Vulnerability, Interdependence and Trust in the COVID-19 Pandemic

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In this PM&R ethics/legal piece, we will be focusing on the experience of vulnerability, interdependence and trust during the COVID-19 pandemic. There are various theories and approaches that can be used to explore ethical considerations. The analytical frames we use are important because they impact how we define the problem, what we focus on, what types of solutions are proposed and the language we use to think through the complexities. In medicine, we are familiar with principles of biomedical ethics\(^1\) for example – respect for autonomy, beneficence, non-maleficence, and justice. And in pandemic planning, ethicists often consider the greater good, or a focus on the consequences and maximizing the number of lives saved\(^2\). In this piece, we are going to take a step back and think about relationships and what being in
relation to others means for the current crisis. In the ethics of care, or care ethics\(^3\), relationships, interdependence, vulnerability, proportionality and context are important concepts and undergirding these ideas is the importance of trust.

These issues came to the forefront for many of us during the COVID-19 crisis as we all found ourselves in unprecedented and novel personal and professional terrains. I moved to New York City earlier this year and was soon immersed in acute care clinical ethics at the U.S. epicenter of a global pandemic\(^4\). The ethical issues were complex, and multi-layered. For the first time in my career, resource allocation at the bedside became a reality as discussions about possible rationing and prioritizing were taking place. Colleagues across the country reported similar conversations as we wavered between crisis standards of care and what we have come to expect as usual standards. In a healthcare system that was already full of disparities based on race, disability, zip code, access, and wealth, COVID-19 cruelly revealed the fissures. On the other hand, this infectious disease, equalized all of us as potential patients, and forced us to shelter in place and limit activities, including medical practice. As I reflected on the experience, I kept returning to the concepts of vulnerability, trust and interdependence. These are familiar concepts for rehabilitation professionals, as we are often witnessing or experiencing adjustment to disability and the ways in which each of us lives in interconnected and interdependent ways. Healthcare providers, who are typically powerful in the dynamic of patient care, were physically vulnerable and potentially exposed to a ferocious disease with no cure. People with disabilities were vulnerable due to a lack of access, and co-morbidities that might impact their access to ventilators or other interventions if there was a scarcity. African American and Latino/x communities were particularly hard hit by the disease, and by the early summer, after the death
of George Floyd, trust in systems, justice and equality were waning. Even as we write, things continue to evolve in this pandemic.

In this series of essays, the invited authors approach vulnerability, interdependence and trust from multiple levels and perspectives. We presented some of this work previously in a webinar sponsored by the AAMP&R entitled, Ethics, Disability and Trust: Closing the Gap in PM&R’s Response to COVID-19 on May 6, 2020. We delve deeper into those topics now.

The first piece is by Cheri Blauwet, MD, Assistant Professor of PM&R at Spaulding Rehabilitation Network/Harvard Medical School. She highlights the vulnerability of healthcare providers during the COVID-19 pandemic and raises questions about the line between professional duty and personal risk. The second author Rebecca Brashler, LCSW, HEC-C, Assistant Professor of PM&R at Northwestern University Feinberg School of Medicine and a Clinical Bioethicist and Director of Global Patient Service at Shirley Ryan AbilityLab, focuses on vulnerability and trust in the context of the clinician-patient relationship and the multiple ways that trust can be undermined or fostered during this pandemic. The third author, Kristi L. Kirschner, MD, Clinical Professor in the Departments of Medical Education and Neurology and Rehabilitation at the University of Illinois College of Medicine, focuses on the societal level, the unfinished work of the ADA and how the trust in our laws and systems for protections of vulnerable populations is inadequate. Throughout the pieces, the authors remind us that crises such as the COVID-19 pandemic shed light on and amplified previously existing dynamics. We hope this will be an invitation for our readers to continue thinking about the role of relationships, caring and trust in their own practice, in time of crisis or calm. As always, I welcome comments and ideas for ethics columns at dem9199@med.cornell.edu.
Put on Your Own Oxygen Mask First

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For those of us in clinical medicine, COVID approached like a tsunami. We knew that it was coming, and we knew that it would be bad, but we were unsure of when it would hit and exactly how catastrophic the damage would be. As a physiatrist practicing primarily in an outpatient setting, the profile of my work started to change. Our clinics closed, elective procedures were cancelled, and we were told to stay home unless called for redeployment. Any physician, at any time, could be called to the line of duty.

