

THE INTERSECTIONALITY OF ABLEISM AND
PEDIATRIC PALLIATIVE CARE

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ABSTRACT

Since the early nineteenth century, physicians have been offering the tracheostomy as a second chance at life. This procedure both saves and inextricably changes lives. Medical providers have barely scratched the surface of understanding the complexities of offering this technology. Ethically, however, we have an obligation to improve the process. We must support the patients and their caregivers and utilize everything at our disposal to ensure that we are safeguarding their quality of life.

I would like to dedicate
this paper to the patients
and families of the
Progressive Care Unit
of the Children's Hospital of Philadelphia

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I would like to thank all of the amazing people I have had the pleasure of working with in the MAUB Program at Temple University. This program has revolutionized my way of looking at everything and I am eternally grateful.

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CHAPTER 1: THE INTERSECTIONALITY OF ABLEISM AND PEDIATRIC PALLIATIVE CARE

I am a nurse who has spent her career caring for patients who are dependent on technology to live. Specifically, a nurse caring for patients that have a tracheostomy tube and require mechanical ventilation to breathe. The tracheostomy tube is placed for a variety of medical reasons. The tube allows a patient who cannot breathe to do so through the help of a machine. This procedure is invasive but often lifesaving. The person with the tracheostomy is now dependent on this machine to live. Offering this life saving technology is a miracle of modern proportions and cannot be taken lightly. A tracheostomy tube and a ventilator are not just lifesaving but are life changing. While most patients and caregivers are grateful for the second chance at life that this procedure can create, some patients do not feel that way. After hearing some patients and caregivers comment they would never have done “this” (the tracheostomy) if they knew what life would be like, I was moved to improve the process. My thesis offers solutions to improve the process of offering this technology. This paper aims to better prepare persons living with disabilities and their caregivers through empowering strategies for living a life accompanied by this technology. We must be more responsible in the way this technology is offered.

A trach is inserted by surgically creating an opening in the anterior wall of the trachea, inserting a tube through the opening, or stoma, to allow passage of air and removal of secretions. Instead of breathing through the nose and mouth, the patient now

breathes through the tracheostomy tube. Medical history depicts that the tracheotomy is one of the oldest surgical procedures. There are ancient Egyptian engravings of “tracheostomies” being performed and even a heroic story of Alexander the Great saving a soldier by performing a tracheostomy with his sword. However most great philosophers including Hippocrates condemned the procedure because of the risk of bleeding associated with the major blood vessels surrounding the windpipe. The surgical procedure became accepted as a legitimate medical procedure to survive diphtheria in the 17th and 18th centuries. The procedure was avoided whenever possible because of complications until it was properly understood and indications were clearly defined. The procedure was performed in over 200 patients with 50 surviving. (Meher 2005). There is no documentation of their quality of life post tracheostomy.

The quality of one’s life is not easily defined. As medical professionals it is easy to lose sight of the quality of one’s life over quantity, particularly in pediatrics. In pediatrics the guardians, parents, or caregivers are tasked with the decision to place a tracheostomy tube and begin technology dependence. We place a tremendous burden on a loved one of an ill individual. There are many deleterious effects this burden can have on a family. One study found, “Parents can face decisional conflict and pressure in conversations about life-saving measures like tracheostomy, contributing to parents’ diminished quality of life in the short term” (October et al., 2020). Pressure in decision-making conversations may not be isolated to the stressful environment. Emotional colleagues noted that not only did the providers heavily weight the benefits of tracheostomy versus the risks, they also minimized associated burdens, such as

significant impact on lifestyle, the need to manage complex medical needs, financial and emotional burdens and potential challenges to family and social relationships.” (Fitzgerald 2020).

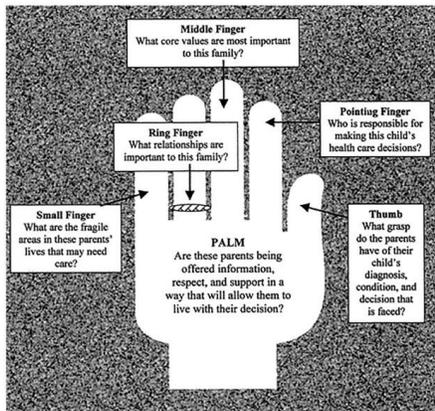


Illustration 1: The CLAASSEN Tool

The CLAASSEN tool was developed by a Nurse practitioner studying the Pierce decision making model. The Pierce model was developed to aid adults making healthcare choices. Pierce studied the decision making process to improve nurse’s understanding of complex decision making. Claassen took Pierce’s work one step further. Marjanne Claassen is a clinical nurse specialist in the Pediatric Lung Center at the Children's Hospital in Denver, Colorado. She completed her M.S. with an emphasis in chronic illness at the University of Northern Colorado, Greeley. She found that she could augment Pierce’s decision making model to aid caregivers with different medical options. Claassen found that, “Although Pierce’s work is with adults and was published in a critical care journal, it is applicable to chronicity and parental surrogacy as well.” This nurse wholeheartedly agrees with Pierce’s finding, “Nurses currently have understanding of the decision

experience of parents who must decide on a treatment alternative that may inextricably change the course or quality of their lives.” (Claassen 2000).

