


BENO



**BIO
QUARTERLY**

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Revealing and Dealing with the Hidden Bottleneck of Ethics Education within Healthcare



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The term *curriculum* comes loaded with baggage of being formal and parochial, certainly not austere enough for health care where many clinicians have advanced degrees. Often misunderstood, the simple meaning of curriculum is...education plan. Being intentional about education seems reasonable. Still, it may come with the baggage about education – certainly overlapping in ethics while also a field unto itself – and evoke foreignness.

So keep it simple. Start with a more familiar analogy within health care: supply chain. The last metaphor one might use for ethics education within health care is “supply chain,” but in fact it should be the first. The “product” in the supply chain is an ethics topic, one that is by no means totally discrete, yet loosely definable. The supply chain’s “producer” or “manufacturer” is someone knowledgeable in health care ethics. The “warehouse” is the ethics program, meaning ethics committee members and ethics consultants. “Transport” is the method or mode for conveying the ethics topic.

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Presidents' Greetings

FROM THE OUTGOING PRESIDENT



Greetings from Northeast Ohio!

I hope everyone has had a wonderful summer! With the arrival of cooler temps, return to school, and football season, fall has arrived and we have now entered another academic year.

This year will be a transition year for BENO. I have decided after four years it is time for me to step down as BENO's president. It has been my pleasure and privilege to serve the members of BENO for the last four years and help further the mission of this great organization! I cannot thank my co-officers, Alan and Amy, and our board members enough for all of their help and support during my tenure!

I have no doubt that I am leaving the presidency in great hands. I will remain on the board for one additional year, and I look forward to assisting Josh Crites, PhD and the other officers with our important work.

Thank you for entrusting the organization to my leadership over these last few years! I look forward to continued collaboration with our wonderful members!

Warm regards,

Cassandra

FROM THE INCOMING PRESIDENT



As the incoming President, it is my pleasure to greet the members of BENO and readers of BioQuarterly! With summer rapidly moving toward fall, the regular pacing of BENO's activities are well underway--planning for the 2022 conference and increasing the reach of our organization into healthcare ethics across Ohio. We are planning next year's conference, and hope to be able to hold the conference in-person (perhaps with hybrid options). As much as we want to be in person, we will continue to assess options and prioritize safety.

Although my role on the BENO board has changed slightly, I look forward to continuing to work with BENO's general and board members on endeavors to fulfill our mission. I am also excited to welcome new board members after this summer's elections. Thank you to all who showed interest and to all who voted.

The BENO board will continue to have a service orientation to the organization's members. Please help us by letting us know how we might improve your capacity to engage in ethics-related activities at your home institutions.

My best,

Josh

FOLLOW BENO ON:



Is this metaphor complete? Or is it missing something? If so, what is missing? Even amateur logisticians will notice that the metaphor sketched above doesn't include a customer or consumer. The customer is the end-point of the supply chain. Some might argue that the customers are, in fact, ethics program members, but if that's so, the goal of ethics education in health care is solely to educate ethics program members. But that's wrong if we want to get the product – ethics education – to anyone beyond ethics program members themselves. Treating ethics program members as the end customer of ethics is the hidden bottleneck in ethics education within healthcare.

Answer the next questions from your organization's perspective, and be honest: what percent of your product – topics from ethicists or used for ethics program member education – makes it out of the warehouse, meaning beyond those in ethics programs? How strong is the transport direct from the manufacturer to customer or from the warehouse to customer? Do you look at product gathering dust in the warehouse and ask, "Where's the warehouse fire? What's wrong with stacking up product until warehouses burst at the seams?"

