns are frequently not given analgesic or anesthetic agents during invasive procedures, including surgery. Despite recommendations to the contrary in textbooks on pediatric anesthesiology, the clinical practice of inducing minimal or no anesthesia in newborns, particularly if they are premature, is widespread.²⁴⁹

The sluggish scholarly and scientific momentum in changing clinical practices of using anesthesia and pain relief for newborns certainly reflects a perception of children as less than fully human. Concern about newborn suffering was finally accelerated by dedicated efforts to raise public awareness carried out by an outraged mother named Jill Lawson. Her son, Jeffrey Lawson, was born prematurely in 1986 at 26 weeks' gestation and died several weeks later, following heart surgery. His mother found out after his death that his surgery had been conducted using a paralytic drug to immobilize him, but no anesthesia was used. He had been conscious throughout. Jill Lawson proceeded to share her son's experience widely and wade into the conflicted accounts of newborn pain in medicine and public opinion, "[making] her son's

²⁴⁸ Anand, K. J. S., and P. R. Hickey. "Pain and Its Effects in the Human Neonate and Fetus." *Pre- and Peri-Natal Psychology Journal* 3, no. 2 (Winter 1988), 103.

²⁴⁹ Anand and Hickey, "Pain and Its Effects in the Human Neonate and Fetus," 103.

experience into something of a crusade against what she [saw] as inhumane treatment of infants.”²⁵⁰ Indeed, even widely agreed-upon recommendations may take a long time to shape clinical practice, as evidenced by a 2003 article referencing ongoing inadequate pain management for premature infants in NICUs despite the established scientific knowledge of their ability to experience pain.²⁵¹

Attending to pain and suffering in children

Although attention to children’s physical pain and suffering has increased in recent decades, stories like those of Jeffrey Lawson and so many others reflect a nagging inability or unwillingness on the part of adults who are unable to recognize or perhaps even imagine the possibility of children’s real experiences of suffering. In turn, this slow evolution has hampered adult readiness to respond empathically to such suffering. Characterizations of suffering have been so thoroughly based on adult experience that they categorically exclude children. For instance, “The Nature of Suffering and the Goals of Medicine,” a 1982 article by academic physician Eric Cassell published in the esteemed *New England Journal of Medicine*, repeatedly references the significance of “the past” in a sufferer’s experience—loss of the security or memories of the past, loss of the sense of self known in the past, and so on. Cassell asserts, “A person has a past. . . . It damages people to rob them of their past and deny their memories, or to mock their fears and worries. A person without a past is incomplete.”²⁵² If a basic rendering of

²⁵⁰ Rovner, Sandy. “Surgery Without Anesthesia: Can Premies Feel Pain?” *Washington Post*, August 13, 1986.

²⁵¹ Simons, Sinno H. P., Monique van Dijk, Kanwaljeet S. Anand, Daniella Roofthoof, Richard A. van Lingen, and Dick Tibboel. “Do We Still Hurt Newborn Babies?: A Prospective Study of Procedural Pain and Analgesia in Neonates.” *Archives of Pediatrics & Adolescent Medicine* 157, no. 11 (November 1, 2003): 1058–64.

²⁵² Cassell, Eric J. “The Nature of Suffering and the Goals of Medicine.” *New England Journal of Medicine* 306, no. 11 (1982), 642. See also Cassell, Eric J. “Recognizing Suffering.” *The Hastings Center Report* 21, no. 3 (1991): 24–31.

what it means to suffer must entail having a past that can be remembered or placed in jeopardy, then it is little wonder that the suffering of children was and is difficult to acknowledge and address. There is a substantive connection, I believe, between Cassell's take on suffering and the lack of recognition of suffering in children like Jeffrey Lawson.

Recognition of other kinds of suffering beyond physical pain thus remains vital, especially with respect to children with life-threatening conditions. Operative definitions of children shape care here as well, and philosopher Thomas Attig explores their consequences for children with terminal illness.²⁵³ His work thus resonates with Pitkin's points about how definitions of children are both evident in the way we treat them and also have serious implications for how we treat them. Attig contends that when we see children as "islands of innocence," we fail to take seriously their capacity for existential suffering in the face of terminal illness.²⁵⁴ He notes, "we tend still to think that existential suffering requires advanced cognitive abilities and a spiritual maturity that are common in adults but rare in children, save perhaps for adolescents."²⁵⁵ Attig instead urges that children are not very different from adults with respect to this capacity for existential suffering, and offers ways adults should support children as they cope with terminal illness. Noting that terminal illness disrupts the stories of children's lives just as it does for adults, Attig attests that the experience of suffering as brokenness unravels the patterns of daily life and the "distinctive combination of experiences, activities, expressions, and interactions with others" for children and adults alike.²⁵⁶

²⁵³ Pitkin, Barbara. "Honoring Children's Bodies." *Journal of Lutheran Ethics* 4, no. 1 (January 2004).

²⁵⁴ Thomas Attig, "Beyond Pain: The Existential Suffering of Children," *Journal of Palliative Care* 12, no. 3 (1996): 20.

²⁵⁵ Attig, "Beyond Pain," 20.

²⁵⁶ Attig, "Beyond Pain," 20.

The vulnerability of children facing life-threatening illness is magnified when adults fail to see children's capacity to suffer. While this failure allows adults to be free of distress because they continue to see such children as "unaware and untroubled," their ensuing lack of support and consolation can leave children to cope on their own.²⁵⁷ Denying the existential suffering of children may be motivated by a desire to protect children and a need for adults to protect themselves from vicariously experiencing a child's pain, but it can further mask the suffering and prevent the kind of care most needed. Attig urges caregivers to appreciate the ways in which children's own personal experiences, more so than their age or intellectual development, shape their perspectives on illness and its meanings. This attentiveness can allow for greater support for children, but only if adults are willing to create a secure place where "expression of children's existential anguish is clearly allowed and welcomed and where the need for comfort is recognized."²⁵⁸

Strong echoes of Attig's points emerge in a recent commentary by Amy Robertson, a physicist in her mid-30s who was diagnosed with juvenile arthritis at age 2. Reflecting on "some of the meta-messages about bodies that I internalized through a lifetime of regular interactions with medical culture," her first such message was that "my body belongs to other people," which she gleaned from having decisions made about her body without her consultation or consent.²⁵⁹

She goes on to describe another meta-message:

A second message I internalized was that adults, including medical professionals, need me to not express my pain. I saw that when I showed my pain the medical professionals around me became frantic, emotionally distant, sad, or forceful in their actions toward my body. I wanted these people, whom I cared about, to be okay. To make things okay, I became what I felt they needed me to be: cheerful, brave, and compliant. I buried my pain to save them from their own and to save myself from feeling their pain alongside

²⁵⁷ Attig, "Beyond Pain,"21.

²⁵⁸ Attig, "Beyond Pain,"23.

²⁵⁹ Robertson, Amy D. "What I Learned From My Childhood as a Patient: Internalized Messages About Bodies." *JAMA Pediatrics*, June 24, 2019, E1.

them. I was praised for my bravery in not crying during blood tests and for my determination in completing physical therapy.²⁶⁰

Robertson names how these and other messages have fostered an inclination toward feelings of profound disembodiment. She laments the resulting “fundamental distrust of my body, symbolizing a deep rejection of myself,” and the loss of the wisdom she knew her body could offer. She urges medical professionals to respond by “invit[ing] patients to participate in their health care as embodied, agentive humans with powerful healing potential.”²⁶¹ This brief commentary leads me to wonder how many other such narratives will be written as a growing number people will reach adulthood after having spent extensive time as children in the hospital environment. It leads me to wonder as well about the untapped possibilities for empowering children beyond simply affirming their compliance with care and actually fostering stronger, wholistic understandings of their bodies and the wisdom of how their identities interact with their bodies, no matter their physical condition.

“I don’t want to be a hero”

I recall the distress of a pediatric ICU nurse who was tending to a nine-year-old boy in his final days. She was grappling with his existential suffering and her own lack of permission to engage it. The boy was dying of complications from many years of treatment after having been diagnosed as an infant with a rare cancer. Like many pediatric cancer patients whose disease does not respond to established treatments, he had spent much of his life in hospitals as his parents sought experimental treatment far from home. His loving, dedicated mother, like many mothers in similar situations, adamantly refused to talk to him about the question of whether he

²⁶⁰ Robertson, “What I Learned From My Childhood as a Patient,” E1.

²⁶¹ Robertson, “What I Learned From My Childhood as a Patient,” E1.

would survive his illness. Hospital staff tried to respect her preference but also struggled mightily with what to say when the boy constantly said, “I want to go home,” as they knew he would never make it out of the hospital again.

Because of the long duration of his cancer treatment at many institutions and the power of social media to amplify his story, this boy’s story was publicly known to multitudes of people who cheered him on and followed his journey both in his home state and in the state where he was being treated, as well as on a national level by those who had followed his family’s efforts to advocate for greater resources for childhood cancer patients. On this particular day his nurse emerged from his room in tears, struggling with what he had just expressed while his mother was out of the room. “I don’t want to be a hero,” he said, clearly knowing that his survival thus far had inspired many people to label him as one. The narrative of a young fighter whose family never gave up and who always overcame obstacles left little room to equip him or his family to honor his suffering openly as death approached.

Unfortunately, the themes of this young boy’s story are all too common, given how often stories of very ill children become emphatically sentimentalized and sensationalized. In my chaplaincy work I have witnessed on countless occasions this kind of valorization of children’s pain and suffering, imbued with pity as well, and although it usually stems from sincere efforts to encourage and support, it can also stunt the possibilities for engaging children in the full range of their experience. Often this is attributable more to adult discomfort with the existential suffering than anything else, as with Robertson’s experience described above. Affirming this kind of imposed adult interpretation of children’s suffering also encourages children to censor their expressions of suffering when they sense doing so would fall outside the boundaries of what is expected of them. It is not surprising, then, that children like the boy described above choose to

name their honest feelings with someone like a nurse instead of an immediate family member. All who hope to care well for hospitalized children, whether as a parent or professional caregiver, ought to consider the high stakes of our definitions of children and how we engage our care accordingly. We ignore them at our peril and to the profound detriment of the children who beckon us to witness their struggles and triumphs more fully.

Marketplace vulnerability

In addition to the vulnerability that ensues from the way children are defined theologically and philosophically, vulnerability also stems from how they are defined in the healthcare marketplace. Postindustrial capitalism continues to have extensive influence on the medical industry in the United States—if even healthy children are measured by society as “adults to be,” then sick children whose trajectory toward the assumed capabilities of adulthood might be delayed, complicated, or curtailed altogether are vulnerable to being less valuable in a society increasingly organized around market-driven factors. The market-driven character of healthcare imposes additional layers of vulnerability for children in hospitals. It shapes immediate aspects of their care through a technological imperative that favors sophisticated and extensive intervention yet also dictates access and affordability of care based on the vicissitudes of insurance companies and other stakeholders. The drive for profitability underlies marketplace medicine as well. This is true especially in settings like neonatal intensive care units (NICUs) that are often key sources of profit for hospitals, producing revenue that exceeds most other departments and specialties. Pediatric bioethicists John Lantos and William Meadow assert that “The NICU has become the economic engine that keeps our children’s hospitals running. The survival of hospital-based pediatrics as we know it is increasingly on continued commitment to

the technologies and the personnel that enable the survival of extremely premature babies.”²⁶²

Their assessment reveals the manifestation of what pioneering neonatologist Mildred Stahlman had warned her peers about years earlier, stating

The potential for enormous financial gain that has developed around newborn intensive care, for physicians, for hospitals, and for companies producing highly technical instruments or new drugs, also may have serious consequences for the ethical practice of medicine. Big money breeds greed, not selfless service, and neonatologists are not immune to temptation. The ethics of the marketplace has never been thought appropriate to provide the standards for ethics to be applied to the practice of medicine. This gradual and subtle shift of the responsible sense of service to one of a business mentality, not so new in other disciplines, is now pervading the practice of neonatology, to its detriment.²⁶³

Stahlman’s prescient words remain sobering for those who would seek to guide their practice by ideals of service and patient-focused care, but who do so in the midst of powerful and ubiquitous market realities that shape the conditions for care in the first place.

Catholic ethicist Charles Camosy also examines the healthcare marketplace in relationship to neonatal intensive care and describes the resulting “culture of overtreatment” in American NICUs, identifying profitability as a key component, along with the perspective of parents who fear what they see as giving up and who “want everything done” for their baby.²⁶⁴ Reflecting on Catholic social teaching’s imperative to pursue the common good, Camosy raises concerns about the extremely disproportionate share of limited health care resources directed toward imperiled newborns. Camosy names improperly regulated market forces, along with a technological imperative that treats technological innovation as an end in itself, as sinful social structures that drive the profitability of the NICUs and detract from the common good. He sees

²⁶² Lantos, John D, and William Meadow. *Neonatal Bioethics the Moral Challenges of Medical Innovation*. Baltimore: Johns Hopkins University Press, 2006, 131.

²⁶³ Stahlman, Mildred T. “Ethical Issues in the Nursery: Priorities versus Limits.” *The Journal of Pediatrics* 116, no. 2 (1990), 170.

²⁶⁴ Camosy, Charles. *Too Expensive to Treat?: Finitude, Tragedy, and the Neonatal ICU*. Grand Rapids, Mich.: W.B. Eerdmans Pub. Co., 2010, 158.

in the culture of overtreatment in NICUs a failure to recognize that the market cannot satisfy important human needs, for not all such needs can be commodified.²⁶⁵

Certainly, modern medicine confers very real benefits to children who in earlier generations were afflicted in countless ways by diseases and conditions for which there are now vaccines, medications, surgery, and dizzying new therapeutic options. Without dismissing these valuable contributions, it is nonetheless important to assess what it means for children that healthcare in the US has evolved not as a public good automatically available to all but as an industry modeled on the ways of businesses and consumer-led sectors of society. Focusing on the general population and not just children, pastoral theologian Abigail Rian Evans explores this history and points out that a market exchange mentality is ill-suited to care for the sick in general, asserting that “The marketplace is not the appropriate arena for patients weakened by illness who cannot defend their rights or negotiate their needs.”²⁶⁶ Moreover, marketplace medicine creates divided loyalties for physicians, as the structure of managed care and its financial incentives often creates conflict with what ought to be a doctor's first obligation to patients.²⁶⁷ This amplifies the medical model as society's prioritized definition of health, says Evans, and gives ongoing legitimacy to overuse of technology and to the exorbitant costs of healthcare, which result not from medicine's failures, says Evans, but from its successes relative to its internal aims.²⁶⁸

In the marketplace of healthcare, however, success for the industry and institutions of healthcare does not translate directly into thriving for patients and families. Pediatric oncologist

²⁶⁵ Camosy, *Too Expensive to Treat?*, 163.

²⁶⁶ Evans, Abigail Rian. *Redeeming Marketplace Medicine: A Theology of Health Care*. Cleveland, Ohio: Pilgrim Press, 1999, 15.

²⁶⁷ Evans, *Redeeming Marketplace Medicine*, 15.

²⁶⁸ Evans, *Redeeming Marketplace Medicine*, 49.

Raymond Barfield describes the pressures that make it particularly difficult to “stand by... children and their families when you don’t know how to save the patient.”²⁶⁹ He observes,

Modern medicine discourages doctors from getting to know the human beings they are treating. A physician is given twenty minutes with a patient, and then the doctor’s performance is judged based on how much revenue was generated for the medical institution. It’s not that the institution doesn’t care about humanity; it’s that the institution doesn’t know humanity. The hospital administration spends its energy on finance, risk management, and documentation. I have a lot of respect for people who enter administration, because they are up against enormous forces. But many of their attempts to do good work end up causing agony for the sick and for those who care for them.²⁷⁰

Layers of bureaucracy and revenue-driven priorities create amplified vulnerability for pediatric patients who are excluded from the power dynamics that shape their care and thus precariously rely on others to make provision for them. Even their adult parents and caregivers are often subject to overwhelming constraints when they try to advocate for children.

As I continue to emphasize the importance of recognizing and responding to children as fully human in the hospital setting, I can’t ignore the countless mental pictures I carry of stressed parents in vinyl recliners, seated next to their ill child’s bed or crib and surrounding monitors, machines, and IV poles, sifting through paperwork from insurance providers, hospital entities, specialist providers, durable medical equipment companies, pharmacies, and so on, trying to sort out which bill to pay, which denied claim to contest, which prescription to ask for, which appointments need scheduling. We cannot expect parents or others to attend more fully and humanely to children without honestly appraising the substantial impediments that have evolved to prevent them from doing so, siphoning attention away from an engaged presence with children and clouding minds with anxiety and overwhelming obligations.

²⁶⁹ Barfield, Raymond. “The Miracle In Front Of You.” Interview by Janice Lynch Schuster. *The Sun Magazine*, January 2016, 6.

²⁷⁰ Barfield, “The Miracle In Front Of You,” 6.

Children as burdens in a market anthropology

Roman Catholic moral theologian Todd David Whitmore further illustrates the vulnerability that accrues to children by the way they are defined. He articulates how the market delimits definitions of all human beings and of children in particular. Especially as health care continues to adopt market language that shapes the way patients and providers engage with one another, the impact of this change on children must be taken seriously, because once again they are disproportionately affected in a way that renders them vulnerable to forces over which they have no say.

Whitmore notes the relative dearth of Catholic teaching on children, keenly identifying some of the most problematic aspects of the market mindset that enters the vacuum left by underdeveloped theology, and describing what ensues when an unhindered and uncritical market approach is allowed to functionally define children and childhood. Tracing the emergence of the market mindset through the Western historical shifts from agrarian to industrial society, Whitmore revisits how the economic and domestic spheres came to be separated and how this impacted families and children.²⁷¹ He posits that even the arrangement of having one parent work outside the home while the other tends to domestic life was also probably a fleeting phenomenon, if not one that is perennially reserved for those who can afford it. Aside from the debates about professional nonparental care for children, Whitmore contends that the movement of economic activity out of the domestic sphere created a dynamic by which substantial amounts of care for children also moved out of the domestic sphere. This movement meant that children became subject to the formative influences of larger economic systems beyond the preferences of

²⁷¹ Whitmore, Todd. "Children and the Problem of Formation in American Families," *Annual of the Society of Christian Ethics*, January 1, 1995, 269–70. For more on how the shift from agrarian to industrial society shaped views of children as assets and burdens, see Miller-McLemore, Bonnie J. *Let the Children Come: Reimagining Childhood from a Christian Perspective*. Families and Faith Series. San Francisco, CA: Jossey-Bass, 2003, 2-6.

their own families.²⁷² Whitmore thus contends that the question of *who a child is* gets established by the larger forces of the market. In the economic machinations of contemporary society, he says, the logic of how to define children will necessarily turn on adult self-interest—for example, the child may be considered as capital, or as an investment of her parents.²⁷³

Whitmore warns that without a theological articulation of who or what children are, we easily become captive to overextended market logic, a phenomenon which he sees as “one of the most pervasive and therefore significant dangers” for children.²⁷⁴ Such religious articulation in the Catholic tradition, however, is currently limited to discussion of the family unit more generally and falls short of clarifying why children have rights or why adults should be obligated towards them.

Whitmore describes how the overextension of the market drives a three-part anthropology. This market anthropology bears heightened consequences for children, who are more easily victimized and threatened by an overzealous market economy where everything is measured by exchanges. The first component of this market anthropology, says Whitmore, is that persons are portrayed as commodities. In the capitalist system, the worker produces labor or merchandise that is sold to the employer, and this instrumentalization of both the production and of the worker exemplifies a market mindset where everything is understood in terms of exchange, where goods that are not commodities are unrecognizable.²⁷⁵ The second component of a market anthropology portrays persons as consumers, and in a consumer society, explains Whitmore, “persons have value only insofar as they can purchase commodities. The market can

²⁷² Whitmore, "Children and the Problem of Formation," 269.

²⁷³ Whitmore, "Children and the Problem of Formation," 273.

²⁷⁴ Todd Whitmore (with Tobias Winwright), “Children: An Undeveloped Theme in Catholic Teaching,” in *The Challenge of Global Stewardship: Roman Catholic Responses*, ed. Maura A. Ryan and Todd Whitmore (Notre Dame, Ind: University of Notre Dame Press, 1997), 163.

²⁷⁵ Whitmore, "Children: an Undeveloped Theme," 169.

expand only if persons buy products.”²⁷⁶ Rather than having intrinsic worth, a person is deemed valuable in society by contributing to the ongoing exchange of products and labor. Not only does this contradict the core theological claim of humanity’s intrinsic value as image-bearers of God, but it perpetuates extreme inequalities. Rampant inequality is certainly evident in contemporary access to healthcare, where medical needs are often addressed based on one’s ability to pay.²⁷⁷ The third component of the market anthropology follows logically from the first two. If a person is unable to be of use to the capitalist system by being a commodity or a consumer, then that person is necessarily a burden. Since the market does not confer intrinsic dignity to anyone, the status of burden is easily placed on those who are not contributing to the system of exchange. This category can thus include the poor, elderly, and children. Whitmore explains, “when persons are neither commodities nor consumers, they are nonentities; their claims for recognition are understood as burdens.”²⁷⁸

A recent commentary by Hala Durrah, a health care advocate and parent of a chronically ill child, illustrates the deficits of the patient-as-consumer trend prevalent in healthcare currently, and I believe her depiction of her daughter’s experiences illustrates how children, as among those who do not produce or consume, function as burdens in a system predicated on supposed consumer choice. Her daughter Ayah became sick shortly after birth and required a liver transplant by age five. Describing painful medical procedures, agonizing pain and other symptoms, and the accompanying stress of uncertainty about her daughter’s prognosis, Durrah reflects, “I do not know of any ‘consumer’ experience that would encapsulate all of that—the sheer sadness or the raw emotions of it all. How do we use a word like *consumer*, which usually

²⁷⁶ Whitmore, "Children: an Undeveloped Theme," 170 .

²⁷⁷ Durrah, Hala. “My Child Is Sick; Don’t Call Her A ‘Consumer.’” *Health Affairs* 38, no. 3 (2019): 502–505.

²⁷⁸ Whitmore, “Children: an Undeveloped Theme,” 175.

implies a choice, in an industry in which the ability to make our own choices is rare, and in which no one chooses to become sick?”²⁷⁹ Durrah goes on to note other discordant features of health care in comparison to consumer activity, including the lack of awareness about what the cost of any of their care will be, and the way which her daughter’s trusted caring medical providers aren’t inclined to see her daughter as a consumer either—they too recognize that the relationship of communication, compassion, and empathy is far more than will ever emerge from a consumer’s brand loyalty to a certain product.²⁸⁰ As Durrah sees it, the use of consumer language may have been intended to empower patients in their care, but it neglects the equally necessary work of addressing systemic shortcomings whose remedies are beyond the reach of any individual patient, no matter how savvy and empowered of a shopper he or she may be.

Whitmore puts forward a threefold theological rejoinder to this problematic market anthropology that relegates persons to categories of commodities, consumers, and burdens. He describes theological grounding for understanding children as gifts of creation, as image-bearers of God, and as signs of a future that points far beyond the self-interested desires of adults.²⁸¹ Proposing a correlating response to children shaped by faith, hope, and love, Whitmore enjoins Christians to embrace children as gifts rather than commodities as the market would identify them. He likewise insists that because children are created in the image of God and inherently valuable, they ought not be regarded as a means to an end by anyone or any institution, including parents who would rather fashion children in their own image. Finally, says Whitmore, as signs of a future that extends beyond adult desires, children remind us that our future is centered

²⁷⁹ Durrah, “My Child Is Sick; Don’t Call Her A ‘Consumer,’” 503.

²⁸⁰ Durrah, “My Child Is Sick; Don’t Call Her A ‘Consumer,’” 503-504.

²⁸¹ Whitmore, “Children: an Undeveloped Theme,” 177-178.

around God.²⁸² This emphasizes the need to form children in identities of faith that will equip them to contribute to the common good rather than to rampant market forces. Whitmore describes our responsibility toward children as stewardship,²⁸³ and I believe this aptly depicts a fitting adult response to the vulnerabilities present in hospitalized children as well. Stewardship evokes care that is conducted with a deep respect for that which has been entrusted, rather than a perfunctory means to an end defined by one's own aims. Such care can witness to faith, hope, and love as enduring realities in the child's theologically envisioned identity, no matter the extent of their abilities or needs. Stewardship orients care of the vulnerable within a wider frame where responsibilities stem as a gracious response to gifts that have been entrusted; this contrasts sharply with a market mentality where the influence of revenue streams can inhibit efforts to see the vulnerable as anything other than a burden to be accommodated or perhaps avoided altogether. Unfortunately, principlist ethics has too often colluded with the same value judgments implicit in the marketplace. In both, vulnerability is cast as a deficit to be dealt with by those in power, reinforcing an implicit corresponding concept of an idealized autonomous decision-maker who has somehow transcended vulnerability's perils altogether. This dichotomizing of vulnerability and autonomy is deeply problematic and obscures the layers and shades of vulnerability that pervade all human life.

Vulnerability as Divine Attribute

Theologian David Jensen is singular in looking at vulnerability both as an essential component of children's reality and, even more importantly, as a value at the core of the Jewish

²⁸² Whitmore, "Children: an Undeveloped Theme," 176-179.

²⁸³ Whitmore, "Children: an Undeveloped Theme," 180.

and Christian theological traditions, and hence he provides vital insight for the theological anthropology I propose. A Protestant systematic theologian with a bent toward thinking theologically about concrete matters, he offers a more in-depth look at the theological significance of children's vulnerability in his book *Graced Vulnerability: A Theology of Childhood*.²⁸⁴ Jensen considers the ways in which children have been defined throughout the course of Christian tradition and, similar to Pitkin and Miller-McLemore, the broad strokes of innocence or depravity with which they have been depicted. As with Whitmore, Jensen too wants to counteract unhelpful views of children that regard them as less than fully human. He takes issue with thirteenth-century theologian Thomas Aquinas' emphasis on the importance of developing reason, saying that it leads to seeing children as incomplete and regarding development as a series of stages where previous ones are superseded entirely by subsequent ones.²⁸⁵ In Aquinas' view, as Catholic theologian Cristina Traina describes, stages within childhood are delineated by the development of reason. Aquinas held that reason began to emerge around age seven and that by about age 14 children entered into a fuller state of capacity for rational choice, coinciding with puberty and its concomitant potential for commitment to relationships such as marriage or taking on holy orders.²⁸⁶ Traina sums the enduring legacy of Aquinas' views of childhood: "What Thomas bequeaths first of all is a theological justification for a developmental model of childhood."²⁸⁷ Despite the internal cohesion of Aquinas' framework of human development, its basis in the overall aim of rational development is

²⁸⁴ Jensen, David H. *Graced Vulnerability: A Theology of Childhood*. Cleveland: Pilgrim Press, 2005.

²⁸⁵ Jensen, *Graced Vulnerability*, 9.

²⁸⁶ Traina, Cristina. "A Person in the Making: Thomas Aquinas on Children and Childhood." In *The Child in Christian Thought*, edited by Marcia J. Bunge, 103–33. Grand Rapids, Mich: W.B. Eerdmans, 2001, 112-120.

²⁸⁷ Traina, "A Person in the Making," 129.

problematic for those like Jensen who want to decouple rational capabilities from measures of human maturity.

Jensen suggests instead that children reflect the *imago dei* not by passing through stages toward adulthood but in their very manifestation of human vulnerability, which endures throughout human life stages and, he boldly asserts, reflects the character and action of God. For Jensen, vulnerability is apparent in the way in which God opts for covenant relationship with finite human beings. In covenant, Jensen sees an embrace of difference and diversity, where the God who creates such variety is also inclined to be in relationship with that variety rather than limit relationships to only divine ones. “God chooses to relate to others who are *not God*,” Jensen summarizes, highlighting the significance of the power differential bridged through gracious intention.²⁸⁸ Moreover, Jensen sees God’s willingness to enter covenant relationship with figures who would typically be outsiders as further evidence of God’s identification with vulnerability. “Indeed, covenant itself blurs the distinctions between insiders and outsiders,” he contends.²⁸⁹ This inclusion extends to the children of such outsiders as well, as Jensen remarks: “As Israel heard the cries of the vulnerable children in its midst, it did not draw the line between children worthy of care and those who were not. All children, regardless of heritage, were blessings of God entrusted to the community’s care.”²⁹⁰ The fullest expression of this vulnerability comes with the incarnation, the belief that God became enfleshed in the person of Jesus Christ, the divine intentionally joining the outsider status of human being. In the basic human vulnerability of being born as an infant, and in the searing vulnerability of dying by crucifixion, Jesus exemplifies what it means to be vulnerable: “to expose oneself to possible harm and injury—to

²⁸⁸ Jensen, *Graced Vulnerability*, 16.

²⁸⁹ Jensen, *Graced Vulnerability*, 17.

