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Beyond Marginalization: Rethinking Dignity, Disability, And Care In Bioethics

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Poza marginalizacją: nowe spojrzenie na godność, niepełnosprawność i opiekę w bioetyce

Streszczenie

Artykuł analizuje zjawisko podwójnej marginalizacji osób z niepełnosprawnością oraz ich opiekunów w dyskursie bioetycznym i praktyce klinicznej. Zwraca uwagę, że współczesna medycyna i bioetyka często ujmują niepełnosprawność głównie w kategoriach diagnostycznych i funkcjonalnych, redukując bogactwo doświadczenia do kodów chorobowych, rokowań i wyników terapii. Równocześnie codzienny wysiłek emocjonalny, psychiczny i duchowy rodziców oraz innych opiekunów pozostaje w dużej mierze niewidoczny. W oparciu o fenomenologię Edmunda Husserla oraz teologię ciała Jana Pawła II autor proponuje relacyjne, ucieleśnione i zakorzenione w nadziei ujęcie ludzkiej godności. Szczególnym miejscem refleksji jest praktyka hospicjum dziecięcego, w której wyraźnie ujawnia się etyczny sens obecności, uznania i współdzielonej kruchości. Zaproponowane podejście poszerza tradycyjny model autonomii oraz wskazuje na potrzebę rozwinięcia języka bioetyki tak, aby obejmował on doświadczenie relacyjne, ucieleśnione oraz teologiczno-antropologiczne.

Słowa kluczowe: niepełnosprawność, godność, fenomenologia, teologia ciała, opieka paliatywna dzieci

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1. Introduction: The Problem of Dual Marginalization

The question of how to understand, protect, and nurture the dignity of people living with disabilities remains one of the most urgent ethical challenges in contemporary healthcare. Despite the exponential growth of biomedical technologies and the refinement of ethical principles, a profound gap persists between the lived reality of disabled persons and the categories through which they are analyzed in clinical and bioethical discourse. In many medical environments, disability is primarily conceptualized

in terms of deficits – loss of function, deviation from norms, diminished capacity, or compromised autonomy. The clinical gaze, shaped by diagnostic precision and technological intervention, tends to fragment a person into symptoms, measurements, and treatable components. Jackie Leach Scully notes that "disabled people are often objectified by medical discourse even when that discourse intends to help them".[1] Such objectification, even when benevolently motivated, narrows the horizon of meaning within which disabled persons are encountered.

At the same time, caregivers – often parents, siblings, or spouses – find themselves positioned at the periphery of ethical conversations, even though their daily participation in care is integral to the moral and emotional ecosystem of healthcare.[2] Their experience is marked by a distinctive form of vulnerability: a constant oscillation between hope and despair, exhaustion and resilience, frustration and love. Yet these experiences rarely appear inethical guidelines, academic debates, or hospital ethics consultations. As a result, caregivers become invisible agents, tacitly expected to carry the emotional and practical weight of care without recognition of their moral agency. This invisibility is not merely an oversight; it is a structural feature of a system that privileges abstract principles over concrete relationships.

In this article I call this phenomenon "dual marginalization": the simultaneous reduction of disabled individuals to clinical objects and of caregivers to functional supports. Dual marginalization is not simply an ethical error; it is a conceptual limitation embedded in the theoretical foundations of modern bioethics. To move beyond it, we must adopt a richer understanding of human experience – one that includes embodiment, relationality, and vulnerability as central categories. By bringing phenomenology and the Theology of the Body into conversation, we can develop a more adequate ethical framework for disability and care.

2. Reassessing Autonomy: From Independence to Relationality

Autonomy has long occupied a central position in bioethics, functioning as a safeguard for individual rights and a counterbalance to medical paternalism. Its primacy is rooted in a particular philosophical anthropology that equates moral agency with rational self-governance, independence, and the capacity for informed decision-making. Yet this model, while historically effective in securing patient rights, remains limited when applied to contexts marked by dependency and vulnerability.

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1 Jackie Leach Scully, *Disability Bioethics. Toward a Moral Reconstruction* (Lanham, MD: Rowman & Littlefield, 2008), 42.

