

Biomedical Ethics

The Value of Person-Centered Care

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Let's look at the case of a man I have been in close contact with for most of my life. Mr. J has recently gone through the traumatic experience of lower-limb amputation. In the following months, Mr. J stated in his visits to his PCP that he has trouble with doing small tasks, that even getting out of bed and making breakfast feels like too big of a chore. He relays that he regards his future with a sense of apathy, and that he has stopped attending social events or maintaining a sense of routine in his life. After asking a few more questions, the physician concludes that Mr. J may have depression, however, the severity of the depressive state is currently unclear. The physician begins to develop a plan for Mr. J, suggesting therapists, anti-depressants, and support-groups that pertain to individuals living with an amputation. But Mr. J is incredibly unreceptive, shrugging off the doctor's efforts as a waste of time, saying he'd prefer to deal with this issue on his own rather than make a big deal out of it. The physician struggles with how to respond, and here we dive into the crux of the moral dilemma. Should Mr. J be afforded the autonomy to make his own decisions regarding his healthcare, or could his debilitating mental health be an impediment to his decision-making capacity, thus prompting medical experts and trusted family members to get involved?

While some answers are made very clear under black and white moral frameworks such as Kantian and Utilitarian ethics, looking at the scenario under a Care Ethics lens stands to unpack a lot more. Notable as being a framework without principles or rules, care ethics places the fundamental unit of morality in caring relationships and human character (Aufrecht). Contextualizing situations and acknowledging their uniqueness allows caregivers and care-receivers to have better relationships with one another. Considering the needs of everyone involved, as well as valuing compassion, generosity, and self-sacrifice in a "good person", the goal under care ethics is to end oppression for all (Sander-Staudt, IEP). The essential question to ask is, "Would I do this action to someone I care about?". Through this, there are several ways to respond to the dilemma from the perspective of the physician, as well as from the perspective of the family.

Turning to the matter of autonomy, we must consider the issue that many depressed individuals have issues with appreciation; namely, they possess minimal amounts of concern for their own welfare, and future possibilities hold little value (Hindmarch et al.). Countless studies have been conducted using a myriad of different methods to try and determine if a person with depression can understand the information presented to them in terms of importance. In making the aforementioned point, I have referenced four papers: Depression and Decision-Making Capacity by Hindmarch et al., Autonomy Stress and Treatment of Depression by Bhutani et al., Sociotropy Autonomy and the Interpersonal Model by Bieling and Alden, and Sociotropy Autonomy and Patterns of Symptoms by Bagby et al. While it is generally accepted that the

frameworks for decision making can be skewed in depressed patients as feelings of despondency and hopelessness frequently overwhelm them, the parameters of such conclusions are still unclear (Hughes and Graber). However, is this considered reasonable grounds for interference? One argument is that individuals should be afforded the right to actions that may cause harm, but only to themselves; a prominent example of this being smoking cigarettes because though it does not have any immediate effects on health, it negatively impacts a person's health in the long-term. The same can be said of depression, which is considered a global illness. Yet, it is widely considered appropriate for a practitioner to interfere if they believe their patient may suffer serious injury to themselves. Thus, care ethics demands that we analyze the situation by gaining more specifics and adopting a nurturing attitude. Asking things such as how severe Mr. J's depression is, has he made any past attempts at suicide, is he currently contemplating suicide, how has the traumatic event of losing a limb affected him, etc.

For some insight, let's look at a famous example of physician expertise versus patient autonomy. Dax Cowart was involved in a terrible accident that left him seriously disabled and in a tremendous amount of pain. Because of his deformities, the medical team ignored Cowart's protestations that the pain was too great to endure and continued to treat him according to the paternalistic model of care. With this prolonged suffering came multiple suicide attempts and several years of dissatisfaction until Cowart could confidently say he had recovered. In an interview conducted with Mr. Cowart and Robert Burt, questions were asked about whether Cowart, armed with the information that life after his incident would truly get better, maintain his decision about wanting to die. Based on his experiences, Cowart maintained a strong preference for autonomy and that regardless of the circumstances, the right over one's own body is an inherent facet of a competent human being (Cowart 16). Moreover, when asked if his agony and hopelessness for the future affected his decision, Dax clarified that the freedom to make our own choices allows us to make right and wrong ones; for him, prolonging his life was not the first priority because the pain was too unbearable, and those needs were not being addressed (Cowart 17). In connection with our original dilemma, Dax ensured that had he been afforded a more caring physician-patient relationship where his needs, values, and desires were understood and fought for, and if his mental and emotional health were addressed, along with his physical health, then his beliefs about his future could have been altered. Therefore, an assumption could be made that Mr. J's priorities lie not in prolonging his life, but in ending suffering, in whatever meaning that word takes.