²⁹⁰ Jensen, *Graced Vulnerability*, 3-4. Here Jensen draws on Exodus 22:21-22, which refers to the command not to oppress the alien and not to abuse any widow or orphan.

live on the edge, open to the world's profound beauty and its threatening violence."²⁹¹

Furthermore, a vital facet of this understanding of divine engagement with vulnerability lies in the way that vulnerability is not an essence but a characteristic of relationship. Vulnerability therefore is not primarily an essential feature of childhood but emerges in the midst of difference in the relationships that mark children's lives. Children are vulnerable *to others*, and Jensen emphasizes that this God-given relatedness is a vulnerability into which all people are born and which no one outgrows.²⁹² For Jensen, locating and identifying vulnerability with the divine being is an emphatic call to respond to the myriad ways in which children's vulnerability is overlooked or exploited, whether through poverty, sex trafficking, violence, or disease.

Jensen's work invites us to consider how issues of power relate to vulnerability. If vulnerability is manifest not as an essence of childhood but as a quality borne out by relationships, then the differentials of power and how power is understood or exercised will have great bearing on whether vulnerability is rightly appreciated or exploited among children in healthcare settings. Vulnerability elicits care, but the shadow side of such care is that it can proceed without regard for recognizing or empowering the vulnerable person. Caregivers can hoard power and authority and reinforces a passive, less-powerful role for the recipient of care, and this is abundantly true when the recipient's needs are readily apparent, as with hospital patients. Jensen depicts a response to vulnerability animated by a divine love that yields power in order to enter into a relationship of mutual love and care, where power is directed for the good of the other. In the incarnation, the divine expression of ultimate power is profoundly manifest in a physically vulnerable human infant, reflecting a divine solidarity with the basic vulnerabilities of

²⁹¹ Jensen, *Graced Vulnerability*, 19-21, 25-26, 47.

²⁹² Jensen, *Graced Vulnerability*, 49.

childhood. Caregivers of children would do well to model such a bridge, drawing near to those with less power and neutralizing any misuse of power, rather than distancing themselves and taking advantage of what can otherwise remain an unhelpful power differential.

In such moves of drawing near, adult caregivers may discover a shared vulnerability hidden behind a child's more readily apparent vulnerabilities. Parents and clinicians are vulnerable too—to the uncertainty that confronts them, to the moral distress that can emerge from ethically fraught situations, to the anxieties about all the possible outcomes of any medical decision, and to the impact of such outcomes on a child's identity and quality of life. Locating vulnerability in the relationships and not just in the patient can foster recognition of just how deeply our needs are entwined.

Conclusion

Hospitalized children share aspects of vulnerability in common with other children and with other hospitalized persons, but their particular vulnerability also extends to include distinct features. Unlike the experiences of adults who encounter illness or injury as an interruption of well-established patterns of life and ability, children, especially of very young ages, may experience the conditions that require their hospitalization as a totalizing overhaul of their budding identities. Thus, not only are hospitalized children vulnerable in a different way than hospitalized adults, they are also vulnerable in ways that surpass the more straightforward vulnerabilities of childhood in general posed by immaturity in physical and cognitive development. They are also rendered vulnerable by operative cultural definitions of sick children that undermine their full humanity, and by being implicated in systems that functionally define

them, such as the American marketplace model of healthcare that grants voice and power to those who produce and consume.

The layered realities of vulnerability for hospitalized children reveal the insufficiency of the principlist approach with respect to vulnerable populations, which consists of protecting vulnerable populations. Ensuring protection alone cannot be a comprehensive response to the kinds of vulnerability described above. Such vulnerability warrants greater recognition and inclusion of children especially. It is possible to uphold a standard of protection and yet stop woefully short of a fuller understanding of the perspectives and experiences of those in need of it. Protection alone does not exhaust the ethically warranted response to vulnerability. Efforts to protect may even unwittingly become complicit in reinforcing limited views of children, by overshadowing their identity with an exclusive focus on those who have the power to protect. Furthermore, when vulnerability is regarded in bioethics as an unfortunate and sometimes temporary condition, it bypasses engagement with the basic vulnerability that marks all of human life, the vulnerability which is not anomalous but normal and enduring. Jensen's theological elevation of vulnerability engages with this truth, providing a narrative where vulnerability is a divinely embraced universal human reality rather than an exception to be accommodated. As with vulnerability, dependence can likewise be easily oversimplified as a condition of reliance on others to meet one's needs—children are routinely and succinctly referred to as “dependents,” for instance, even though that nomenclature reflects only one aspect of who children are, albeit a very salient one. Theological perspectives on dependence can expand a narrowly conceived notion of dependence and enrich our regard for those whose dependence is most stark. The following chapter pursues these inquiries, exploring dependence as a second emphasis in a theological anthropology of hospitalized children.

Chapter 4

Dependence: human norm, not deficit

Children are dependent on others to have their basic needs met—our society assumes this and uses phrases like “helpless” to describe the youngest among us who need comprehensive assistance. When I visit patients in our adult hospital units, a discussion of their ability to perform “activities of daily living” is often underway with other staff members who are trying to gauge a patient’s recovery or loss of function and whether they will need outside resources to help them conduct everyday tasks like feeding, bathing, dressing, and getting around. In contrast, we don’t talk in the children’s hospital about whether pediatric patients are independently proficient in “activities of daily living” because we understandably treat them from the outset as being *dependent* minors in the care of at least one adult who provides such support and sustenance. While this kind of obvious dependence describes vital features of children and their needs, it does not extend into further meanings of dependence that also can inform our understanding of who they are and how their needs interact with the needs of others. In this chapter I investigate theological perspectives that expand dependence by considering the breadth and depth of relationships that shape all individuals. This enhanced understanding of dependence has a lot to offer in the context of principlist ethics and its focus on decisions, where children can too easily be simply portrayed as utterly dependent, requiring the help of others not only for their day-to-day needs but also to speak for them in decisions about their medical care.

But there is more to dependence than being non-autonomous as a decision-maker, and even those ostensibly autonomous adults making decisions for children are caught up in tides of dependence as well. Ethicists Larry Churchill and David Schenck provide a compelling example of the multifaceted influences that shape surrogate decision-making, noting that many people in

such roles undertook decisions with a keenly relational and narrative approach.²⁹³ Rather than focusing on abstract concepts of right or wrong, these individuals sought to fulfill a role toward their loved one, assessing along the way what various decisions would mean for their loved one's fulfillment and possibilities going forward. This tendency was evident as well in a group of parents of babies diagnosed prenatally with spina bifida who were given the option of pursuing maternal-fetal surgical intervention. In the interviews, some couples indicated that what helped their decision-making process was to envision future conversations with their as-yet-unborn child. Churchill and Schenck write, "For several couples, their story included an anticipated conversation 10 years in the future in which the couple is trying to explain to the child the reasons for the choice to accept or decline the prenatal surgery."²⁹⁴ In addition to whatever considerations these parents may have been weighing in regard to their child's best interests and the risks and benefits they were willing to face, they were also exploring what it meant to live into their role as parents, and anticipating the relational import of their decisions even before their children had even been born. Their decisions were not independent adult actions but actually dependent on what they took to be the dynamics of the parent-child relationship that their decisions would impact.²⁹⁵

I argue in this chapter, then, that although dependence can simplistically be regarded as a disadvantageous state and as something which human beings are meant to outgrow, it ought to be

²⁹³ Churchill, Larry R., and David Schenck. "One Cheer for Bioethics: Engaging the Moral Experiences of Patients and Practitioners beyond the Big Decisions." *Cambridge Quarterly of Healthcare Ethics: The International Journal of Healthcare Ethics Committees* 14, no. 4 (2005): 389–403.

²⁹⁴ Churchill and Schenck, "One Cheer for Bioethics," 396.

²⁹⁵ Similar relational themes of the importance of fulfilling a role are present in recent pediatric psychosocial oncology literature, where the concept of being "a good parent" emerged as a guiding factor in parental decision making for children nearing end of life. See Hinds, Pamela S., Linda L. Oakes, Judy Hicks, Brent Powell, Deo Kumar Srivastava, Sheri L. Spunt, JoAnn Harper, Justin N. Baker, Nancy K. West, and Wayne L. Furman. "'Trying to Be a Good Parent' As Defined By Interviews With Parents Who Made Phase I, Terminal Care, and Resuscitation Decisions for Their Children." *Journal of Clinical Oncology* 27, no. 35 (October 5, 2009): 5979–85.

better understood and valued as a lifelong feature of human selfhood and relationships. Hospitalized children, as a population whose dependence is more starkly visible, cast human dependence in bold relief and confront the individualistic tenor of dominant approaches to healthcare for adults and children alike. Following the previous chapter's discussion of vulnerability, the present chapter explores dependence as a second feature of a theological anthropology of hospitalized children. I push beyond easily appreciated versions of dependency toward a more profound appraisal of the baseline realities that counteract straightforward notions of independence. Further demonstrating pastoral theology's relevance for pediatric clinical ethics, I draw heavily on pastoral theologians who have elaborated on themes of dependence in ways that invite crucial reconsideration of individualistic approaches to identity and social relationships.

A key premise for this chapter is that, along with its narrow regard for children, principlist medical ethics has a constricted understanding of dependence. Moral philosopher Alasdair MacIntyre's work provides insight into the philosophical aversion to human dependence that undergirds this constricted understanding, and feminist ethicists have critiqued this aversion and made further inroads into articulating a relationship of compatibility between autonomy and dependence. I discuss both MacIntyre and feminist approaches and their limitations in regard to children before exploring the concept of the "living human web" in the second section as a vital theological response to limited and disparaging accounts of dependence. This metaphor was first articulated by Bonnie Miller-McLemore, and it both corrects and expands the prior concept of the "living human document" first popularized in pastoral theology by Charles Gerkin. Within the metaphor of the web, dependence is recast as a social reality rather than an

individual deficit, and this provides footing from which to better understand the systemic dynamics that influence ethical deliberation in healthcare settings.

Having situated dependence within the complex network of social realities in which all individuals are embedded, I take a further step in the third section to argue that dependence is also manifest in the relationships that are necessarily for the self to emerge in the first place. Pastoral theologian Archie Smith's early work on the "relational self" provides grounds for seeing social relationships as part of the very makeup of the self, and his portrayal of false ideology as the human predicament offers a means of liberation from negative interpretations of dependence. The work of Ian Burkitt and Barbara McClure also bolsters this claim that selves are not only embedded in relationships, but relationships are also embedded in the very composition of the self.

Finally, I contend that the dependency of children in healthcare specifically must be re-envisioned as well, from a deficiency that needs to be supplemented by the actions of others, to an integral component of what it means for them to embody the fullness of human experience. To this end, I employ pastoral theologian John Swinton's work to re-envision dependence by distinguishing, as he does, between inclusivity and belonging, where the former simply means accommodating the presence of those with pronounced dependencies and the latter implies a sense of incompleteness without the contributions of those with dependencies. This perspective paves the way for elevating the important contributions of hospitalized children and avoids a reductionist attitude that might otherwise refer to them primarily based on the needs that others must meet for them. The voices woven throughout the chapter create a tapestry better reflective of the common, shared reality of dependence, and the multi-directional dependencies that exist

even in situations that tempt us to oversimplify the stark needs of some and the abilities of others to meet those needs.

Dependence in medical ethics

In situating dependence within a pastoral theological anthropology, I want to highlight how it contrasts with the portrayal of dependence that emerges from the principlist model of medical ethics. The principle of respect for autonomy reflects an understanding of autonomy as a capacity that an individual either possesses or lacks: as Beauchamp and Childress describe, “The autonomous individual acts freely in accordance with a self-chosen plan... A person of diminished autonomy, by contrast, is in some respect controlled by others or incapable of deliberating or acting on the basis of his or her desires and plans.”²⁹⁶ Dependence thus represents an aberration from the norm, a deficit whereby outside interference or assistance mars the individual self’s governance and renders one in need of a spokesperson who can adequately advocate for one’s interests. Dependence gets characterized as an individual trait, a demerit on the ledger of what reasonable people are presumed to possess. Though Beauchamp and Childress do not make specific reference to dependence in this way, I infer their position from their extensive emphasis on competence and incompetence. They put great stock in the definition and assessment of an individual’s ability to demonstrate competence in the tasks of decision making and they carefully address the measures necessary, through forms of protection and surrogate decision making, to compensate when there is determined to be a lack of competence in a patient or research subject.²⁹⁷ The resulting categories of persons are thus divided into those in need of

²⁹⁶ Beauchamp, Tom L, and James F Childress. *Principles of Biomedical Ethics*, 6th ed., New York: Oxford University Press, 2009, 99.

²⁹⁷ Beauchamp and Childress, *Principles of Biomedical Ethics*, 6th ed., 112ff.

help and those able to provide help, an overly brittle, one-dimensional reading of the persons caught up in the pathos, complexity, and uncertainty of ethically challenging clinical scenarios.

Scottish philosopher Alasdair MacIntyre describes this phenomena well in his book *Dependent Rational Animals: Why Human Beings Need the Virtues* where he reflects on his own earlier work in *After Virtue: A Study in Moral Theory*.²⁹⁸ MacIntyre, whose work has had tremendous influence on theological studies and Christian ethics, assesses that in his theoretical approach to moral development he did not factor in consideration for the biological basis of human development and the realities that accompany it.²⁹⁹ He remarks that most moral philosophy likewise casts “the ill, the injured, and the otherwise disabled...almost always exclusively as possible subjects of benevolence by moral agents who are themselves presented as though they were continuously rational, healthy, and untroubled,” an approach which prompts us to think of the disabled as a “separate class, not as ourselves as we have been, sometimes are now and may well be in the future.”³⁰⁰ This description coheres with how the principlist approach has set autonomy and dependence in contrast rather than seeing dependence as an enduring reality still manifest in degrees in those we deem to be autonomous decision makers. MacIntyre wonders, as do I, what difference it would make to see vulnerability, affliction, and “the related facts of dependence” as a central, not peripheral, feature of the human condition.³⁰¹

MacIntyre arrives at what he seems to see as a groundbreaking conclusion, that the virtues required for developing into independent rational agents must be understood in relationship with those virtues needed for our ability to respond to vulnerability and disability in

²⁹⁸ MacIntyre, Alasdair C. *Dependent Rational Animals: Why Human Beings Need the Virtues*. Chicago, Ill.: Open Court, 1999; MacIntyre, Alasdair C. *After Virtue: A Study in Moral Theory*. Notre Dame, Ind.: University of Notre Dame Press, 1981.

²⁹⁹ MacIntyre, *Dependent Rational Animals*, x.

³⁰⁰ MacIntyre, *Dependent Rational Animals*, 2.

³⁰¹ MacIntyre, *Dependent Rational Animals*, 4.

others as well as ourselves.³⁰² He calls for “virtues of acknowledged dependence” alongside virtues of independent rational agency, contending that both are necessary for realizing human potential.³⁰³ His influential work in virtue ethics nonetheless still aligns with adult-centric approaches, especially evident when we consider virtue development alongside his rendering of dependence. The kind of virtue envisioned by virtue ethics in general and by virtue approaches to medical ethics is not within the grasp of children, but is established over time if at all, making it more like the developmental approaches that straightforwardly associate forward progress with the accrual of time. MacIntyre tries to resituate autonomy by claiming that “virtues of independent rational agency need for their adequate exercise to be accompanied by what I shall call the virtues of acknowledged dependence,” but this correlating of independence and dependence does not adequately affirm dependence when independence is lacking due to maturity or other reasons. This model thus leaves little theoretical room for articulating the significance of children’s utter dependence, focusing instead on the merits of continuing to acknowledge how shades of dependence persist alongside the acquisition of independent (adult) rationality.

Feminist responses to autonomy

MacIntyre’s arrival at seeing dependence not as an anomaly but as central to the human experience came only after his entire production of what he had thought to be an exhaustive moral philosophy in *After Virtue*. In an analogous way, dependence and its significance have been afterthoughts in principlist medical ethics, and it has been feminist approaches to ethics, including ethics of care approaches, that have primarily addressed the place of dependence.

³⁰² MacIntyre, *Dependent Rational Animals*, 5.

³⁰³ MacIntyre, *Dependent Rational Animals*, 8-9.

Some of these have articulated what is known as “relational autonomy.” However, I find that these efforts still fall far short of addressing the dependence in the *absence* of autonomy, as is the assumed baseline with children. Instead, these accounts work to esteem dependence as a coexisting reality with autonomy as opposed to being mutually exclusive with autonomy. That is, such endeavors elevate the important nuances of how dependency mingles with autonomous action, but do not redeem dependency apart from the presence of autonomy, however it may be defined. In a recent edited volume, *Relational Autonomy: Feminist Perspectives on Autonomy, Agency, and the Social Self*, various understandings of what this means are laid out by feminist contributors who take issue with the ideal of autonomy as self-sufficient independence.³⁰⁴ In their introduction to the volume, the editors briefly describe five main areas of critiques of autonomy that have emerged in feminist theories, noting that “none of them justifies rejecting the concept of autonomy altogether.”³⁰⁵ These areas are: “symbolic critiques” that take issue with operative ideals of an “autonomous man” in discussions of autonomy; “metaphysical critiques” aimed at the problematic individualism that casts agents as atomistic instead of socially embedded; “care critiques” that counter autonomy’s normalizing of independence and obscuring of dependency and interconnection; “postmodernist critiques” that engage psychoanalytic theory to demonstrate how intrapersonal and interpersonal conflict and systems of power shape supposedly free individual will; and “diversity critiques” that explore the realities of intersectional identities to challenge autonomy’s presumed integrated self.³⁰⁶

While a detailed discussion of the book’s claims is beyond the scope of this work, what is strikingly relevant here is that its contributors largely persist in upholding a view of autonomy as

³⁰⁴ Mackenzie, Catriona, and Natalie Stoljar, eds. *Relational Autonomy: Feminist Perspectives on Autonomy, Agency, and the Social Self*. New York: Oxford University Press, 2000.

³⁰⁵ Mackenzie and Stoljar, *Relational Autonomy*, 5.

³⁰⁶ Mackenzie and Stoljar, *Relational Autonomy*, 6-12.

an intentional capacity, even as they advance its important relationally-oriented features. For instance, ethicist Linda Barclay describes how even in the context of powerful socially deterministic influences, an autonomous person can “fashion a certain response.”³⁰⁷ In another chapter, philosophers Carolyn McLeod and Susan Sherwin describe how oppression in health care produces diminished self-trust, an adult concern which hardly registers as salient for children experiencing oppression in the healthcare environment or elsewhere.³⁰⁸ Autonomy and dependence are envisioned as able to coexist, yet there is silence when it comes to the significance of dependence entirely *apart* from morally autonomous capabilities. Nuances of how relational considerations weigh into individuals’ choices, preferences, life plans, and so on are considered, but that autonomous action is a starting point for agents who interact with one another is an assumption that goes unquestioned. That is, there is much discussion of what autonomy consists of, but not a reckoning with what implications there are when individuals are generally agreed upon to be lacking autonomy regardless of whether it is defined as a capacity, competence, or procedural phenomenon. Even when autonomy is described in relational terms, the authors do not venture into how to regard the moral lives of those straightforwardly viewed as non-autonomous, namely, children. Elsewhere, ethicist Marian Verkerk similarly discusses care models of ethics and distinguishes between the notions of autonomy as self-sufficiency and autonomy as the moral capacity to make decisions for one’s own life.³⁰⁹ Neither of these capacities are ascribed to children in medical ethics. Thus, despite the important advances

³⁰⁷ Barclay, Linda. “Autonomy and the Social Self.” In *Relational Autonomy: Feminist Perspectives on Autonomy, Agency, and the Social Self*, edited by Catriona Mackenzie and Natalie Stoljar. New York: Oxford University Press, 2000, 55.

³⁰⁸ McLeod, Carolyn, and Susan Sherwin. “Relational Autonomy, Self-Trust, and Health Care for Patients Who Are Oppressed.” In *Relational Autonomy: Feminist Perspectives on Autonomy, Agency, and the Social Self*, edited by Catriona Mackenzie and Natalie Stoljar, 259–79. New York: Oxford University Press, 2000.

³⁰⁹ Verkerk, Marian A. “The Care Perspective and Autonomy.” *Medicine, Health Care, and Philosophy* 4, no. 3 (2001), 291.

feminist voices have made in critiquing and revising a conventional approach to autonomy, a persistent silence remains about what it means not to have it at all.

Pastoral theology and dependence

Children and their extreme dependence thus remain largely unheard and unseen in principlist and feminist approaches to bioethics. While there may be exceptions in feminist bioethics, from my reading of this particular volume I find the discussion remains adult-centric in its scope and concerns. Although it seeks to value dependence as a feature of human identity, it does not ask what is at stake for those who are dependent but not autonomous. This risks reifying dependence as a deficit and merely directing attention back to those with autonomy, as the principlist model does. Dependence persists in being described from the perspective of the benevolent one providing care to some Other, to harken back to MacIntyre's observation.

Even Beauchamp and Childress acknowledge the validity of critiques from feminists and others who “question the model of an independent, rational will that is inattentive to emotions, communal life, reciprocity, and the development of persons over time.”³¹⁰ Yet they maintain that a relational conception of autonomy is defensible as long as it does not neglect or obscure the main features of autonomy as they describe it.³¹¹ This rejoinder perhaps illustrates most succinctly what remains problematic with respect to children and dependence. Assessing dependence in service to the larger question of autonomy still ignores what it means to be non-autonomous and dependent.

³¹⁰ Beauchamp, and Childress. *Principles of Biomedical Ethics*, 6th ed., 102.

³¹¹ Beauchamp and Childress, *Principles*, 6th ed., 102.

Children occasion an opportunity to explore dependence apart from trying to preserve the centrality of autonomy. Since we are not trying to prove they are autonomous, we can ask different questions about dependence rather than how it can still be compatible with autonomy. Pastoral theologians have adeptly asked similar questions about the interplay of self and social relationships within and among persons and community and in relationships marked by power differentials. Thus, continuing to build a theological anthropology provides an inroad for making the dependence of children visible as a worthy point of inquiry, lifting them from the obscurity where ongoing stigmatization and devaluation of dependence has rendered them beyond the scope of interest.

Religious traditions have long affirmed the social character of human life. Abigail Rian Evans notes that in a Jewish and Christian perspective, regarding humans as body, mind, and spirit is still insufficient for a full appreciation of our nature: “We are defined not only by our internal workings but also by our social relationships.”³¹² Lisa Cahill likewise insists that relationality is essential to any theologically informed bioethics.³¹³ And yet, as religious ethicist David Smith observes, “Christian bioethics has not been as sensitive to the social character of selfhood as it might be.”³¹⁴ A recent book by Christian ethicist Sandra Sullivan-Dunbar attempts a more thorough treatment of dependency from a theological perspective, with aims that include demonstrating that many accounts of Christian love have failed to account for dependent care relations, and showing how the theoretical avoidance of dependency has led to such theological distortions.³¹⁵ Sullivan-Dunbar defines dependency as “the need for care and assistance from

³¹² Evans, *Redeeming Marketplace Medicine*, 71.

³¹³ Cahill, Lisa Sowle. “Bioethics, Relationships, and Participation in the Common Good,” 207.

³¹⁴ Smith, David H. “Religion and the Roots of the Bioethics Revival.” In *Religion and Medical Ethics: Looking Back, Looking Forward*, edited by Allen Verhey, 9–18. Grand Rapids, Mich: Eerdmans, 1996, 14.

³¹⁵ Sullivan-Dunbar, Sandra. *Human Dependency and Christian Ethics*. Cambridge University Press, 2017, 9.

other persons to survive and achieve basic well-being” and maintains that although obvious dependencies exist in infants and children, dependency persists in mature able adults as well, who are dependent on entities such as the government, employers, and various other relationships.³¹⁶ She connects the range of types of dependency, noting “Those dependencies that are mediated through complex social and economic systems are instantiations of our more basic dependencies.”³¹⁷ In an observation that bears relevance for children, especially those in the hospital, she notes that as society grows more complex, it has become easier to emphasize direct, hands-on types of dependency; conversely, things like consumer choices or decisions about employment, which involve a “complex interplay of our dependence and autonomy, have come to be perceived as more purely autonomous ... while the conceptual realm of ‘dependency’ has altered and been stigmatized.”³¹⁸ She traces attitudes regarding dependency from a preindustrial view where dependence was assumed to be a universal social condition rather than the state of one individual, to industrialization’s shift toward seeing dependence as a negative psychological and economic state.³¹⁹ What also easily gets overlooked, she asserts, is the fact that even the most dependent among us are also moral agents: “Just as there are no purely autonomous human beings – our autonomy is *always* conditioned, shaped, and constrained – so even in our most dependent phases of life, we find ways to express our desires and achieve our ends.”³²⁰ Sullivan-Dunbar aims to recast Christian love in a way that resists neat categories of helper and helped, thus adding rich theological insight to my current efforts to expand the dependency of children

³¹⁶ Sullivan-Dunbar, *Human Dependency and Christian Ethics*, 14.

³¹⁷ Sullivan-Dunbar, *Human Dependency and Christian Ethics*, 14.

³¹⁸ Sullivan-Dunbar, *Human Dependency and Christian Ethics*, 14.

³¹⁹ Sullivan-Dunbar, *Human Dependency and Christian Ethics*, 53, drawing on Fraser, Nancy, and Linda Gordon, “A Genealogy of Dependency: Tracing a Keyword of the U.S. Welfare State.” In *The Subject of Care: Feminist Perspectives on Dependency*, edited by Eva Feder Kittay and Ellen K Feder, 14–39. Lanham, Md.: Rowman & Littlefield Publishers, 2003.

³²⁰ Sullivan-Dunbar, *Human Dependency and Christian Ethics*, 15.

beyond their immediate and visible needs for “care and assistance from other persons to survive and achieve basic well-being”³²¹ toward a relationally grounded understanding of how children’s dependencies further reveal the realm of human dependencies more generally.

Sullivan-Dunbar’s work aligns well with pastoral theology’s efforts. Because of their commitment to interdisciplinary dialogue and to elevating the visibility and voices of the marginalized, pastoral theologians can add vital, timely, and compelling understandings for relationships of dependence that avoid denigration and seek the flourishing of all, regardless of ability or capacity, and which avoid individualistic credit or blame for independence and dependence. Theological footings, in well-crafted conversation with interdisciplinary partners, can expand beyond otherwise rationalistic and atomized readings of human beings.

Dependence as a social reality

If dependence is an enduring social reality in the sense that it reflects the relationships with people and systems around us, then finding a way to speak of this reality is vital, especially in contrast to areas of discourse like medical ethics that still gravitate toward talking about individuals in isolation from contextual factors. Bonnie Miller-McLemore’s addition of the concept of the “living human web” to the field of pastoral theology, describing how the field has shifted in the past two decades, has unexplored implications for the task of developing a more robust theological anthropology of hospitalized children. The articulation of the living human web, and the action it summons forth from those in pastoral theology who wish to attend to issues of suffering and healing, has much unfulfilled potential with regard to children.

³²¹ Sullivan-Dunbar, *Human Dependency and Christian Ethics*, 14.

As background to the significance of the living human web, it is helpful to understand the use of the phrase “living human document” and the role it has played in pastoral theology. Originally coined by Anton Boisen, the founder of the clinical pastoral education model and an influential figure in the development of pastoral counseling, the term conveyed Boisen’s concern for keeping the data of human experience at the forefront of pastoral concern, rather than losing it in the realm of theological language and written texts or documents, such as scripture or doctrine. The term was lifted to prominence in the 1980s by pastoral theologian Charles Gerkin in his book *The Living Human Document*. Gerkin contends that the full potential of Boisen’s image has seldom been reached. He notes that it has usually “been taken as an admonition to begin with the experience of persons in the development of ministry theory” but that Boisen intended further to mean that “the depth experience of persons in the struggle of their mental and spiritual life demanded the same respect as do the historic texts from which the foundation of our Judeo-Christian faith tradition are drawn.”³²² Boisen wanted pastoral caregivers to avoid simplistic categorizing and stereotyping and to give merit to the individual living human document and its integrity. Gerkin explains that for his own purposes, revisiting Boisen’s intent can produce new insight into the field of pastoral counseling, where the weight of psychological and behavioral sciences can too easily threaten to strip such images from their religious moorings.³²³

Explaining why he feels Boisen’s image is paradigmatic, Gerkin emphasizes the way in which pastoral counseling involves a hermeneutic task, that is, an interpretive task, which can also be understood as a “fusion of horizons of understanding,” drawing on the theories of

³²² Charles V. Gerkin, *The Living Human Document: Re-Visioning Pastoral Counseling in a Hermeneutical Mode* (Nashville: Abingdon Press, 1984), 38.

³²³ Gerkin, *The Living Human Document*, 39.

twentieth-century German philosopher Hans-Georg Gadamer.³²⁴ Interpretive work is vital to pastoral counseling relationships because it supports the deep need of persons to make meaning of their experience. For Boisen, a suffering person exhibited a need to reorganize his or her inner world, and the pastoral counselor thus had to engage in the interpretive task of understanding the living human document and the meaning it conveyed both for the other person's life-world but also for the therapeutic relationship.