2 Ibidem, 45.

For many individuals with profound disabilities, autonomy cannot be exercised through the traditional mechanisms of consent or self-directed decision-making. However, this does not mean that they lack autonomy. Rather, it indicates that autonomy itself must be reinterpreted. Havi Carel argues that "illness often diminishes our agency, but it also reveals the extent to which agency is always already relational and dependent".[3] What disability exposes is not a failure of autonomy but the inadequacy of a model of autonomy that fails to account for the interdependent nature of human life.

A more adequate concept is relational autonomy, which recognizes that autonomy is formed, exercised, and sustained within relationships of trust, care, and mutual interpretation. Decisions made on behalf of disabled individuals – for example, by parents of children unable to speak or by caregivers interpreting non-verbal cues – are not a negation of autonomy but a collaborative enactment of it. The ethical focus thus shifts from the solitary agent making isolated choices to the network of relationships within which decisions are made. Relational autonomy aligns more closely with the reality of dependency, enabling a morally nuanced appreciation of the agency of disabled persons.

Moreover, many disabled individuals communicate meaning, preference, or resistance through gesture, expression, posture, or mood – forms of communication that remain invisible in models of autonomy limited to verbal or cognitive expression. Recognizing these forms of embodied agency requires epistemic humility on the part of clinicians and a willingness to engage in interpretive dialogue with caregivers, who often possess intimate knowledge of the disabled person's communicative repertoire. In this expanded understanding, autonomy is not merely a procedural requirement but a relational practice rooted in empathy, attentiveness, and mutual respect.

3. Phenomenology and the Lived Experience of Illness

Phenomenology, particularly as developed by Edmund Husserl, provides a methodological and philosophical foundation for rethinking disability and care. Husserl insists that philosophy must begin with Erlebnis – lived experience – as the primary source of meaning. Central to this view is the distinction between the body as Körper (a physical object) and the body as Leib (the lived, experiential body). Husserl writes: "the body is not a thing, but a centre of orientation, the bearer of the here and the now".[4] This insight

[3] Havi Carel, *Phenomenology of Illness* (Oxford University Press, 2016), 114.

[4] Edmund Husserl, *Ideas Pertaining to a Pure Phenomenology and to a Phenomenological Philosophy. Second Book*, trans. R. Rojcewicz, A. Schuwer (Dordrecht: Kluwer Academic, 1989), 167.

disrupts biomedical tendencies to treat the body primarily as a malfunctioning machine, inviting instead a more holistic view of embodied experience.

Illness, from a phenomenological perspective, is not simply a physiological event but a transformation of the person's lived world. S. Kay Toombs argues that "the experience of illness is first and foremost an embodied experience, a disruption not simply of function but of the lived world".[5] The ill body challenges the taken-for-granted structures of everyday life, altering temporal rhythms, spatial orientations, and interpersonal relationships. For disabled individuals, these disruptions may be constant, reshaping identity, agency, and belonging.

Phenomenology highlights that ethical care begins not with principles but with attention – the capacity to perceive and respond to the world as it is experienced by the other. Husserl describes this as "mutual empathy", a process through which one gains access to the other's horizon of meaning.[6] This empathy is not emotional contagion or sentimentality; it is a disciplined attentiveness to the other's embodied expressions, gestures, and modes of being.

Such attentiveness is particularly crucial in contexts where verbal communication is limited or absent. Many profoundly disabled individuals express discomfort, pleasure, recognition, or resistance through subtle shifts of posture, facial expression, or vocalisation. Caregivers who spend years interpreting these signs possess an embodied knowledge that cannot be captured by formal assessments or standardized protocols. Their interpretive expertise is a phenomenological skill that bioethics must learn to value. Phenomenology thus shifts the ethical focus from abstract reasoning to the concrete, embodied, intersubjective encounter in which dignity is disclosed and enacted.