Over years of intensive training and personal sacrifice to both physical and mental health, clinicians are indoctrinated to put the needs of the patient above their own. Along this journey, each of us makes personal decisions regarding how to shape our career based on an assessment of risk tolerance and life circumstances. As a person with a spinal cord injury (SCI) and life-long wheelchair user, I have grappled with these decisions for many years. While actively shaping my career path as a medical student, I easily gravitated toward PM&R – a choice that has been intellectually challenging and personally fulfilling, but also with a reasonable degree of inherent risk. I made this decision because although I chose a career intended to serve, and save, the lives the others, I also recognized the importance of preserving my own health – the proverbial “put on your own oxygen mask first.”

After spending years making these curated decisions, I quickly realized that it could all be upended in the time of COVID. I became very concerned about experiencing increased, and disproportionate, health risks if I were asked to work on the front lines. To my initial surprise, I very quickly realized that I was not alone. In expressing apprehensions to trusted friends and colleagues, I learned that a partner in my clinical practice had severe asthma. A classmate from medical school had ulcerative colitis and was on immunomodulating medications. A woman in
the office next door was 20 weeks pregnant. We all shared the same fears and uncertainties, and we all struggled with the same impossible dilemma. Whose needs came first: our patients, or our own?

As one would imagine, early conversations around this issue revealed its complexity. Acting on an instinct of self-preservation during this profound health crisis, many clinicians with disabilities and other medical conditions had quiet conversations with their supervisors or department chairs. In these discussions, they chose to take the risk of disclosing their personal medical information in return for the hope of not being re-deployed to a high-risk area of the hospital. For most, this was an extremely difficult decision. Months, if not years of striving to assimilate, or “pass” in order to keep up with the mainstream, and to be the ultimate team player were negated.

In the weeks that ensued, many of these quiet conversations evolved into formal requests for disability accommodations that began to trickle into occupational health services and human resources across our healthcare system. Given the duration of the pandemic and the uncertain trajectory of “the curve,” this trickle soon became a flood. Stories began to emerge out of Italy, Spain, and other hard-hit regions about young, otherwise healthy health care workers losing their lives. Many of us began to realize that altruism could be fatal, particularly for those with increased health risks. At our rehabilitation network alone, requests for accommodations (both staff and faculty) increased more than tenfold from February to May 2020. Staff were inundated and pressed to rapidly process these requests in a fair and consistent manner.
Ultimately, clinicians were forced to grapple with the intimate and highly personal decision of how to navigate the fine line between self-preservation and self-sacrifice. For each individual, which is the higher moral imperative? And, last but not least – does this proverbial fine line shift when the social contract between the health care system and its’ clinicians faces challenges due to issues such as a lack of PPE?

In attempting to find the answer to these impossible questions, it is important to remember that for many, the right to self-preservation is protected under the law. Individuals with “traditionally defined” disabilities like spinal cord injury, as well as those with chronic health conditions like severe asthma or depression, are protected under the Americans with Disabilities Act of 1990 (ADA) and the subsequent Americans with Disabilities Amendments Act of 2008 (ADAAA). These describe disability as “a physical or mental impairment that substantially limits one or more major life activities, a person who has a history or record of such an impairment, or a person who is perceived by others as having such an impairment.” (1) Under this definition, individuals with disabilities may request reasonable accommodations which can be used to assist them in performing the essential functions of their job (2) – for example, temporary re-deployment of a physician to work in a non-clinical area of the hospital. That said, for many clinical staff, providing bedside care can be seen as an “essential function,” and thus the duration of such accommodations is necessarily limited.

Under normal circumstances, despite these legal protections that have been in place since the ADA was passed nearly 30 years ago, reasonable accommodations are rarely requested by clinicians. Why might this be the case, and how is COVID changing the future landscape of who “opts in?” First and foremost, most clinicians with chronic health conditions
Like asthma have historically never considered this to be a “disabling” condition. Second, even if a clinician does readily self-identify, many do not disclose due to fear of either implicit, or explicit bias that would have a detrimental impact on their career. This is particularly true for clinicians with disabilities that may carry with them a significant perceived stigma within healthcare – for example learning disability, ADHD, and mental health disability such as severe depression. In these cases, clinicians may feel an immense pressure to assimilate and to keep their disability status “in the closet.” Yet, it is increasingly recognized that physicians with disabilities bring an important element of diversity to the health care workforce and have a lived experience that can enhance competent, patient centered care (3, 4).