For Miller-McLemore, where the document metaphor was static and individualistic, the "living human web" reflects the interconnected and dynamic conditions that shape individuals and the narratives by which they make meaning. Influenced by systematic theologian Catherine Keller's *From a Broken Web*³²⁵ which envisioned a renewed concept of interconnected selfhood over against the patriarchal ideal of separation, Miller-McLemore builds a vision for a web where any analysis of individual pathology is interwoven with analysis of the larger structures that render persons superior or inferior based on demographic factors.³²⁶ This vision aligned with growing feminist literature at the time which increasingly challenged patriarchal and individualist ideologies. Elsewhere, Miller-McLemore notes that the web was not intended as a rejection of close attention to individuals or of insights from psychology relevant to their care, but was instead meant to place the individual in "inextricable relationship to the broader context."³²⁷ Attending to the wider structural influences on individual struggles meant a heightened recognition of the need to hear from marginalized voices from within their own

³²⁴ Gerkin, *The Living Human Document*, 45.

³²⁵ Keller, Catherine. *From a Broken Web: Separation, Sexism, and Self*. Boston: Beacon Press, 1986.

³²⁶ Miller-McLemore, Bonnie J. "The Living Human Web: Pastoral Theology at the Turn of the Century," In *Through the Eyes of Women: Insights for Pastoral Care*, edited by Jeanne Stevenson Moessner, 9–26. Minneapolis, MN: Fortress Press, 1996.

³²⁷ Miller-McLemore, Bonnie. "Feminist Theory in Pastoral Theology." In *Feminist and Womanist Pastoral Theology*, edited by Bonnie Miller-McLemore and Brita Gill-Austern. Nashville: Abingdon Press, 1999, 90.

contexts. Attending to individuals in a solitary way could overlook the questions of whether other voices were being silenced, and therefore closer investigation of a web of interconnections revealed the urgency of listening to those whose voices had not yet been heard.³²⁸ While earlier trends in pastoral theology and pastoral counseling especially had been preoccupied with the “document” of individual lives, focusing “close attention to an individual’s ‘full uniqueness,’ made known through intimate, emotional self-disclosure,” the web prompted analysis of social construction and power relationships and urged giving voice to those previously silenced.³²⁹ Miller-McLemore notes that although the web metaphor has been interpreted in a number of ways over the years, she aligns with the liberationist interpretation, where the web most strongly points to “the need to attend to social inequities and injustices that perpetuate suffering. Basically, this means identifying the political prejudices or discrimination based on difference that shape health, illness, and care.”³³⁰ This approach necessitates focus on the social location of both recipients and providers of care, no longer allowing abstract theoretical approaches to go unquestioned.

This raises a crucial question for pastoral theology and my own work: How visible are children in the web? Particularly in the midst of a persistently adult-centric, market-driven healthcare milieu, to what degree have children reaped the benefits of efforts that identify the social and other determinants that shape their health, illness, and care, for better or worse? The web metaphor holds potential to elevate and address the situations of children, but there is still much that remains to be gleaned from analyzing their place in systems. When it comes to children, I believe the “document” mindset still prevails, where children are more or less silenced

³²⁸ Miller-McLemore, “The Living Human Web,” 20-22.

³²⁹ Miller-McLemore, Bonnie. “Revisiting the Living Human Web: Theological Education and the Role of Clinical Pastoral Education.” *The Journal of Pastoral Care & Counseling* 62, no. 1–2 (Spring-Summer 2008), 14.

³³⁰ Miller-McLemore, “Revisiting the Living Human Web,” 10.

because of their immaturity in being able to articulate self-reflection and self-disclosure—the skills necessary for a deep understanding of the “document”—and in the absence of those abilities, their chief identity persists as dependents. In the hospital context, where value is so centered around adult assessments, recommendations, deliberations, and decisions, it is all too easy to regard children as people in the making, or to align with the current metaphors, as documents that do not yet have much to say. In the setting of the web, however, much more can be said and appreciated about children and their identity, experiences, and impacts upon the people and circumstances around them.

On a basic level, the web better reflects the dynamic triad that is in place from the outset when it comes to pediatrics. Unlike in adult scenarios where there might simply be a patient-physician dyad, the pediatric setting begins with patient, provider, and parent or guardian. As the preceding chapter on vulnerability demonstrated, the multilayered needs of children and of hospitalized children specifically present needs that surpass the capacity of parents alone to meet. The web encourages closer scrutiny of children’s vulnerability and dependence and interrogates simplistic notions of assuming that parental responsibility ought to be sufficient for responding to their needs. In the living human web, a more honest appraisal of the systemic assumptions, preferences, and injustices can lead to a more accurate portrait of the multidirectional dependencies in place. That is, parents too are dependent on social supports and provisions within healthcare in order to meet the needs of their children. Families and communities are dependent on larger scale protection and promotion of children’s well-being. A web mindset prompts continuing consideration of what responsibilities are set in motion by those who cannot advocate for their own needs, and who should bear those responsibilities. Miller-McLemore’s earlier reflections in *Also a Mother: Work and Family as Theological Dilemma* express this well

as she examines the dangers of esteeming personal sacrifice of mothers without recognizing the multidirectional influences and needs they face. Describing the “broader network of dependencies that make up human community,”³³¹ she contends,

Mutual regard and self-giving belong within a more comprehensive context of familial, social, and cultural support. Mutual love is the ideal. But particularly with children, mutual love does not begin mutually, and their care involves a certain measure of parental self-loss and self-renunciation. In the interlude, in the larger network of care, many hands must rock the cradle and share the burdens of self-giving and dependence... When the less adept and dependent child cannot give back, the necessity to give, in response to the needs of a child, depends upon a broader context of give-and-take.³³²

The web allows us both to zoom in and zoom out on the easily identifiable dependencies of children, and locate many other places in the network of care where dependence is created, met, or ignored in wider relationships and systems.

Particularly as pediatric healthcare continues to make great strides in treating conditions and illnesses, there will continue to be unprecedented and complex navigation of how and what should be offered to children, at what cost, under what burden, to what end. The technological innovation and narrative of progress can create such enthusiasm for new medical frontiers, to the exclusion of careful deliberation over these matters, as I illustrated earlier through the example of surgical intervention for Hypoplastic Left Heart Syndrome. As adults continue to sort out their values and motives when they reach these new frontiers, it is more vital than ever that adults have a robust self-understanding of how they view children and how to account for children’s many types of needs, and their own adult needs in relationship to those of children. The web can be a helpful metaphor for preserving accountability, lest the voices of children continue to be silenced in the matrix of social and power structures that stubbornly rest on their relatively

³³¹ Miller-McLemore, *Also a Mother*, 167.

³³² Miller-McLemore, *Also a Mother*, 166.

unexamined notions about children needing first and foremost to simply be protected from harm and protected for the sake of their future interests.

Hospitalized children still await the benefits of the shift from the document to the web, in part because the overreliance on the medical model of illness corresponds to pastoral theology's conventional overreliance on psychology and its attendant developmental theories. Both the medical model and dominant developmental psychological stage theories prefer to rely on supposedly objective, measurable assessments of progress or decline and thus leave little room for the messiness introduced when context and subjective experiences are taken into account. Perhaps assumptions about lack of subjective experience especially in young children reinforce the appeal of a two-dimensional "reading" of children as "documents," rather than a nuanced, dynamic attempt to perceive their place in the web. Just as feminist scholarship has elevated the perspectives and experiences of women, thus helping to expose the androcentric assumptions operative in many realms including clinical ethics, so too do we need greater attentiveness to the experiences and perspectives of children, in order to refine practices of care in ways that honor their vital place within the complex web around us.

Reflecting on the living human web metaphor's implications for theological education, Miller-McLemore notes that one benefit of clinical pastoral education programs was the way in which they invited students to examine how their own religious claims had been formed, to "explore where they came from, what moral and religious idolatries they foster, what emotional and political needs they serve, and how they have evolved" in one's development.³³³ The present project encourages similar critical attention to our beliefs, religious and otherwise, about children, so that we can more fully engage them in the medical environment and reflect

³³³ Miller-McLemore, "Revisiting the Living Human Web," 13.

thoughtful attention to them as we carry out our caregiving responsibilities on their behalf, and so that we can be ever more self-aware of our assumptions about their dependence and how our interpretation of their dependence might be serving adult purposes.

Miller-McLemore further assesses the relationship between the document and the web in pastoral theology, noting: “I still see the discipline’s primary subject matter as the document, the person, with psychology as a key resource—but now the document is more honestly situated within the web.”³³⁴ This retention of the document’s importance serves as a reminder that with children as well, we need not shift to a completely systems-focused interpretation of children, as though they are not intelligible as “documents,” but instead we ought to appreciate their richness as people who are just as intertwined in contextual factors as those of all ages. Just as attention to an individual can prompt us to see the surrounding web, so greater attention to the web can pique our interest in its lesser-known quarters and prompt us to see children more fully.

Furthermore, Miller-McLemore asserts that both the document and web metaphors have contributed to the ongoing pastoral theological work of developing empathy, and recognizing the limits of empathy.³³⁵ “Pastoral theology’s trademark of empathy for the living human document is confounded by the limitations of empathy in the midst of the living human web,” she notes acknowledging that “Sometimes a person must admit an inability to understand fully the lived reality of the oppressions suffered by another. There may be boundaries beyond which empathy itself cannot go.”³³⁶ Despite these limits being stretched by the shift from the document to the web, writes Miller-McLemore years later, the value and power of empathy remains a trademark of pastoral theology, and can be fostered with “an original source of vitality” in pastoral

³³⁴ Miller-McLemore, Bonnie J. “The Living Human Web: A Twenty-Five Year Retrospective.” *Pastoral Psychology* 67, no. 3 (June 1, 2018), 307.

³³⁵ Miller-McLemore, “The Living Human Web: A Twenty-Five Year Retrospective,” 317.

³³⁶ Miller-McLemore, “The Living Human Web,” 21.

theology, namely, compassion for individuals.³³⁷ That is, even when others' experiences of marginalization transcend our ability to relate to them, we can nonetheless attempt to understand them more fully through close empathic engagement with individuals. With regard to the dependencies of childhood, I believe this kind of empathy, fostered by deep critical engagement with selves and their contexts, can provide us with a better grasp of the varied dependencies we all possess, and the way in which our well-being is caught up, indeed dependent upon, many others throughout life. While distinct, the dependence that is characteristic of childhood is not something we leave behind as we age, but gets expressed in different ways and distributed widely throughout the web. Empathy thus can represent a way to go beyond the comfortable objectifications of children and childhood and draw us into all that we have yet to learn from the closer readings of their lived realities in places like hospitals. We all stand to benefit.

Stories from the web of children's health

A sobering example of the interconnected web in which children's health flourishes or flounders can be found in the story of lead poisoning. In a recent commentary, physician Bruce Lanphear reflects on the deeply entrenched power of the chemical industry and the legislative failures that have allowed continued lead exposure to harm children around the country.³³⁸

Lanphear notes that even at extremely low blood levels, lead exposure in children has been

³³⁷ Miller-McLemore, "The Living Human Web: A Twenty-Five Year Retrospective," 318.

³³⁸ Lanphear, Bruce. "Still Treating Lead Poisoning After All These Years." *Pediatrics*, July 17, 2017, e20171400. Lanphear notes that over 500,000 children have a blood lead level of over 50 parts per billion, that 23 million homes have one or more lead hazards, that unknown numbers of Americans drink water from lead water lines, and that federal standards for lead in dust, soil, and water have failed to protect children. While much attention has been given to the Flint water crisis, children in hundreds of US cities have higher blood lead levels than children in Flint. See also Kristof, Nicholas. "America Is Flint." *The New York Times*, February 6, 2016. <http://www.nytimes.com/2016/02/07/opinion/sunday/america-is-flint.html>.

linked with lower IQ, academic difficulties, and higher rates of attention related disorders such as attention-deficit/hyperactivity disorder (ADHD) and conduct disorders.

A “living human document” approach to this predicament would all too easily consider a narrowly confined picture of a pediatric patient with a behavioral disorder and his or her parents’ capacity to manage and advocate for that child’s well-being in the midst of a myriad of medical and psychological interventions, educational accommodations, and so on. From the vantage point of the living human web, by contrast, no assessment of this child is complete without reckoning with far-reaching systemic factors that may have contributed in the first place—through action *or* neglect—in allowing lead to poison the child’s body and burden his or her present and future health and which may predict his family’s capacity to identify, address, and adapt to the health needs that result. In our contemporary patient-focused health care culture, it is all too easy to look only at an individual patient without attending to the data points scattered throughout the web that impact the patient. Lanphear admits that that regulation of lead and other toxins that harm children will only be prevented by regulatory changes, which he states “will not happen anytime soon.”³³⁹ He urges pediatricians to be more involved in advocacy even while acknowledging that such training, along with training in environmental health, is usually beyond the scope of community pediatricians. Until we find compelling ways to implicate larger systems in accountability and responsibility for children’s health, we will continue to place disproportionate expectations on individual caregivers, both parents and physicians, to address problems whose roots lie well beyond their reach.

A compelling example of a children’s hospital trying to address the “web” more thoroughly is Boston Children’s Hospital’s Community Asthma Initiative. It formed in respond

³³⁹ Lanphear, “Still Treating,” 2.

to the high number of emergency room visits and hospital admissions for asthma, which were disproportionately high among children of color, by extending their reach into the community, working with partners such as landlords, home-visiting groups and policy makers to try to improve the environmental conditions in homes and schools that most often trigger asthma.³⁴⁰

Dependence at the core of selfhood

Having considered the significance of moving from a view of individuals as isolated documents to seeing their embeddedness in a web of relationships, I turn to a more radical notion, the social nature of persons themselves, as evident not just in their outward relationships with others in the web but also in how those relationships are constitutive of selfhood in the first place. With a dominant medical ethics view of children rooted in the idea that children's identity is incomplete because they are not yet autonomous, it is helpful to consult social and theological understanding of selfhood in order to appreciate the relational self that is vibrantly present from birth.

The limited view of personhood so apparent in conventional Western thought and in much of medical ethics literature is described well by social scientist Ian Burkitt, who pinpoints some of the key problems with the Western conceptions of the self, particularly those stemming from seventeenth-century French philosopher Rene Descartes. Through a focus on the Cartesian essentialism of "I think, therefore I am," says Burkitt, "we humans identify our existence through mental reflection on our own selves," and this leads to a understanding of the self as "substance, the nature of which is thinking, so that self is to be found in the mind as distinct from the

³⁴⁰ See "Community Asthma Initiative," <http://www.childrenshospital.org/Centers-and-Services/Programs/A--E/community-asthma-initiative-program>.

body.”³⁴¹ Measuring the self by essentialist qualities tied to the dualistic functions of the higher “mind” as opposed to the base material of the “body” not only devalues the integral nature of the body but also devalues those whose selves may be more fully expressed or experienced through the body rather than the mind.

In contrast to dominant Western conceptions of an individual, autonomous self, Burkitt posits instead that individual identity is secondary to social realities, such that we are “social individuals” rather than “self-contained atoms.”³⁴² Burkitt contends that humans are fundamentally social selves for three primary reasons: we are born into places and times not of our own making, we *become* selves jointly with others rather than *find* our selves through thoughts and feelings, and our identities are often profoundly forged in struggles such as political ones. He maintains that “social relations are *a priori* of individual experience in a *historical* sense.”³⁴³

Describing the problematic way in which traditional views of the self reflect the privilege of their proponents, Burkitt remarks, “Those who assume that their self-identity is a given right or natural fact—say, a straight white man in Britain—are those in a privileged position whose identities have automatic ‘right of way’ in most social contexts.”³⁴⁴ His central argument is that we are *social selves*, and he contends that “to truly understand ourselves and answer the question of ‘who am I?’ we must first of all abandon the image of ourselves as self-contained monads or self-possessed individuals who can only find out about their identity by looking for and identifying some essence within them that is the secret truth of self.”³⁴⁵ For Burkitt, selves

³⁴¹ Burkitt, Ian. *Social Selves: Theories of Self and Society*, 2nd ed. (London: Sage Publications, 2008), 6–7.

³⁴² Burkitt, *Social Selves*, 3.

³⁴³ Burkitt, *Social Selves*, 138, italics original.

³⁴⁴ Burkitt, *Social Selves*, 3–4.

³⁴⁵ Burkitt, *Social Selves*, 187.

simply do not exist apart from the relationships that establish and shape them. His views cohere with those expressed earlier by African-American pastoral theologian Archie Smith, whose work is worthy of closer note because of the theological grounding for what he calls the relational self.³⁴⁶

In other words, a robust theological understanding of the dependence of children must move beyond simply acknowledging the vitality of relationships as they exist between persons. We must take a closer theological look at how relationships are actually constitutive of the self, that is, how individual selves are themselves shaped by social and relational realities. This entails a view of dependence that is defined not only by dependence between persons, but dependence that is also manifest within the individual who is reliant on relationships as selfhood emerges, a selfhood thus paradoxically only established by social interactions.

Smith's basic concept of the relational self is intricately tied to his development of a paradigm for ethics and therapy that can accommodate both individual and structural factors. In his critical and constructive work, he draws on ethical perspectives shaped by his experience in a black church tradition, where familiarity with oppression forged an endeavor to describe how the emergence of the self interacts with larger social factors. As one of the first black pastoral theologians, Smith's analysis of race and the impact of racism and political, social, and economic injustice on black Americans added crucial insight and correctives to therapeutic models that had been informed mostly by white pastoral theologians.

From this contextual vantage point, Smith describes three paradigms that he perceives in theories of psychotherapy, each with varying levels of attention to the individual and structures.

³⁴⁶ Smith, Archie. *The Relational Self: Ethics & Therapy from a Black Church Perspective*. Nashville, TN: Abingdon Press, 1982. Of note, Smith taught for decades at the Graduate Theological Union and Pacific School of Religion, where at the latter he became the first tenure track African-American faculty member.

In what Smith calls paradigm one, attention is focused on the individual as the source of dysfunction, and therapeutic approaches concentrate on helping individuals cope with and adjust to their situations within existing social circumstances. This paradigm is well established in American society, where dysfunction is explained in personal terms and society is not a major object of analysis or change. Individuals are subject to critique, but the social order itself is not. Like therapeutic models, ministry models reflective of paradigm one also tend to be individually focused and favorable toward privatized religious practice, with emphasis on individual rescue and salvation.³⁴⁷ Paradigm one ignores the “emancipatory potential” of therapy and ministry in the struggles of oppressed people, says Smith. By neglecting to address the social aspects of oppression, and focusing instead only on the individual’s supposed deficits and deviance, this paradigm upholds “the prevailing normative order of things.”³⁴⁸

By contrast, the therapeutic model Smith calls paradigm two locates the problems of individuals within oppressive social structures. Casting individuals as the victims of dysfunctional institutions, this paradigm avoids critique of the individual in favor of placing blame entirely on systems and structures. However, Smith notes that efforts to address dysfunctional systems often slip back into paradigm one’s models of problem solving. This happens because the emphasis on paradigm one is so deeply internalized and because the solutions to address paradigm two are relatively undeveloped in comparison to entrenched individual-focused approaches. Thus, even when systems are identified as the location of the problem, the means of addressing the problems at the systemic level remain underutilized and individuals continue to be the focus of intervention. Smith highlights the need to recognize that

³⁴⁷ Smith, *The Relational Self*, 40-41.

³⁴⁸ Smith, *The Relational Self*, 41.

creative solutions for both individual and systemic problems must recognize and seek to mitigate the manifestation of the systemic problems and their “disruptive effects” in the individual agent.

Smith calls paradigm three the relational paradigm, in that it conceptually links the individual and society with the purpose of connecting personal and social transformation. Smith emphasizes the importance of not rejecting either of the first two paradigms, but analyzing the dialectical relationship between the two. “There can be no true understanding of the self or self-conscious selfhood apart from the web of relations and historical circumstances in which individuals are embedded,” explains Smith.³⁴⁹ Human selves are more than the historical and social circumstances within which they find themselves, but they are also always marked by relationality, the “indwelling presence of others” that shapes our reality and by which we shape others’ realities.³⁵⁰ Paradigm three upholds a vision of human liberation in which individuals can act as agents to creatively form communities that strengthen instead of exploit the weak. Individuals do not find fulfillment and freedom as solitary individuals, but as members of society, where the self is understood as “a constituent member of the web of life.”³⁵¹ Paradigm three thus frames the relational self and distinguishes it from modern liberal perspectives where the self is ahistorical and solitary.³⁵²

Here Smith draws heavily on the work of the American social psychologist and philosopher George Herbert Mead and his dialectical understanding of mind, self, and society.³⁵³ For Mead, the social self is not a formed entity at birth, but unfolds through a social process of

³⁴⁹ Smith, *The Relational Self*, 51.

³⁵⁰ Smith, *The Relational Self*, 51.

³⁵¹ Smith, *The Relational Self*, 53.

³⁵² Smith, *The Relational Self*, 57.

³⁵³ Smith, *The Relational Self*, 56. Burkitt also draws heavily on Mead’s work in *Social Selves*.

interaction, communication, and reflection.³⁵⁴ The social process itself is a condition for the emergence of the self, such that there is no self prior to or apart from this interaction. This view stands in contrast to the modern liberal interpretations of self that portray individuals as “innately and autonomously possessing a self already at birth.” Smith notes that this dominant western view of individuals in turn shapes a perspective where “Relationality is seen as a by-product of human association, rather than the fundamental datum constitutive of human existence.”³⁵⁵ Furthermore, Smith remarks that a social location of oppression brings heightened awareness of the shortcomings and dangers of the ingrained Western individualistic perspective. The relational self is thus especially compelling for those who find strength in connecting their own suffering to the suffering of others. For Smith, social transformation rather than individualism can address the individual’s suffering, and thus the dialectic relationship between personal and social change must be preserved. Integral to that transformation is a concomitant freedom from what Smith sees as the core human predicament: false ideology.

False ideology: the human predicament

Dialectic relationships between the individual and social realms lead to the kind of transformation Smith envisions when there is freedom from oppressive ideology. Smith thus offers an alternative reading of freedom and autonomy where instead of dependence being the culprit of our predicament, it is instead the grip of false ideology that holds us back. This term is evocative of nineteenth-century German philosopher Karl Marx, and indeed Smith acknowledges Marx’s influence on his own thinking, particularly the notion that “self-knowledge is produced

³⁵⁴ Smith, *The Relational Self*, 59.

³⁵⁵ Smith, *The Relational Self*, 57.

through discourse and in specific social and historical contexts and in struggle.”³⁵⁶ Smith notes, however, that individualism remains prized and Marx’s characterization of the social character of knowing remains marginalized.³⁵⁷ As long as autonomy and individualism are esteemed in this way, dependence is portrayed as a problematic state meant to be outgrown or overcome in order to achieve a self-sufficient mode of living. Aside from whether or not this is a reasonable or attainable goal for any human being, it nonetheless underlies and drives the values of dominant Western culture where people are averse to prolonged states of dependence on others. I suggest that this attitude contributes to a widespread view of childhood dependence as a temporary problem primarily needing to be accommodated by adult action.

For Smith, the ultimate predicament from which persons must seek freedom is not dependence but false ideology. Noting the way in which the family and other institutions serve as power brokers in the wider economic, social, and political power systems that connect individual and social life, Smith attests that the values of those ideological constructs shape individual development to an extent that cannot be ignored. Internalized beliefs, whether or not they are recognized, are often manifestations of the socialization that has transpired and which reproduces forms of domination and oppression along the lines of race, sex, and class; I believe “age” ought to be added as a key category as well.³⁵⁸ Smith characterizes false consciousness as a person’s complicity with ideology, often unwittingly: “False consciousness functions to distort the individual’s grasp of reality and to adjust the person within the prevailing and taken-for-granted outlook of society.”³⁵⁹ Furthermore, Smith claims that false consciousness and ideology

³⁵⁶ Smith, *The Relational Self*, 166.

³⁵⁷ Smith, *The Relational Self*, 166.

³⁵⁸ Smith, *The Relational Self*, 158.

³⁵⁹ Smith, *The Relational Self*, 29.

represent “*the overidentification of the human subject with the existing power arrangements and the confirmation of infallibility, divine or absolute status upon the existing society.*”³⁶⁰ Smith

explains further,

Ideological categories may be thought of as unquestioned assumptions which underlie specific contexts and ways of thinking. They in turn guide our everyday activity. The underlying assumptions are taken for granted by the society and remain largely unrecognized and unchallenged in the exigencies of daily living.³⁶¹

Smith rightly notes that if the church is to be a prophetic and liberating power, it must deeply understand the structures of domination that affect those who comprise it and hinder the church’s practice.³⁶² Because Smith is exploring how a black church ethic can be liberative, he emphasizes the danger of churches becoming unwitting conspirators in the kind of Cartesian individualistic mindset that seeks to detach the individual from the social and historical realities in which individuals are embedded.³⁶³ Smith is not advocating for freedom from social structures or for the abolishment of those structures, but rather urging the importance of creating alternative structures in the face of oppressive structures and ideologies. Smith’s assertion that the relational self’s identity is rooted in “the primal reality of God” is his liberating alternative to the constructed social ideologies that seek to define the self.³⁶⁴

By grounding the self in relationships and specifically in relationship with God, Smith claims relational dependence as an integral part of how humans are created and oriented, rather than as a liability or shortcoming of the self. A more robust theological anthropology can thus be liberating as it invites freedom from an ideological view of dependence as a burdensome

³⁶⁰ Smith, *The Relational Self*, 29, emphasis original.

³⁶¹ Smith, *The Relational Self*, 158-159.

³⁶² Smith, *The Relational Self*, 165.

³⁶³ Smith, *The Relational Self*, 165.

³⁶⁴ Smith, *The Relational Self*, 28.

characteristic of individuals and offers instead a vision of dependence situated within abundant interwoven relationships.

Even though Smith does not make the connection and joins other scholars of his generation in ignoring implications for children, his description rings true for the present consideration of children. Dominant social lenses through which we see children shape our perceptions of them as utterly dependent, and our societal preoccupation with the privatized realm of the nuclear family prompts us to attribute responsibility for addressing a child's dependence on his or her own parents, without recognizing how children and their families are deeply dependent on wider relationships in society.

More recently, pastoral theologian Barbara McClure has drawn on Smith's work and expanded the concept of the relational self, with the aim of equipping the field of pastoral counseling to move beyond an individualistic focus toward a greater understanding of how selves are not only embedded in but constituted by the many relationships and systems in which they are situated. With Smith and Burkitt, McClure also endorses the contemporary shift towards relationality, calling attention "beyond the monadic self to the ontologically social self."³⁶⁵ McClure argues that context is not only crucial for understanding the self, but for *constituting* selfhood in the first place. She notes that the self is more than a mere "interpreter" of social realities, as social relationships themselves play integral roles in meaning-making and co-constructing of a self's narratives, arguing that "[a]lthough relationality is a vital aspect of human development and experience, theories built on it do not contribute enough to our understanding of the social nature of persons and the processes by which they become selves."³⁶⁶

³⁶⁵ McClure, Barbara J. *Moving beyond Individualism in Pastoral Care and Counseling: Reflections on Theory, Theology, and Practice*. Eugene, OR: Cascade Books, 2010, 185.

³⁶⁶ McClure, *Moving beyond Individualism*, 186.

Noting the resonance of her model with Burkitt's theory, McClure shares his view that the search for a "relationship" between the self and society is fruitless, and that to look at society or an individual is actually only to see the "social being" from two different angles.³⁶⁷

Like Burkitt, McClure too insists that "the self and society do not shape each other such that some quality of persons exists prior to socialization that is then molded by society; there is no core or authentic self that is remaindered outside of the social self."³⁶⁸ Summarizing this theoretical approach, she writes:

Nothing that makes us unique, nothing personal about us, nothing about our *selves*, exists in us as something wholly innate: it is only in relation to others (who are themselves embedded in and mediate their social, cultural, and political environment) that we become unique and separated from the matrix in which we live. Positing a self that is formed entirely within relationships and socio-cultural contexts is not to say there is no real self; rather that there is no self prior to interaction with persons embedded within social orders. It is only as we become more "social" that we are increasingly unique and individual.³⁶⁹

For McClure, the self is social in character, through and through. Her work underscores the premises upon which typical depictions of dependence are established, where individual selves are either self-sufficient or reliant on others. Instead, truly social selves are dependent on others for their very being, requiring the rich soil of relationships and contexts in order to yield specificity and uniqueness.

The relational selves of children

Along with Smith's framework of false consciousness as the mechanism by which oppressive structures distort the development of the free and responsible social self, McClure's

³⁶⁷ McClure, *Moving beyond Individualism*, 189.

³⁶⁸ McClure, *Moving beyond Individualism*, 190.