Philosophers David Hume and Immanuel Kant say something about this supply chain. Hume's is/ought distinction is a caution about confusing what exists, or current state, (is) with desired state or normative prescription (ought)¹. In other words, just because ethics knowledge and skills stay within the ethics program doesn't mean this *should* happen. Understandably, any number of different biases may reinforce this confusion – confirmation bias, availability heuristic, the curse of knowledge effect, status quo bias, and the authority bias. A perspective shift is helpful. Ask someone else with different answers to have a confidential conversation. Try to see with a different view. Kant's categorical imperative

rightly situates, or at least calls into question, who are the true stakeholders of ethics education: Are we treating those who benefit from ethics knowledge and skills as ends-unto-themselves by empowering them to educate others themselves? Or are we treating committees as mere means to our own ends by using the ethics program as a resume-builder, for free meals, or for social interaction?² Intent is complex, so give yourself a break if you answer the latter question affirmatively.

The foundational patchwork of sources influential to contemporary health care ethics programs provide expectations and define stakeholders. The New Jersey Supreme Court's opinion *In re Quinlan* (1976) describes ethics committees not as self-serving, but as partners with clinical teams, "diffusing" or "sharing" responsibility with them and advising them.³ A President's Commission report takes up the purpose, process, and function of ethics committees. "Of particular importance here is the way ethics committees can expose the actual decisionmakers in a hospital setting to various ethical and social considerations."⁴ Who are the decision makers, the customers in the supply chain? It mentions "people within medical institutions," all those in those institutions who must "address issues

responsibly," and the community.⁵ To be explicit, customers are clinicians and providers, patients, family members, community, and even society.

Deluding ourselves that knowledge stops with ethics programs and being wrong about customers has consequences. Many systems now refer to *customers*, as opposed to *patients*, and this puts the consequences front-and-center. Patients, family members, and the community have choices. They may go elsewhere if a system doesn't get the ethics information they care about into their hands. Clinicians and providers may turn elsewhere, entirely side-stepping your supply chain and warehouses to go online or with a totally different manufacturer or vendor. Is this a big deal? Yes, it certainly is. How are different supply chains going to give context, processes, and the right info for *your* organization?

So we roll out the trucks and launch the drones to clear product out of the warehouses? No! Stop! Consider that your customers have changed before you get on your Segway or charge the drone to head out for deliveries. Compared to twenty years ago, the clinicians, providers, patients, families, and community have changed a great deal. In fact, the pace of change is quicker than ever.

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Personal and professional demands are at an all-time high. Time, including breaks, is a luxury. Customers are no longer sitting in an educational center waiting for a lunch-and-learn. They are on-the-move, and need a product and delivery system equally mobile and convenient so they can 'stay' on-the-move.

At face value, the pandemic has dramatically shifted the landscape in favor of remote learning models. Many still prefer in-person learning. Make didactic education interactive for learners. Case studies with discussion or questions, small group work, polling, and learner presentations will keep learners focused and interacting with material. Consider learning *in situ* for the learner by offering it in huddles at the start of a shift or during rounds. Another way is the just-in time method at the bedside if the educator-responder is able to go quickly upon request. No matter the education mode, focus on what the learner needs to know, use their experience to relate to the current topic, and allow for feedback or evaluation of the learning experience.

With the new focus on virtual or on-line learning, many different platforms host virtual environments – ZOOM, Google Meet, Web-Ex, and Microsoft Teams. It is likely your system already has a specific platform for virtual interactions. Know how to use the technology prior to holding an educational offering, as technical difficulties can easily

derail an on-line class. Many IT departments offer classes or have resources for learning how to use and troubleshoot issues in an on-line platform. Once you have mastery of the mode, make sure that the presentation is going to hold the learner's attention. Unlike classrooms where it is easy to gauge reactions, educators often have no idea what the learners are doing nor their reactions in online settings. An easy fix is to incorporate interactive software into your presentations to keep the learner engaged and responding throughout the presentation. Interactive software examples include Menti-meter, Powtoons, Prezi, Pear Deck, Captivate or Articulate, and Kahoot (many have free versions to try before purchase).