In our current global context, these concerns are likely here to stay. Environmental conditions and climate change will continue to impact our population and may lead to other viral pandemics and various forms of natural disasters. Although it is difficult to know what may lie ahead, it is nearly certain that a chronic medical condition, which may not be “disabling” in our present time, could evolve to become a disability in the future.

Ultimately, I did not request an accommodation, although I did take on numerous other COVID-related, non-clinical tasks across our health care system. I learned that there are many ways to use my clinical skills, and serve, in the time of a public health crisis. Broadly, our Department stepped up to the plate by finding a way to use every clinician’s talents, inclusive of sending some to the front line, while also developing an innovative telehealth rehabilitation program for patients who have experienced critical illness due to COVID. Although it now seems that we are past the peak of our “curve”, I believe that COVID has made all of us look at things
very differently, particularly in questioning our own fragility, and grappling with the fine line between professional duty and personal risk.

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Vulnerability and Trust with Patients

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Patients seeking PM&R care have always been vulnerable. They come to us following traumatic injuries/illnesses that threaten their independence, their livelihood and the pursuits that bring them joy. I have started to think about that as the “old” vulnerability. COVID 19 has altered our world and has disrupted our patients’ lives in profound ways. And while not the
focus of this article, we also share a renewed sense of urgency to confront racism within our organizations, our academic field and our communities during this historic moment in the midst of a global health crisis. The obstacles, oppression and disadvantages that threaten a patient we see today who is black, newly disabled and coping with COVID, magnifies her vulnerability exponentially. The speed with which we have had to retool our care delivery model to meet the challenges brought about by the pandemic seems unprecedented. While writing about the changes in our rehabilitation practice, I am mindful of the fact that what is true today may be out of date tomorrow. However, there may still be value in taking stock of what we have experienced to date, while acknowledging that we will likely be compelled to change course again in the near future.

Trust in PM&R

Building rapport and gaining trust is often the first step in being able to effectively partner with patients to achieve the best rehabilitation outcome. To build a therapeutic alliance, patients need to trust that we have the requisite knowledge and skills to care for them. STILL, after all these years, we are often asked about our expertise -- "What is a physiatrist?", "Shouldn’t I be seeing a neurologist or some other specialty?" "Will I be medically safe in a room without telemetry, with nursing ratios different than those in the ICU, and treatment plans that don’t include daily imaging?" “Will you be able to care for my medical needs while also helping me recover?"

Today patients have an added sense of vulnerability that arises from the pandemic. They want to know that there are no COVID 19 positive patients on their floor. They have heard
repeatedly that congregate living arrangements can be breeding grounds for the virus and they ask how we will keep them safe.

In my conversations with patients coming to us for post-COVID care, many look for reassurance that we have experience caring for others with the same diagnosis. While we have never been able to promise a particular outcome, we have always been able to talk about our expertise. While a spinal cord injury is a rare event to a new patient, we can provide data on how many other patients with similar injuries we care for each year. Obviously, we are not able to say the same about the post-COVID population. There’s still much that we do not know. While we utilize therapeutic approaches that have been effective for patients with similar impairments, we have only had experience treating post-COVID patients since the spring of 2020.

Trust in the Care Model:

Building trust in our care model and the interdisciplinary team has historically been easy. The rehabilitation process – our “secret sauce” – sells itself. Our therapeutic community succeeds by creating a safe, supportive environment where patients learn adaptive coping skills from individuals who have come before them and gain confidence by helping others. Often when struggling to gain the trust of a particularly guarded patient or when unable to engage someone who is depressed or “stuck”, it is a peer visitor, another patient or a non-clinical staff member who steps in to provide a spark of encouragement. However, because of social distancing, many of the benefits of our milieu have been lost. Creating an on-line therapeutic
environment to take the place of the spontaneous banter that used to flow from our hallways as patients interacted with each other is challenging.