4. The Theology of the Body: Embodiment, Fragility, and Communion

While phenomenology illuminates how meaning appears through lived experience, John Paul II's Theology of the Body offers a complementary theological anthropology that grounds the dignity of the human body in its symbolic and relational nature. According to John Paul II, "the body, in fact, and it alone is capable of making visible what is invisible: the spiritual and the divine".[7] The body is thus not a mere biological entity but the visible expression of the person.

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5 S. Kay Toombs, *The Meaning of Illness. A Phenomenological Account of the Different Perspectives of Physician and Patient* (Dordrecht: Kluwer Academic Publishers, 1993), 45.

6 Edmund Husserl, *Husserliana IX. Phänomenologische Psychologie* (The Hague: Martinus Nijhoff, 1973), 125.

7 John Paul II, *Man and Woman He Created Them. A Theology of the Body*, trans. Michael Waldstein (Boston: Pauline Books & Media, 2006), 203.

Within this framework, disability does not diminish dignity; rather, it reveals the profundity of human relationality. The vulnerable body becomes a site where communion – rather than independence – is both needed and offered. The Theology of the Body challenges bioethics to recognize the sacramental dimension of care: caregiving gestures such as feeding, bathing, holding, or comforting mediate recognition of the person's worth. These acts are not merely technical tasks but meaningful expressions of love, solidarity, and moral fidelity.

Daniel Sulmasy reinforces this view, arguing that "dignity cannot be reduced to autonomy; it is something that belongs to human existence itself".[8] When the capacity for rational control diminishes, the deeper truths of dignity often become more visible: the mutual dependence that marks human life, the vulnerability that invites compassion, and the relational bonds that sustain meaning.

The Theology of the Body also emphasizes communion – the idea that persons are constituted through relationships. Disabled individuals, who often require daily assistance, reveal the communal dimension of the human condition. Their lives challenge cultures that idolize independence and productivity, reminding us that human flourishing is rooted in interdependence. For caregivers, the daily labour of care becomes a form of participation in the mystery of the body as the expression of the person. Their touch, presence, and patience become signs of the sacredness of the embodied other. By integrating phenomenological insight with theological anthropology, we gain a more comprehensive understanding of dignity – one that affirms the moral significance of embodied vulnerability.

5. Embodied Encounters in Pediatric Hospice Care

The convergence of phenomenology and the Theology of the Body finds powerful illustration in pediatric hospice care, where medical technologies recede and the human dimensions of care come to the fore. In such settings, families and caregivers confront the fragility of life in its most intense form. The horizon of cure fades, but the horizon of meaning deepens.

In my own work in the children's hospice in Kraków, I have witnessed moments that reveal the depth of relational ethics. Parents who continue to read bedtime stories long after their child has lost the ability to respond; mothers who spend hours interpreting subtle facial movements, believing they detect signs of recognition; fathers who hold vigil through the night, whispering prayers or memories into the silence. These acts may appear

[8] John Paul II, *Man and Woman He Created Them. A Theology of the Body*, transl. Michael Waldstein (Boston: Pauline Books & Media, 2006), 203.

small or even futile from the perspective of biomedicine, but phenomenologically and theologically they are rich with meaning.

Toombs describes such gestures as "the moral weight of being there", a fidelity that defies quantification.[9] One father, when asked why he continued reading to his unconscious daughter, replied: "I want her to know I'm here". This expression of presence is not a sentimental flourish; it is an ethical stance grounded in a profound recognition of the other's dignity. Carel notes that embodied presence "cannot be replicated by any technological means".[10] The caregiver's body becomes a living sign of solidarity, proximity, and love.

These encounters reveal that the deepest forms of care are often silent, embodied, and mutual. The suffering body and the caring body enter into a shared space of vulnerability, where meaning cannot be captured by clinical data. In such contexts, care becomes a relationship rather than a procedure – an act of recognition that honors the intrinsic and relational dignity of the person.

6. Hope as Ethical Practice and Existential Fidelity

Hope, within contexts of profound disability or terminal illness, is often dismissed as denial or naïve optimism. Yet such a view misunderstands the existential and ethical depth of hope. Sulmasy argues that hope is "the virtue that sustains the will to care".[11] In this framework, hope is not oriented primarily toward changing clinical outcomes but toward sustaining relationships.