What is the best advice for warehouse supervisors – ethics program leaders? First, communicate and reinforce the message that ethics committee and consultation team membership know expectations, including time commitments. A good rule-of-thumb for committee members is to spend just as much time planning, reading, and educating outside a committee meeting as in. Second, hold people accountable after establishing the expectation. This may entail having difficult conversations with those only attending meetings (sometimes sporadically

at best). Third, meet people where they are. The reality of the pandemic is the ethics team may only get five to ten minutes in a team meeting for education. Make... every... second... count. Finally, consider education, development, and learning theory presentations and discussions as the few items that stay within the warehouse.

For instance, Adult Learning Theory – Four Principles of Andragogy as outlined by Malcolm Knowles provides a guideline for developing educational offerings targeted specifically to adult learners.⁶ Adults need involvement in the planning and evaluation of education, experience as the basis of learning activities, topics that impact their practice, and problem-centered, not content-oriented, learning. When using adult learning for education, focus on need-to-know info, provide self-directed learning, use the learner's own experience as part of the educational experience, and tap into learners' intrinsic motivations. Faculty members' roles in adult learning are to guide learners, incorporate current or past experience in the learning process, share evaluations and provide an opportunity for learners to provide feedback on the learning experience. Adult learners are eager to learn, but want to be able to use the knowledge they gain in their practice. Do not waste time with nice to know and focus on need to know. With this, you can get the right product to consumers who want it.

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- [1] David Hume, "A Treatise of Human Nature: A Critical Edition," eds. David Fate Norton and Mary J. Norton (Oxford, UK: Clarendon Press, 2007).
- [2] See, for instance: Immanuel Kant, "Groundwork of the Metaphysics of Morals," eds. and trans. Mary Gregor and Jens Timmermann (Cambridge, UK: Cambridge University Press, 2012).
- [3] 70 N.J. 10, 355 A.2d 647.
- [4] President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, "Deciding to Forego Life-Sustaining Treatment," (Washington, D.C.: U.S. Government, 1983).
- [5] Ibid
- [6] Kurt, S. "Andragogy Theory – Malcolm Knowles."





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Patients who live alone with minimal support systems present unique challenges for hospice staff. Hospice can help people to remain in their own homes, which many prefer to an institutional setting. When Hospice gets involved, patients are typically already living with other family members, such as a spouse or adult child. Other patients, however, live alone. Even when these patients' living situations are stable at the time of admission, we always anticipate a functional decline that will demand a greater level of care at some point in the future. However, for a number of reasons, people are resistant to changing their living situation, even when living at home alone begins to present serious risks.

The concept "dignity of risk," introduced in the 1970s, recognizes the value in accepting some level of risk in a living situation. While the discussion initially concerned persons with mental and physical disabilities, the concept is also relevant to hospice patients, who have for the most part not considered themselves disabled in the past, but now find their capacity to adequately care for themselves waning. The challenge is finding a balance between allowing people to accept the risk, and making sure they are

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safe in their home environment.

The starting point for the discussion of safety is an assessment of their physical and mental capacity. While we routinely encounter people with significant deficits in one or both of these areas on admission, they usually already have a support system in place. In contrast, those people who live alone often have little in the way of support, because they haven't needed any previously. With this population, there are two significant obstacles. First, patients may be in denial regarding their diminished ability to perform activities of daily living at present or in the future. Second, patients' mental status may fluctuate over time, particularly when "normal" forgetfulness escalates to the point of outright confusion, as when forgetting to take medications leads to deterioration in mental status. Persistent deficits are easier to address: patients may be persuaded to accept help for constant conditions, or constantly poor mental function may lead the healthcare team to involve surrogate healthcare decision makers. In contrast, people with variable decision making capacity will assert – correctly, at that moment – that they don't need help, leading to a familiar cycle. Their capacity declines such that they have a crisis, necessitating hospitalization or other inpatient level of care. Once they've stabilized

and regained capacity, they want to return home with no additional help. Because they currently exhibit decision making capacity, they are allowed to do so, but the home care team anticipates recurrence of this pattern.

