

Dignity and the Life Worth Living: Ethical Reflections on Pediatric Intensive Care

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**DIGNITY AND THE LIFE WORTH LIVING:
ETHICAL REFLECTIONS ON PEDIATRIC INTENSIVE CARE**

INTRODUCTION

Brightly lit, the pale blue and yellow walls – each decorated with a picture of a contemporary cartoon character – were indicative of the kind of week ahead in the pediatric intensive care unit (PICU): relatively calm, sedate, sad but less than tragic. Though rounds began early in the morning, the whispers of the clinical team had more to do with roused patients' ability to hear what was said than to ensure their sleep.

Like the medical and neonatal intensive care units (MICU and NICU, respectively), the stakes in the PICU are high. Decision making for minors differs significantly, of course, from decision making for adults. From the outset, adults are presumed – in absence of significant evidence to the contrary – to possess capacity to make decisions for themselves. Due to such capacity, clinicians must obtain informed consent from adult patients for treatment. In stark contrast, pediatric populations are not presumed to possess capacity to make their own decisions and, with very limited exceptions, do not enjoy the legal authority to consent to their own treatment. Depending on the age of the patient and his or her complicity with the proposed plan of care, this can result in immense confusion, frustration, anger, rage, and depression. Parents and guardians enjoy broad discretion in choosing particular healthcare interventions for children, but only insofar as they act in the best interests of children in ways that conform to the legal standards prohibiting abuse and neglect.

QUALITY OF LIFE: STILL A DIFFICULT DISCERNMENT

If Captain Jack Sparrow had gone into medicine, I imagine he would be a lot like Dr. L. Insisting on being called by nickname only, a thoroughly disgruntled and crass man wearing small black glasses and donning untrimmed facial hair met me as I entered the PICU on an overcast Tuesday afternoon. Our paths had crossed multiple times over previous years, but this week he would shock me in new and different ways – something he was, according to most, wont to do. From the start, the bioethicist situated in the PICU must realize (at least) two things. First, children have different cognitive capacities, and this fact significantly influences their ability to participate – perhaps only through assent – in their care. Second, children belong not only to their families, but also to their communities, which are invested in their well-being. While children have historically been viewed as the property of their parents, there is a growing interest on the part of the state in the welfare of these developing members of society.

According to Dr. L., the mortality rate in the PICU closely mirrors the MICU: about one in five patients perish during the stay – be it long or short – on the unit. Many children are (temporarily) sustained on ventilators and PEG tubes. To borrow Dr. L.'s words, "the PICU is where you come if you trip and fall leaving the NICU." The distinguishing factor regarding treatment criteria between the NICU and PICU is that the patient has, at some time or another, left the hospital after birth. If the patient is born

critically ill, he or she will be treated in the NICU; thereafter, he or she will be treated in the PICU, up until age 22. Such a broad age range covers a massive scope of potential maladies, including rational suicide attempts, poison ingestion, and the physiological deterioration of the severely disabled. Since many decisions in the PICU are laced with uncertainty surrounding the “potential” of children – for instance, imagining how today’s decision to perform neurosurgery will later impact the child’s future capacities as an adult – notions of quality of life and best interests are frequently blurred.

“WHY BOTHER TREATING SOMEONE WHO CAN’T APPRECIATE IT?”

On Wednesday, I had the pleasure of meeting Stephanie, a six-year-old female who presented to the PICU with seemingly countless co-morbidities. Among them – though by no means the most significant – were devastating neurocognitive impairments she had experienced since birth. These impairments would, and currently do, leave Stephanie with the intellectual capacity of a six-month to two-year-old for the rest of life. And, no doubt, her persistent co-morbidities, requiring frequent visits to the PICU, will surely shorten that life. Stephanie’s case raises questions about quality, meaning, purpose, function, and dignity. For Dr. L., this is no life worth living: “Why bother treating someone who can’t appreciate it? Don’t you agree that this is a terrible waste of resources? Shouldn’t we allow another sick kid to have this bed, rather than helping sustain a life like *this*?”

Dr. L.’s comments are unfortunate, and his sentiments are wrong. Yet they remain in line with the general expectation of this man’s (or perhaps someone who witnesses cases like Stephanie’s each day for 30 years) disposition: coarse, limited, privileged. While I did not address Steve’s questions explicitly, I continued to ruminate on his ideas for the remainder of that week, even allowing them to steal a night’s sleep or two. The major issue to be taken away from Dr. L.’s notion of the kind of life worth living does not, to my mind, lie in the idea itself, but in the notion that such a concept could be perpetuated in generations to come, through education. Will future medical students believe a life worth living looks a particular way, functions to a particular end, accomplishes certain tasks? This is a critical moral issue, and one much more urgent than remedying the broken image of suffering possessed by a single physician. Dr. L. would later bring me to a room in the back of the unit to show me a picture of Stephanie. She looked, as he put it, “as normal as she could.” It was her school picture from last year. She was clothed in a lovely dress, wearing bright red glasses – adorable as any six-year-old could be. Dr. L. pointed to the picture: “Why do they do that? The parents, I mean. Does dressing her up make them feel like she can have meaning in her life?”

MORAL OF THE STORY

Hard as it is to believe, Dr. L. is a good man, father, and doctor. He cares deeply for his patients, and he makes them well with ease. But he is grossly mistaken in his overarching philosophy of what it means to be human, to have meaning, and what justice looks like in the clinical setting. I will eventually broach this topic with Dr. L. in the future, but I – and we who live in the realm of bioethics – must meet a challenge

beforehand. Appealing to abstract moral notions such as “personal dignity,” “subjective meaning,” and “existential suffering” will not appeal to the minds of Dr. L. and those who think like him. We have done well in academic theology to develop language to attribute meaning to the indescribable. We know that persons with intellectual disabilities should be treated with dignity and respect, and we know it for sure. But when we are faced with the Dr. L.s of the world, we frantically grope for reasons that transcend idiosyncratic values.

The moral task ahead is to develop something of a rational, thoroughly philosophical defense of why autonomy fails to show up on a PET scan. If we truly believe in the dignity and respect of those who are the most vulnerable, we must be willing to awaken the restlessness of reason and conjure up a defense whose refutation can only come from cogent argument, not merely religious belief or personal value. Our ethical defense of patient dignity – pediatric and otherwise – is as strong as our ability to ground it in norms which can be respected by even the most ardent skeptic. In the world of science, which often places biology above biography, this may be the only way for the bioethicist to meet others where they are – even Dr. L.