³⁶⁹ McClure, *Moving beyond Individualism*, 189.

warning that an emphasis on individualism has obscured our perceptions of the social self is useful for describing how dominant understandings of autonomy perpetuate harmful ideology. Such narrow understandings overshadow the socially constructed and significant elements of selfhood that are emerging in children regardless of whether they are in possession of cognitive maturity. When these understandings of autonomy constrict our view of selfhood, they prohibit us from considering the importance of the social self and the more richly construed versions of dependence that flow from it. Smith's construct invites a more empowering regard of children, appreciating their nascent identities in formation through the relationships around them.

The concept of a relational self also recasts the supposedly independent views of parents as themselves contingent on the dialectic relationships emerging with their children. Rather than seeing parental decision making on behalf of children as a rational, detached exercise based on pre-set positions, it is true in a real way to say that the parents can form their values and preferences *with* and *in response to* their children, as all parties shape one another.³⁷⁰ Dominant views of autonomy measure children by what they are unable to contribute; a relational view of selfhood acknowledges the interpersonal influence that reflects the contributions of all constituents and encourages a more nuanced, multidirectional view of clinical encounters.

“Joshua”

A patient situation I was involved with several years ago is illustrative of Smith's relational self and the need to recognize that “There can be no true understanding of the self or

³⁷⁰ This theme is discussed further in chapter 5. For further theological insight on the ways in which children form parents see Gudorf, Christine E. “Parenting, Mutual Love, and Sacrifice,” in *Women's Consciousness, Women's Conscience: A Reader in Feminist Ethics*, edited by Barbara Hilkert Andolsen, Christine E. Gudorf, and Mary D. Pellauer, 175–91. Minneapolis, Minn: Winston Press, 1985. Miller-McLemore draws on Gudorf's essay as a key counterexample to oversimplified cultural notions of motherly sacrifice and parental formation of children (*Also a Mother*, 162-167).

self-conscious selfhood apart from the web of relations and historical circumstances in which individuals are embedded.”³⁷¹ I offer my own reflections here as an example of both the limits of a traditional notion of a dependent individual and the possibilities inherent with a more textured recognition of relational selves situated in layers of context. “Joshua” was an 11-year-old African refugee who suffered a devastating neurological injury after a suicide attempt by hanging. As his prognosis became clear, his physicians explained to his parents that the Joshua they knew was gone, and that his condition would never improve and might even progress to brain death. He would never walk, go to school, eat, or play soccer again. His parents responded that they were adamantly opposed to withdrawing life-sustaining technologies, and that even if Joshua existed in this condition indefinitely, he would at least be, as his mother put it with the help of an interpreter, “in our hands.” To them, the fact that he would never be the same was certainly a source of shock and grief, but it in no way lessened their view of Joshua as their son, as a member of their family. His intellectual and physical capacities were not what made his selfhood valuable; to them, he was valuable for his enduring presence among the living.

Joshua’s family had only been living in the US for a few years after that point, after being multiply displaced by wars in two African countries, where they had tried to raise their children in refugee camps and had survived abysmal conditions. They had witnessed family members killed by machetes and guns, and their extended family who survived were scattered throughout several African countries. The family was just beginning to find their bearings in the US and felt deeply grateful to be alive and together—Joshua was one of four children ages 12 and under.

To most staff members, the anguish of what had happened to this boy was compounded with the difficulty of trying to understand how his family could persist in endorsing what so

³⁷¹ Smith, *The Relational Self*, 51.

many others would deem to be an unacceptable quality of life. The seemingly straightforward measures of what it meant for Joshua to no longer be Joshua, however, carried little weight for this family. Affirming even the most basic level of survival was their goal for him, and this was surely shaped by a past in which death at the hands of others had been a constant threat to which so many had succumbed. For this family, making decisions about Joshua's care entailed appreciating the fullness of his relational self, seeking to preserve his basic enduring place as a son and a brother in their family, even if his own individual flourishing was to be profoundly stunted.

I spent a great deal of time with both the family and the staff through Joshua's six-week hospital stay, until he was transferred to a long-term care facility with a tracheostomy and a feeding tube. I was constantly confronted with the reminder that the oft-mentioned "cultural issues" in complex patient situations belong not only to patients and families but also to the medical system, which certainly persists as a well-established culture that prizes individualism, technology, progress, and science, and which leaves little room for conceptualizing drastically different accounts of what it means to have a life worth living. Moreover, the contemporary medical culture's perpetual default to the aggressive use of ever-enhancing technology fashions endless scenarios in which physical life is sustained apart from any discussion or consensus about the acceptability of potential outcomes. Had his situation occurred just a few decades prior, or in a less resource-rich country, the absence of modern life-sustaining technologies would have prevented such agonizing decisions and value conflicts altogether. Joshua was entangled in a living human web from which his selfhood was inseparable, yet one where none of the many narratives centered around him could fully define him.

Dependence as integral to communal life

Having described how pastoral theology contributes to a better understanding of the dependence of children by placing their identities in context of the living human web, and having explored the concept of social or relational self in contrast to the autonomous self, I turn now to the work of practical theologian John Swinton, who builds on these concepts by asking what it would mean for those who have disabilities of various kinds to truly *belong* in community rather than simply be a perfunctory presence. Swinton's thought is shaped by his background in psychiatric nursing and his more evangelical theological orientation. While disabilities are the focus of much of his work, his insights are relevant here because they parallel the question of how to go beyond simplistic notions of inclusion when talking about children in the pediatric health care setting as well. Just as classic notions of the individual self limit children by highlighting their lack of cognitive maturity, and thus cast them as non-actors in the realm of rational deliberation among fully developed selves—that is, adults—so too Swinton reflects on how it is all too easy in community to ignore the selfhood and contributions of those who are regarded as disabled. I find compelling parallels in the way that Swinton theologically envisions communities of “belonging” and the way in which the social and relational selves of children might be more fully acknowledged in the communities of practice that emerge in the pediatric hospital setting. Swinton's work gives us additional footing from which to view dependence as a normal aspect of human experience, rather than a deficit needing special accommodation.

Swinton explores what it means to have a life narrative whose story is not just told by oneself – he and colleagues creatively ask questions of who “stories” us, urging a theological grounding for our stories as rooted in the creator God and in the richness of Christian

community.³⁷² Acknowledging the dominant view that autonomy is a desired good, Swinton suggests that the idea of the self being sovereign is as illusory for all people as it so starkly is for people with disabilities. Perhaps autonomy needs new content, says Swinton, and we need to reconceive of ourselves with “dependent-independence” as our basic identity, knowing that as created beings, our dependence remains part of our selfhood, and that acquiring independence is not to be equated with unfettered freedom, as modernity would tempt us to believe. Swinton describes a way of conceiving individual identity within relationships, particularly for those who live with persistent needs that render them deeply dependent on others:

Might it then be the case that a person can be completely dependent, yet treated as independent as a form of respect for their personhood? Might our natural state be one of *dependent-independence*? Autonomy then would be based on relationships and would be required for and intended to enhance relationality. Autonomy could then be perceived as a gift given in relationship. *We need one another in order to be autonomous and to sustain autonomy.*³⁷³

This description of autonomy sourced in and sustained by relationships aligns with aspects of autonomy I have explored thus far in this chapter. Rather than speaking of children as incomplete persons with respect to the development of autonomy, we can conceive of them alongside adults in their emerging, dynamic relational autonomy, growing in the dynamism of their personhood as their relationships likewise grow and deepen. Declaring children primarily non-autonomous indicts them for something they are seen to lack; affirming that *all* people, adults included, lack self-sovereign autonomy and are also dependent on relational bonds to sustain their identity, creates a common human ground for assessing the abundance rather than scarcity of one’s identity.

³⁷² Swinton, John, Harriet Mowat, and Susannah Baines. “Whose Story Am I? Redescribing Profound Intellectual Disability in the Kingdom of God.” *Journal of Religion, Disability & Health* 15, no. 1 (January 2011): 5–19.

³⁷³ Swinton et al., “Whose Story Am I?,” 12.

Elsewhere, Swinton describes what is at stake when a community only skims the surface of what it means to include those with profound disabilities such as intellectual disability. He builds on the idea of dependent-independence and illustrates what it means for a body of people to remain keenly aware of their dependence, which he contends they can only do when they have established a culture of real belonging, not just representational inclusion. For Swinton, the litmus test for this kind of belonging is not simply being welcomed to participate, but that one is *missed* when his or her absence is felt by the community.³⁷⁴ Swinton attests, “People need to be concerned when you are not there; your communities need to feel empty when you are not there. The world needs to be perceived as radically different when you are not there. Only when your absence stimulates feelings of emptiness will you know that you truly belong. Only when your gifts are longed for can community truly be community.”³⁷⁵ This kind of belonging cannot be mandated or legislated, reminds Swinton, and thus it is a theologically vital component of human community, where identity as God’s creations allows us to realize and recreate what it means not just to be included in the goodness of God’s creation but to belong in it.

This kind of belonging precedes any understanding of autonomy, self-representation, or freedom, says Swinton.³⁷⁶ Moreover, this type of belonging is a prerequisite for justice and equality, not a movement toward such aspirations. We are called to long for one another in the midst of our vast differences, says Swinton, and in so doing we can discover the kind of hospitality that conventional notions of autonomy would never lead us toward, particularly as we enact communities of belonging with those living in deep dependence.³⁷⁷

³⁷⁴ Swinton, John. “From Inclusion to Belonging: A Practical Theology of Community, Disability and Humanness.” *Journal of Religion, Disability & Health* 16, no. 2 (April 2012), 184.

³⁷⁵ Swinton, “From Inclusion to Belonging,” 183.

³⁷⁶ Swinton, “From Inclusion to Belonging,” 184.

³⁷⁷ Swinton, “From Inclusion to Belonging,” 175, 183.

In the midst of discussing inclusion and belonging, Swinton also wrestles with how to even define disability. He describes the limitations of the social model of disability, which emphasizes the shared experiences of oppression among those for whom society has reacted negatively to their difference. Particularly in the United States, says Swinton, this has led to an understanding of disabled people as an oppressed minority in need of political liberation.³⁷⁸ Nonetheless, he remarks, it is problematic and can be arbitrary to categorize disability based on a perceived difference, especially because, as he notes, “difference is the norm,” with genetic diversity being seen across all humans.³⁷⁹

Our tendency to attach certain meanings to particular kinds of differences, and thus to label disabilities, constitutes a “thin description” of persons with disabilities, says Swinton, calling to mind the distinction between “thin” and “thick” descriptions made by anthropologist Clifford Geertz.³⁸⁰ Whereas thin descriptions only look at the “bare bones” of a phenomenon, thick descriptions engage the context and possible meanings inherent within dynamic actions and actors. Swinton finds that disability itself has become a thin term leading to thin versions of inclusion; Christian theology instead calls for a thick description of human beings, where all are engaged fully no matter what differences they present.

Swinton’s portrayal of mutually dependent persons resonates strongly for me as I consider the context of hospitalized children and how the dominant medical ethics gaze regards them. The vision of a community of belonging offers a way of unifying people in the midst of their differences, acknowledging the real needs addressed among them, and still preserving the

³⁷⁸ Swinton acknowledges too that this approach has had its benefits, such as the adoption of the 1990 Americans with Disabilities Act (“From Inclusion to Belonging,” 176).

³⁷⁹ Swinton, “From Inclusion to Belonging,” 179.

³⁸⁰ Swinton, “From Inclusion to Belonging,” 180. See also Geertz, Clifford. *The Interpretation of Cultures: Selected Essays*. New York: Basic Books, 1973, 3-30.

real variances in their responsibilities and capabilities. Some may need total physical care as they cannot meet basic needs for themselves, but even those who are physically more independent are in a real sense dependent on the others in order for all of them to flourish together in their humanity. This vision invites consideration of what it would look like in the pediatric health care setting to regard any adults-only approach to medical care or decision making to be “missing” the children as real participants. While many children because of age or capacity may not literally be able to contribute their voices, this in no way need limit the kind of inclusion and “thick description” of who they are as people and how their identity and differences impact and are impacted by those around them, including parents, family members, and staff caregivers. The living human web of relationships remains broken and incomplete if the presence and influence of children are not taken into consideration.

Swinton’s community of belonging reframes dependence, moving it along with autonomy from something that one “possesses” to something that is salient because of how it functions in relationships with others. Both dependence and autonomous action acquire significance because of how they are addressed by others. In the realm of pediatric clinical ethics, this move encourages a systemic approach to dependence rather than a simplistic view of dependence as a deficit located in the individual. I would argue this is true for adult patients as well—whereas hospitalization may highlight or exacerbate the pre-existing dependence that we associate with childhood, in the case of adults, dependence is usually seen as a negative aberration from their default state. Anyone admitted to the hospital has been determined to be dependent on 24-hour medical care for their health and safety, so the hospital context only amplifies the circumstances that create a new level of dependence. In health care, we may find ourselves suddenly dependent, sometimes in prolonged situations of needing care from others

whose abilities or expertise exceed our own. Swinton depicts how this dependence need not be stigmatized or burdensome, where theological footing provides a way to respect and honor the most dependent among us, whether they are two or ninety-two.

For those of us in less stark states of dependence, including those “autonomous” decision makers such as parents of pediatric patients, living into the pervasive reality of dependence means coming to terms with our lack of control, a task which can bring anxiety but also relief to those faced with what feel like superhuman responsibilities as they search for meaning and guidance in decision making amidst life-threatening circumstances. Creating a thicker description of hospitalized children allows us to see our social selves and our intertwined dependencies, and to acknowledge the contingencies of various outcomes that transcend our rational capacity to predict, understand, or choreograph.

Perhaps pediatric ethics has spent so much energy trying to articulate the range of acceptable conditions for parental or guardian decision making because there is an ever present but elusive hope that doing so might somehow mitigate the tragedy and suffering that persists even in the midst of the most well-reasoned, thoroughly deliberated decisions. Swinton has something to say about this as well, noting that advances in modern medicine and its technology have raised the “necessity” of humans articulating a theodicy, that is, an explanation for evil and suffering. When suffering was rampant and uncontrollable, such as when infant mortality was historically very high, there was an accompanying level of acceptance as to its inevitability. Now, as suffering feels more and more like it ought to be eradicated by our medical proficiencies, the question of why God would allow such evil to persist arises more stubbornly.³⁸¹ As Swinton suggests in his pastoral approach to theodicy, communities of faith

³⁸¹ Swinton, John. *Raging with Compassion: Pastoral Responses to the Problem of Evil*. Grand Rapids, Mich: William B. Eerdmans Publishing Company, 2007, 38

can resist and respond to evil in resilient ways that surpass the ability of any individual. Thus, the operative individualism in our health care context also contributes to a thin description of human beings, and shortchanges our vision for how individuals might be supported in community as they suffer and yearn for healing. With regard to children, this framework also validates the real suffering of those others who are deeply embedded in the child's relational identity, such as parents, siblings, and grandparents. They share in the sufferings of the child and seek to honor that individual child as a person even as they navigate the uncertainty and often harrowing levels of responsibility that the child's specific dependencies evoke.

When I envision this tension experienced by those in relationship with children who suffer, I recall one mother whose seven-year-old daughter was close to death after exhausting the available treatments for her refractory leukemia. This mother honestly expressed the terrible difficulty she had in trying to stay in relationship with both God and her daughter—in her understandable anger, she wanted to reject a God who would allow her daughter to die, and at the same time, she yearned to retain an image of a loving God to whom she could entrust her daughter after death. For that mother, caught in the bind of theodicy and profound parental bonds, it was crucial to have a community around her—including a chaplain—with whom she could hold such tensions simultaneously. In the medicalized context of dying, where so much attention is focused on the physical dependency of the dying person, there is a persistent need for “thicker” understandings of the dependencies present within and among many people around that person as well. A pastoral understanding of belonging and dependence like Swinton's more closely attends to the experiences of those who suffer. In Christian theological terms, it points to the God who chose not to be distant, removed, separate, or autonomous, but who in the incarnation of Jesus came to share fully in human, bodily suffering and death. Likewise, the

Christian the view of the godhead as a Trinity reflects the notion of a social self, where the three persons of the Father, Son, and Holy Spirit are distinct but dependent identities, whose selves are only fully revealed in relationship with one another.

Conclusion

Moving past simplistic renderings of dependence that still foreground independence and autonomy as normative, I argue that dependence can be affirmed theologically as a thread running through all of human life. Rather than seeing dependence as needing to be resolved or left behind as development proceeds, it can be regarded as an integral descriptor of what makes us fully human and situates us in the relationships that shape us most deeply. As I have described, dependence includes not only the straightforward reliance that is readily visible in hospitalized children, such as in their need for physical and emotional care and needs for medical treatment, but also those layers of dependence manifest in a living web of social realities and power dynamics, in the intrapersonal development of selfhood in the first place, and in the mutual belonging that renders a community incomplete when any are missing. Equipped with this theologically richer view of dependence, I now turn to the third of three features of my theological anthropology, proposing that the concept of agency is likewise ripe for theological animation beyond the simplified understandings of individual autonomous action that bioethics has too often employed. While the dominant emphasis on autonomy has cast vulnerability and dependence as features that jeopardize the ability to express oneself or wield influence, theological anthropology can recast them as compatible with and contributory to a new understanding of agency that is not bound to notions of self-sufficiency or cognitive prowess.

Chapter 5

Agency: discovering new modes of expression and influence

Recently I led a staff support session following the death of a four-year-old girl with a complex cardiac history and a host of other medical problems. She had at last succumbed to her physical ailments after spending a life mostly in the hospital – her parents told me she had never spent longer than three months at home without a hospital admission. Though many reflections were shared in that session with staff who had cared for this little girl, what stood out to me was not the recounting of what she had been through medically or what her parents had demonstrated in their dedication to her care, but rather attestations of the impact she had on her caregivers in the hospital. Of the many things that were shared in that hour shortly after her death, what remains etched in my mind is the crying medical provider who simply stated of this little girl: “she brought out the best in us.”

In the midst of this child’s young age and many limitations, the influence she exerted simply by being fully who she was provides a succinct picture of children’s agency at work in the hospital setting. This child drew out the technical skills, practical wisdom, and genuine care of the staff who tended to her every need. This is the kind of agency that cries out to be recognized and affirmed, and it is the kind of agency that invites us to honor the identity and relationships present among even the youngest, smallest, and least “capable” children. It is the kind of agency that gets entirely overlooked when autonomy is the sole preoccupation of the medical context. Certainly, the parents’ decision-making on this child’s behalf was significant, and it too was driven by their deep knowing of their daughter and their sense of what would be best for her at any given turn. However, until clinical ethics develops language and habits of acknowledging these other layers of influence and how they shape otherwise abstract notions of

surrogates determining “best interests” for one who is “incompetent,” we will continue to be impoverished in our efforts to describe the powerful nuances of the deep kind of agency that children of all ages and capacities bring to bear on the relationships of kin and care that develop around them from the moment they make their presence known.

Agency thus joins vulnerability and dependence as a third vital feature of a theological anthropology of hospitalized children. My placement of this feature last among the three is deliberate, in that it corrects any tendency to regard children only or primarily as objects or recipients of care and concern, which is a risk when vulnerability and dependence are the areas of focus. While it is important to recognize and respond to the many ways in which children’s needs and identities interact with adults’ successes and failures at meeting those needs, it is also crucial to reflect on the ways in which children, even those under the duress and limitations posed by illness and hospitalization, manifest their own subjectivity. My attention in this chapter will turn especially to the ways in which that subjectivity should be recognized as social and spiritual, particularly in ways that may be hard to see when more recognizable forms of physical or cognitive agency are profoundly hampered.

As a third feature of the theological anthropology I propose, agency reflects the importance of counteracting yet another aspect of how the principle of respect for autonomy is often characterized. Agency offers a corrective to the way in which autonomy has lulled us into equating the expression of goals, preferences, and choices with rationality, and thus has allowed us too easily to conflate subjectivity and autonomy. With so much weight given to respecting one’s autonomy and to determining whether someone is competent to make medical decisions, most clinical ethics approaches have not surpassed those concerns in a way that invites a more robust portrait of how the individual in question—whether or not they have decision-making

capacity—exerts their identity and influence on the relationships, environment, and systems around them. In other words, influence and impact are not limited by one’s ability to make rational choices or to steer oneself toward particular self-fulfilling goals.

And yet, there persists a deeply unfortunate tendency in the healthcare environment to ascribe subject status to those who are deemed to possess decision-making authority, a tendency that sidelines the importance of affirming the subjectivity of those who are determined to lack this power. This creates a situation where many patients are first and foremost known for their lack of competence and fosters an approach to them that regards them as passive recipients rather than active participants in their experience. Certainly, this is true for some older adults who, due to dementia or other diagnoses, are profoundly limited in the degree to which they can deliberate or reflect about their health care situation.

This oversimplified non-competent, non-participant designation is pervasively operating in the background from the outset in pediatrics, where *all* patients are deemed to lack what it takes to independently sort out their medical situations. This tendency leads to a dangerous and narrow mindset regarding children, where focus gravitates toward parental or guardian responsibility, almost to the complete exclusion of consideration for the child’s perceptions and meanings related to their circumstances. And often, unlike for older adults with dementia, children are still in the process of living into the development of greater awareness and engagement with their subjective experience over time and ought to be accommodated as such, difficult as it may be for adults to incorporate that kind of consideration into practice. I recall an earnest six-year-old boy with leukemia whose hospital room was icy cold. He had changed the thermostat because he had overheard staff talking about how he was “a little hot” and he had picked up on enough to know that that was a bad thing. Indeed, the detection of a fever has

crucial importance in oncology care, and this boy was trying to address his situation with what little information was available to him. Adult attempts to refrain from burdening him with the details of his care had only had the effect of further minimizing any recognition of his role at the center of his own care. My memories of the goosebumps I developed from the chilly temperature in his room continue to remind me of the importance of equipping children with the tools to enter into their medical care in the ways that they desire and are ready for, rather than making assumptions about what they can understand or what they should or should not be told about based on their age.

As I have stressed previously, I do not intend to downplay the profound importance of adult responsibility for protecting and promoting the health interests of children, or to cast adults as having less than compassionate motives in doing so. Nonetheless, it is all too possible for adults to proceed in their roles as decision makers and power brokers in the pediatric health care setting without ever pausing to truly reflect on what the child's own experience contributes to the situation, no matter whether that is expressed in words or simply enacted through the relationships that the child is shaping and through which the child is by extension impacting the surrounding environment of people and circumstances.

I begin this chapter by identifying key reasons why agency is a necessary area of focus for hospitalized children, giving rationale for why the hospital can be a place where children are susceptible to having their agency ignored or overlooked. In the second section, I discuss how medical ethics literature has tried to address the matter of agency through focusing on assent. I contend that agency invites a broader regard for children where concepts of autonomy and even assent have cast quite narrow interpretations. I then engage broader interpretations of agency in the third section, drawing on the discipline of childhood studies and tracing how views of agency

within it remain prominent even as they continue to evolve. Building on the delineations of agency in childhood studies, I then incorporate theological resources for articulating agency, whose richness stems in part from being unconstrained by popular developmental assumptions. Drawing on the work of Bonnie Miller-McLemore, who has extensively considered what it means for children to be agents and to have a vocational life, I propose that theology fosters a spaciousness where the multidirectional realities of child and adult spirituality can foster growth in ways that are not demarcated by age, health status, or abilities. Finally, building on these insights, I recommend ways to recognize and nurture children's agency in the hospital setting. Children's spirituality provides a vibrant lens for appreciating the way in which children enact their agency as they engage in the relationships around them, in the way that they play, and in the way that they express meaning in relation to their situation that is not simply shaped by the adults around them. Agency adds vital language to describe the ways in which children's spirituality can manifest and mature in timelines that are not bound to developmental ideas of normal stages nor to hierarchical power relationships with adults. Agency likewise reminds adults that even as they continue in their hopes to guide children spiritually through difficult health related experiences, they too might be guided in significant ways if they can be receptive and responsive to children's own spirituality.

Why agency especially matters in the hospital

It is worth noting upfront why I believe agency is particularly important for this project, focused as it is on the specific population of children who find themselves patients admitted to hospitals. Examining how agency manifests and operates in general social settings, or in

families, or in schools, may lead to important contributions, but there are at least five key reasons why describing agency for hospitalized children is crucial.

First, articulating agency is important because it counteracts tendencies to describe pediatric patients in exclusively passive ways. It seeks to illuminate the ways in which, even in the face of their typical developmental limitations or diagnosis-specific limitations, they nonetheless retain subjectivity in the midst of the experience of being a *patient*, a word which itself connotes passivity at the hands of others.³⁸² More so than with adult patients, pediatric patients are all the more likely to be regarded as having little to engage with in terms of reflection on their predicament and priorities for moving forward.

Second, agency prompts attention to the aspects of the patient's experience that transcend merely physical descriptions of their condition. While children even outside the hospital setting are also regarded in relationship to their stature and other bodily developmental factors, children within the hospital environment are much more likely to be described in reductionist terms that refer to their physical condition and not much beyond that. Childhood studies scholar Bernard Place describes this trend in his ethnographic research on pediatric intensive care units. He notes the extensive technological efforts to externalize data about what is going on internally for any given patient, resulting in a situation where "the further one gets to the *inside* of the intensive care unit...the more the clinical gaze of the nurses moves away from the corporeal body of the child towards those devices which *represent* that corporeality."³⁸³ His words come to mind as I picture the large-screen "patient dashboards" recently installed in every ICU patient room in the

³⁸² Neuberger, Julia. "Do We Need a New Word for Patients? Let's do away with 'patients.'" *BMJ: British Medical Journal* 318, no. 7200 (June 26, 1999): 1756–58. Neuberger writes, "Patient comes from the Latin 'patiens,' from the Latin 'patior,' to suffer or to bear. The patient, in this language, is truly passive—bearing whatever suffering is necessary and tolerating patiently the interventions of the outside expert" (1756).

³⁸³ Place, Bernard. "Constructing the Bodies of Critically Ill Children: An Ethnography of Intensive Care." In *The Body, Childhood and Society*, edited by Alan Prout, 172–94. Basingstoke: Palgrave Macmillan, 2007, 177.

hospital where I currently work. They are an imposing presence, supposedly convenient for clinicians to quickly ascertain lab numbers, medications, and so on. In the pediatric ICU, the screens are often bigger than the actual patients themselves. Place sums up pediatric ICUs as locations where, “with their symbolic representations of death and rebirth, children lie enigmatically between being alive and being dead, and between being social and non-social entities. Between being human and non-human. Between being people and being things.”³⁸⁴ Moreover, because of the medical model’s near-exclusive preoccupation with identifying, documenting, and addressing specific problems, not much attention remains for wider features of the child’s identity and well-being. I recall a nurse on the ICU at St. Jude who astutely discovered that a component of her infant patient’s pain was from teething discomfort, a normal developmental phenomenon that had gotten overlooked by the medical team in the midst of the tiny patient’s critical condition. Attention was so focused on treating her cancer and related symptoms that no one had thought to consider typical infant experiences apart from the illness. Moreover, when there does happen to be greater attentiveness to the child’s experience, it is usually initiated because there is again a problem, namely, the coping of the child or family members. In the electronic medical records system of the health system where I currently work, there are care plans that staff can initiate for addressing the problem of “impaired coping” of patients and family members.

The medical model is thoroughly focused on problems, and thus attending to the wider experience of a patient or family member is also a problem-focused endeavor rather than simply a response to understandable attempts to integrate their experiences into their larger pictures of their identities and relationships. I would add that the pressures, starting at the time of admission,

³⁸⁴ Place, “Constructing the Bodies of Critically Ill Children,” 174.

to identify a discharge plan and barriers to discharge also deeply shape the way staff are formed in their interactions with patients. Like many aspects of contemporary healthcare, this focus on discharge also developed for good reasons—it is important to have a sense of what needs to happen before a patient can go home safely with whatever they need next, and to not waste costs and time from patients staying longer unnecessarily. “Care management” representatives, usually nurses or social workers, are tasked with coordinating supplies, referrals, transfers, and the like. However, despite their justifiability, I would argue that these efforts contribute to an environment where attending to the meaning and subjective experience of patients and their loved ones has become a luxury of sorts, that can be undertaken if time or energy allows after the paperwork has been processed. Chaplains attend primarily to those aspects of the person’s experience, but the relatively small number of chaplains in most health systems, and the pressure for them to demonstrate measurable impacts they have beyond that kind of scope, such as showing a correlating reduction in length of stay or decreased patient use of intensive treatment at end of life, or less burnout among staff, further underscores the sense that simply tending to the psychological and spiritual well-being of patients is as “ancillary” a concern as are the staff designated to attend to such concerns.