I wish to accentuate the thumb and the palm in the graphic presented above. The questions asked in these areas are supported by the urban bioethical principle of Agency. This is an opportune time to introduce the term Ableism. The definition used in this piece is ‘ableism,’ i.e., how disability is constructed through able-bodied norms (Campbell, 2009). This definition is thorough and true. Ableism clearly displays how an individual without a disability or technology dependence can never actually understand the lived experience of an individual with a disability or one who depends on technology to breathe. A medical provider can offer statistics about tracheostomy, one study found that, in a single-setting PICU study, physicians were “almost three times more likely to state benefits than risks [of tracheostomy], stressing the benefit of shortening the PICU stay over other potential benefits” (Hebert, Watson, Madrigal, & October 2017, p. e594). The person without a disability or dependence on technology can offer very little information on quality of life for this patient population. It could be said that what information that is given is skewed due to the inpatient hospital perspective of the provider. We have a moral obligation to offer this technology and information about life with technology more responsibly. We can look to the urban bioethical principle of Solidarity for assistance. We look to a credible messenger.

The man who popularized both the term ableism, and the social model of disability was Michael (Mike) Oliver. He was a pioneer in the field of disability law and social policy. He became disabled after a swimming accident which left him wheelchair bound for the remainder of his life. Oliver was a scholar, teacher, mentor, activist, and

friend and has influenced and supported the disabled people's movement in the UK and around the world. Oliver was a credible messenger whose ideas have challenged professionals in health and social care, education, and design to recognize the disabling nature of institutions and their own practices. Oliver emphasized the social model of disability. This model builds from the proposition that it is structural barriers, such as a lack of wheelchair ramps or a failure to provide sign language interpreters, which impede disabled people rather than the impairments themselves. In other words, systemic barriers constitute an ableist society that disables disabled people and keeps them largely unemployed and in poverty. In every advanced capitalist country, disabled people face tremendous barriers in housing, transportation, and employment. These barriers are so widespread and comprehensive that most individuals do not give them a second thought. (Oliver 1990). Who is to blame for this phenomenon in our society? To answer this question, we must begin to look comprehensively at the continuity of care throughout the life of the patient. We cannot look only at the immediate solutions.

I wish to shine a light on the connection of the experience of technology dependent patients and families and medical professionals. Medical professionals offer technology and medical interventions to "cure" disability or "normalize" the lives of their patients. One can never guarantee the removal of this life-saving technology. The offering of technology dependence must be introduced to caregivers in a way that properly admits that their child's life could be "different" forever. One could offer time to reflect upon this choice and speak to other persons living with technology dependence who may provide insight that a clinician cannot. The principle of Solidarity demands that we look to credible messengers to deliver information to families about what life after a

tracheostomy looks like. We must recognize that offering this solution affects the quality of a person's life. A tracheostomy is not always an emergent procedure. In many cases, in the critical care setting of a hospital, the patient is intubated and has failed multiple extubation attempts. There is often time for a family meeting and a time for discussion to clarify goals with the caregivers. (Fitzgerald 2020). It is essential to introduce a family to the palliative care team of the hospital. The very offering of 'palliative care' is defined here as holistic care that takes all these dimensions into account from the moment of diagnosis onward, seeing no inherent contradiction between palliation and cure-oriented care. (Browning 2005).

After spending time observing the palliative care team at Chop, I was surprised to learn that we do not offer a specific tool to providers to guide these conversations. I was also surprised to find that we do not connect families unless the caregivers specifically ask to be put in contact with a family that has a similar medical experience. The idea of ableism and palliative care should be introduced prior to a discussion surrounding the need for tracheostomy. I believe that we should incorporate ableism in medical education. There is tremendous benefit to requiring a course regarding disability studies. I cannot think of a single detrimental effect to adding these requirements. Ableism and palliative care intersect and medical professionals can provide tangible strategies to overcome the ignorance or ableist bias that can be experienced by these persons and their caregivers.

