

Reconsidering Autonomy:

Ethical Reflections from the Frontlines of IDD Dental Care

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Abstract

Ever since the first publication of Beauchamp and Childress's landmark bioethics textbook, US healthcare has championed patient autonomy as the guiding principle of doctor/patient encounters. Although US bioethics seems to regard autonomy as sacrosanct and beyond questioning, we wonder whether dominant ways of understanding patient autonomy fail to consider the lived experiences of large swaths of disabled people who routinely interact with healthcare providers. Reflecting on our experiences treating and working with patients with intellectual and developmental disabilities (IDD), we interrogate and ultimately challenge the bioethical principle of autonomy by critically engaging with the philosophical ideas undergirding it, namely personhood, consent, and desire.

Background

A few months ago, we had a 12-year-old patient visit our office for a cleaning. Like many of our patients, Billy (not his real name) is intellectually disabled. For the past decade, a major focus of our practice has been treating people with intellectual and developmental disabilities (IDD). This particular patient came to the office with his father, although many, especially adults, are brought to their appointments by other caregivers, such as guardians or employees at their group homes.

At the end of the cleaning, Dr. Andy asked Billy which flavor toothpaste he wanted applied to his teeth. "We have piña colada, chocolate, strawberry, or bubble gum."

"Bubble gum!" Billy answered. As Dr. Andy started to open the toothpaste, Billy's dad cut in.

"If you give him a list of choices, he's just going to pick the last option."

Billy's Dad has always seemed to be a supportive and caring parent, and so we don't want to criticize him. The comment did, however, feel dismissive. Billy was asked what he wanted and he answered. There was no reason to doubt that he was expressing his choice: perhaps it is usually the case that what he wants just happens to be the last option presented to him. That doesn't make those choices any less "real." But even if the father's suggestion is correct that Billy is not really voicing his desire so much as parroting the last thing he hears, it is not the place of a healthcare provider to join Billy's father in this judgment. People with disabilities are often not encouraged to speak up, to voice their needs and wants, to take up space. Doctors and dentists have a unique opportunity to care for IDD patients simply by choosing to engage them in friendly conversations, even about "trivial" issues. Perhaps Dr. Andy was the only person that day to ask Billy to speak up for himself. By asking Billy to participate in his care, Dr. Andy was not only empowering Billy to take ownership of his dental health — he was, for the onlooking father, modeling one way of interacting with Billy, one that takes as its point of departure a real interest in Billy's desires.

Over the past few months, we've thought a lot about Billy, his simple request for a toothpaste flavor, and his father's dismissive commentary on Billy's choice. We've allowed this scene to provoke us into thinking about important questions about personhood, desire, consent, and authority. Although these concepts have been undertheorized, they all nevertheless converge in discussions of bioethics, even when they are not explicitly named. For instance, was Billy's choice of toothpaste flavor truly reflective of his desire? Should his choice be ignored because "he's just going to pick the last option?" Or should his choice be ignored because he's a minor? Should Dr. Andy believe the father and give Billy a flavor other than bubblegum, since Billy didn't really want bubblegum in the first place? Say the choice offered was weightier: a big filling or a crown? Should Dr. Andy even offer Billy those choices, or should he simply consult the father? The father, of course, is the agent authorized to offer consent on Billy's behalf for his dental and medical treatments. But the father has just given Dr. Andy good reason to believe that he is not very interested in figuring out what his son wants. It is in the end the son who is Dr. Andy's patient. And yet it is the son's father who has authority to enact and withhold consent on his son's behalf.

These ethical reflections are not simply abstract exercises for philosophers but are in fact practical concerns for doctors who treat IDD patients. The law and, to a lesser extent, bioethics have tried to offer a straightforward way out of this bind: patient autonomy is signified via informed consent, whether it is contractually enacted by the patient's own signature or by the signature of someone authorized to offer it on the patient's behalf. This, we have often been told, is the very foundation of the doctor/patient relationship.

Although Western bioethics seems to regard autonomy as sacrosanct and beyond questioning, we wonder if the dominant ways of understanding patient autonomy fail to consider the lived experiences of large swaths of disabled people who routinely interact with healthcare providers. What we offer in this essay are reflections on the limits of theories of patient autonomy, informed by encounters that Dr. Andy has had with IDD patients. This essay is exploratory and creative: we are imagining new ways-of-being with our most vulnerable patients, and we are inviting other healthcare experts to join us in these imaginings.

