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DISABILITY AND COMPASSIONATE CARE:

A NEW VISION FOR PERINATAL HOSPICE

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The domain of deontology may appear, especially today, as the most vulnerable in the field of medicine; but it is essential, and medical morality should always be considered by practitioners as the norm of their professional practice that deserves most attention and above all the greatest efforts for its defense.

John Paul II
(*Address to The World Medical Association*, October 1983)

INTRODUCTION

It might seem self-evident to say that our personal experiences leave indelible marks on who we are and how we think. Nevertheless, I feel compelled to begin with this thought, as events, encounters, and even mistakes possess the powerful ability to shape our understanding of ourselves and the world around us. One such pivotal experience for me was my time working as a chaplain in perinatal hospice care in Poland. This journey was not just a professional engagement; it was a deeply personal odyssey that taught me invaluable lessons about life, empathy, and the essence of human dignity.

During my tenure in Poland, I witnessed firsthand the critical importance of having healthcare teams who not only understand and support the desires of parents expecting children with terminal conditions but also recognize them as loving guardians of profoundly disabled children. These parents—who choose to bring their children into the world despite knowing their lives will be brief—demonstrate a remarkable blend of courage, love, and resilience. They require and deserve a care environment that acknowledges and supports their experience.

I quickly realized that this field of care inherently carries a particular understanding of human disability or illness. Whether consciously or unconsciously, this understanding markedly influences the nature and scope of care provided to vulnerable perinatal hospice patients. The quality and effectiveness of that care depend heavily on the caregivers' underlying anthropology and their view of human disability. This realization led me to explore the most influential contemporary narratives on human disability. My goal was to identify perspectives that could best respond to the needs of parents who choose to carry affected pregnancies to term, ensuring they receive comprehensive support consistent with the mission of Catholic perinatal hospice care. At the root of this mission lies a commitment to recognizing the inherent dignity of every human life, regardless of its limitations.

Understanding and addressing the complex needs of these parents requires a nuanced approach that considers their emotional, spiritual, and practical challenges. Healthcare teams must be equipped not only with medical expertise but also with deep empathy and respect for the parents' journey. This holistic approach fosters a supportive environment where parents feel valued and understood, enabling hem to navigate their challenging path with dignity and grace. Moreover, this exploration aims to bridge the gap between contemporary disability narratives and the practical aspects of hospice care. By integrating these narratives, we can develop care practices that are both compassionate and effective, providing parents with the reassurance that their children, despite their profound disabilities, are recognized and cherished as full members of the human family.

In summary, the interplay between personal experiences, conceptual understandings of disability, and practical caregiving forms the backbone of effective perinatal hospice care. This book aspires to deepen our understanding of these dimensions, with the ultimate goal of enhancing the support provided to parents and structuring it in accordance with the compassionate mission of Catholic perinatal hospice. Through this work, I hope to offer insights and guidance that will benefit healthcare providers, parents, and all those accompanying the sacred journey of caring for life, however brief it may be.

Adam's story

I was first introduced to the importance of perinatal hospice care through an encounter with the wonderful parents of a boy named Adam, who was diagnosed with microcephaly in the 16th week of pregnancy. I met them at the Office of Children's Hospice in Krakow, Poland. The couple was convinced that they wanted to bring Adam into the world and provide the necessary care for him to live, however brief his time with them might be. Despite their strong resolve, I could sense their struggle: a heavy burden of fear, uncertainty, disappointment, and anger. The couple was evidently searching for meaning in the midst of their first child's inevitable, profound intellectual impairment and eventual premature death.

In that search, Adam's parents turned to the perinatal hospice care team—of which I, as a chaplain, was a member—for assistance. It became clear that they were seeking a particular attitude of appreciation and validation of their son's life from us. They needed reassurance that Adam, despite his severe physical and neurological disabilities, would be acknowledged as fully human and his life valued equally. At the same time, they hoped to be seen and supported as loving and faithful caregivers of their unborn son. Responding appropriately to these parental expectations depends, I believe, on how the care team understands the nature and meaning of disability, particularly profound intellectual impairment. In this context, Pope John Paul II (JPII) emphasized on numerous occasions the importance of correctly understanding the human condition in the face of illness and disability. He also warned that "deontology is the most vulnerable field of today's medicine."[1]

Acknowledging the magnitude of this challenge, my book aims to contribute to the rediscovery of a proper anthropology and an understanding of profound human disability in the perinatal hospice setting, particularly from a Catholic perspective. I argue throughout that only by adopting such a framework can perinatal hospice teams offer the full measure of respect and appreciation for the human dignity due to unborn children with severe impairments, and support to the families who care for them. Although this work is primarily intended to enrich the practices of Catholic perinatal hospice centers, I believe it may also prove beneficial to non-Catholic centers and to anyone involved directly or indirectly in the care of individuals with profound intellectual disabilities. I am aware that my study is by no means exhaustive; much remains to be explored in the field of medical anthropology and disability within contemporary Western healthcare. Nevertheless, I hope that this book can serve as a starting point for further inquiry into these and underexamined issues.