This piece aims to make urban bioethical connections between ableism, the offering of tracheostomy and pediatric palliative care. Medical professionals limit themselves by adhering to "curative" goals of care. I agree with Michael Oliver and his observation, "The problem is that doctors are socialized by their own training into

believing that they are 'experts' and accorded that role by society. When confronted with the social problems of disability as experts, they cannot admit that they do not know what to do. Consequently, they feel threatened and fall back on their medical skills and training, inappropriate as they are, and impose them on disabled people. They then appear bewildered when disabled people criticize or reject this imposed treatment.” (Oliver 1990).

In my graduate studies in Urban Bioethics, I was introduced to the idea of a credible messenger. A credible messenger is an individual that can transcend divides in race, class, gender, or inherent distrust in a profession through similar credible life experiences. Although the credible messenger is most often introduced in the setting of restorative social justice, The experience can bring the same healing and solidarity to medical complexity. This messenger has lived the experience that a medical provider has not. Any contact I have had with credible messengers in the MAUB program at Temple University have been exceptional. Through “witnessing” their lived experience I gleaned real world applicable knowledge that cannot be taught through a textbook. I would also suggest that the concept of credible messengers be introduced into medical provider education. Providers should spend time working with the adult trach vent dependent population and see how they live. Hospitals are a rich source of credible messengers. These persons living with a disability could educate parents and patients about their lived experience with ableism. These messengers are becoming increasingly important because the numbers of medically complex children are rising, "Approximately 3 million children in the US are medically complex” (Alliance for Health Policy, 2018). The exact number of children who are trach-vent-dependent in the US is unknown, but approximately 4000

children receive tracheostomies in this country each year” (Agency for Healthcare Quality and Research, 2018). A “medically complex” child is a vague umbrella term used to describe a wide range of medical conditions that present unique challenges and require special care on an ongoing basis. Sometimes the child has been diagnosed with a rare illness that is functionally limiting at best and at worst, life-threatening. These children require long hospital stays, and often even when they are discharged to home, they are frequently re-admitted. Additionally, when they are not hospitalized, they require extensive home care with the presence of skilled nursing. (Somas Home Health Care, 2018).

At The Children’s Hospital of Philadelphia, we perform about 75-80 tracheostomies per year. Decannulation is the medical term for removal of the tracheostomy tube. In 2017, CHOP successfully decannulated 26 patients. In 2018, CHOP performed 31 successful decannulations with 1 failure (the tracheostomy tube had to remain in place) and 9 of those 31 successful decannulations required airway surgery to remove the tube. In 2019, CHOP performed 64 decannulations, 3 failures, and 26 patients required airway surgery for decannulation. In 2020, there were 39 successful decannulations. In 2020, there were three months when patients were unable to be seen due to the global pandemic. In 2020, there were 2 failures and 14 of the 39 patients required corrective airway surgery to be decannulated. In 2021, (thus far) we have successfully decannulated 67 patients and 14 of those 67 required reconstructive airway surgery to be decannulated. This is the largest number of successful decannulations to date in CHOP’s history. We seem to be getting better at the successful removal of the tracheostomy tube, however almost no data is captured regarding the time in between.

What is it like to live life as a technology dependent person? We need more qualitative data, more active witnessing of the narratives of these families and their struggles. “Much less is known about the lived experience and moral features of daily life for parent caregivers of children who are trach-vent-dependent. The studies which do exist reflect troubling themes and raise important questions about the unintentional ways healthcare professionals and society may contribute harm through implicit bias and its effects on stigmatization and isolation, resulting in worse out-comes for these children and families.” (Fitzgerald 2020). We need to go beyond the objective data collection of tracheostomy placement to decannulation. We must look at the comprehensive quality of life of our patients. We must stop reinforcing the idea that the end goal is always to return to a “normal” life. This is Ableism.

We can and must modernize the pedagogy of medical education. Medical professionals are introduced to the concept of cognitive bias during their schooling. They are taught about empathy but what active strategies are they taught to incorporate this knowledge into their clinical practice? Moreover, their schooling is not geared to understand the experiences of their patients whom many have lifelong chronic illness and medical complexity. This is evidenced by the following, “We may most often think of the considerable harms of implicit bias relating to racial, gender or other stereotypes. It is also important to consider that the concept applies to other biases. For example, an implicit bias for ability, or for quality of life that is free from medical technology might inform behavior and attitudes that undermine compassionate, respectful care for children who are trach-vent-dependent and their families” (Narayan, 2019). The pervasive ableism in society and medical education sabotages the Clinicians ability to empathize as

a human being. We all have implicit bias, or an unconscious association, belief, or attitude toward any social group. Due to implicit biases, people may often attribute certain qualities or characteristics to all members of a particular group, a phenomenon known as stereotyping.” (Cherry, 2020).