It should be noted that we are not arguing that bioethics ought to adopt two different definitions of autonomy, one for the disabled and non-disabled. Instead, we suggest that autonomy, precisely because it fails to attend to the full realities of persons with disabilities, is therefore not a good foundation for bioethics.

Rethinking Autonomy

The American Dental Association Code of Ethics is based upon five principles: patient autonomy, nonmaleficence, beneficence, justice and veracity. Noting that these principles "can overlap each other as well as compete with each other for priority," the ADA nevertheless insists that dentistry ought to be based upon these "fundamental principles," which it claims is "the profession's firm guideposts."¹ The first four of these principles form the foundation of contemporary medical ethics, particularly following Beauchamp and Childress's classic 1979 text.² Each principle is given its own chapter, beginning with autonomy. While the authors caution that all four principles must be carefully balanced, its first-place position in the discussion may give the impression that autonomy is the most important principle for healthcare workers to safeguard. As philosopher Rachel Haliburton points out, many bioethicists see

autonomy as the “central value they need to defend,” and interpret and apply the other three principles in light of the first (p. 39).³ All roads lead back to patient autonomy.

But over-prioritizing patient autonomy in healthcare settings is problematic precisely because the concept of autonomy that many bioethicists and providers work with is often “narrow and undertheorized,” argues philosopher Susan Dodds (p. 216).⁴ Based on modern philosophical and legal understandings of personhood,

“the conception of autonomy used in bioethics is rationalistic, atomistic, and individualistic. It assumes something like an atomistic individual, making a choice wholly for herself or himself. It assumes that, paradigmatically, individuals are equally rational and able to reflect on complicated choices once given adequate information. It ignores the social circumstances and power relations that affect choice contexts.”⁴

Any talk about self-determination must take for granted some idea of self: who is it that is doing the determining? In healthcare settings, a self-determining person is assumed to be a rational individual who knowingly pursues her own good (even though we have scores of research clearly demonstrating that humans do not tend to act rationally). This assumption is reflected in the pride of place afforded to informed consent contracts: the individual whose name appears on the form has reached her own decision without undue interference by her healthcare provider.

And yet, this conception of personhood overlooks the myriad ways that every single one of us is always already inextricably bound up with other people. Just as there is no self-determination apart from self, there is no self apart from others. We become who we are only in relationship with other people. These relationships are not “add-ons” to an already formed self, but they are in fact constitutive of that very self.

Buddhist monk Thich Nhat Hanh offers the following example to explain what he calls “interbeing:”

“Looking into a flower, we can see that it is full of life. It contains soil, rain, and sunshine. It is also full of clouds, oceans, and minerals. It is even full of space and time. In fact, the whole cosmos is present in this one little flower. If we took out just one of these “non- flower” elements, the flower would not be there. Without the soil’s nutrients, the flower could not grow. Without rain and sunshine, the flower would die. And if we removed all the non-flower elements, there would be nothing substantive left that we could call a “flower.” So our observation tells us that the flower is full of the whole cosmos, while at the same time it is empty of a separate self-existence. The flower cannot exist by itself alone.”⁵

In fact, claims Hanh, this is the case with everything that exists: “everything relies on everything else in the cosmos in order to manifest— whether a star, a cloud, a flower, a tree, or you and me” (p. 14).⁵ We exist only in interrelationship. “To be is to inter-be,” he concludes. Or as Simone Weil puts it, “To say ‘I’ is to lie” (p. 132).⁶

We believe the concept of interbeing undermines the very foundation of patient autonomy. The idea that an individual, independent substance which calls itself “I” shows up to a doctor’s office

ready to make a decision completely unencumbered by any “outside influence,” so to speak, is not based on an accurate account of personhood. Patients and doctors *inter-are*. If bioethics is going to continue to take “autonomy” as its first principle, then the concept at the very least ought to be revised to reflect a thicker conception of persons — not as independent but *interdependent*, always already existing in relationship. If a person is constituted by her relationships, then any theorization of autonomy should have relationship at its heart.

Some ethicists, following the lead of feminist philosophers, have tried to reframe the concept of autonomy in the wake of metaphysical critiques of the human. They believe that while traditional bioethical notions of autonomy fall victim to modernist myths about personhood, there are nevertheless important features of autonomy that should be retained. Rather than throwing the baby out with the bathwater, so to speak, these ethicists propose that we think about autonomy in explicitly relational terms.