The ultimate goal of rehabilitation is community reintegration, including return to home, school, work, and parenting. This focus has been significantly disrupted and community trips are no longer possible. There is also a great deal of uncertainty about the world that our patients will re-enter after discharge. Individuals with disabilities are at high risk for job loss, financial stress, and problems accessing medical care in their communities during the COVID pandemic. Community resources are currently harder to locate and therefore discharge plans may be more tenuous.

However, crisis often leads to innovation. We have embraced telemedicine and remote therapy and have found some unexpected benefits. “Seeing” patients in their home environments can provide a more complete understanding of their lives. It has relieved the hassle and expense associated with travel – often an ordeal for those with mobility impairments. Many patients have been enormously grateful for these opportunities. Although reimbursement at the moment may be similar to a face-to-face encounter, most clinicians acknowledge that it does not always hold the same value. During telehealth we have to substitute the patient’s report for hands-on elements of our exams. Also the quality of the visit will only be as good as the technology available in the patient’s home. Since, trust is often based on truth-telling, it seems important to acknowledge what can and cannot accomplished using telehealth platforms.
Family Trust:

Changes in family involvement, more than all these other factors, truly make our patients frighteningly vulnerable. With stringent visitor restrictions today, many of our patients feel the immense loss of family support. A family member’s presence reminds us that the individual in the bed is loved and valued. Relatives are literally the voice of the patients who are non-verbal or confused – our most fragile patients.

The primary way I see facilities trying to make up for the loss of family presence is through technology – utilizing Facetime, zoom meetings and other on-line platforms to connect virtually. But, just like telehealth, we need to be honest with our patients and ourselves about what we cannot replace with technology. A virtual visit cannot replace a tender hug from a child, a helping hand from a parent or the ability to retreat in silent companionship with a spouse at the end of a difficult day. I believe we are called upon to fill that gap with some additional support, kindness and understanding of our own if we do not want to see our outcomes suffer.

Care Ethics:

Care Ethics calls out the need to not only find new technological advances today but also to find new ways to communicate that we care deeply about our patients as fellow human beings. Communicating our concern from behind a mask is not always easy – flashing a quick smile is no longer possible. But we can intentionally take a few additional minutes during each
interaction to connect on a human level as a small gesture to help replace the loss of their family support and make our patients feel less alone during these extraordinary times.

When we truly care about those who we care for, we are reminded that we are all vulnerable, we are all interdependent and we are all in this together.

Reference


COVID-19 reveals the unfinished work of the ADA

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I began my career in physical medicine and rehabilitation (PM&R) in 1990—the year that the Americans with Disabilities Act (ADA) was enacted in the United States. The next few years saw the emergency of the independent living movement, civil disobedience actions that forced public transit to become accessible, and the emergence of disability studies as a new interdisciplinary field of study. It was a thrilling time to come of age in this young field of medicine, and social activism and disability civil rights in health care became a natural part of my identity as a physiatrist.
Although I have seen real progress in society since the passage of the ADA, there are also real disappointments. One of these disappointments — and a frankly inexplicable reality — is the stubborn resistance of the health care sector to embrace the needs of those with disability. Despite the fact that people with disabilities make up 20-25% of the population and are high users of health care services and experience significant health disparities, health care has lagged behind other sectors of American society in addressing issues of access, training, and attitudinal bias and discrimination. COVID is amplifying and exposing these deficiencies. It is now evident that many COVID survivors will have long-term sequelae of the illness — including permanent reductions in lung capacity, kidney disease, and neurologic complications. (1) It may become our modern polio, creating a new generation of people with chronic disability.