Thirdly, the hospital environment further jeopardizes attention to children’s agency by focusing extensively on privacy, confidentiality, and infection prevention. The domino effect of these priorities mean that children may have very little interaction beyond their immediate family and staff caregivers. These realities mean we must up the ante for how we appreciate the creative ways pediatric patients continue to enact their social agency even when they are removed from their routine social spaces such as neighborhood, school, place of worship, and placed in an environment that emphasizes not sharing personal information. In a few short decades most

hospitals and children's hospitals as well have gone from a shared ward type of setup to private or semi-private rooms; most families today expect a private space for themselves and their child. In the handful of children's hospitals where I have spent time in the past decade, I can picture few occasions where I saw more than one pediatric patient in a playroom at a given time. Considerations for infection prevention, along with the acuity of their condition that keeps many patients from leaving their hospital rooms, contributes to an environment that looks less like a social space for children and more like a highly individualized, privatized, personalized place and experience –which is what healthcare prides itself on becoming. But for children who are in such heightened periods of social development, this privacy likely feels much more like isolation than it might for adults.

A fourth reason why I find it imperative to attend to children's agency in the hospital setting is rooted in the fact that pediatric health care is systemic from the beginning. Whereas adult patients might make decisions in a dyad with their health care provider, for pediatric patients there is always a triad of patient, family or guardian, and health care provider. Perhaps one could suggest that this integration of the child in a multi-participant system might *safeguard* attention to a child's agency, but I would suggest that the risk of focusing predominantly on the adults in the mix can just as easily create the risk of overlooking the child's subjective experience and contributions to the scenario. All too often, this triad is effectively still a dyad, with adult caregivers and medical providers doing the describing, strategizing, and assessing of the child's situation. By no means do I intend to paint adults in these situations with a negative brush, nor do I mean to overlook the fact that many children are not able to verbally contribute to these proceedings; nonetheless, it is still important to preserve the triad by building in ways to

recognize and affirm the young subjects whose health is the very reason the triad has come into existence.

Most pediatric settings have adopted a family-centered care approach that reflects this triad. Here too, however, it is important to proceed with caution lest we assume that family-centered care ensures attention to the subjectivity of children. It emerged more in response to overly paternalistic versions of medical care, where providers were failing to take family preferences into account. In the pediatric setting, family-centered care is as geared toward increasing parental involvement and authority as anything else, and I would say still cedes much of the work of attending to the children in the mix to the families themselves, thus underscoring the privatized modes of parenting that predominate in wider cultural assumptions as well. A more robust appreciation for the agency of pediatric patients could offer both families and staff a more engaging way of accounting for the way that children shape the web of people and circumstances around them. When these efforts are carried out well, all parties can sometimes find a remarkable way forward that perhaps would not otherwise be envisioned. I think of a nine-year-old girl who was nearing the end of her life due to the spread of her cancer, which was compromising her ability to breathe. Normally, a tracheotomy would not be offered to such a patient because it would risk causing further discomfort and complications and only prolong the inevitable. But in this girl's case, just a little more time was exactly what she was hoping for—she wanted to survive long enough to meet her expected new baby sister. She underwent the tracheotomy and it allowed her to fulfill this goal, one that was reached because the adults in her situation were carefully crafting decisions in fruitful partnership with her.

A fifth reason agency is worthy of attention in the pediatric health care setting relates to the way in which children's own agency can be the impetus for their need for medical care in the

first place. I refer here to a particular subset of patients, to be sure, and does not refer to the myriad of premature newborns, or oncology patients, or patients with chronic diseases who comprise much of the typical population of a children's hospital on any given day. But there is a subset of pediatric patients whose own actions, whether stemming from curiosity, extracurricular interests, or inclinations toward self-harm, are the occasion for their hospitalization. I think of the children who have gotten into accidents related to a choice they made, whether, for instance, that meant swimming when they did not know how to swim, or riding dirt bikes for a hobby, or swallowing foreign objects, or attempting to harm themselves or end their lives—the latter category being one in which I meet a new face at least weekly.

For these patients, further harm can be imposed by proceeding with their medical care with only a focus on the adults who are deemed capable of making reasonable decisions, thereby failing to engage the child's agency as an integral part of their hospitalization. If we cannot engage with their agency and grapple with it honestly, and not just by pathologizing or dismissing it, we also miss the opportunity to come alongside that child and family in processing their experience and moving forward. In the best-case scenario, attending to the child's agency in these types of admissions becomes a source of empowerment, and in the worst cases, failure to see the child's actions as an expression of their agency is yet another influence on their feeling unheard, unworthy, or unforgiven, and may contribute to perpetuating their complicated efforts to be understood going forward.

The above reasons for attention to agency underscore why theology can be a resource in response, in that it can help to articulate self and experience in ways that connect to but are not limited by the material and physical realities that often constrict other fields and disciplines, medicine included. As I will show later in this chapter, theological regard for agency can

contribute to an anthropology that does not measure people by their rationality or independence from the care of others, but instead provides language and a framework for esteeming the full humanness of all people and their meaningful influence on those around them regardless of their capacity for formal reasoning or overt intention.

Assent in pediatric bioethics

Before exploring how agency is understood from both childhood studies and theological perspectives, it is worth first highlighting how it is distinct from the traditional notion of autonomy that I have been addressing throughout this project. In the principlist medical ethics model, as I have previously stated, children are first and foremost regarded as patients who lack autonomy and who require decision makers to act in their interests. As I have noted, this approach tends to bypass quickly any attention to the child as a patient and as a person and focuses instead on the optimal conditions for determining the range of appropriate decision makers and decisions.

Beauchamp and Childress mention agency in the context of the Kantian injunction to avoid treating people merely as means to an end. For them, this means respect for autonomy entails assisting others in achieving their own ends and fostering their capacities as agents.³⁸⁵ The concept of assent has emerged in medical ethics literature as a way of trying to appreciate children's developing autonomy. Pediatricians, researchers, and ethicists have explored incorporating assent as a means of including the child's participation. The American Academy of Pediatrics Bioethics Committee notes

Pediatric practice is unique in that the developmental maturation of the child allows for increasing longitudinal inclusion of the child's voice in the decision-making process.

³⁸⁵ Beauchamp and Childress, *Principles of Biomedical Ethics*, 6th ed., 104.

Assent from children even as young as 7 years for medical interventions may help them become more involved in their medical care and can foster moral growth and development of autonomy in young patients.³⁸⁶

Exact definitions of assent have been inconsistent, however, and a strict interpretation of assent requires all the same elements as informed consent for adults. The Committee suggests that assent should include several elements including helping patients with a developmentally appropriate awareness of their condition, telling them what they can expect, assessing their level of understanding, and finally – only if the treatment or intervention is *not* required, lest the child decline to assent to mandatory care – soliciting the child’s willingness to accept the proposed care.³⁸⁷

Some might argue that the concept of agency is adequately addressed by attending to assent. However, while assent is an important development in pediatrics, focusing only on it without considering other expressions of agency limits our appreciation for the full humanity of children and their experience in the medical context. Because assent’s importance derives from the notion of autonomy as envisioned by principlist ethics, it persists in reflecting a narrow view of human development, one that remains rooted in prizing the attainment of rationality and independence above all else. It does not account for the way agency might be expressed by those who are unable to give assent because they are too young or for any number of reasons, but who nonetheless express their selfhood in ways that impact the people and circumstances that comprise their health care situation. Moreover, it perpetuates the culture of a dilemma-focused bioethics, where moments of crucial decision are abstracted from the larger contextual factors shaping care. Lastly, much of what has been written about assent is directed primarily at

³⁸⁶ Katz, Aviva L., Sally A. Webb, and Committee On Bioethics. “Informed Consent in Decision-Making in Pediatric Practice.” *Pediatrics* 138, no. 2 (July 25, 2016), e8.

³⁸⁷ Katz et al., “Informed Consent,” e8.

children's participation in research and is focused less on the day-to-day clinical realities experienced by hospitalized children, their families, and their health care teams.

Attention to assent may appear on the surface to be a progressive movement in pediatrics, but its history reveals otherwise. Compared with other disciplines that consider children and development, such as psychology, childhood studies, and religious studies, medicine has been slow to arrive at the discovery that children could be considered full persons. As pediatrician William Bartholome reflects shortly after the AAP Bioethics Committee's 1995 adoption of human subjects protection language for use in general pediatric practice,³⁸⁸ his prose reveals just how novel the concept of listening to children was at the time. His perspective also reflects a very adult-centric and autonomy-centric understanding of childhood.³⁸⁹ In an illustrative passage following Bartholome's expressed excitement about the incorporation of the concept of assent, he asserts:

Ever since the explosion of information about child development began to unfold in the second half of this century, there has been increasing recognition of the need for a conceptual framework that recognized the developing capacity of children for autonomy, for rationality, and for participation in decisions about their lives. Respect for children as moral agents requires a respect for the developing capacity of the child for making choices, for the exercise of autonomy. Autonomy can be thought of as the process by which the "self" of the child is continuously asserted, constructed, de-constructed, and re-constructed. From the exuberant "I did it" of the toddler to the profound "I do" of the bridegroom, the evolving "self" must work at the business of autonomy. To become a self-governing person, one must relentlessly practice the governing of one's self. We are also becoming increasingly aware that the use of force, coercion, and manipulation in dealings with a child are destructive of the child's sense of predictability and control; they undermine the child's sense of trust in parents and other adults and threaten the child's evolving sense of self-control, of mastery of one's life.³⁹⁰

³⁸⁸ American Academy of Pediatrics Committee on Bioethics. "Informed Consent, Parental Permission, and Assent in Pediatric Practice." *Pediatrics* 95, no. 2 (February 1, 1995): 314–17.

³⁸⁹ Bartholome, William G. "Hearing Children's Voices." *Bioethics Forum* 11, no. 4 (1995): 3–6.

³⁹⁰ William G. Bartholome, "Hearing Children's Voices," *Bioethics Forum* 11, no. 4 (1995), 4.

Despite Bartholome's exuberant acknowledgement of new research on child development, he casts children as adults writ small. He remains preoccupied with the trajectory of self-governance and mastery to which children aspire, now with the magnanimous help of less manipulative physicians! Additionally, Bartholome later stresses the importance of respecting children "for the persons they are in the process of becoming," further echoing the impression that when it comes to being fully human, children are on their way but not there yet.³⁹¹

Agency in Childhood Studies

The discipline of childhood studies provides a more spacious reading of children's active participation in their lives. While the medical realm has preoccupied itself largely with children's specific contributions to their medical decision making, childhood studies invites consideration of the broader questions of how children experience and impact their medical care. This wider net evokes inquiry into their meaning-making, their expressions of subjectivity even when decision making is not their responsibility, and the ripple effects of the relationships that are shaped by the child in the midst of such situations.

Childhood studies as a field of inquiry emerged in the 1980s and 1990s, largely from sociology and anthropology, drawing together those who felt strongly that existing disciplinary ventures had not adequately attended to children. The editors of *The Palgrave Handbook of Childhood Studies* note in their introduction to the volume that sociology had not significantly responded to the twentieth-century's developments in terms of understanding of children and their development, even with the emergence of three international declarations regarding the

³⁹¹ Bartholome, "Hearing Children's Voices," 6.

place of children in society by the League of Nations and, later, the United Nations.³⁹² The editors summarize the key motivations that furthered childhood studies scholarship, where one motivation was the desire to provide an alternative to the dominant socialization theories that described children merely in terms of how they are formed for future adulthood. As the editors summarize, childhood studies scholars sought a new paradigm in order

to enhance the visibility of children here and now, while they are children, and to understand, accept and recognize children and their life worlds in their own right. Children are not here merely or first of all to become adults, though, of course, we all expect and hope they will become adults. However, this expectation and hope had, in lore and science, gained so much attention and conveyed so much significance that it was more or less forgotten that children also have a life while they are children. To insist that this life has a worth in its own right amounts to saying that it should not necessarily be formed according to criteria for a successful later adult life.³⁹³

Another key motivation centered around agency, with early childhood studies scholars contending that sociological perspectives on children up to that point had largely reduced them to vulnerable recipients of care and protection, without regard for the ways in which they participate in their own lives or the wider social fabric.³⁹⁴

In a chapter in the same volume, sociologist Allison James, a prominent figure in childhood studies, recounts the ways in which childhood studies sought to counter the rise of developmental psychology, which had largely created theories based on efforts to universalize child development and stage theory. These models, however, states James, were motivated by efforts to understand how human development replicates human evolution, or to generalize about

³⁹² These three being: the 1924 Geneva Declaration of the Rights of the Child (by the League of Nations), the 1959 Declaration of the Rights of the Child (by the UN General Assembly), and the 1989 United Nations Convention on the Rights of the Child (Qvortrup, Jens, William A Corsaro, and Michael-Sebastian Honig. "Why Social Studies of Childhood? An Introduction to the Handbook." In *The Palgrave Handbook of Childhood Studies*. Houndmills, Basingstoke, Hampshire; New York: Palgrave Macmillan, 2009, 2.)

³⁹³ Qvortrup, Jens, William A Corsaro, and Michael-Sebastian Honig. "Why Social Studies of Childhood? An Introduction to the Handbook." In *The Palgrave Handbook of Childhood Studies*. Houndmills, Basingstoke, Hampshire; New York: Palgrave Macmillan, 2009, 5.

³⁹⁴ Qvortrup, Corsaro, and Honig, "Why Social Studies of Childhood?," 5.

how all children or adults think or act; ultimately, they were geared toward understanding how adults are produced. They were not focused on children's present lives or on the way in which culture shaped development.³⁹⁵ The critiques James describes toward dominant theories of the twentieth century certain apply as well to the approach to pediatric medicine as evidenced in the preceding section, which reflects a view of pediatric patients as emerging persons and largely passive recipients of care.

Agency thus emerged as a dominant concept in childhood studies because it validated the attending to children as social actors and as active participants in the world around them. With respect to this present project, it is also important to emphasize the way in which focusing on agency was a way to counteract the standardization of childhood that developed from twentieth-century efforts to describe "normal" physical and mental development of children. Child development research had emerged in response to late nineteenth-century industrialization and urbanization and the associated impacts on children, including considerations for their growth and health in the midst of crowded housing situations, and their need for education and standardized approaches to schooling. As Martin Woodhead remarks in the Palgrave volume, the mission of child development theorists was to identify universal, rule-governed patterns of behavior, thinking and reasoning. He notes that even the very phrase "child development" serves to naturalize, essentialize, and universalize particular understandings of childhood.³⁹⁶ The prevailing emphasis of this work was on establishing standards of "normal" development—what

³⁹⁵ Allison James, "Agency," in *The Palgrave Handbook of Childhood Studies*, ed. Jens Qvortrup, William A Corsaro, and Michael-Sebastian Honig (Houndmills, Basingstoke, Hampshire; New York: Palgrave Macmillan, 2009), 35–37.

³⁹⁶ Woodhead, Martin. "Child Development and Development of Childhood." In *The Palgrave Handbook of Childhood Studies*, edited by Jens Qvortrup, William A Corsaro, and Michael-Sebastian Honig. Houndmills, Basingstoke, Hampshire; New York: Palgrave Macmillan, 2009, 47-51. For a similar discussion, see also Turmel, André. *A Historical Sociology of Childhood: Developmental Thinking, Categorization, and Graphic Visualization*. Cambridge; New York: Cambridge University Press, 2008.

children supposedly have in common, not their diversity of identities and experiences.³⁹⁷ While the impetus for this body of work was justifiable given the historical context, it also hampered any attention to the particular and enculturated experiences of children and to any regard for their own understanding of their lives.

Critiques of agency have emerged in recent years as well, particularly in response to approaches to agency that rest on individualistic and cognitive capacity. Eberhard Raithelhuber, in a recent volume covering new approaches to agency in childhood studies, argues for a move away from a conventional notion of agency as something that people “have” or “possess,” calling instead for a relational and relativistic perspective on agency, where agency is not an intellectual or biological attribute but a situatedness from which one can bring about transformative and creative impacts on the environment.³⁹⁸ He summarizes, “Hence, agents are those human beings and things that have a specific status within a network of social relations, i.e. social positions that can originate causal events in their environment.”³⁹⁹ Raithelhuber notes that at this point in the trajectory of childhood studies as a discipline, approaches to agency are “scrambled” but he asserts that his call for new relational perspectives on agency is a vital response to the need to continue describing agency as a reality that transcends the individual, as something that exists in interconnectedness and is brought about in relations.⁴⁰⁰

³⁹⁷ In a comment relevant to the pediatric ethics assent discussion, so much of which rests on associating age with certain levels of reasoning capacity, Woodhead notes “What is frequently overlooked in developmental accounts is that giving primacy to children’s age as a proxy for their developmental stage is not inevitable, nor ‘natural.’” (“Child Development and Development of Childhood,” 52).

³⁹⁸ Raithelhuber, Eberhard. “Extending Agency: The Merit of Relational Approaches for Childhood Studies.” In *Reconceptualising Agency and Childhood New Perspectives in Childhood Studies*, edited by Florian Esser, Meike S. Baader, Tanja Betz, and Beatrice Hungerland. London; New York: Routledge, 2016, 91, 97.

³⁹⁹ Raithelhuber, “Extending Agency,” 97.

⁴⁰⁰ Raithelhuber, “Extending Agency,” 90, 96.

Precisely because of what is often compromised in the hospital setting, and because conventional expressions of agency might not be readily visible, it is incumbent for this project to consider what agency *does* look like for hospitalized children, and what it means that agency is a vital component to a theological anthropology of this population. I would reiterate the importance of highlighting agency as a way of affirming the humanity and subjectivity of patients who may lack the cognitive capability to reason with others about their medical care, but who nonetheless are actively engaged participants in their context, particularly through the relationships that mark the contours of their social worlds both outside of the hospital and within it. The example with which I opened this chapter aligns with this approach; surely the four-year-old girl's impact on the staff who cared for her could be regarded as an expression of her agency, in a way that was not tied to her cognitive abilities or a calculated effort to impact others or make decisions.

Childhood studies in the hospital context

A relational expression of agency is evident in a book that continues to be widely cited in childhood studies and specifically in childhood studies work related to the medical context. Anthropologist Myra Bluebond-Langner's book *The Private Worlds of Dying Children* stemmed from research for her doctoral dissertation, for which she spent nine months observing pediatric oncology patients and their interactions with family and staff at a large midwestern teaching hospital.⁴⁰¹ At the time, cure rates for childhood cancer were dismally low, such that the children she observed were universally not expected to ultimately survive their diseases. Bluebond-Langner approached her study with questions of how children "come to know that they are dying

⁴⁰¹ Myra Bluebond-Langner, *The Private Worlds of Dying Children* (Princeton, N.J.: Princeton University Press, 1978).

when no one tells them, and how they conceal this knowledge from their parents and the medical staff.”⁴⁰² She ultimately argues that “the children’s acquisition of information about their world and their place in it is best understood as a socialization process, and that their decision not to reveal their awareness reflects their knowledge of the order to which they have been socialized, of how it is acceptable to die in this society.”⁴⁰³ This emphasis on socialization dovetails with the same theme in childhood studies more generally, where children are not assumed to have a fixed nature or developmental trajectory but instead are dynamically shaped by socializing influences. Her rich descriptions of the children reveal the ways in which they creatively engaged their surroundings and found expression for their own subjectivity even in the face of mortal peril.

Bluebond-Langner does not sentimentalize the children’s actions but depicts an environment in which they find their own ways to interact with the experience of their illness, even when adults were particularly focused on protecting them from the full reality of their situations. Bluebond-Langner describes the “mutual pretense” that was evident when children who were aware that they were going to die pretended not to know this in the presence of their parents, who were intent on keeping the children from the knowledge that they would die.⁴⁰⁴ The subtleties of mutual pretense reflect the kind of relational agency that Raithelhuber and others want to advance. The children not only knew more than they let on, but they also factored what was at stake in the relationships around them as they proceeded with carrying and processing that knowledge.

Allison James notes that part of the legacy of how child health has been constructed is that “children who are sick or disabled are doubly marginalized. Not only do they, as children,

⁴⁰² Bluebond-Langner, *The Private Worlds*, ix.

⁴⁰³ Bluebond-Langner, *The Private Worlds*, ix.

⁴⁰⁴ Bluebond-Langner, *The Private Worlds*, 198-209.

share in childhood's conceptual isolation from the adult world but, through disablement or disease, find their social personhood subject to further qualification."⁴⁰⁵ As may also be true for adults in the medicalized world of the hospital, children may be subjected to a world where their "handicapped identity" is seen as the central organizing factor of their personhood.⁴⁰⁶ James laments the dearth of research on the experiences of disability or sickness from children's points of view, but finds Bluebond-Langner's account a notable exception in which "children are revealed as knowing and watchful commentators about the progress of their own disease (cancer) who actively manage adult perceptions of themselves."⁴⁰⁷ Bluebond-Langner's work thus depicts not only children's perspectives but also how children creatively confront ideologies of childhood which adults impose on them.

Bluebond-Langner's work is especially significant for my project because it is situated at the intersections of childhood studies and the healthcare context. It has been so widely regarded, yet so little similar work has been produced in the decades since. However, I want to highlight two recent publications from pediatric oncology literature that revisit questions of whether and how to involve children in treatment decision making. Bluebond-Langner is a contributing author in the first, where Brian Sisk et al. trace the history of prognostic disclosure to children beginning with the purely protective stance where clinicians tended not to disclose to children for fear of causing harm.⁴⁰⁸ By the late 1960s, this attitude gave way to a growing favorable attitude toward disclosure, one that by the late 1980s was swinging from "don't tell" to "always tell."⁴⁰⁹

⁴⁰⁵ James, Allison. *Childhood Identities: Self and Social Relationships in the Experience of the Child*. Edinburgh: Edinburgh University Press, 1993, 82.

⁴⁰⁶ James, *Childhood Identities*, 83.

⁴⁰⁷ James, *Childhood Identities*, 83.

⁴⁰⁸ Sisk, Bryan A., Myra Bluebond-Langner, Lori Wiener, Jennifer Mack, and Joanne Wolfe. "Prognostic Disclosures to Children: A Historical Perspective." *Pediatrics*, August 25, 2016, 1.

⁴⁰⁹ Sisk et al., "Prognostic Disclosures to Children," 4.

This shift represented not only growing psychological research about the importance of fostering open and honest communication and supportive relationships for children in cancer treatment, but also the increasing complexity related to pediatric cancer prognoses. Where once most childhood cancers were uniformly fatal, now improved outcomes mean that survival is much more likely but treatment courses may vary considerably and unpredictably.⁴¹⁰ Sisk and colleagues note that currently, there is a much-needed effort to move away from the “always tell” mindset and instead pursue careful attention to the needs and situations of patients and families. They note,

Perhaps most important, clinicians must answer the question, ‘What are we trying to accomplish with prognostic disclosure?’ Is knowing in and of itself important? Or is the utilization of knowledge by patients what matters? How do we provide the greatest benefit for our patients while doing the least harm? As a first principle, pediatric patients should be given the choice to initiate such conversations in a safe and open atmosphere. Children should know they will not be lied to, but neither will they be forced into disclosure discussions. Clinicians should be trained to identify a child’s cues, to engage in such conversations if they occur, but not to prod or force such discussions. Striving for openness in and of itself, regardless of the individual factors for an individual family, may be detrimental. Rather, clinicians should respect that every patient and parent has unique needs, and these needs may present differently over time and depending on the context.⁴¹¹

I appreciate Sisk et al.’s efforts to engage the challenges of responding to children and families in their unique needs, rather than prescribing a one-size-fits-all approach tailored more to adult needs and preferences than those of children. As pediatric oncology advances toward new horizons of possibility, so should its caregivers be equipped proportionately to advance their capacities for attending to the specific circumstances of the children in their care.

In the second article, Katherine Kelly et al. dig further into the crucial importance of paying attention to the actual child’s preferences, rather than assuming that a particular approach

⁴¹⁰ Sisk et al., “Prognostic Disclosures to Children,” 4.

⁴¹¹ Sisk et al., “Prognostic Disclosures to Children,” 7-8.

of disclosure or secrecy is best.⁴¹² Based on interviews of 29 cancer patients ages 9-17, the authors suggest that the concept of “having a say, as I need at this time” captures the ethos of children’s desired involvement in the decision-making process. Their findings add momentum to the search for a middle ground between the historical pendulum swings, both the unquestioned call for the full involvement of children and adolescents in decision making and the earlier prevailing practice of keeping information and choice from children that dominated when Bluebond-Langner was immersed in the oncology ward.

A number of contextual factors influenced the study participants’ perspectives, and age was less of a predictor in their desire to be involved than was their disease status. Their preferences ranged from wanting to make their own treatment decisions, to wanting to be involved in treatment decisions, to not wanting to hear information at a given point. They varied in the extent of their desire to defer to the recommendations or decisions of the adults they trusted, both parents and clinicians. The study authors stress the importance of seeking the child’s voice, something that has been lacking from other pediatric research that has advocated a certain model of shared decision making without incorporating children’s perspectives.⁴¹³ Their work reflects the ironic persistence of adult agendas even in the midst of efforts to include children. Part of expressing agency in the health care setting requires that children have the freedom to choose how they participate, and patients like those interviewed in the study may demonstrate insight into their choices that surpass what might be expected of them based on solely on developmental models of cognitive and moral development. For instance, a 13-year-old boy with Ewings sarcoma, a form of bone cancer, explained to the researchers that he felt it was

⁴¹² Kelly, Katherine Patterson, Catriona Mowbray, Kimberly Pyke-Grimm, and Pamela S. Hinds. “Identifying a Conceptual Shift in Child and Adolescent-Reported Treatment Decision Making: ‘Having a Say, as I Need at This Time.’” *Pediatric Blood & Cancer* 64, no. 4 (April 1, 2017).

⁴¹³ Kelly et al., “Having a say,” 6 of 8.

best that his parents had made decisions for him, because he might not have made an optimal choice in the midst of feeling sick and wanting to get chemo over with. As with adults who may want assistance from family members rather than make significant medical decisions alone, children too have their own ways of participating in their care, even if it means simply affirming their trust in those charged with making the decisions.

Vocation and agency

The emergence of childhood studies provides a footing for speaking to the ways in which children experience and express themselves as social actors and participants in relationships, offering a counterpoint to the formulations of cognitive development that so narrowly characterize children's contributions to decision-making in their medical care. Theology too can provide vital language and deep roots for understanding agency as an aspect of what it means to be human. It draws in particular on aspects of human life and relationships that transcend simple biological development or sociological concepts. When understood theologically, agency adds to a dynamic theological anthropology, offering a wider regard for who children are in the healthcare context and urging adults to attend more deliberately to them in the midst of what otherwise becomes a realm where only grownup provision, protection, and authority make any difference.

The theologian whose work is most relevant to this discussion is Bonnie Miller-McLemore, whose articulations of the agency and vocation of children are particularly fitting here. Building on the perspective of "feminist maternal theology" set forth in her earlier book *Also a Mother: Work and Family as Theological Dilemma*,⁴¹⁴ she engages the same four

⁴¹⁴ Miller-McLemore, Bonnie J. *Also a Mother: Work and Family as Theological Dilemma*. Nashville: Abingdon Press, 1994.

premises in her book *Let the Children Come* toward an investigation of “not only how fresh understandings of children might influence motherhood but also how contemporary experiences of mothering shape understandings of children.”⁴¹⁵ The four premises of this theological perspective consist of first giving privileged voice to the marginalized—mothers and children in this instance; second, challenging the contradictory demonization and idealization of children and women’s bodies; third, enriching the debate about Christian doctrines of love, sin, and grace by considering the unequal parties of adult and child; and fourth, expanding claims for justice and liberation across differences to include children and mothers for whom the principle of equality cannot entail sameness with adult males.⁴¹⁶ These commitments undergird her foray into questions that go beyond the dominant foci of both feminism and theology, expanding inquiry further than just women’s issues or issues of children’s religious formation.

In *Let the Children Come*, Miller-McLemore’s primary thesis is that “children must be fully respected as persons, valued as gifts, and viewed as agents.”⁴¹⁷ Situating her book not as a manual for raising children nor a reflection on how children think about God, she instead claims the task of describing how adults have thought about children and how they ought to think about children.⁴¹⁸ To this end, she traces first the dominant view of children as assets in agricultural societies, where they held a vital place in family economies. Subsequently, she identifies the shift toward seeing children as emotionally priceless, a psychological compensation for the economically burdensome status of children after industrialization.⁴¹⁹ She distinguishes between views of childhood that see children as a means to some other end, usually adulthood, as opposed

⁴¹⁵ Bonnie J. Miller-McLemore, *Let the Children Come: Reimagining Childhood from a Christian Perspective* (San Francisco, CA: Jossey-Bass, 2003), xxxi.

⁴¹⁶ Miller-McLemore, *Let the Children Come*, xxii.

⁴¹⁷ Miller-McLemore, *Let the Children Come*, xxiii.

⁴¹⁸ Miller-McLemore, *Let the Children Come*, xxv.