What do we as medical professionals reinforce through our implicit bias? We can improve medical training to include the perspective of people living with a disability by incorporating their lived experience into medical education. I believe this would change the way a medical professional wields the offering of this medical technology. Empathy is an emotional experience between an observer and a subject in which the observer, based on visual and auditory cues, identifies and transiently experiences the subject's emotional state (Hirsch 2007). Medical professionals are taught in their training to be empathetic. We want to connect with our patients and families. We want to share in their hopes and we can within reason. We must refract what we are hearing from our caregivers and send back a realistic picture of hope. In the Progressive Care Unit at CHOP, we celebrate the decannulation as a milestone. Our Clinical Nurse Specialist issues a monthly email to let everyone on the unit know which patients have been decannulated. This is unconsciously reinforcing the implicit bias that life is better without a trach. One of CHOP's slogans is *Hope Lives Here*. After spending time with the Palliative care team, I found that much of the day was spent analyzing the timing of difficult conversations and tempering expectations of caregivers, even tempering hope. How much does hope matter? What are the dangers of hope? Hope for the future of a “normal” life. How do we prepare families for “normal” life outside of the hospital?

I often receive feedback from families that there are not enough home care nurses available to care for their child at home. This is evidence families and caregivers are not adequately prepared caregivers for the realities that they will face outside of hospital walls. Home nursing was “a mounting problem for several years before the pandemic,” said Meg Frizzola, a pediatric critical care doctor and Chair of Pediatrics at Nemours/Alfred I. duPont Hospital for Children in Wilmington, Delaware. “Now we’re just at crisis level.” (Burling 2021) The mother of one of my patient’s (Alexis Stull) said, “I hope none of you ever have to know what it feels like to leave your child in a hospital. Let alone, leave her in the hospital for months for ZERO REASON only because you don’t have nursing at home,” Alexis Stull wrote. This is heartbreaking to hear. As a medical professional I feel an implicit responsibility for this mother’s pain. She went on to say, “We are lost. We are sad. We are defeated. We are frustrated. We do not know what to do. We just want her to come home.” Is it ethical to continue to create a patient population without ensuring continuity of care throughout that patient’s life?

Since the early 1990s, there has been an increasing recognition that the problem of disability lies in society’s failure to accommodate the person who has the bodily impairment” (Fougeyrollas & Beauregard, 2001; Oliver, 1990; Shakespeare & Watson, 1997). “We recognize this failure yet what do we as medical professionals do to actively combat it?” (Neely-Barnes 2011). Sadly, “The position of family members within the social model of disability is less clear than the position of people with disabilities. From a political standpoint, the social model of disability pits disabled and non-disabled people in a struggle against each other” (Gabel & Peters, 2004) when non-disabled themselves, family members may be viewed as a barrier to a more inclusive society for people with

disabilities” (Neely-Barnes 2011). “Qualitative research findings also show that families may collude with an ableist agenda and look for ways to make their member with a disability appear less disabled. For example, McKeever and Miller (2004) found that mothers looked for ways to increase social, cultural, and symbolic capital of their children such as dressing them nicely in new clothes or encouraging the children to use adaptive devices that made them appear less disabled” (Neely-Barnes 2011). I see this regularly at the hospital with pictures to celebrate milestones. Caregivers will look to use costumes that can incorporate or hide ventilator tubing. There is a hallway when you enter the hospital that features pictures of children who have overcome monumental medical adversity. One picture states, with negative connotation, “She relied completely on a ventilator to stay alive.” I believe that this misstep is a result of lack of education concerning the social model of disability, ableism and cognitive bias. Physicians are required to spend a great deal of their training in the hospital setting, where they are only exposed to patients that are trach-vent-dependent and doing poorly. This can contribute to implicit bias and this could be corrected by spending time with technology dependent patients thriving outside of the hospital. An empowered advocate is a great prognostic indicator for any hospitalized patient. It is theorized that the roles parents take on in the community, represent the degree of empowerment the parent feels in the situation. The most empowered parents employed advocacy and education in an attempt to change the environment that their family member with a disability occupies. The urban bioethical principle of Social Justice can be employed to change the pervasive ableist ways of our society. Social Justice can aid us to correct these issues. Social Justice has been applied in various battles for equal rights by other groups of marginalized people for years.

Disability rights are human rights. Gabel and Peters (2004) argue that the social model of disability is a form of resistance to the medical model which oppresses people with disabilities. Resistance holds the potential of increased empowerment. (Neely-Barnes 2011). This paper contributes to the literature through identifying ways in which empowerment can be manifested as part of resistance to ableism.

Clearly, the problems introduced in this thesis are multifaceted and need to be addressed through multiple reinforcing strategies: education of physicians and other healthcare professionals; regulatory reform; changes in healthcare financing; hospital quality improvement efforts; as well as broad social changes in the ways in which our society views children, families, medical complexity, technology dependence, death, and dying.

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