This is not to say that more drastic intervention is needed earlier. In borderline cases, additional factors beyond mere functionality should be considered. One of the most important is helping to preserve the person's identity: how does this person understand themselves? A few years ago I had a patient, S, who was initially admitted while living at his youngest child's home; but following an argument (partly due to S's increasing albeit intermittent confusion), the child tried to place S in an extended care facility. When S realized the move was intended to be permanent, rather than a respite stay, he walked out and found his own apartment. The attending physician established that S had capacity. A large part of S's identity was in being "the father;" which is to say, self-determination was his primary concern. Many of our conversations focused on his own father dying of the same disease, and he was trying to live up to his father's "old-school" model of parenting. S frequently left his stove on, and continued to drive, which worried the interdisciplinary team; he eventually agreed to move in with a grandson, with whom he had the best relationship of his family mem-



bers. The time living by himself had been important to the maintenance of his identity, and prepared him to accept his grandson's help for the last few months of his life.

Even when patients have good relationships with their children, they often still want independence from them. P was a woman living in senior apartments; she had good support from that community, although COVID-19 had made socializing more difficult. Her daughter lived nearby and was active in her care, which she accepted, but strongly resisted the idea of moving in with the daughter so she would have people around 24 hours a day. After a nurse found P unresponsive at a routine visit, she was hospitalized, and agreed to move in with the daughter, "for a short period of time." While P never regained her prior level of functioning, she was able to arrange 24 hour care in her apartment, and move back to her apartment. She died shortly thereafter, but was able to meet her goal of being able to die in her own home.

Social support was important for P, but for some patients it is a primary consideration for their wellbeing. D had been manager of her trailer park for many years, and even after her retirement was still actively involved with that community. This stood in contrast to her estrangement from her children: only one of her adult children was involved at all with caregiving, and his availability was limited due to his work hours and distance from her. Neither he nor D ever discussed her moving in with him, although he pointed out that it would be easier for him if she moved closer to where he lived. The community of the trailer park had been an essential part of her support and self-understanding, more so than the familial relations, and she strongly resisted any suggestion of relocating. However, she became increasingly unable to manage her own medications, which led to periods of delirium; once her medications were adjusted and she regained her decision making capacity, she insisted on returning home. It was finally with the encouragement of her neighbors that she agreed to an assisted living facility near her son, and she died shortly after moving. While her decline had been precipitous in the final weeks, and the interdisciplinary team acknowledged that the move kept her safe, the move had taken a mental toll and may have ultimately hastened her death.

Another patient, C, had a strained relationship with her only child, close relationships with her neighbors at the trailer park in which she lived. She was happy

to receive help, and was no longer wanting to drive. Although she had several falls, and periods in the middle of the night where she was disoriented and scared, she resisted moving to a nursing home because of concerns about privacy and quality of caregiving. C was proud of her career and achievements, and was worried about being reduced to a diagnosis and a set of tasks in an institutional setting. Privacy was also a concern, since she'd been used to being by herself and taking care of herself, and was distressed at the thought of having others help her with bathing and toileting (she had also declined a home health aid from hospice). She came to our inpatient unit for a respite following a fall, and while there her son was able to arrange a placement at an extended care facility; however, she died in respite before she could go. As with D, her death was not completely unexpected, but the home care team was concerned that the stress of the impending move was a factor in her accelerated decline.

That's not always the case, of course. M had been living alone in an apartment, with caregivers for a few hours a day, at the time of her admission. She had limited contact with her family, who lived out of town, but was very much attached to her two small dogs. Her condition worsened, but it was unclear how much was disease progression and how much as inadequate caregiving. M agreed to long-term care facility placement once she recognized she could no longer adequately care for her dogs, and found someone to look after them (who agreed to send pictures and videos of the dogs). We anticipated a decline, both due to disease progression as well as the change in living circumstances, but with proper medication management and increased socialization, she stabilized and improved such that she no longer met hospice criteria, and was discharged.