⁴¹⁹ Miller-McLemore, *Let the Children Come*, 3-6.

to views that regard children as ends in themselves, which allow adults to freely engage with children apart from a developmental motive.⁴²⁰ She traces the contributions of modern psychology as a driver for contemporary views of children, particularly in casting children as victims, and suggests that feminist theology has provided a crucial counterpoint in its affirmation of children as agents, first in affirming children as bearers of the image of God and second as sources of spiritual insight.⁴²¹ In keeping with her desire to articulate what this identity of children as moral and spiritual agents demands from adults, Miller-McLemore notes that conventional understandings of children have severely narrowed adults' awareness of how wide-ranging those demands might be. She notes that cultural assumptions about parents needing to be in control of their children—who are presumed to be pure and innocent—reinforce the notion that the primary task of parenting is to shape children into socially acceptable adults.⁴²² This echoes dominant approaches to pediatric medical ethics as well, where discussion is largely focused on parents weighing their own values and beliefs with the recommendations of other adults, namely, medical providers, as they determine the optimal choices for achieving their child's best interests in a way that fosters future development and flourishing.

Miller-McLemore admits that accommodating the agency of children brings complexity and frustration to the work of parenting, as I would contend is true in the healthcare environment as well. Attention to agency confronts adults who care for children with the reality that what we often want to simplify perhaps ought not be simplified in the first place. When we suspend our tendency to see children as passive recipients of adult instruction or formation, we enter into the messiness, unpredictability, and ambiguity of navigating how we might proceed in complex

⁴²⁰ Miller-McLemore, *Let the Children Come*, 137.

⁴²¹ Miller-McLemore, *Let the Children Come*, 138.

⁴²² Miller-McLemore, *Let the Children Come*, 143.

situations while truly factoring in children's perspectives and contributions. In contrast to the spiritual ideals of solitude and silence that some Christian perspectives have espoused, feminist theologians like Miller-McLemore desire also to affirm the value of busyness, noisiness, and chaotic realities of life with children as sites for spiritual enrichment.⁴²³ Acknowledging the connected but freestanding agency of children provides a corrective against parental tendencies to overidentify with their children as well.⁴²⁴

On this point, Miller-McLemore's perspective is particularly valuable to heed in the hospital setting, where such temptation is considerable. For parents who spend extraordinary amounts of time accompanying their children during hospital admissions, advocating for their medical needs, subordinating their own priorities and schedules in light of their child's health care concerns, and narrating the history of their child's condition for every new medical provider they encounter, preserving a sense of the child's own distinct agency and experience, especially if the child is pre-verbal or nonverbal, can require utmost intentionality. Such situations lend themselves far more easily to a scenario where the parent and child function and are regarded as one entity. Cultivating an awareness of how a child's agency is discernable even in the midst of enmeshed family relationships can be a valuable counterpoint to the tendency toward fused identities of parent and child in the hospital setting.

Vocation redefined

Affirming the agency of children, especially as it is expressed in their identity as spiritual beings, provides a corrective against the bodily reductionism that is pervasive in the medical environment, where vital signs, symptoms, problem lists, and care plans address every physical

⁴²³ Miller-McLemore, *Let the Children Come*, 149.

⁴²⁴ Miller-McLemore, *Let the Children Come*, 157.

system and measure empirical data, leaving little attention to that which cannot be easily quantified or viewed but which is nonetheless integral to the hospitalized patient's experience. On this note, Miller-McLemore's more recent work on the vocational life of children resounds powerfully, particularly as she shapes an approach to vocation that provides a theological affirmation of agency without relying on a certain level of cognitive prowess.⁴²⁵ That is, Miller-McLemore locates the vocation of children, among other places, in their *relationships* with God and with the people closest to them. Moving beyond the kind of definition of vocation that is circumscribed by the adult worlds of paid labor and career paths, the vocation of children speaks to their inherent spirituality, which happens "between us as much as within us" and is marked by relations with others from the very interpersonal outset of life—birth itself.⁴²⁶ Whereas for adults vocation is often considered something that springs from an *internal* sense of leading, "For children, by contrast, vocation often arises in the here and now at the juncture of interpersonal interaction, in their *external* impact on and interchange with the world based on the very traits that comprise childhood itself" – including, notes Miller-McLemore, their vulnerability and dependence.⁴²⁷ Moreover, unlike typical notions of vocation that stress what one aims to become in the future, the vocation of children affirms being present more than an intention of becoming something different. This lack of any connotation of striving for increased rank, success, or achievement likewise places this understanding of the vocation of children in striking contrast to adult concepts of career trajectories.

⁴²⁵ Bonnie Miller-McLemore, "Childhood: The (Often Hidden Yet Lively) Vocational Life of Children," in *Calling All Years Good: Christian Vocation across the Lifespan*, ed. Kathleen Cahalan and Bonnie Miller-McLemore (Grand Rapids: Eerdmans, 2017), 38-62. For more on the vocational life of children, see Patrick M. Brennan, ed. *The Vocation of the Child*. Grand Rapids, Mich.: William B. Eerdmans Pub. Co., 2008.

⁴²⁶ Miller-McLemore, "Childhood," 43, 46.

⁴²⁷ Miller-McLemore, "Childhood," 46, 48, italics original.

I want to pay particular attention to Miller-McLemore's depiction of children's vocation as a quality that forms adult vocation and faith—that children form adults, contrary to assumptions that only adults do the formational work in their responsibility for raising children. This relational power of even the youngest children to evoke growth in adults is all but ignored in the health care realm, I would argue, except for what often become overly sentimentalized accounts of how certain ill children “teach” others so much about what is important in life. A richer and more textured account of how children's vocational life entails eliciting spiritual struggle and sometimes maturation in the adults around them is sorely needed.

There is an expected level of responsiveness from any parent or caregiver for young children who is enjoined to accommodate their needs for attention, food, sleep, and so on. Then there is the realm of responsiveness to the kind of child who is hospitalized, perhaps as the result of a sudden accident or new diagnosis, or as part of a prolonged series of hospitalizations for a complex or chronic illness. What is called forth from parents and caregivers of such children, however, encompasses not just the basic bodily caregiving and navigating of medicine or equipment or the dizzying hospital system and terminology itself, but also the considerable tasks of attending to the difficult emotions and moral and existential questions that can arise for both child and adult when something so out of the ordinary strikes in childhood.

Giving attention to the kind of vocational life of children Miller-McLemore describes means granting importance to the ways in which the medical scenario interacts with the child's spiritual identity and experiences and the ways in which those in turn interact with the spiritual life of adults, and how the child's experience calls forth new questions from the adult as well. This utterly contrasts with the notion so embedded in much Christian teaching and practice, that the parents are somehow responsible for a one-way formation and instruction of the child.

Instead, in the context of illness and hospitalization, children and adults form each other. As pediatric medicine encounters ever new frontiers, young patients are quite literally leading their caregivers into uncharted territory and provoking all the questions and new moral quandaries that ensue.

I have many times witnessed parents privately expressing their sense of helplessness over not knowing how to show their child the way forward because they have never experienced anything like what their child is undergoing. In those moments, when parents can find an openness within themselves to truly experience what it means that “a little child shall lead them” (Isaiah 11:6), there can be unprecedented moments of awe and a willingness to explore dimensions of faith as visceral trust and surrender rather than as a didactic code of belief and behavior. This tender territory brings to mind those occasions where I have asked parents of gravely ill children, “what is giving you strength right now as you go through this?” and the parent of even the tiniest, youngest child will answer that their child is their greatest source of strength, even as she or he is the greatest source of concern. To me, this reflects a validation of the child’s spiritual identity, not limited in the least by their physical frailty or developmental immaturity but made powerful through the bonds of relationship that the child elicits and deepens.

Of the many patient stories I can recall where parents were formed by children in powerful ways, one comes to mind that especially resonates with Miller-McLemore’s emphasis on how children evoke spiritual formation for adults simply by being who they are. I was called to provide pastoral support once to a couple who had flown in from out of state to meet the baby they had long been planning to adopt. The newborn baby girl was now in the NICU, having been diagnosed after birth with Trisomy 21, commonly known as Down syndrome. Not knowing of

this diagnosis prenatally, the adoptive parents were confronted with a myriad of emotions as they faced the task of mentally letting go of the baby that they had envisioned and grappling with the unpredictability that any new parent must come to grips with when a new person enters the world. These parents felt strongly that they needed to back out of the adoption but were in the thick of sorting through their feelings of guilt and shame, reckoning with the extent to which they had assumed they had knowledge and control over the circumstances of becoming parents. Their anguish was deep as they wrestled with the dynamic situation of having to choose whether or not they could proceed with committing to raise this child who presented them with such drastically different realities of parenthood than they had expected.

This child's agency as a spiritual being was not calculated or rational, but it powerfully elicited an experience for those adoptive parents of searching their own priorities and assumptions. I choose this scenario in part because it is far afield from the oft-heard, more sentimentalized iterations of how children with special needs can teach others so much about what matters in life. While this is no doubt true, it is important to remember the inherent complexity of such situations in order to avoid carelessly ignoring the real challenges, risks, and loss that come with engaging agency.

Agency transforms caregivers

This chapter's opening story of the young patient who "brought out the best in us" resonates with many other accounts of patients that I have witnessed, heard, and read about. This kind of agency elicits powerful short- and long-term change, forming caregivers deeply in their vocational identity and practice in ways that formal education and training could never match. Patricia Fosarelli recounts what was "probably the first step in the journey that led me to become

a physician-theologian” when her frustrated late night attempts to start an IV on a six-year-old were met with the girl’s question, “Does God want you to hurt me?”⁴²⁸ Pediatrician and religious ethicist Margaret Mohrmann offers another story of vocational formation, recounting the death of “Sherry,” a NICU patient whose death occurred just as she was being anointed and prayed for. She writes,

The association of Sherry’s death with the anointing ritual marks, in my memory, the beginning of my gradual journey into agnosticism about “coincidences” or, at least, about any facile dismissal of them as perceptual illusions or wishful thinking. In the years to come, I would observe so many instances in which events coincided in significant but inexplicable ways that I was compelled to set aside both skepticism and any claims to understanding. What I carry with me instead is a deep sense of wonder at the apparent power of the connections among us and, I suspect, between us and that which transcends humanity. I don’t know what happened at the moment of her aunt’s anointing and the women’s prayers. I don’t know whether or how those actions determined, in some fashion, the time of Sherry’s death. I do know that my life in medicine was deepened and enriched by my increasing willingness to recognize the inexplicable and to leave it unexplained.⁴²⁹

I recall a similar experience that left an indelible impression on my last day of work at Boston Children’s Hospital before moving to Nashville. A four-month-old baby girl who had been ailing in the NICU for months was nearing her last breaths. Her parents were in such distress and despair that they couldn’t bear to be present with her at the hospital, a reality which caused nursing staff to struggle but also prompted them to fill in the gap with their own presence. I stood by with others as a nurse held the baby in a rocking chair. The family was Catholic, and our staff priest was present to anoint and pray for the patient as the parents had requested. She died as we all recited the Lord’s Prayer together.

⁴²⁸ Fosarelli, Patricia. “The Spiritual Issues Faced by Children and Adolescents at the End of Life.” In *A Time for Listening and Caring: Spirituality and the Care of the Chronically Ill and Dying*, edited by Christina M Puchalski. Oxford; New York: Oxford University Press, 2006, 83.

⁴²⁹ Mohrmann, Margaret E. *Attending Children: A Doctor’s Education*. Washington, D.C.: Georgetown University Press, 2006, 41.

These accounts of agency are very different from how agency is described elsewhere, and they run the risk of becoming stories about adults instead of about children. But that risk of focusing on adults is actually higher if we fail to adopt language to name and claim the nuances of influence that credit even the youngest and most powerful children with the capacity to significantly impact those around them. What else would we call it?

Recognizing and nurturing agency in the hospital

Both childhood studies and theology invite greater attention to the forms of agency that bear significance in the hospital setting, especially in contexts where overt versions of agency are greatly limited. Both offer guidance for seeing and affirming the sort of agency that is harder to detect in children whose capacities may be temporarily or chronically limited.

I want to focus on spirituality as a key lens for recognizing children's agency in the hospital. There are other lenses, to be sure, but this one is well suited to the task at hand in particular because it transcends simplistic developmental categories, allowing spirituality to be understood in ways as varied and unique as the sick, disabled, disfigured, injured, abused, or dying patients who express themselves and search for meaning and hope in the midst of struggle. Spiritual health may be vibrant even when physical or psychological health is greatly compromised. Children's spiritual struggles may or may not be validated by family members who insist on testifying to a specific version of faith.

Although literature on spirituality and health tends to focus on how adults use religion or spiritual beliefs for coping, the pediatric setting begs for multilayered appreciation of the ways in which a child and family members might embrace or reject very similar or very contrary beliefs. A concrete way to honor agency in hospitalized children is to pursue their own perspectives on

spirituality or religious faith, rather than assuming they align with their parents' affiliation or lack thereof. Faith formation literature presumes a handing-down of established parental and communal faith, but the crises that unfold in the hospital can often mean that adults are struggling mightily with their beliefs even as they seek to reassure and comfort children.

Miller-McLemore describes shortcomings of such faith formation literature, including the widely popular *Stages of Faith* by the supposedly “unequivocal expert” James Fowler.⁴³⁰ She examines his and other theories and notes that they are actually predicated on adult faith. Stage theories largely derive childhood faith from adult accounts of faith development, and are weighted toward the envisioned adult outcomes.⁴³¹ Miller-McLemore rightly observes, “It is hard to have a stage theory that does not overvalue the final frame.”⁴³² Drawing on the work of psychologist Tobin Hart, she seeks to interpret children's spirituality beyond verbal, didactic expressions of abstract beliefs, noting that children's spiritual wisdom “is not just what they know and say but how they live and embody this knowledge in daily life.”⁴³³ Children's spirituality can possess a depth and maturity regardless of whether their physical, cognitive, or moral development has reached particular milestones.

I cringe internally when I detect that someone has the impression that my work as a pediatric chaplain consists mostly of talking with parents and praying for their sweet innocent sick child's healing, as though religious faith is universally a balm and never problematic. I picture the pious sixteen-year-old girl struggling to find a healthy way to embrace her faith. Her

⁴³⁰ Fowler, James. *Stages of Faith: The Psychology of Human Development and the Quest of Meaning*. San Francisco: Harper Collins, 1995.

⁴³¹ Miller-McLemore, Bonnie. “Children's Voices, Spirituality, and Mature Faith.” In *Children's Voices: Children's Perspectives in Ethics, Theology and Religious Education*, edited by Annemie Dillen and Didier Pollefeyt, 17–48. Leuven: Peeters, 2010, 30.

⁴³² Miller-McLemore, “Children's Voices,” 30.

⁴³³ Miller-McLemore, “Children's Voices,” 39.

eating disorder had begun with a diligent renunciation of sweets for Lent, and the severity of her illness became viciously combined with the Wesleyan zeal for perfection and holiness that her parents had so deeply instilled in her. I picture the ten-year-old boy admitted for suicidal ideation, whose grandmother and guardian worried that the Baptist church Vacation Bible School had convinced him far too effectively of how superior the next life would be. He was grieving the death of both his grandfather and a beloved cat and wanted to be reunited with them and free from his many present struggles. These vignettes convey the often complex manifestation of children's spirituality within their hospital experiences and underscore the need for care that is as attentive to their spiritual vitality and struggles as it is to the details of their medical care.

Examples: play and silence

Play and silence are two ways to recognize agency through children's spirituality in the hospital. The role and importance of play has been increasingly established in children's hospitals through the growing number of professional Child Life Specialists, with whom chaplains often collaborate in addressing the emotional and spiritual needs of patients and families. Play evokes spirituality in that it is "engaged for its own sake" rather than as a means to another end, as pastoral theologian Jaco Hamman observes.⁴³⁴ Play with others aligns with spirituality in that it "invites, sustains, and deepens loving and intimate relationships."⁴³⁵ For children facing new, frightening, or painful experiences, play offers a nonthreatening way to explore feelings and seek reassurance. Moreover, because it is "tied to persons and state of mind

⁴³⁴ Hamman, Jaco. "Playing." In *The Wiley-Blackwell Companion to Practical Theology*, edited by Bonnie J. Miller-McLemore. Malden, MA: Wiley-Blackwell, 2012, 43.

⁴³⁵ Hamman, "Playing," 42.

more than place or situation,⁴³⁶ play is accessible to children even in the midst of dire situations of illness, and allows them to craft an experience that is not bound to the sadness, concern, or sympathy that may dominate in the actions and affect of the adults around them. Hamman claims play as a form of embodied theology and as a “form of knowing and a way of seeing and engaging the world.”⁴³⁷ While outside observers might feel sorry for hospitalized children because they are kept from their ordinary playing at home, school, and outside activities, the hospital too can be a site where play is an expansively creative expression of identity and a liberating respite from the goal-driven, measurable medical care happening around them.

Theologian Jerome Berryman, founder of the *Godly Play* model of engaging children with scripture that has shaped religious education programs, notes that “Children are better than adults at tracking relationships without language, because they are not yet as dependent on language as adults.”⁴³⁸ He suggests that silence is a key component of how children demonstrate spiritual maturity, and that this invites us to see how richly spirituality can be *experienced* when it is not constrained by verbal expression. I once witnessed a powerful incidence of a child’s silence when, after a few stable days in a regular hospital room, a weary six-year-old boy who had recently undergone a heart transplant faced several complications that caused him to be transferred back to the ICU. Visiting with him, I sensed his mother and grandmother were unwilling to let him express frustration and discouragement as they adamantly insisted that he voice praise and faith, especially in my presence. When I tried to ask him how he felt about what

⁴³⁶ Hamman, “Playing,” 43.

⁴³⁷ Hamman, “Playing,” 47. Here Hamman echoes other voices in modern psychology and psychoanalytic theory who have esteemed play as a means for understanding and healing, especially Anna Freud, Erik Erikson, and Donald Winnicott.

⁴³⁸ Berryman, Jerome. “Children and Mature Spirituality.” In *Children’s Spirituality: Christian Perspectives, Research, and Applications*, edited by Donald Ratcliff. Eugene, OR: Cascade Books, 2004, 29.

was happening, his mother would quickly attest to the power of prayer and faith and how it would bring about his healing. She would ask him to recite a verse of scripture or song for me, or to tell me about how much Jesus was helping him. At one point the boy appeared quite angry and stopped engaging in conversation altogether. As often happens, I had to navigate how I might both affirm a parental stance of upbeat optimism while also make space for expression of a child's honest and valid frustration. I experienced the boy's silence as a profound lament. He had lived with a congenital heart defect and all the treatment and time in hospitals it entailed, and now he had undergone a risky but lifesaving transplant that his family had long awaited and prayed for but which also signified the death of someone else's child, a fact which this boy likely knew. In silence he could protest with a wordless alternative to his mother and grandmother's stance of praise and hope. In his situation, his family's impulse to protect him using the language of faith glossed over his anguish and led to a missed opportunity to support him more fully. In my prayer at the end of my visit that day I tried to affirm his experience and the possible range of what he may have been feeling, along with raising the hopes and praises his family had expressed. Striking such a balance is a challenging but worthy endeavor in pediatric chaplaincy; I believe that even the smallest efforts can have a significant impact when it comes to ensuring that children's own experiences are seen and validated in the midst of the adult portrayals of those experiences.

Along with numerous other expressions of spirituality, play and silence equip hospitalized children to engage with their full selves in experiences of illness that cannot be exhaustively described with the language of biology and chemistry. Paul Thayer, a scholar in both religion and child life, reminds caregivers of terminally ill children to remember that having fun is also permissible and important even in the midst of sobering circumstances. Play and other

activities invite children to engage with spiritual themes such as unconditional love, forgiveness, hope, safety, legacy, and loneliness.⁴³⁹ Like Berryman and Hamman, Thayer too warns spiritual caregivers against relying on verbal and abstract renderings of spirituality. He advocates developing a keener sense of the kind of key words and symbols, such as those that appear in children's drawings, in order to recognize the cues of children's spiritual concerns.⁴⁴⁰ He laments the medical model's preoccupation with documenting and assessing problems, noting that this can shape spiritual care into a checklist where a problem like "spiritual distress" is identified and then "resolved" once goals and interventions are documented.⁴⁴¹

Within the context of spiritual care for children and parents, Thayer also invites caregivers to recognize how children raise ethical questions. He contrasts children's style of ethical deliberation with the dilemma-focused nature of adult ethical concerns, offering a compelling depiction of how children's lack of autonomous status does not hinder them from exercising a moral imagination. He writes,

Statements made by children that may indicate ethical questions include, "Why do we have to...?" "What's the use of..." "What do we do now?" "I wish we could just..." or "What do you think is the right thing to do?" Sometimes children are the first to raise questions about the course of treatment.⁴⁴²

As Thayer depicts, attentive spiritual care can foster children's agency in the face of daunting situations. Hearing children's concerns and affirming their questions and wisdom can in turn equip adults to engage ethical questions from a starting place marked by curiosity and wonder.

⁴³⁹ Thayer, Paul. "Spiritual Care of Children and Parents." In *Hospice Care for Children*, edited by Ann Armstrong-Dailey and Sarah F. Zarbock, 2nd ed., 172–89. New York: Oxford University Press, 2001.

⁴⁴⁰ Thayer, "Spiritual Care of Children and Parents," 177.

⁴⁴¹ Thayer, "Spiritual Care of Children and Parents," 177.

⁴⁴² Thayer, "Spiritual Care of Children and Parents," 178-179.

Conclusion

Looking back at how recently the emphasis on agency summoned greater adult attention to children as subjects begs the question—what else are we missing now? Which features of our current practices with children will prompt us decades from now to look back with disbelief at our narrow-minded regard and concern for them? Agency points bioethics to keep mining the riches of interdisciplinary contributions, lest healthcare catch up all too late with what others know well about how children relate and flourish. Along with vulnerability and dependence, agency adds to a vital theological anthropology, one that equips adult caregivers to honor the full humanity of children in the hospital environment. In a final chapter, I consider how the benefits of embracing this theological anthropology reach beyond childhood and into the entire lifespan. No matter their age, surely adults too deserve to have not only their autonomy respected, but also the fullness of their humanity.

Chapter 6

Childhood as lifelong vantage point

“I am still every age that I have been”⁴⁴³

In this final chapter I contend that a theological anthropology of childhood deepens a theological anthropology for humans of all ages. In order to situate autonomy differently, and to esteem the experiences of children differently, it will benefit us not only to better articulate who children are but also to articulate how, in their vulnerability, dependence, and agency, they reveal aspects of the human experience that are not limited to childhood but endure across the lifespan. A recent encounter highlights this point and serves as a helpful introduction to the contours of my present argument. In my work as a hospital chaplain, I first met “Paul,” a 70-year-old man hospitalized following a stroke, about a day prior to his transfer to the rehabilitation hospital where he would subsequently spend several weeks. He had spent about two weeks in our acute care hospital, a jarring experience after a life lived very independently and in good health. Paul was married but described a perfunctory relationship with his wife: “we get along, but that’s about the extent of it.” He felt she was “putting on a good façade” at the hospital but had no interest in investing in caregiving for him. He had two adult sons who both lived in another state. He was recently retired. His main enjoyment came from winter ski trips by himself. He would budget carefully and save up for months, then head West and ski for weeks at a time. When I met him it was early October, and rather than dreaming about ski trips he was wondering if he’d regain enough function even to drive a car again. He starkly drew a line for the future he was worried about: “I’m not going to one of those nursing homes. I wouldn’t send a pet pig there. I’d rather die.”

⁴⁴³ L’Engle, Madeleine. *A Circle of Quiet*. (New York: Farrar, Straus and Giroux, 1972), 199.

Paul's capacity to make his own medical decisions was intact. His autonomy was being respected by all involved in his care, and as a professional adult white male he was already accustomed to the kind of social status where he could rely on his preferences being heard and honored. And yet, he found himself in such a bewildering state of dependence that I wondered if he really would prefer death and might eventually use his autonomous decision-making power to act on that preference. "I do my own thing, I have never depended on others," he asserted. I asked what it had been like to let others take care of him in the hospital. "Weird," he stated, and began to cry.

Having his autonomy respected in the healthcare setting may mean that Paul is protected from a certain amount of harm, but it does not describe a means of fostering his well-being or promoting his flourishing. For someone like Paul, having his autonomy respected only serves to meet the minimum requirements of what is expected in the hospital. It does nothing further to address the reality or implications of the loss of autonomy that prompted his admission to the hospital in the first place. His fear of vulnerability and aversion to his dependent state are not resolved by his fully intact capacity to make medical decisions for himself. Paul's sudden confrontation with his dependent state left him at a loss to imagine a life worth living. Autonomy as it is typically cast only describes a thin layer of the thick reality encompassed by a life like Paul's. His circumstances are a reminder that respect for autonomy may prevent egregious paternalism but it alone does not mitigate suffering or foster flourishing, and therefore we ignore at our peril those things that we must also attend to in order to do more than just retain a regard for autonomy. Thus, we need a clinical ethics that does more than guide decision makers in dilemmas. Paul's story further motivates me to contend with the ways in which vulnerability, dependence, and agency continue to be salient aspects of a theological anthropology across the

human lifespan, far beyond childhood. I seek an understanding of human life that invites a more honest grappling with these realities even in the midst of supposedly autonomous decision-making and the independence typically associated with adulthood.

Perhaps it seems out of place to shift toward a lifespan application of what I have earlier argued are vital interpretations of childhood. However, I suggest that one way of testing and affirming the value of these interpretations is to ask whether they continue to apply, even if to a different degree, across human life. Casting features of childhood in bold relief does not have to mean that we set childhood fully apart, but enables us better to see what deep aspects of being human are most pronounced in childhood. Subsequently, we can more fully appreciate how those aspects continue to reverberate as the years go forward, rather than getting left behind in an earlier supposedly finite stage. Attention to vulnerability, dependence, and agency also persists in importance beyond childhood, especially as more and more people live longer into older adulthood and navigate decline in their ability to care for themselves, make their own decisions, or express a supposedly autonomous, cognitively intact preference in keeping with their beliefs and values as developed over a lifetime.

Moreover, coming demographic shifts invite further consideration of the continuities in human experience from childhood through adulthood and old age as well. The United States Census Bureau projects a 2020 national population in which just over 22% of the population is under age 18 and where 16% are over age 65, and this reflects the trend heretofore where children outnumbered older adults. However, the Bureau projects that in 2035, the US will see the number of older adults surpass the number of children for the first time, with an estimated 78 million people age 65 and older and 76.7 million age 18 and under.⁴⁴⁴ Along with developing a

⁴⁴⁴ United States Census Bureau. "Older People Projected to Outnumber Children for First Time in U.S. History." March 13, 2018. <https://www.census.gov/newsroom/press-releases/2018/cb18-41-population-projections.html>.

better understanding of children and their experience within the healthcare context, there is a growing need to for a similar endeavor with regard to the growing numbers of older adults who will likewise experience the need for greater care and surrogate decision-makers as their dependencies increase.

Rather than diluting my characterization of childhood, I regard this chapter as another effort to see children as fully human, precisely by looking at how those who have typically been seen as paradigmatic of what it means to be fully human—namely, adults—also retain the full humanness exemplified in childhood. Furthermore, this trajectory provides a counter-narrative to overly rigid stage-based models of development that rest on assumptions about what gets completed or left behind from one life stage to the next. In contrast to models in which children are regarded as “unfinished” humans, incomplete in their attainment of the human telos,⁴⁴⁵ this orientation invites a way to consider how even the most conventionally mature adults are also “unfinished” and also build on their childhoods, not leave them behind. It appreciates both the full humanity of persons at every age and the ongoing capacity for growth that persists throughout life. It also acknowledges the way in which earlier eras are retained as time moves on, not in a way that infantilizes adults but which reckons with the fact that we do not leave behind either our experiences or our identities from childhood but carry them forward in all their complexity. This chapter would be unnecessary if my goal were simply to articulate a theological anthropology of hospitalized children for the sake of that population alone. Instead, precisely because I believe that not only do we need better understandings of childhood, but that childhood

⁴⁴⁵ Archard, David. “Children.” In *The Oxford Handbook of Practical Ethics*, edited by Hugh LaFollette. (Oxford: Oxford University Press, 2005), 93. Archard notes how Aristotle cast children as unfinished against the backdrop of the human telos with respect to biological growth, ethical development of virtue, and education as a citizen.

can illuminate more fully what it means to be human at any age, the theological anthropology of childhood I have described must be situated in relation to the whole lifespan.

To that end, I first advocate for religious ethicist John Wall's concept of childism as a methodological tool for de-centering the typical approach to the human lifespan that holds adults at the center of meaning and action. Wall's work elevates children into an integral place, and thus provides a framework from which to consider childhood and adulthood on more equitable footing. This in turn invites consideration of crucial questions around ethical obligations of adults toward children, including those that emerge in the healthcare environment. Secondly, I closely examine Catholic theologian Karl Rahner's "Ideas for a Theology of Childhood," which provides ample theological grounds to situate childhood as an enduring reality of human life. This theological de-centering of childhood offers a framework for dignifying childhood and its arc throughout the lifespan, while successfully avoiding the sort of infantilization that can too easily accompany popular notions of adulthood's "inner child." Rahner also elevates the theological notion of "children of God," demonstrating how humans of every age might discover meaning in retaining this relational identity. Finally, I relate the importance of this ethical and theological framework to current research, ending with a discussion of the Adverse Childhood Experiences Study (ACES) and its findings, which strikingly demonstrate the enduring impact of childhood experiences on adult life and health. The reach of the study's findings continues to grow, and in my view it casts the tasks of understanding and esteeming childhood in even greater light. In the trajectory of my current project, the study's findings represent a vital bridge between the theoretical assertion of childhood's lasting role in the lifespan and the present urgency of addressing childhood more robustly for patients of all ages in the healthcare setting, an urgency which the study's architects highlight as well. I address the way in which the ACES findings,

though sobering, offer a corrective to the risk of sentimentalizing childhood's enduring presence through the lifespan.