As we look toward a post-COVID future, we can choose to embrace this crisis as an opportunity to finish the work of the ADA that has been left undone. Indeed, the work of social justice requires a commitment to both care ethics and distributive justice, emphasizing the centrality of equity and the societal infrastructure needed to support relationships and the common good. During COVID, when we all experience vulnerability to varying degrees, we also expose our fundamental interdependence as a human community. Political philosopher, John Rawls, described a theory of distributive justice that emphasized the “veil of ignorance” in making allocation decisions—e.g., that we should make policy decisions without knowledge of our unique vantage point. (2) Such an approach could advantage those who have been most disadvantaged by social structures and the “lottery of life,” thereby lessening disparities. Below, I outline five ethical and social justice issues exposed during this time of COVID and highlight the urgent need for such considerations.
First, pandemic preparations have emphasized crisis standards of care, most notably how resources would be allocated if need outstrips supply. Publication of these resource allocation guidelines for ventilators have exposed pervasive bias and stigma. The first iterations of several institutional and state guidelines had categorical exclusion criteria for receipt of intensive care and triage for ventilation (such as spinal muscular atrophy, intellectual and cognitive disabilities), and prompted disability advocacy organizations to lodge complaints with the Office of Civil Rights. (3) But categorical exclusions do not tell us about the possibility of medical benefit for an individual patient. Individual health professionals still have to make decisions, and one of the primary causes of discrimination is unconscious bias. There are no objective means, quick trainings, or measures to eliminate such bias.

Second, health professionals are not trained nor knowledgeable about disability, and lack infrastructures to support such care. If health professionals were uncomfortable working with people with disabilities before COVID, they are even less likely to become so during a crisis. Education about disability issues and the team-based models of complex care required to effectively address them are still largely lacking on our medical schools. (4) If you don’t know what you don’t know, and don’t have a team or structure in place, you will be unlikely to create one in a crisis.

Third, people with disabilities have been largely invisible in pandemic planning and are now experiencing disproportionate harms during COVID. The scope of the impact of COVID on people with disabilities will be hard to capture as, unlike race and ethnicity data, disability data is not being collected. Fourteen states are now reporting that 50% of COVID deaths are tied to long-term care (LTC) settings. (5) Most of these people invariably have disabilities of one sort or
another. People with intellectual disabilities in group homes have also been particularly hard hit by COVID. (6) What components of vulnerability are socially constructed and amenable to change? How does poverty, chronic illnesses, age, race/ethnicity, and disability intersect? Without disability data, we will not be able to answer these questions.

Fourth, people with chronic disabilities are not particularly trusting of the health care system and doubt they would receive equitable care in emergency rooms and hospitals during COVID. Since COVID, many people with disability have written about the triage discussions that have played out: Would a person’s ventilator be taken away from them and given to someone else more “worthy” if they came into the hospital? Disability activism is again at work though a grassroots group, #NobodyisDisposable, to empower people with disabilities to be prepared, know their rights, and take action during COVID. (see https://nobodyisdisposable.org/)

Fifth, many health care institutions are not accessible or prepared to meet the care needs of people with disabilities, who are often fearful of losing control of their lives when they come into a hospital. Visitor restrictions during COVID may deprive them of having an advocate or support person with them, an accommodation that can be particularly critical for those with communication or intellectual disabilities. People who are d/Deaf or hard of hearing wonder if they will have access to interpreting services. Will the hospital have accessible medical equipment, bath and shower chairs, trained staff, lift equipment, accessible call lights, or even adequate assistance for toileting? Will health care experts treat them with respect and partner with them as experts in their body? Part of disability non-discrimination must be preparation—having hospitals ready with accommodation policies, procedures, accessible environments,
equipment and trained staff in place and ready to go. Again, hospitals that weren’t disability accessible before COVID, are not likely to become so during a crisis.

Paul Longmore, PhD, a historian and disability activist with polio, wrote about the clash of cultures between health professionals and people with disabilities in 1995:

“Can we bridge the apparent gulf between disabled and nondisabled perspectives? At this juncture, only one course of action seems not only useful, but also essential: the perspectives and values of the disability rights community, as well as attention to the historical and contemporary oppression of people with disabilities, each need to be incorporated into the ongoing debate about medical practice, ethics, and policy.” (7)

Thirty years after the ADA, those words still ring true for me, and COVID has amplified their urgency. COVID has also perhaps opened a window too, as it isn’t really “us” vs. “them.” We all have a sense of vulnerability during COVID—especially health professionals. COVID has exposed our interdependence as a human community, our need for solidarity in following public health guidelines, to adapt, and to use technologies and universal design solutions—solutions that were often created by and for people with disabilities but we all now use. These are the lessons of the independent living community—that we need to respect each other, ensure everyone has a place at the table, and leave no one behind. It is time to finish the job of the ADA and make our health care spaces disability-friendly and genuinely accessible.

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