Understanding and addressing the complex needs of these families requires a nuanced approach that considers their emotional, spiritual, and practical challenges. Healthcare teams must be equipped not only with medical expertise but also with deep empathy and respect for the journey of parents facing such circumstances. A truly holistic approach creates

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[1] John Paul II, *Address at the conclusion of the 35th General Assembly of the World Medical Association* (October 29, 1983).

an environment in which families feel seen, supported, and empowered to navigate their path with dignity and grace. Moreover, this exploration aims to bridge the gap between contemporary narratives about disability and the day-to-day realities of hospice care. By integrating these perspectives, we can develop care practices that are not only medically sound but also compassionate and responsive, providing parents with the reassurance that their children, even in the presence of profound disability, are cherished as full members of the human family.

In summary, the interplay between personal experiences, theological and philosophical understandings of disability, and practical caregiving strategies forms the backbone of effective perinatal hospice care. This book aims to contribute to a deeper understanding of these interconnected elements and enhance the support provided to families, in line with the compassionate mission of Catholic perinatal hospice. Through this work, I hope to offer insights and guidance that will benefit healthcare providers, parents, and all those who participate in the sacred calling of caring for life, however brief its earthly span may be.

Between anthropologies

The quest for an appropriate anthropology—one that offers a robust understanding and appreciation of profoundly disabled human life—must begin with an examination of the fundamental sources that have shaped contemporary Western narratives about disability. This project opens with an analysis of three such sources: (1) secular Disability Studies (DS), (2) the contemporary Catholic Church Magisterium as informed by the teachings of St. Thomas Aquinas, and (3) the writings and teachings of JPII, particularly his *Theology of the Body* (TB).

Each of these substantial sources presents a distinctive way of understanding human disability, shaped by the context of a particular community and its underlying social dynamics. As for the DS, its advocates promote what philosopher Hans Reinders describes as an "anthropology of political citizenship."[2]

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[2] Hans S. Reinders, *Receiving the Gift of Friendship: Profound Disability, Theological Anthropology, and Ethics* (Grand Rapids, MI: Eerdmans, 2008), p. 35.

In contrast, the Magisterium of the Catholic Church reflects what I refer to as a *ratio*-informed anthropology—one that emphasizes a rational appreciation of human dignity. Meanwhile, although JPII's anthropology is rooted in the Thomistic tradition, his perspective introduces a somewhat different emphasis, which I will describe as *relatio*-informed anthropology.

Accordingly, this project entails two stages. In the first, I will introduce the anthropologies proposed by DS and the Catholic Magisterium and explore their positive contributions to our perceptions of disability while also identifying significant limitations, especially regarding the recognition of dignity and full humanity in unborn children with profound intellectual disabilities. In the second stage, I argue that JPII's *relatio*-informed anthropology, especially as developed in *Theology of the Body*, contributes several considerations that are critical for a more complete appreciation and protection of unborn children living with profound disabilities. Consequently, I contend that this vision of the human person should be widely accepted as a solid foundation for perinatal hospice care in both Catholic and non-Catholic healthcare institutions.

Before proceeding further, it is important to clarify that the rationale behind this specific focus on profound intellectual impairment has to do with my experiences in the Krakow Children's Hospice and at Cardinal Glennon Children's Hospital in Saint Louis. In both places, I observed that such impairments were among the most prevalent conditions affecting children in perinatal hospice care. This reality gives rise to a unique set of concerns for parents navigating their child's diagnosis and care. There is substantial literature indicating that public perceptions of intellectual disability often create considerable burdens—not only for individuals with disabilities but also for their families and support networks. Since profound intellectual disability is not my main focus in this project, I will not discuss it in greater detail here; however, the issue certainly warrants separate and extended reflection.

I begin this work by sketching the historical and clinical context of perinatal hospice care. The upcoming chapter will trace its origins and development. I will explain how it has evolved into its current form and point to the distinctive multidisciplinary character of this practice, which calls for close collaboration across medical, psychological, pastoral, and ethical domains.

Ultimately, I will argue that perinatal hospice care embodies a unique set of values that are vital to the healthcare profession. Drawing on the narratives of mothers in perinatal hospice settings, I will demonstrate the importance of this practice in respecting and protecting not only the lives of perinatal children but also the integrity and dignity of their families. The first chapter will conclude by emphasizing the need to ground perinatal hospice practices in coherent and life-affirming anthropological concepts so that its noble mission of compassionate, ethically rooted care can be truly fulfilled.