Hope, therefore, is a practice – a daily choice to remain present in the face of suffering, uncertainty, and loss. For caregivers, hope manifests in countless embodied gestures: continuing routines, maintaining rituals, cherishing moments of quiet closeness, and refusing to reduce the child to a prognosis. Hope protects the relationship from collapsing under the weight of fear or fatigue. It becomes the moral energy that enables caregivers to endure long nights, to interpret ambiguous signs, and to read meaning into subtle gestures.

Phenomenologically, hope reshapes the lived experience of time. It opens the future – not by promising recovery, but by sustaining meaning within the present. Theologically, hope is a participation in God's fidelity, a response to the belief that every human life, no matter how fragile, is held in a horizon of meaning that transcends biological decline. Hope transforms care into an act of witnessing: an affirmation that this life, however brief or impaired, has value.

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9 Toombs, 85.

10 Carel, 152.

11 Daniel Sulmasy, „The Varieties of Human Dignity", *Hastings Center Report* 3/44 (2014): 29.

7. Toward a Relational, Embodied, and Hope-Filled Bioethics

The insights drawn from phenomenology and the Theology of the Body invite a reorientation of contemporary bioethics. First, they demand that caregivers be recognized as moral agents. Their daily labour, emotional involvement, and interpretive knowledge make them indispensable participants in ethical deliberation. Their voices must not be relegated to the periphery of clinical discussions. Scully emphasizes that "the lived experience of disability is epistemically valuable and must inform ethical deliberation".[12]

Second, these insights call for the integration of phenomenological skills – attentive listening, narrative competence, and embodied empathy – into medical education. Toombs warns that without such skills, clinicians risk misunderstanding the lived experience of patients.[13] Training in phenomenology enables clinicians to perceive subtle forms of communication, to recognize the significance of silence, and to interpret gestures that convey distress or comfort.

Third, healthcare institutions must reconsider what counts as ethical success. If success is defined solely by cure or efficiency, the most profound aspects of care remain unacknowledged. A relational model values time spent with families, the cultivation of trust, the acknowledgment of suffering, and the provision of presence. These are not sentimental additions but essential components of ethical care. Institutions must also support caregivers by addressing emotional exhaustion, moral distress, and compassion fatigue. These are not private struggles but systemic ethical concerns that demand structural responses.

Ultimately, a bioethics oriented toward relational dignity must care not only for patients but for those who care for them. Disabled individuals and their caregivers reveal a foundational truth: dignity does not arise from independence, productivity, or cognitive capacity. It arises from relationality, recognition, and embodied presence.

Conclusion: Beyond Marginalization – Toward an Anthropological and Ethical Renewal

The reflections developed in this article suggest that the phenomenon of dual marginalization is not merely a contingent flaw in contemporary healthcare practice but a sign of a deeper anthropological reduction embedded in dominant bioethical frameworks. When disability is interpreted primarily through diagnostic categories, functional limitations, and measurable out-

[12] Scully, 118.
[13] John Paul II, 185.

comes, the richness of lived, embodied experience is eclipsed. At the same time, caregivers – whose daily labour sustains the fragile ecology of care – remain insufficiently recognized as moral agents. What appears at first as a practical oversight reveals itself, upon closer examination, as a structural limitation within a model of bioethics that privileges procedural autonomy, efficiency, and technological intervention over relational meaning and embodied presence.

Reconsidering autonomy in relational terms is therefore not a marginal adjustment but a necessary reorientation. Profound dependency does not negate moral agency; rather, it exposes the fiction of radical independence that has shaped much modern ethical discourse. In the context of disability, autonomy often manifests as a co-constituted practice sustained within relationships of trust, attentiveness, and shared interpretation. Disabled persons continue to express preference, resistance, and meaning through embodied forms of communication, while caregivers participate in an ongoing interpretive collaboration that makes agency visible. To acknowledge this relational dimension is to move from a narrow procedural understanding of ethics toward a richer account grounded in fidelity and mutual recognition.