According to philosophers Carolyn McLeod and Susan Sherwin, relational autonomy involves “explicit recognition of the fact that autonomy is both defined and pursued in a social context and that social context significantly influences an agent has to develop or express autonomy skills” (p. 259-260). Autonomy is not “pre-loaded” into persons; it must be developed, rehearsed, and performed in the context of relationships. Rather than seeing autonomy as “an achievement of individuals,” relational autonomy makes “visible the ways in which autonomy is affected by social forces, especially oppression (p. 260).”⁷

Think about Billy selecting a toothpaste flavor. Had his father not invalidated his decision by dismissing it as a non-decision, Billy would have been given an opportunity to construct his own autonomy in a safe environment. As McLeod and Sherwin rightly note, “autonomy is based on self-trust,” without which “any agent would have little motivation to deliberate on alternative courses of action (p. 263).”⁷ Even though Billy’s father didn’t realize it, he — like Dr. Andy and the dental assistants in the room — was participating in Billy’s autonomy. Instead of talking to Dr. Andy about Billy’s choice, the father could have talked to Billy about his own choice, maybe asking him why he chose the way he did, or telling him that he made a good choice, or reminding his son that he too likes bubblegum! All of these options would have assisted in Billy’s construction of self-trust, which is a minimum condition for any meaningful version of autonomy to be present. Instead, Billy was sent the message that his desires ought not be voiced, presumably because of assumptions about his intellectual state.

Relational Autonomy

Even though we believe that allowing Billy to voice his desires is important, we realize the stakes in the toothpaste flavor story are not very high. Often with our IDD patients, the stakes are much higher. As one of the only general dentists credentialed to treat IDD patients in the operating room, Dr. Andy regularly brings patients into surgicenters to provide them with dental care. Many of these patients require a great deal of support. It is often the case that Dr. Andy cannot perform routine exams until the patients are under general anesthesia. At that point, treatment needs must be assessed on the fly. If the patient requires extensive work, Dr. Andy will speak with the parents or caregivers before undertaking treatment.

Because these procedures take place in hospital settings, where priority is often given to the inflexible demands of bureaucrats and lawyers, healthcare providers tend to find themselves advocating on behalf of IDD patients to no avail. Hospital policies are often created by those

who believe that “informed consent” is the only way a patient’s full agency can be respected. These misguided policies often put healthcare providers who work with IDD folks in very tough binds. Rather than serving our patients, we are made to feel that our primary responsibility is to obey hospital policies.

Here’s an example: Dr. Andy recently scheduled time to examine and treat an intellectually disabled patient who requires a great deal of daily support. On the morning of her procedure, Linda (not her real name) showed up to the hospital escorted by two caregivers who work with her every day in her group home. When the hospital asked if the state-appointed guardian was present to sign an informed consent form, the caretakers explained that Linda had been on a waiting list for a state-appointed guardian ever since her mother abandoned her when she reached 18 years old.

“So then this patient cannot consent to treatment,” a hospital representative said, sending the patient away. There was no reasoning with the hospital. There was no explaining to them what relational autonomy looked like. There was no explaining to them that the two women who spend daily time with the patient were well-positioned to help us interpret what Linda wanted. For that matter, there was no explaining to the hospital that human beings often express ourselves non-verbally, and that doing so does not mean that we are unable to communicate our desires, nor does it mean that we are unworthy of care.

In an essay reimagining autonomy in relational contexts, Catriona MacKenzie and Natalie Stoljar suggest we ought to think of autonomy “as a characteristic of agents who are emotional, embodied, desiring, creative, and feeling, as well as rational, creatures” (p. 21).⁸ Their conception of autonomy does not foreground rationality — instead, rationality is included as a kind of afterthought. “Humans are so many things ... and oh yeah, we’re sometimes rational.” A working conception of autonomy in IDD patients, especially nonverbal ones, doesn’t pretend that an informed consent signature is the only way to figure out what a patient wants. IDD people experience and communicate joy, displeasure, fear, and physical pain. It is up to providers and caregivers who are working with these populations to find new ways to attend to these experiences. This can only be done with time, by not rushing through appointments, by paying attention to nonverbal cues, by listening to the advice of caregivers who spend time with the patients. It’s also up to us to assume, unless we are given compelling evidence to the contrary, that our IDD patients want what most of our other non-disabled patients want: to live free of disease and pain.

We are aware that what we are suggesting could be criticized with accusations of paternalism — the idea that healthcare workers will always act in the patients’ “best interests” and therefore ought to be able to make unilateral decisions on behalf of their patients. But we’re not arguing that final healthcare decisions for IDD patients should be left up to one single person who has legal say over them; that is the hospital’s position. What we are suggesting is that because autonomy is relationally developed, enacted, and at times obstructed, autonomous healthcare decisions should be understood to be arrived at in the context of relationships between patients, caregivers, families, hospital staff, and yes, the treating physicians. While paternalism in healthcare contexts is a concern, it is less likely to occur when patients and the providers who treat them have ongoing relationships of care.