Another example to consider is that of Andrew Solomon, who has been battling depression for many years. In his 2013 TedTalk, Solomons discussed his experiences with mood disorders as well as his findings through years of research. He concluded that depression is a family secret everyone shares, that those who try to bury their condition only worsen it, and that connecting with loved ones has helped most people combat this dangerous illness (Solomons 2013). It's here, as well as with Dax Cowart, that we see relational autonomy being the defining facet of depressive cases. It draws up this idea that while the depressed patient should have the final and overarching authority in their treatment, this decision-making is not isolated from external influences. There is no one individual making the decision, rather it is through constant communication between doctors, patients, family, and friends that the best care can hopefully be

obtained. The goal is not to merely prolong life as a medical mindset might demand, but to prolong a better life with higher quality living.

From here, we can look at the best types of patient-physician relationships to determine what will best help Mr. J. We've established that depressive patients struggle with appreciating their situation, understanding their feelings, and determining their values apart from the distorted perception their illness provides. Therefore, an interpretive or deliberative model can be used because it acknowledges that the patient may not know or comprehend their values. The practitioner adopts the role of a counselor, supplying necessary information and advising what pathways will best help the patient realize their values (E. Emanuel and L. Emanuel 222). There may be some debating, but the physician must never judge a patient's values, and the patient will always have the final say. It's this self-empowerment that will help individuals feel less adrift and isolated in their treatment process. This can only be done through a continual dialogue and an unerring commitment from all parties to attempt to find a solution. It is imperative that there are frequent check-ins since using the interpretive and deliberative model may lead to the physician unknowingly imposing their own values on the patient who is already overwhelmed by their condition, transforming the interaction into paternalism (E. Emanuel and L. Emanuel 225).

While some arguments can be made that care ethics dematerializes the very nature of a patient-physician relationship, there is an archaic paradigm of professional distance that prevents meaningful connection. Caring relationships do not have to be defined the same way; a doctor will not care for a patient the same way a family member will care for the patient. But everyone involved is moving towards the same goal of ending suffering for the oppressed individual through caring practices and collaborating with each other. In doing this, Mr. J's depression will not only be addressed, but his amputation and how it affects his daily life. By treating the whole-self, there can be awareness of how being an amputee changes Mr. J's interactions with his environment and how depression and living with limb loss are interconnected. In a 2018 study, twenty-two participants were recruited to participate in a focus group in order to ascertain the everyday experiences of individuals living with limb amputation. The results displayed a prevalent theme of fluxuation from good days to bad days which were defined primarily by pain and pain management (Day et al. 11). Furthermore, the ability to engage in activities they wanted to do, derive enjoyment, and feel a sense of accomplishment were defining features of good days (Day et al. 14). There was also a common theme of being at odds with their environment and how planning and mentally visualizing journey were required to anticipate barriers. Body image and wearing a prosthetic play a role as well.

All of these details, and the ones that are specific to Mr. J, must be relayed to the medical team who can then begin a person-centered plan reflecting patient value, their capacities, the necessary support, and involvement of family and friends (Duffy and Sanderson 5). The most important part of this process is that the patient is central, that their wants and opinions are heard, that they are the expert on their own experience, and that they are consulted throughout treatment. This format avoids paternalism, the autonomy of the patient is not violated because they are still in control, it incorporates relational autonomy, and involves bolstering Mr. J's physical, rational, emotional, and spiritual health (Aufrecht). In conclusion, caring relationships

must be the basis of Mr. J's care as he battles depression and life with an amputation, and through this, he will not have to sacrifice his autonomy, but his needs will still be met by his medical team and chosen support group.

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