De-centering adulthood: John Wall

A first step in re-envisioning the value of a theological anthropology of childhood for people of all ages is to actually situate childhood differently in the human lifespan, which entails finding language that does not reinforce childhood as merely a preparatory stage. Serious moral engagement with the question of what it means to be a child ought to prompt engagement with the question of what it means to be a human at any age; that is, we must ask what childhood is and what it means not only for the sake of children alone but for the sake of all persons. And because childhood is the season on which all other seasons are subsequently layered over time, it is reasonable to suggest that childhood should actually be closer to the center of gravity of the human life, rather than left behind at the periphery to cede significance when adulthood is reached.

De-centering is one way of characterizing the type of shift that is needed with respect to adulthood in order to position childhood more appropriately. De-centering describes a shift in power and focus especially when a false universal has held central regard in a particular paradigm. For instance, Carol Gilligan's work on moral development theory in the early 1980s, set forth in her book *In a Different Voice*, sought to expose the false universal of the male subject in preceding dominant theories of moral development.⁴⁴⁶ By articulating another approach to moral development, Gilligan revealed that what had come to be thought of as the template for all

⁴⁴⁶ Gilligan, Carol. *In a Different Voice: Psychological Theory and Women's Development*. Cambridge, MA: Harvard University Press, 1982.

human moral development was actually grounded in the particulars of the male subject and male experience.

Pastoral theologian Nancy Ramsay describes a similar movement as it has unfolded in pastoral theology. In a chapter recounting the history of the discipline and its associated guilds, Ramsay highlights de-centering as an increasingly important endeavor, noting: “This strategy emerged with the recognition of the need to deconstruct patterns of privilege that were carried in the assertion of universal or absolute status for particular groups, worldviews, religions, and so forth.”⁴⁴⁷ Specifically, she remarks that pastoral theology continues to need perspectives beyond those belonging to male, European American, and heteronormative voices.

However, careful attention to power differentials related to age continues to be absent here as in so many other efforts to addressing marginalization. Ramsay does not specifically mention the category of age in her call for “de-centering” as an “important formation strategy that is new to pastoral care,”⁴⁴⁸ but I would contend that the false universal of *adult* is as pervasive as any related to gender, ethnicity, or sexual orientation. Furthermore, I would argue that when issues of ageism have been addressed, they are more often concerned with marginalization of the elderly rather than the young. One straightforward reason for this is because it is easier to grapple with marginalized or previously overlooked groups when they begin to make their collective voices heard through; however, there is simply no counterpart for children that comes close to clout of the American Association of Retired Persons, for instance.

⁴⁴⁷ Ramsay, Nancy J. “A Time of Ferment and Redefinition.” In *Pastoral Care and Counseling: Redefining the Paradigms*, edited by Nancy J. Ramsay (Nashville, TN: Abingdon Press, 2004), 43. Ramsey’s edited volume serves as an update and supplement to the *Dictionary of Pastoral Care and Counseling* (Nashville: Abingdon Press, 1990) which she edited along with Rodney Hunter. In her introduction to the updated volume, Ramsey describes how it responds to the “significant intellectual and cultural changes” emerging since the *Dictionary*’s publication, particularly as they manifest in the movement beyond exclusive focus on the “therapeutic paradigm” toward inclusion of “communal contextual and intercultural paradigms” that better accommodate pastoral theology’s growing areas of inquiry (xi).

⁴⁴⁸ Ramsay, “A Time of Ferment and Redefinition,” 43.

For developmental and other reasons, children are not positioned to assert their own needs and perspectives alongside those of adults in the way that women might with respect to men, or people of color might with respect to white people, or LGBT persons with respect to heterosexual persons. While there are certainly examples of how children have advocated for themselves and made their perspectives known in the midst of powerful adult spheres, there remain key channels of influence where children are not represented. They do not vote, or lobby the government, or pay taxes, or sit on boards, or even fill out the ubiquitous patient satisfaction surveys that carry such immense weight in health care.

Since children themselves are not the ones entrusted with articulating the need for de-centering adulthood's dominance, we rely on those who have done so on behalf of children. A prominent voice among them is theological ethicist John Wall, a scholar of religion and a key contributor to the field of childhood studies. Wall's approach, which he terms "childist," aims to de-center the typical adult perspective by reimagining moral relationships in light of children's experiences. In his contribution to the 2006 special issue of *Journal of Religion* focused on religion and childhood studies, Wall asserts that "Children perhaps more than any other group are prone to having their 'saying' capabilities overshadowed by what is 'said' by others about them."⁴⁴⁹ He calls for "learning from children's experiences in such a way as to deepen theological ethics itself," noting that this deepening is contingent on adults permitting themselves to be reshaped in response to children—Wall insists that "Children's experiences must be allowed to disrupt and constantly open up even the interpretive assumptions adults bring to them."⁴⁵⁰

⁴⁴⁹ Wall, John. "Childhood Studies, Hermeneutics, and Theological Ethics." *The Journal of Religion* 86, no. 4 (October 2006), 537.

⁴⁵⁰ Wall, "Childhood Studies, Hermeneutics, and Theological Ethics," 524, 537.

Wall develops his case extensively in his book *Ethics in Light of Childhood*, where he describes childism as “the effort to respond to the experience of children by transforming understanding and practices for all” and calls for “the same kind of profound ethical restructuring” as feminism, which is “not only by and for women but also for the sake of a changed society overall.”⁴⁵¹ Elsewhere, Wall describes how childism “would see not only to understand children’s agency and to empower children’s participation but also to ask how children’s different and diverse lived experiences call for structurally transformed scholarly and social norms.”⁴⁵² This call to move beyond understanding toward transformation of systems and structures points to the benefits possible for more than children. In Wall’s view, an examination of childhood becomes the catalyst for a new appreciation of the breadth of human experience and an overhaul of ethics itself. As Wall summarizes, “Children expose suppressed dimensions of human meaning and relations that only they clearly reveal.”⁴⁵³

Doing this work to recast childhood relies on a better understanding of childhood. Wall describes three common ways of telling the “story” of childhood, which he names “top-down,” “bottom-up,” and “developmental.” I describe them briefly here as they serve as grounding for why Wall proposes an approach of his own. First, in the “top-down story,” childhood exemplifies an unruly start to life and to moral life specifically. Children are seen as needing discipline and rigorous moral formation from above—hence, “top down,” and society’s order and justice rely on the proper education of children lest they remain the irrational creatures they start out as. This approach is exemplified in the work of fourth-century BC Greek philosopher Plato, as he focused on the need to impose rationality on otherwise brutish young people so that

⁴⁵¹ John Wall, *Ethics in Light of Childhood*. (Washington, D.C.: Georgetown University Press, 2010), 3.

⁴⁵² John Wall, “Childism: The Challenge of Childhood to Ethics and the Humanities,” in *The Children’s Table: Childhood Studies and the Humanities*, ed. Anna Mae Duane (Athens: University of Georgia Press, 2013), 70.

⁴⁵³ Wall, *Ethics in Light of Childhood*, 3.

society could rise above childish ways and reach a higher level of ethical order. Wall sees this story in the work of other key figures such as Augustine, John Calvin, and Immanuel Kant. While Wall sees some merit in this perspective, chiefly because it acknowledges the need to regard children as engaged in the larger moral struggles of humanity, he takes issue with the way it undermines moral agency by theorizing agency as submission to a higher moral order imposed from outside. Wall feels this overshadows the inborn human creativity of children and the capacity for moral agency that allows them to grow more fully into moral agents in society; he stresses the importance of seeing morality as more than just obedience or submission to a higher authority.⁴⁵⁴

The “bottom-up” story of childhood, in contrast, emphasizes an original state of goodness rather than fallenness, casting children at the outset as bearers of moral innocence and purity. Wall notes that in this view of childhood, the aim of nurturing children is not to impose outside moral authority on them but to cultivate their innate goodness in a way that can redeem the brokenness of society around them. Children are seen as a paragon of faith in their closeness to and dependence on God, serving as models for those of all ages. Wall cites several examples of Jewish and Christian scripture that reflect this view of children, along with various theologians from the early centuries of the Christian church and prominent figures from more recent centuries such as Jean-Jacques Rousseau and Friedrich Schleiermacher.⁴⁵⁵

The third story of childhood is a developmental one, according to Wall. By this he means an approach that emphasizes a morally neutral starting point that progresses gradually over time toward greater human ethical potential, realized through increasingly rational dialogue.

⁴⁵⁴ Wall, *Ethics in Light of Childhood*, 20.

⁴⁵⁵ Wall, *Ethics in Light of Childhood*, 20-21.

Aristotle's work demonstrates this view, says Wall, along with Thomas Aquinas and the particularly influential work of John Locke, who emphasized education as the key to ensuring that children fulfill their human potential for ever-greater rational progress.⁴⁵⁶ Key figures in psychology over the past century represent this story as well, including Sigmund Freud, Jean Piaget, and Erik Erikson, each positing that human moral and social development occurs gradually and in identifiable stages.

While these are minimal descriptions of the three stories that Wall identifies, a look at their drawbacks is what perhaps matters most here in order to understand why Wall proposes childism as a new story. He suggests that the major shortcoming of the top-down story is that it strips children of any moral agency. By suggesting that all morality must be imposed from outside to children who are seen to lack it entirely, the model denies the innate identity of moral agent that Wall wants to preserve. The drawback of the bottom-up story, despite its important regard for the contributions that children do make, is that it fails to reckon with the real vulnerability of children. By esteeming children as pure and innocent ethical models for society, the bottom-up story risks ignoring the real responsibilities that adults must maintain toward children who remain vulnerable to marginalization and exploitation. Wall notes the paradox of a view that esteems children while also too quickly letting adults off the hook for tending to their needs.

The problem with the developmental model, finally, is that it robs human development of rich moral diversity by setting forth one vision of what it means to reach maturity – that picture may vary among the different developmental schemas, but in each case, there is a single goal for human maturity toward which each stage is oriented. Committing to a developmental paradigm

⁴⁵⁶ Wall, *Ethics in Light of Childhood*, 27.

means “one has to choose one or another image of exactly what is to be developed into in order to be able to chart a coherent trajectory of developmental growth. This means that there cannot be a real diversity of moral paths within any one particular developmental schema.”⁴⁵⁷ This not only distorts moral diversity by narrowing it to one ideal, says Wall, but also by design subordinates childhood to adulthood, measuring children by what they are “*not yet*, namely, developed adults.”⁴⁵⁸ This orientation that evaluates people based on their progress toward a later achievement is problematic not only for children but adults too, remarks Wall – after all, what adult wants to be chiefly measured and valued against the moral capability that still lies ahead of them?

The shortcomings of the developmental model are acutely relevant in the clinical setting, where the medical model generally and clinical ethics specifically have both relied heavily on a progressive stage model of development where gradual growth toward rational decision-making capacity is esteemed as the hallmark of human maturity. Such a developmental schema focused on reaching autonomy does not allow for a diversity of paths within childhood. Particularly for children with life-limiting or life-threatening diseases, it is all the more harmful to assess and measure their moral lives and participation against a theoretical endpoint that can only be acquired with the accrual of years needed to reach adulthood, which may or may not transpire. Thus, the developmental approach inherent in medical ethics and in the dominant psychological trajectories that underlie attitudes about children in the healthcare setting are not conducive to a robust and creative appreciation of their humanity and its inherent worth, a worth that should be independent from their progress on a developmental trajectory.

⁴⁵⁷ Wall, *Ethics in Light of Childhood*, 29.

⁴⁵⁸ Wall, *Ethics in Light of Childhood*, 29, italics original.

Responsiveness to the other

Having identified the ways dominant models of childhood fall short, Wall holds that we are in urgent need of a renewed moral relationship to children and that children will persist in being marginalized as long as adults remain at the center of our views of humanity. Again, in words that resonate strongly with the dominant models in healthcare ethics, Wall asserts that “Especially since modernity, ethical respect has been based largely on the notion of human beings’ independent autonomy. The basis for responding to others is thought to lie in the fact that others possess their own social rationality or freedom.”⁴⁵⁹ Thus, Wall continues, “so long as human dignity is grounded in rational autonomy, children will tend to be marginalized more than any other group.”⁴⁶⁰ Merely trying to extend adult-centered notions of autonomy and rationality to children, says Wall, will not succeed in casting them as equals. What is needed, he argues, is a recasting of moral obligation from a child-inclusive point of view. Wall finds the most promising resources for this in a postmodern ethical account of “the other,” drawing heavily on the work of twentieth-century French philosopher Emmanuel Levinas.

Responsiveness to the other, as a basis for moral obligation, offers greater possibility for equal regard than does an approach that prioritizes those with the most resources and ability to articulate their values. Another facet of responding to otherness, as Wall envisions it, is that by truly allowing the other to disrupt my experience, I will also in turn respond by recreating my own experience. That is, the other de-centers me, and thereby fosters a circular process whereby “My narrative of myself must stretch out in openness to the irreducibility of others to it.”⁴⁶¹ Wall distinguishes the concept of de-centering from that of discourse, noting that discourse rests on a

⁴⁵⁹ Wall, *Ethics in Light of Childhood*, 87.

⁴⁶⁰ Wall, *Ethics in Light of Childhood*, 87.

⁴⁶¹ Wall, *Ethics in Light of Childhood*, 92.

back and forth predicated on adult-centric abilities to engage. Children largely require discourse to be carried out on their behalf, notes Wall, and thus will always be marginalized by a theory of moral obligation that requires such participation. Wall's vision for moral responsiveness to the other, by contrast, presupposes no such homogeneity of ability or participation, but simply an utter regard for the power of otherness to shape a responsiveness that in turn *transforms* the self without negating or subjugating it.

Wall suggests that de-centering adulthood can be represented by the image of an ellipsis, in which there is not one center but two, where both self and other are centers of moral concern. For Wall, situating the moral relationship of children and adults in an ellipsis does not discard their distinctiveness but does invite a more equal regard for their ethical importance. By truly regarding children as moral others in this way, he contends, we can disrupt the limited and harmful interpretation of them which is produced by typical moral thinking.

Narrative expansion

Closely related to the elliptical orientation that Wall describes is the orientation to time and its impact on moral relationship. As Wall explores the ethical aim of childhood, he considers time and its meaning to humans of different ages, and its plasticity and potential for expansiveness. He points to the Enlightenment influences that led to our sense of time having a fixed and objectifiable meaning. Wall asserts this has had the effect of "dehumanizing time itself, characterizing it as a merely empirical object divorced from the subjectivity of its observer."⁴⁶² Wall thinks the effect of this on childhood is that childhood too is seen as an object, since children are regarded as lacking the rational and self-reflective abilities to engage with the

⁴⁶² Wall, *Ethics in Light of Childhood*, 65.

experience of time. Wall posits that the temporal wholeness we seek as we interpret our own life story is accomplished through narrative expansion, with narrative being “the creative interpretation of time over time.”⁴⁶³ On this point, Wall resonates with the urgings of Karl Rahner with respect to childhood and time, as I discuss later in this chapter.

Wall is careful to note that the purpose of human narrating is not to “express one’s inner being” but also to find meaning that is responsive to others and to larger contexts.⁴⁶⁴ This serves as a great counterpoint to traditional conceptions of autonomy that prize individual identity and self-governance as the aims of the human story. Wall encourages his readers to see children and adults on the shared footing of narrative expansion, with the recognition that children’s shorter time of being in the world means they are drawing on less experience as they engage in narration, but just like adults they too are shaping and shaped by others around them. This attention to the other and openness to being transformed by the other is particularly relevant for articulating a theological anthropology that astutely describes not only children but also adults. Existing ethical theories predicated on adult norms and child-derived exceptions only reinforce a mindset that expects the child-based parameters to fall away over time as they are replaced by adult ones. In contrast, a theory of responsiveness to the other invites the adult-based norms themselves to be reshaped by the transformative power of a childist theological anthropology. Unlike ethical exchanges predicated on adult-centric values, where any attempt to accommodate child-based approaches would lead to infantilizing or undermining adults, Wall’s elliptical approach provides footing for an empowering and dignifying ethical exchange between morally substantive parties.

⁴⁶³ Wall, *Ethics in Light of Childhood*, 68.

⁴⁶⁴ Wall, *Ethics in Light of Childhood*, 69.

A childist bioethics?

Wall's perspective is acutely relevant for the healthcare context, where adult patients and adult care continue to function as the norm and pediatrics as the exception. This dominant moral stance in Western medicine aligns with the general societal moral stance Wall describes, where ethical respect is granted based on adult-centric notions of autonomy and rationality, and any ethical approach to children is bound to be a derivative of these central priorities. Subsequently, health care reflects Wall's overarching diagnosis of our problematic moral way of thinking of children: unequal ethical footing creates a situation where adults are concerned about our obligations to children but unable to regard them as moral equals. The kind of shifts that childism calls for would benefit children and adults alike in the healthcare setting too, however. Recasting moral obligation in terms of responsiveness to the other would allow for a more equal ethical footing for children alongside adults and could also prompt beneficial transformation in the way we regard *adult* patients in healthcare. That is, rather than defining children in clinical ethics on terms established by adult norms, we can envision an elliptical relationship that would more fully reflect the mutual transformation of adult and pediatric experiences.

Not only would such a move esteem the place of children while preserving the real responsibilities of adults toward them, it would also esteem the moral standing of adults who are profoundly dependent on others. Rather than measuring them by their "childlike" needs for care and surrogate decision-making from others, we could regard them with the dignified identity of being just as deserving and engaged as ever in a mutual responsiveness with others in a manner that does not rest on their capacity for self-governance. Wall's efforts, when placed in the healthcare context, highlight just how limited traditional moral understandings of childhood have been, and how they detrimentally set up adults to be primarily assessed in terms of their retention

or loss of a certain version of autonomy as well. Because clinical ethics cases with adult patients so frequently addresses a crisis, threat, or new baseline in relation to a supposedly previously intact autonomy, the work of de-centering adulthood has the potential to greatly benefit adults who are all too easily regarded as somehow moving backward on a linear trajectory of moral maturity.

I now turn to a theological work that strongly aligns with Wall's and offers an understanding of how the reality of childhood endures into adulthood in a way that invites greater esteem of both children and adults. Karl Rahner's depiction of how human childhood persists in the relationship between humans and their creator God also elevates the kind of elliptical moral responsiveness to which Wall would summon us, by placing adults and children both in ongoing relationship to a parental God.

Abiding in childhood: Karl Rahner

In a short essay titled "Ideas for a theology of childhood" nestled in volume VIII of his *Theological Investigations*, twentieth-century Catholic theologian Karl Rahner offers a rich theological portrayal of the kind of child-inclusive moral regard that John Wall envisions, and describes a way of identifying childhood's lifelong presence in human life.⁴⁶⁵

From the outset of this piece, Rahner clarifies that his aim is not straightforwardly pedagogical; he notes he would be glad for his ideas to be useful for teachers and parents, but his

⁴⁶⁵ I am indebted to the following for pointing me toward a deeper look at Rahner, both of which offer crucial insights into his work:

Hinsdale, Mary Ann. "'Infinite Openness to the Infinite': Karl Rahner's Contribution to Modern Catholic Thought on the Child." In *The Child in Christian Thought*, edited by Marcia J. Bunge, 406–45. Grand Rapids, Mich: W.B. Eerdmans, 2001.

Miller-McLemore, Bonnie. "Childhood: The (Often Hidden Yet Lively) Vocational Life of Children." In *Calling All Years Good: Christian Vocation across the Lifespan*, ed. Kathleen Cahalan and Bonnie Miller-McLemore, 38–62. Grand Rapids: Eerdmans, 2017.

primary goal is to explore what “the divinely revealed word has to say about children.”⁴⁶⁶ In Rahner’s approach I find resonance with my own: I too am not trying to prescribe specific contours of pastoral care to children in hospitals so much as I hope to articulate a theological anthropology that *informs and shapes* such care—and not just pastoral care—in a manner that regards children more robustly than the current dominant operative anthropology in clinical ethics. Just as Rahner asks “what task does [childhood] lay upon us for the perfecting and saving of humanity?,” so too do I aim to bring insights on childhood that will shape medical and pastoral practice by holding space for a more expansive view both of children and of the tasks laid before those of us who tend to them in hospitals.⁴⁶⁷

Rahner notes the human propensity to think of our lifespans in categories and phases, and asserts that this tendency is “un-Christian” as it obscures the “direct relationship to God which is achieved at each of the stages in human development and growth.”⁴⁶⁸ Our tendency is to regard life in terms of the biological environment in which we live and in terms of our human constructs of time. Rahner contends that we do this far more with regard to childhood than with any other phase of life, seeing childhood as a phase which, once exhausted, gives way to the next. In this view, childhood’s meaning disappears along with it into the next life phase, reinforcing the sense that it is a preparation for the subsequent stages, such that its very existence is to serve the purpose of the stages beyond itself.⁴⁶⁹ Rahner summarizes, “In relation to the future stages of life which await us when we are children, therefore, this subordinate and preparatory function is at its most intense in childhood itself.”⁴⁷⁰ Rahner is careful to note that the antidote to this mindset

⁴⁶⁶ Rahner, Karl. “Ideas for a Theology of Childhood.” In *Theological investigations*, 8:33–50. London: Darton, Longman & Todd, 1971, 33.

⁴⁶⁷ Rahner, “Ideas for a Theology of Childhood,” 33.

⁴⁶⁸ Rahner, “Ideas for a Theology of Childhood,” 33, 34.

⁴⁶⁹ Rahner, “Ideas for a Theology of Childhood,” 34.

⁴⁷⁰ Rahner, “Ideas for a Theology of Childhood,” 34.

is not to be found in idealizing a certain phase or wanting to “remain fixed” there; that is, childhood is not to be lived only for its own sake without regard to the future. What Rahner intends to illuminate, however, is the way in which this chronological, sequential view of human life stages is “only one part of the truth” of the way in which one moves through one’s personal history.⁴⁷¹

Rahner avoids conflating adulthood with reaching wholeness in the lifespan, claiming instead that a human of any age “is at all stages capable of taking himself as a whole.”⁴⁷² This alternative to the successive-stages mindset counteracts the tendency to ascribe incomplete status to those in the early stages of life. He asserts that persons of all ages experience the totality of their lifespan, lived out in freedom before God, and that this totality encompasses and gathers up childhood rather than leaving it behind in a temporal phase. Writing decades before sociologists and anthropologists articulated similar arguments regarding developmental psychology, Rahner advocates jettisoning the common impression that “[childhood] is a mere provisional conditioning for the shaping of adult life in its fulness,” and he does so precisely because childhood more than any other period in the lifespan tends to be at risk of being seen as merely a precursor to a subsequent period.⁴⁷³

Rahner adds that this tendency is not limited to the secular realm, but that in fact Christians are especially prone “to lay special emphasis on the merely subordinate role of childhood” because of the sense in which it is “preparation for the life to come,” paralleling the Christian eschatological thrust that can overshadow life here and now.⁴⁷⁴ This remark is made

⁴⁷¹ Rahner, “Ideas for a Theology of Childhood,” 34.

⁴⁷² Rahner, “Ideas for a Theology of Childhood,” 34.

⁴⁷³ Rahner, “Ideas for a Theology of Childhood,” 35.

⁴⁷⁴ Rahner, “Ideas for a Theology of Childhood,” 34.

almost in passing, but it sets up an important contrast to the theological perspective that Rahner subsequently outlines. His description puts words to the common tendency to value the future at the expense of the present, as when Christians preoccupy themselves with the afterlife to the near-exclusion of attention to the here and now, giving the ideas of salvation or eternal life more priority than the needs and injustices in the present life. Rahner's view of childhood seems analogous to the idea of the eschatological inbreaking of the kingdom of God as a reality in the present, as opposed to a view of earthly life being a preparatory and fleeting reality we should be eager to put behind us. Just as the temporal realities of the hereafter become vital in the here and now, so too every season of human life takes on a value and wholeness in and of itself, apart from where it is situated temporally in the lifespan. As with an eschatological vision that integrates the human present as it moves toward a fully realized future, so Rahner's take asserts that we cannot lose childhood further and further in our past, but "rather we go towards it as that which has been achieved in time and redeemed forever in time."⁴⁷⁵

Having acknowledged the tendency in Christianity toward valuing the future at the expense of the past, Rahner turns to the question of how Christian scripture and tradition regard children, and suggests that Christianity is actually more suited than any other worldview to presuppose that "the child is already the man."⁴⁷⁶ For Rahner, the child is not a precursor to the fullness of a human being, but is actually constitutive of the human being. Rahner explains that a

⁴⁷⁵ Rahner, "Ideas for a Theology of Childhood," 36.

⁴⁷⁶ Rahner, "Ideas for a Theology of Childhood," 37. This language, especially coming from a Catholic theologian, likely prompts contemporary readers to associate it with the "personhood of the fetus" arguments deployed in contemporary abortion debates. And indeed Rahner soon notes, "for this reason [Christianity] protects the child while it is still in its mother's womb" (p.38). While a thorough discussion of this use of Rahner's argument is beyond the scope of this work, what is worth noting here is the extent to which this argument has preoccupied debate around fetal life to the exclusion and near-abandonment of vital concerns about the personhood of children and their needs as full human beings, all too often overlooked in anti-abortion politics. Catholic theologian Todd Whitmore identifies this trend as excessive natalism which focuses on "the gift of creation expressed in procreation at the expense of how it manifests itself at other stages of life." ("Children: An Undeveloped Theme in Catholic Teaching," 177).

child “is not an element in a process advancing and receding incalculably like the tides, but the unique explosion in which something final and definitive is constituted.”⁴⁷⁷ Countering popular developmental paradigms that implicitly equate the fullness of personhood with reaching adulthood, Rahner sees a completeness from the very beginning.

Rahner identifies “the child is the man” in the sense that a child embraces the immediacy of life and, despite not knowing himself fully, comes fully into God’s infinite presence. This finite person, whether child or adult, whether dimly aware of selfhood or decedes into efforts at self-understanding, is complete in the regard of the divine. God knows each person fully from the start, not incrementally over time. This robust theological identity claims a fullness that does not rely on typical psychological developmental categories; likewise, it transcends even the related effort of childhood studies to assert the agency of the child. It can accommodate and reckon with what has yet to be developed and fulfilled in a child and her life, but also assert the present fullness of who that child is before God, where nothing remains incomplete with respect to that person’s identity and capacity to relate to God. The practical and pastoral implications of this deeply grounded assertion are significant here, both for those who are very young in human years and those who, whether old or young, face threats, limitations or losses in their physical or cognitive capacities.

Here Rahner’s work echoes Wall’s concept of being transformed by the other. That is, regardless of how human development casts the matchup of abilities between adults and children, there is an equality of footing in relating as full participants with each other and with God, who grounds relationships that encompass and reveal the completeness of their selfhood.

⁴⁷⁷ Rahner, “Ideas for a Theology of Childhood,” 38.

Children and adults can be transformed by the otherness of God, in that God regards their completeness before they can regard it themselves.

Rahner does not try to pin down every detail of the way in which childhood and adulthood are united, but rather names this unity as a mystery that we live into and to which we are subject, one that we humans do not “preside over or control by [our] own power.”⁴⁷⁸ His point here is a key reminder to the larger discussion in this chapter and overall project: the aim of a theological anthropology is not primarily scientific analysis nor prescriptive actions, but an exploration of the contours of human experience and the invitation to live further into the mystery that imbues it. In everyday clinical encounters in a children’s hospital as well, living into this mystery provides sustenance for resisting the temptation to view everything and everyone through a data-driven, protocol-based, policy-led lens and empowers one to abide in a larger compelling vision of children and their experience that cannot be articulated or quantified by material data alone.

Furthermore, Rahner’s assertion that “the child is the man” serves not only to emphasize the fullness of a child as a person, rather than a precursor to a person, but also gives grounds for seeing the child as a robust moral subject and not as an innocent. This confronts any adult tendency to assume that bearing the weight of medical decision-making can fully address the moral weight of the child’s own experience. Even when adults carry the load of making decisions for children, this does not exhaust the moral experiences of suffering or threat to meaning and identity that may well burden children in such scenarios. Rahner’s work opens space to engage the fullness of a child’s experience even in the midst of situations where adults remain laden with more responsibility. I would contend that some of the richest experiences of

⁴⁷⁸ Rahner, “Ideas for a Theology of Childhood,” 39.

parental ethical decision-making for children occur when parents occupy the kind of ellipsis Wall posits, where their children are the “other” who invite serious moral engagement despite the very real differentials in their abilities and circumstances. Engagement in that sort of ellipsis is bolstered by taking the child as a complete person, as Rahner urges, rather than simply accounting for some future potential of the child at issue in a medical decision. The present wholeness of the child best informs the parental imagination and deliberation through ethically complex situations concerning present and future.