While safety is a priority, the patient's emotional and spiritual wellbeing also needs to be taken into account. That means identifying and supporting their values, especially with regard to their self-understanding. The support that people receive, from neighbors as well as pets, has a big impact. Figuring out what's truly important for the patient is the work of the entire interdisciplinary team, and rarely offers easy answer. Allowing a level of risk for the sake of maintaining patient dignity is challenging as we consider patient safety, but is essential for providing the best care.

BOOK REVIEW

The Heart of Addiction by Lane Dodes Harper Collins, 2002

Robert M. Guerin, PhD, Clinical Ethicist, University Hospitals Cleveland

Lance Dodes's *The Heart of Addiction* is approaching its 20th anniversary, at a time when overdose deaths in Cuyahoga County are set to surpass the record number of overdose deaths reported in 2017. So it seems timely to return to its insights.

Dodes is a Training and Supervising Psychoanalyst Emeritus at the Boston Psychoanalytic Society and Institute and was Assistant Clinical Professor of Psychiatry at Harvard Medical School. His experience with addictive behaviors is vast, and *The Heart of Addiction* seems to be a product of this experience. Here is what he tells us: addiction is a psychological (as opposed to a physical) phenomenon. Early in the book, he writes: "*Virtually every addictive act is preceded by a feeling of helplessness or powerlessness. Addictive behavior functions to repair this underlying feeling of helplessness. It is able to do this because taking addictive action (or even deciding to take this action) creates a sense of being empowered, of regaining control—over one's emotional experience and one's life*" (p. 4). A page later he tells us that "*rage at helplessness... is the nearly irresistible force that drives addiction*" (p. 5). Dodes defends this claim with multiple case reports from his practice, along with references to studies that suggest that addiction is not a matter of "getting hooked" but a drive to regain some control, however displaced.

Dodes is a psychoanalyst. So it is no surprise that his interpretation of addiction is psychoanalytically oriented: "*Every addiction results from a redirection of energy to a substitute or displaced action (usually because another, more direct, action is not considered permissible)*" (p. 6). Addictions are indications of unconscious conflicts, to put this oth-

erwise. For some personal reason, the person who suffers from an addiction at once wishes to act in some way and yet cannot. Stuck in a corner, the person with an addiction makes a compromise with himself. According to Dodes, it is as if someone says to himself, "I can't do this, but I also can't do nothing, So I'll take a drink."

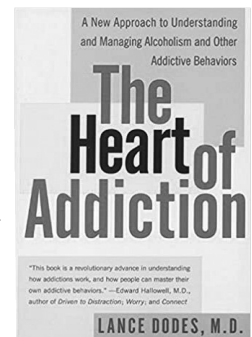
To see this more clearly, let me provide an example from the book. Dodes introduces us to Walter Millis who built a successful restaurant business, having four locations at the time that he visits Dodes for a consultation. Walter suffers from alcoholism and drinks in binges about once a month, often taking long absences from work. As Dodes and Walter begin to explore the circumstances surrounding Walter's addiction, Walter cancels an appointment, stating that he is at his cabin, bingeing. When Walter returns to Dodes's office, they learn that Walter had discovered prior to the binge that his business account for payroll had been overdrawn. He learned that his nephew Jeffrey, whom he raised after his sister's death, was taking the money. As Walter and Dodes continue to talk, Dodes learns that Walter always defended Jeffrey, even when Jeffrey's actions were clearly indefensible (we learn later that this defense is related to Walter's relationship with his father). So when Walter learns that Jeffrey had taken the money, he could not fire him, as one might expect, and as he himself likely wanted to do. But he also could not stand idly by. So he did what he usually did: he binged. Binging is a compromise between firing his nephew and feeling utterly powerless.