We cannot definitively say what Linda wants from Dr. Andy. She is nonverbal and has an autism diagnosis. What we do feel comfortable suggesting, though, is that *whatever Linda wants will*

not suddenly change when the state appoints her a guardian. Whether or not she has a guardian to authorize her treatment, Linda will likely want the same thing we all want from dentists: help with our oral health. In equating informed consent with autonomy, the hospital has unfortunately confused authority with competence. A state-appointed guardian will have the authority to speak for Linda. It does not follow, however, that the guardian will have the competence to do so. It may well be the case that those who are most competent to advocate for and with Linda are those whose very voices the hospital chooses to ignore.

Beyond Autonomy

So far in this essay, we've been reworking the concept of autonomy, perhaps realizing that US healthcare ethics and law are not going to rid themselves of principlism anytime soon. But we'd be remiss if we concluded without raising the question: Does patient autonomy add something important to healthcare? Put differently: Can healthcare be ethical without an explicit acknowledgment of patient autonomy?

For all of their flaws, many misguided bioethical accounts of autonomy seem to want to safeguard the belief that persons are not interchangeable, that they have unique desires which are fitting to their unique situations-in-life, and that these desires help them achieve their own flourishing. These ideas are worth preserving, especially in healthcare settings, but it's possible to champion them without flattening them down to a hospital-approved notion of "autonomy." In fact, we already have a good concept to help us out: love.

What would it look like if the foundation of bioethics weren't autonomy, but were instead a commitment to work for the good of our patients because we and they are mutually bound together in this world in love? Admittedly, love does not often feature in bioethical discussions. But that does not mean that love does not come to bear on doctor/patient encounters; it may just mean that healthcare and ethical professionals are simply not comfortable talking out loud about love. And why not? We are helping our patients lead happy, healthy, flourishing lives; we are caring for them and nurturing them; we are sharing in their joys and pains. Love, it seems to us, is a perfectly fitting word to describe these relationships of mutuality, compassion, and care.

According to Catholic ethicist Edward Vacek, "love is an emotional, affirming participation in the dynamic tendency of an object to realize its fullness" (p. 44).⁹ When dentists and healthcare workers participate in a patient's movement toward their own flourishing, and when we do so with an awareness that we are emotionally involved with them, we love them. What is important to note about this definition is that it is serious about what "autonomy" tries (but often fails) to safeguard; namely, the belief that a person has unique desires, that these desires help "internally nudge" a person to his or her own flourishing, and that our responsibility is to help our patients continue along their way. Patients arrive to us already in motion; to love them is to help them continue that motion, and to be emotionally involved in their journey.

It is love, and not some universal concept of autonomy, that helps us navigate both Billy's and Linda's respective situations. It is love that attends to Billy's toothpaste flavor option, that attends to the voice that announces itself in this choice, that encourages that voice to keep speaking up for itself. It is love that attends to Linda's desire to be free of pain-inducing oral disease, that attends to the many ways she expresses her desires beyond words, that advocates alongside her as she makes her way through a healthcare system that does not always affirm her full personhood. And it is love, in the end, that shares Linda's disappointment that she will not

receive dental treatment because a panel of bioethicists somewhere decided what “autonomy” should always look like.

Perhaps some will criticize us for suggesting that the bioethics guiding healthcare providers ought to be based in a difficult-to-explain concept like “love.” But as we have tried to show, autonomy is a much more nebulous concept. It is much easier to determine whether a doctor has acted lovingly toward a patient than to figure out whether the consent form the doctor has collected truly reflects her patient’s desires.

Conclusion

In conclusion, we are not suggesting that the principle of autonomy in bioethics be replaced by love. What we are suggesting is that when healthcare providers allow love to guide their encounters with patients, the “heavy lifting,” so to speak, that autonomy pretends to be doing is no longer necessary. Nor are we suggesting that love should be a guiding principle only in healthcare providers’ encounters with disabled patients. What we are suggesting is that because some IDD patients require a lot of support, much of it visible, from families, friends, and other caregivers, the love involved in these situations is more readily apparent to folks who are not accustomed to looking for it in healthcare settings. It is our hope that by calling attention to the love already inherent in many relationships between IDD patients and those who support them, we might encourage doctors and dentists to begin to think through important bioethical issues in ways that push beyond limited and limiting notions of autonomy and consent.

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