For Rahner, this wholeness is also reflected in asserting the range of moral experiences in childhood. He asserts that a Christian perspective insists that a child’s very existence marks the origination of the fraught conditions of human life, including “guilt, death, suffering and all the forces of bitterness” as opposed to childhood being “a pure source which only becomes muddied at a later stage.”⁴⁷⁹ Rahner characterizes this moral landscape not as one of cynical fatalism but as a necessary corollary to the knowledge of the extent of divine grace and redemption. In this way Rahner provides theological grounding for affirming the validity of children’s engagement with moral life.

Here again, Rahner’s point offers a significant contrast to the way in which pediatric clinical ethics tends to focus on protecting children from the sting of moral realities around them. Even when adults are summoned to deliberate and take responsibility for decisions, this should not eliminate the summons to also engage what those decisions mean for and to the children in question. While I do not want to minimize the real responsibility of adults to keep children from harm and to titrate their exposure and engagement with moral realities such as suffering and death, I also contend that adults do a serious disservice to children when we see our surrogate

⁴⁷⁹ Rahner, “Ideas for a Theology of Childhood,” 40.

decision making as a way of bypassing the acknowledgement that children encounter “all the forces of bitterness.” In the context of a children’s hospital, this can be all the more pronounced, as dire circumstances can heighten adult fears about the impact of difficult information on children.

I recall a five-year-old boy whose rather straightforward broken arm had led to a complication called compartment syndrome, which necessitated partial amputation of his arm. In the days following surgery, his parents were insistent that no staff member disclose or make any reference to his missing arm or hand. Surely they too were overwhelmed by the weight of what it would mean for their child to adjust to this loss, but their impulse to protect him from suffering constituted an undermining of his need and ability to engage with his new reality, not to mention his need to retain trust in the caregivers on whom he was relying to help him move forward through this crisis.

Rahner characterizes the Christian understanding of and experience of the child as “both idealistic *and* realistic at the same time.”⁴⁸⁰ Rahner says scripture admits the “immaturity and weakness” of children but that when Jesus esteems the child as the prototype for those to whom belong the kingdom of heaven (Matthew 19:14), he is not referring to innocence. Rahner claims that something of greater importance resides in this action of Jesus: “that we can be like children in being receivers and as such carefree in relation to God, those who *know* that they have nothing of themselves on which to base any claim to his help, and yet who trust that his kindness and protection will be extended to them and so will bestow what they need upon them.”⁴⁸¹ Rahner carefully esteems children without idealizing them, simply identifying their capacity to relate to

⁴⁸⁰ Rahner, “Ideas for a Theology of Childhood,” 41.

⁴⁸¹ Rahner, “Ideas for a Theology of Childhood,” 41.

God in a valid way that holds true for persons of any age. He also avoids glorifying any simplistic notion of innocence. To say that the kingdom of God belonged to those who were innocent, meaning free from the moral complexity of life, would only deepen the idea that the kingdom of God is otherworldly and not something that can truly be experienced in the messiness of the present life.

Rahner describes childhood as ultimately a mystery, something that both unfolds from an “absolute origin” but which also “comes to meet one.”⁴⁸² To the degree that we are able to deliver ourselves over to this mystery, he continues, we experience a preserved childhood state in which “we are open to expect the unexpected, to commit ourselves to the incalculable.”⁴⁸³ Furthermore, childhood that endures throughout life allows for a greater understanding of what the childhood at the beginning of our lives really meant. Rahner identifies this as the mystery of the childhood we live into, not that we lose, that ultimately illumines what it means to receive the kingdom of God “and so become children.”⁴⁸⁴

I sense how radical Rahner’s claim is when I consider how deliberately I need to think about the child as inherent to the whole of the lifespan. A conventional developmental, stage-based mindset is so influential that it is quite mentally demanding to imagine a different approach to wholeness and the enduring presence of a child in the adult. What grounds this so simply and beautifully, however, is the idea that each individual of any age is a child of God, able to relate to God directly and fully. This is precisely where Rahner moves next.

⁴⁸² Rahner, “Ideas for a Theology of Childhood,” 42.

⁴⁸³ Rahner, “Ideas for a Theology of Childhood,” 42.

⁴⁸⁴ Rahner, “Ideas for a Theology of Childhood,” 43.

Children of God

A further way of articulating the unity of the child and the adult is to consider their common identity as children of God, a designation that spans our human years. Central to the task of describing a theology of childhood is the work of understanding what it means to be a child of God. Rahner is careful to note that the concept of being a child of God is not merely a metaphorical outgrowth from our human experience of childhood, but rather it is a reality whose primary meaning only *seems* to be simply human. With carefully chosen prose, Rahner outlines a trajectory of meaning: “it is only through the revelatory usage of the terms ‘child’ and ‘childhood’ that the depths and fulness of the human concepts as such can be realised and appreciated in their entirety.”⁴⁸⁵ Rahner aims to show that the only way human childhood and parenthood are fully understood is when they are actually regarded in their relationship with God. He describes what childhood across the lifespan consists of:

Childhood as an inherent factor in our lives must take the form of trust, of openness, of expectation, of readiness to be controlled by another, of interior harmony with the unpredictable forces with which the individual finds himself confronted. It must manifest itself as freedom in contrast to that which is merely the outcome of a predetermining design, as receptivity, as hope which is still not disillusioned.⁴⁸⁶

Rahner reiterates his assertion that childhood is not limited to a biological state at the beginning of life but it rather “a basic condition which is always appropriate to a life that is lived aright.”⁴⁸⁷ Biological childhood for him is situated as only “the beginning, the prelude, the foretaste and the promise of this other childhood, which is the childhood proved and tested and at the same time assailed, which is present in the mature man. In other words we must take childhood in this *latter* sense as the true and proper childhood, the fulness of that *former* childhood, the childhood of

⁴⁸⁵ Rahner, “Ideas for a Theology of Childhood,” 44.

⁴⁸⁶ Rahner, “Ideas for a Theology of Childhood,” 47.

⁴⁸⁷ Rahner, “Ideas for a Theology of Childhood,” 47.

immaturity.”⁴⁸⁸ Rahner suggests that the childhood that lives at the root of our lives, inherent in our being, must “manifest itself as freedom in contrast to that which is merely the outcome of a predetermining design, as receptivity, as hope which is still not disillusioned.”⁴⁸⁹ I find it hard to entertain these thoughts over such deeply embedded social constructs of childhood and of what it means to leave it behind. Likewise, it feels challenging to fully imagine the power of adults who truly possess hope unburdened by disillusionment, and to regard that sort of hope, receptivity, and freedom not as naïve or childish but as the blossoming of what began in childhood.

From Rahner’s depiction, childhood can be understood as a posture – not just a quality but an orientation of identity, an “orientation to God” as Rahner names it, and not metaphorically but in reality, one that achieves its perfection in the relationship of being a child of God. Rahner summarizes: “Childhood is openness. Human childhood is infinite openness. The mature childhood of the adult is the attitude in which we bravely and trustfully maintain an infinite openness in all circumstances and despite the experiences of life which seem to invite us to close ourselves.”⁴⁹⁰ Valuing openness in this way also underscores points I explored earlier, namely, the significance of the inherently relational core of human identity, which contrasts sharply with any characterization of a person as purely autonomous or defined only with respect to himself or herself as fully in control of life’s circumstances. If openness to another is foundational to the human experience, beginning with the lifelong experience of being a child of God, then relational considerations truly shape the human life more profoundly than anything else.

Rahner describes human openness itself as being modeled on the “self-bestowal of the Father upon the Logos” which gives us a share in the divine nature; that is, our identity as

⁴⁸⁸ Rahner, “Ideas for a Theology of Childhood,” 47.

⁴⁸⁹ Rahner, “Ideas for a Theology of Childhood,” 47.

⁴⁹⁰ Rahner, “Ideas for a Theology of Childhood,” 48.

children of God is predicated on the openness and self-giving love between persons of the triune God.⁴⁹¹ Again, this way of characterizing childhood is profoundly different from seeing childhood as an incomplete beginning that will be subsumed by later chronological life stages. Rahner depicts the persistence of childhood in a way that upends every stage theory of human development, asserting: “In the child a man begins who must undergo the wonderful adventure of remaining a child forever, becoming a child to an ever-increasing extent, making his childhood of God real and effective in this childhood of his, for this is the task of his maturity.”⁴⁹² For Rahner, childhood is something we grow into throughout our lives as we move toward biological maturity, not something we grow out of. The developmental stage of childhood from a human perspective is only an inkling of what childhood really is. In the end, the fullness of childhood exists in the totality of the lifespan, and the fullness of childhood is best understood through our lifelong standing as children of God.

The gifts of Rahner’s theological undertaking are many. Most distinctively, he invites us to encounter childhood through theological terms, in such a profoundly different way from how it is popularly characterized. With disciplined imaginations we might envision a childhood truly lived into during the full span of human life and marked along the way by freedom and openness and an enduring relationship to the divine.

Revisiting “Paul”

Rahner’s perspective on childhood opens up possibilities for someone like Paul, whose story of dependency following a stroke began this chapter. Rather than viewing his health crisis

⁴⁹¹ Rahner, “Ideas for a Theology of Childhood,” 49.

⁴⁹² Rahner, “Ideas for a Theology of Childhood,” 50.

only through the lens of diminished independence, Rahner's points remind us that there is also an opportunity for him to reconnect to the identity of being a child of God, discovering an openness to change and to receiving care as he continues to grow and adapt to the difficult circumstances older adulthood has brought him. Historian and public theologian Martin Marty reflects on this sort of juncture at the end of a book that he wrote on children, *The Mystery of the Child*, which was inspired in large part by Rahner's work.⁴⁹³ In the closing chapter, Marty grapples with the injunction of Jesus in Matthew's gospel: "unless you change and become like children, you will never enter the kingdom of heaven" (Matt 18:3, NRSV). Acknowledging that aging adults may find it defeating to hear childlikeness esteemed even as they are "in the process of surrendering some of their own hard-achieved independence," Marty reckons honestly with both the sense of loss and the renewal of possibility that can emerge when those in later decades of life consider the call to "childness."⁴⁹⁴ While the twin tendencies of regret and envy can surface as aging adults consider the narrowing of abilities and functions, says Marty, there is nonetheless an enduring opportunity to tend to the childness in one's own life.

Marty is careful to point out that, along with Rahner, he is not describing a "second childhood"—a term he finds stigmatizing and inaccurate to the meaning of childhood in the first place—but rather the basic condition or quality of being open and in positive relations with others.⁴⁹⁵ When the aged are able to overcome their resistance to change, and to embrace a conversion of sorts as their sense of forward continuity in life gets disrupted by decline, there Marty sees the "mystery of the child" manifest anew. Childness thus reflects the kind of evolving relationship that we are never meant to outgrow. It's not a return to a second childhood if it is

⁴⁹³ Marty, Martin E., *The Mystery of the Child*. (Grand Rapids, Mich: William B. Eerdmans Pub., 2007), 107.

⁴⁹⁴ Marty, *The Mystery of the Child*, 232, 237.

⁴⁹⁵ Marty, *The Mystery of the Child*, 236.

indeed a rediscovery of rootedness in a parental divine love that relativizes our human notions of independence in the first place. The daunting work for someone like Paul consists of reframing his identity and sense of purpose in a manner that transcends his physical ability and the life such ability enables.

Childhood's presence in adult health

This final section discusses research on Adverse Childhood Experiences (ACEs) that demonstrates in a very practical way how adult health is impacted by the enduring effects of childhood. This relates to the wider arc of this project by demonstrating a concrete way in which theoretical approaches such as those of Wall and Rahner can better equip us to holistically connect childhood and adulthood in practical ways. Furthermore, the ACEs work represents yet another confounding influence on the traditional conception of adult autonomy. That is, ACEs demonstrate that respecting the autonomous decisions of rational adults still entails reckoning with the enduring impact of their childhoods, something over which they did not have autonomous choice.

Though sobering, ACEs research offers a crucial counterpoint to any tendency to romanticize the way that childhood can endure throughout the lifespan. While we do well to embrace Rahner's call to recognize the childlike openness that can and ought to persist throughout the lifespan, we also must acknowledge that the aspects of childhood that continue to find expression into adulthood can be detrimental ones, reflecting hardship that goes unresolved and becomes increasingly problematic into later years as it manifests in health problems. For many adults, an inability to safely experience such openness of spirit stems from early and often unaddressed traumatic experiences. ACEs work thus offers another practical reason to do away

with conceptions of childhood that see childhood as a preliminary, completed, left-behind stage of life. The persistence of childhood, for good and for ill, ought to be better understood and addressed in adult populations, as something that is not “outgrown” but which evolves throughout our lifetimes. Wall’s call for de-centering adulthood also gives theoretical legitimacy to this needed change in perspective.

Additionally, I address the ACEs findings here to underscore how the vulnerability, dependence, and agency that characterize a theological anthropology of childhood remain just as true in later years. We never outgrow these facets of our full humanity. This theological anthropology, then, can come alongside the scriptural injunction to change and become like children, offering a more complicated but also more promising way to wrestle with the enduring perils of human childhood and the enduring possibilities of growth and healing. Knowledge of ACEs prevents us from an overly optimistic rendering of what it means to retain childhood throughout life. By incorporating data from the lived experience of children who have reached adulthood, ACEs findings steer us toward the urgent need to find integrative ways to de-center our narrow views of adult health in order to address both child and adult well-being. ACEs findings drive home the sobering point that our cultural tendency to view childhood as something that we grow out of, something that gives way to adulthood and gets left behind, is inaccurate to a dangerous degree. If we hope to promote human flourishing as lives advance in years, we must account for the enduring impact of childhood flourishing or lack thereof.

ACEs: an overview

Research related to the concept of adverse childhood experiences continues to grow, stemming from the findings of the original ACE study, which was published in 1998 following a

survey of over 9,000 adults in a California HMO.⁴⁹⁶ The study was motivated by the fact that the relationship between disease and health risk behavior in adulthood had not yet been examined in relationship to adversities in childhood. The survey asked about seven categories of adverse childhood experiences: psychological, physical, or sexual abuse; violence against one’s mother; and living with household members affected by substance use, mental illness, or incarceration. More than half (52%) of respondents reported one or more category of experience.⁴⁹⁷

The study found a “strong graded relationship between the breadth of exposure to abuse or household dysfunction during childhood and multiple risk factors for several of the leading causes of death in adults.”⁴⁹⁸ Specifically, “The number of categories of adverse childhood exposures showed a graded relationship to the presence of adult diseases including ischemic heart disease, cancer, chronic lung disease, skeletal fractures, and liver disease.”⁴⁹⁹ Vincent Felitti, the physician and lead author of the ACEs study and much subsequent related work, along with his colleagues, also hypothesized that the relationships between childhood adversity and adult health could be even stronger than the study itself suggested, in part because older adults tended to report lower numbers of ACEs, which could be “an artifact caused by premature mortality in persons with multiple adverse childhood exposures.”⁵⁰⁰

⁴⁹⁶ Felitti, Vincent J., Robert F. Anda, Dale Nordenberg, David F. Williamson, Alison M. Spitz, Valerie Edwards, Mary P. Koss, and James S. Marks. “Relationship of Childhood Abuse and Household Dysfunction to Many of the Leading Causes of Death in Adults.” *American Journal of Preventive Medicine* 14, no. 4 (May 1, 1998), 245–58. Of the 9,508 respondents, 8,506 were included in data analysis; in this group, the average age was 56.1 years, 52.1% were women, 79.4% were white, and 43% were college graduates, with only 6% having not graduated from high school.

For more information on ACEs, see the CDC website <https://www.cdc.gov/violenceprevention/acestudy/index.html>

⁴⁹⁷ Felitti et al., “Relationship,” 249.

⁴⁹⁸ Felitti et al., “Relationship,” 245.

⁴⁹⁹ Felitti et al., “Relationship,” 245.

⁵⁰⁰ Felitti et al., “Relationship,” 252.

Felitti et al. trace the pathways by which childhood adverse experiences can lead to adult health problems, positing that behaviors like smoking, alcohol and drug use are adopted as chronic coping devices in response to the anxiety, anger and depression produced by exposure to high levels of adversity in early years. That is, substance use and other coping mechanisms which are regarded as purely problematic in the medical and social context “may, from the perspective of the user, represent an effective immediate solution that leads to chronic use.”⁵⁰¹ This important consideration of the short-term psychological benefits of behaviors that mitigate the difficulties of youth, however, is unfortunately overlooked or ignored outright in the dominant approach to adult disease. The authors note,

Because adverse childhood experiences are common and they have strong long-term associations with adult health risk behaviors, health status, and diseases, increased attention to primary, secondary, and tertiary prevention strategies is needed. These strategies include prevention of the occurrence of adverse childhood experiences, preventing the adoption of health risk behaviors as responses to adverse experiences during childhood and adolescence, and finally, helping change the health risk behaviors and ameliorating the disease burden among adults whose health problems may represent a long-term consequence of adverse childhood experiences.⁵⁰²

The authors call for strategies that align well with the overall urgings of this project to consider the ways in which the healthcare context interacts with the vulnerability and dependence of childhood and the need to take children’s agency seriously. ACEs reveal the importance and urgency of this increased serious attention for the whole life span and not just childhood. However, note Felitti et al., both because of the time delay between childhood and the onset of many adult health problems, and because of the sensitive nature of inquiries into

⁵⁰¹ Felitti et al., “Relationship,” 254.

⁵⁰² Felitti et al., “Relationship,” 254.

subjects like childhood sexual abuse, medical practice tends not to pay close attention to the relationship between ACEs and adult health.⁵⁰³

Felitti reiterates these points a decade later in a short commentary on subsequent research looking at the effects of adverse childhood experiences on childhood health, noting that

Many of our most intractable public health problems are the result of compensatory behaviors like smoking, overeating, and alcohol and drug use, which provide immediate partial relief from the emotional problems caused by traumatic childhood experiences. Those experiences are generally unrecognized and become lost in time, where they are protected by shame, by secrecy, and by social taboos against exploring certain areas of human experience.⁵⁰⁴

Felitti traces what he believes are two pathways by which disease results from adverse childhood experiences: first, disease can manifest as the delayed consequences of coping behaviors such as smoking, overeating, drug use, and promiscuity. Second, disease can be caused by chronic stress and its impact on the body, particularly through cortisol levels and inflammatory processes.⁵⁰⁵

He goes on to note that our public health efforts to address matters like smoking and overeating usually fail to take into account the full picture of what is going on in a patient's life and history, and thus fail to see how hard it is for people to give up something that "almost works." These unconsciously attempted solutions for coping in turn become a public health problem, Felitti contends, while also admitting how daunting it is to imagine how primary prevention could be carried out in light of these realities. He suggests that improving supportive parenting skills on a broad level could have as great an impact as a vaccine in accomplishing primary prevention of harm.⁵⁰⁶

⁵⁰³ Felitti et al., "Relationship," 255-56.

⁵⁰⁴ Felitti, Vincent J. "Adverse Childhood Experiences and Adult Health." *Academic Pediatrics* 9, no. 3 (June 2009), 131.

⁵⁰⁵ Felitti, "Adverse Childhood Experiences," 131.

⁵⁰⁶ Felitti, "Adverse Childhood Experiences," 131.

More than ten years after the original ACEs study, in 2010, a follow up study aimed to assess the impact of ACEs using a more diverse population, particularly as the original ACEs work drew on data from “a medically insured sample of predominantly white, middle aged adults from Southern California.”⁵⁰⁷ This subsequent study also found a dose-response relationship, with the risk of adult health concerns rising along with number of ACEs experienced in childhood. This study again highlighted the need for more research as to the exact pathways by which adversity causes adult health concerns. Echoing the original ACES study, Gilbert et al. suggest that toxic stress and allostatic load—referring to the physiological adaptations induced by acute stress—can “damage the metabolic, cardiovascular, immune, and nervous systems” and that in children, the disruption of such systems can negatively impact brain development related to “planning, problem solving, self-regulation of behavior, and management of emotions.”⁵⁰⁸ Another follow up ACEs-focused study examined the risk of premature mortality related to ACEs, and found a moderate association between ACES and premature death, and specifically that those with six or more ACEs died roughly 20 years earlier than those with no ACEs.⁵⁰⁹

As research related to ACEs continues to proliferate, other scholars have examined how various professions are integrating these findings. Larkin et al. assert that due to the findings of ACEs research, there has been a convergence of neurobiology and epidemiology, which I find responsive to the overall need to move from individual-focused accounts of health to more

⁵⁰⁷ Gilbert, Leah K., Matthew J. Breiding, Melissa T. Merrick, William W. Thompson, Derek C. Ford, Satvinder S. Dhingra, and Sharyn E. Parks. “Childhood Adversity and Adult Chronic Disease: An Update from Ten States and the District of Columbia, 2010: An Update from Ten States and the District of Columbia, 2010.” *American Journal of Preventive Medicine* 48, no. 3 (2015): 345–49. In this 2010 study, nearly 54,000 adult (18 or over) respondents from DC and ten states completed an optional ACES questionnaire along with a state-based, random-dial telephone survey called the Behavioral Risk Factor Surveillance System (BRFSS).

⁵⁰⁸ Gilbert et al., “Childhood Adversity,” 346.

⁵⁰⁹ David W. Brown et al., “Adverse Childhood Experiences and the Risk of Premature Mortality,” *American Journal of Preventive Medicine* 37, no. 5 (November 2009): 389–96.

systemic ones. Larkin et al. summarize the generational flow of how “ACE-related mental health, behavioral, and social problems among parents become ACE for the next generation” and call for continued awareness and focus on life course perspective models of health.⁵¹⁰ A recent meta-analysis of ACEs research likewise conveys a sense of urgency in developing programs to increase children’s resilience in the face of adversity and to implement policies that are geared toward a life course approach to health.⁵¹¹

ACEs and autonomy

I include this overview of the ACEs research because it further confronts the problems posed by simplistic notions of respect for autonomy in clinical ethics. Just as I have argued that focusing on autonomy carries problematic implications for how children are regarded in the healthcare context, so too an overly simplistic understanding of autonomy fails to account for the lived realities of so many adult patients whose health and choices continue to be shaped and constrained by detrimental childhood experiences. Until we have more robust ways of acknowledging and accounting for that kind of layered reality in patients’ health stories, we will continue to presume an exaggerated individualistic notion of what constitutes autonomous choice. Unrealistic individualism is reinforced any time we envision a patient’s choices reflecting personal preferences alone, and likewise when we envision the remedy for their ailments in isolation from context. Ignoring the systemic factors that cause or exacerbate adult

⁵¹⁰ Larkin, Heather, Joseph J. Shields, and Robert F. Anda. “The Health and Social Consequences of Adverse Childhood Experiences (ACE) Across the Lifespan: An Introduction to Prevention and Intervention in the Community.” *Journal of Prevention & Intervention in the Community* 40, no. 4 (October 1, 2012): 268, 269.

⁵¹¹ Hughes, Karen, Mark Bellis, Katherine Hardcastle, Dinesh Sethi, Alexander Butchart, Christopher Mikton, Lisa Jones, and Michael Dunne. “The Effect of Multiple Adverse Childhood Experiences on Health: A Systematic Review and Meta-Analysis.” *The Lancet Public Health* 2, no. 8 (August 1, 2017): e356–66.

health problems also leads to neglect of the healing that is needed in relationships and systems far beyond the individual, reinforcing perceptions that individuals alone are the site where healing is needed.

I have little doubt that findings related to adverse childhood experiences will continue to inform our awareness of health trajectories across the lifespan and heighten our sense of urgency around the need to bolster resilience for children and adults alike. I wonder whether and how the clinical context will incorporate this growing awareness into a “thicker” understanding of what it means to respect patient autonomy. I do believe that a continued attitude towards human development that sees childhood as a stage we “grow out of” will only hamper efforts to engage in a life course approach to health. ACEs work invites us to acknowledge that adult autonomy is messy, not straightforward, and that efforts to respect whatever autonomy we ascribe to an individual patient will also entail reckoning with the contextual factors that have shaped a patient’s preferences and beliefs, for better or worse. Honoring the principle of respect for autonomy may provide a protection against egregious paternalism, but it does not resolve the deep influences of pre-existing threats to well-being that hinder the physical, emotional, relational, and spiritual flourishing of far too many people.

Autonomy’s limits

I am reminded of an ethics consult in the hospital I currently work in, where a patient’s seemingly autonomous preference was deemed to be at odds with proceeding in a medically appropriate manner. The patient was a man in his 60s, who had been homeless for some time and had a long history of substance abuse and broken relationships, beginning with having been abandoned by his family of origin. The ethics consult was prompted when the staff caring for the

patient, who knew that his wishes were to “go down swinging and never give up” in the face of multiple comorbidities and acute illness, struggled with continuing to provide aggressive care beyond what they felt was beneficial to the patient. A daughter-like figure in the patient’s life kept advocating for his wishes to be honored, but staff were unsure how to respect this patient’s preferences while also setting reasonable limits on their interventions. The ethics consultants endorsed the staff in their medical judgment and recommended that staff not feel obligated to carry out extreme measures simply because the patient had wanted them.

This scenario illustrates, among other things, the importance of holding principles such as beneficence alongside respect for autonomy. However, it also reflects the way in which this patient was compelled by a sense of lack and struggle in his life up until that point, which prompted him to ask for the kind of medical treatment to which he felt he was entitled. The discomfort this created for the staff, in turn, stemmed from the tension between their efforts to both respect his autonomy and proceed with sound medical practice. The staff’s awareness of the patient’s previous deprivations and hardships created a heightened fear of depriving him further in the last days of his life. They wanted to respect what little autonomy they felt he had, but doing so was starkly at odds with the reasonable use of medical interventions. The staff were faced with treating “the child [who] is the man,” as Rahner would put it, as they confronted the ripple effects of his life’s many adverse experiences and wrestled with how to honor his preferences that had evolved accordingly.

Responding to ACEs

Until ACEs research is taken seriously and addressed on a wider scale, we will continue to see the harrowing effects of adversity in childhood reverberate through the lifespan and

manifest in adult health problems. ACEs research underscores two points crucial to my overall argument: first, as mentioned above, the reality of ACEs and their scope and impact provides a counterpoint to any temptation to romanticize the concept of childhood's enduring presence into adulthood. Lest we only focus on the positive, even idealized, notions of carrying openness and other childlike qualities into adulthood, ACEs soberingly invites us to see that the vulnerabilities of childhood do not get left behind as the years pass, but rather that, as Felitti puts it, "what happens in childhood—like a child's footprints in wet cement—commonly lasts throughout life."⁵¹² Secondly, as the above case story illustrates, I believe the ACEs study complicates simplified notions of respect for autonomy, and that we ignore those complications at our peril. How exactly to account for the impact of childhood experiences in the adult's decision-making capacities is not straightforward, but at the very least we need to find a way to reckon with the constraints that ACEs represent in the face of what we all too easily theorize as unfettered adult reasoning.

There is currently no established approach to address ACEs in adult healthcare, so it may be premature to expect ethics to have such an approach. However, the longer a concept of adult autonomous choice exists in a vacuum, the longer we rob ourselves of the important work of addressing what has gone unaddressed in those adults. We likewise delay our understanding and recognition of those adversities in today's children and delay our ability to prevent them. Additionally, we neglect important opportunities to name and engage the profound resilience that enables children and adults to survive or even thrive in the face of past and present adversity.

⁵¹² Felitti, "Adverse Childhood Experiences," 131.

Conclusion

This final chapter illustrates that a fuller theological anthropology of childhood enriches not only our understanding of children but also our appreciation for childhood's enduring presence within the entire lifespan. Wall and Rahner fuel our ethical and theological imaginations, urging us to place childhood in a wider context for the sake of children and adults alike. Their work can equip much-needed efforts to foster healthcare that neither glosses over childhood nor infantilizes adults. Along with the findings thus far demonstrating how adverse childhood experiences reverberate through the whole life course, the work of Wall and Rahner underscores how narrow and brittle the principlist understanding of adult autonomy has been. Respect for autonomy may be a starting point in clinical ethics, but it alone does not ensure flourishing. Moving beyond autonomy to incorporate wider concerns in bioethics is thus urgent not only for children, who are defined primarily by their deficits in basic renderings of autonomy, but also for adults, for whom autonomy is only one consideration in the larger fabric of identity and well-being.

The health, futures, and fates of children and adults are tied up together intimately and inextricably, as has always been true and as ACEs research continues to bear out. Wall and Rahner invite us into a moral and theological space where a keen responsiveness to one another's differences, against the backdrop of a shared identity as children of God, might bring transformation and flourishing for all.

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