The Heart of Addiction is written for those who wish to take control of their addictions. In this sense, it can feel like a self-help book. The downside is that greater theory and technique is omitted (for those interested in an elaboration of the psychoanalytic presuppositions, see his publications in *The International Journal of Psychoanalysis* and *Psychoanalytic Quarterly*). The upside, however, is a clear, common-sense introduction to a seemingly incomprehensible issue. Not only are the case reports vivid and instructional, his debunking of various myths of addiction are clearly conveyed for the lay reader to appreciate.

Let me conclude this review by discussing some of the ethical implications of this book. Dodes is clear that addiction is not a disease. Yet it is not a matter of weakness of will, either. It is an expression of an unconscious displacement, the uncovering of which will re-empower those who feel helpless. The fact that addiction is an unconscious process challenges all-too-common moralizing attitudes toward those who suffer from addictions—they are responsible for their illness and therefore deserve little sympathy. This fact also challenges those who place addiction in the same category as a (biological) disease, as if those who suffer from addictions are powerless to change without medication. The problem with reducing addictive behaviors to biological processes is the consequential removal of agency from those who suffer from the addictions. According to the old dichotomy: at the least, they are unlucky; at worst, inhuman.

The ethical upshot to understanding addiction as an unconscious process, whose meaning is an ineffectual attempt at regaining some control, is that addiction lies on the same continuum as autonomous decision-making. The road to recovery lies on the path of reflection and deliberative action, i.e., self-governance. It is a matter of understanding the inhibitions that preclude direct resolution to helpless situations, in which drinking, say, seems like a reasonable alternative. According to Dodes, once the inhibition to direct resolutions is understood, patients gain a capacity to reflect in those circumstances, instead of enacting old problematic behaviors. The treatment of addiction might therefore be understood as an ethical enterprise: an inquiry into who the patient is and who the patient wishes to become.

The Heart of Addiction is nearing classic status. But its insights are by no means antiquated. Current readers will find practical approaches to old problems of addiction.



UPCOMING EDUCATIONAL OPPORTUNITIES

ASBH 23rd Annual Conference: Bioethics and Humanities at the Crossroads

October 11-16, 2021

Virtual meeting.

Follow link at <http://asbh.org>

The Bioquarterly invites readers to inform us of upcoming ethics education opportunities. Events occurring after each publication deadline can be added to this column. Please email Title, Date(s), Location/Virtual, and contact link to Gena Cohen, Beno Administrator at genacohen@yahoo.com.



Cartoon courtesy of Maxwell Schaller
from Columbus College of Art and Design

BENO 2021 BOARD ELECTION RESULTS

Congratulations to our newly elected/re-elected Board members! We welcome your dedication and expertise.

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Kelli Schweitzer, MSN, RN, NPD-BC

Ohio Nurses Association

I began oil painting as a hobby in late December 2019, not knowing how much the world would change within six months. The COVID-19 pandemic began to impact our day-to-day lives in March 2020. After a few more months, many Ohioans were sheltering in place and struggling with this altered reality. All of us were suffering, but none more than the people impacted more directly by the pandemic.

The perspective is roughly from Mt. Adams in Cincinnati, and is a composite from several photos. Mt. Adams still has some green space and terrific views of downtown Cincinnati. Some details clearly are my artistic license, such as the prominent view of the sun low on the horizon to what would be the southern sky.

Everything has significance. The sky is sweltering, meant to evoke "the hot zone." The lines of trees are meant to be a firewall, implying a separation from others. The city, or at least downtown, lies beyond; still distanced from other people.

The flowers, building, and reflections of the sun are mostly in cool, steely colors, which conveys a sense of detachment. You can be surrounded by creation, and it still feels impersonal ... in the middle of the hot zone. Even the contrast of the warm sky tones with the cool city and nature tones can feel awkward, almost like they don't go together; this is similar to the awkwardness of day-to-day life (the downtown) in the pandemic (the sky).

-Steven J. Squires



**Steven J. Squires (b. 1977) Cincinnati in Isolation, 2020,
Oil on canvas, 11x14"**