Phenomenology deepens this reorientation by reminding us that illness and disability are not simply biomedical states but transformations of the lived world. The distinction between the body as object and the body as lived experience discloses the inadequacy of purely technical approaches to care. Ethical responsibility begins with disciplined attention to the horizon within which the other experiences time, space, and relationship. Such attentiveness demands epistemic humility – an openness to the interpretive knowledge of caregivers whose long-term immersion in the communicative world of the disabled person generates forms of insight unavailable to standardized assessment. Ignoring this experiential knowledge risks perpetuating not only social marginalization but epistemic injustice.

Theological anthropology, particularly as articulated in the Theology of the Body, offers further grounding for this relational vision. If the body is indeed the visible expression of the person, then vulnerability does not diminish dignity but reveals its depth. Disability becomes a privileged site where the truth of human interdependence is disclosed. In this light, caregiving gestures such as holding, feeding, bathing, or maintaining vigil are not reducible to technical tasks; they are meaningful acts that mediate recognition and communion. In pediatric hospice care, where the horizon of cure often recedes, this truth becomes especially evident. When biomedical success is no longer possible, the ethical horizon shifts toward presence, accompaniment, and the preservation of dignity within fragility. Care is revealed not as a strategy for control but as a relationship sustained in fidelity.

Hope, understood as existential steadfastness rather than naïve optimism, sustains this relational orientation. It allows caregivers and clinicians to remain present in situations marked by uncertainty and suffering. Hope does not deny biological limits; instead, it protects the meaning of the relationship from collapsing under them. It reshapes temporality, opening space for significance within the present moment even when future recovery is improbable. In this sense, hope becomes an ethical practice – the daily renewal of commitment to the intrinsic worth of a life that cannot be measured by productivity or prognosis.

Moving beyond marginalization therefore requires more than the inclusion of additional perspectives within existing frameworks. It calls for a deeper anthropological renewal in which relationality, embodiment, and vulnerability are recognized as constitutive features of human dignity. It requires institutional cultures capable of valuing relational goods such as trust, continuity, and moral presence alongside clinical outcomes. It also demands educational formation that cultivates attentiveness, narrative competence, and embodied empathy as central clinical skills rather than optional virtues.

Ultimately, moving beyond marginalization requires a transformation of vision. Only through such a transformation can bioethics fully honor the moral significance of both disabled individuals and those who care for them. It calls bioethics to look again at the vulnerable body not as a problem to be solved but as a locus of encounter. In that encounter, dignity is neither conferred nor negotiated; it is recognized. Dignity does not arise from independence, efficiency, or cognitive capacity; it emerges from the relational space where vulnerability encounters fidelity. To move beyond dual marginalization is therefore to recover a vision of the human person in which fragility is not a deficit to be managed but a condition that makes solidarity, compassion, and communion possible. In recognizing our shared vulnerability, the moral community itself is enlarged.

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Summary

This article explores the phenomenon of dual marginalization affecting both disabled individuals and their caregivers within contemporary bioethics and healthcare practice. It argues that clinical and ethical discourse often reduces disability to diagnostic and functional categories, overlooking the richness of lived, embodied experience and the complex moral labour of family caregivers. Drawing on Edmund Husserl's phenomenology, the article highlights illness as a disruption of the lived world and emphasizes the ethical significance of attention, empathy, and intersubjective encounter. John Paul II's Theology of the Body complements this perspective by grounding human dignity in embodiment and communion, presenting the body as a visible sign of the person and as a site where vulnerability and relationality reveal deeper moral truths. Through examples from pediatric hospice care, the article shows how practices of presence, touch, and vigil embody an ethics of recognition that cannot be captured by outcome-based metrics. Hope is interpreted not as naïve optimism but as a virtue sustaining the will to care in the face of suffering and uncertainty. The article concludes by proposing a relational, embodied, and hope-filled bioethics that recognizes caregivers as moral agents, calls for the cultivation of phenomenological skills in medical education, and redefines ethical success in terms of trust, connection, and fidelity rather than cure and efficiency.

Keywords: disability ethics, phenomenology, Theology of the Body, dignity, pediatric hospice care