

E.G. Howe, "Seeing the Invisible," *The Journal of Clinical Ethics* 33, no. 2 (Summer 2022): 159-60.

## *At the Bedside*

# Seeing the Invisible

*Edmund G. Howe*

### ABSTRACT

This article focuses on three different ways that we may demean people by seeing them as less than they are, and describes ways we may best avoid doing this. More specifically, I explain how we may not see the physical and emotional issues that plague patients and others. This may be because they choose not to disclose their difficulties to us. We may also err when we see only one aspect of who and how others are. These challenges pose ethical quandaries that involve equity, improved communication with patients, and subjecting ethical principles to empirical study before we adopt them. I explore the means to do these.

In this issue of *The Journal of Clinical Ethics*, Bernard Lo, in "Clinical Medical Ethics: How Did We Start? Where Are We Heading?" discusses how bioethics affected him, and how he

affected it.<sup>1</sup> He cites bioethics' predominant remaining needs. Each issue that Lo raises warrants full discussion, but I will discuss only three here. These issues are (1) equity, (2) careproviders communicating more clearly, and (3) subjecting the ethical principles we follow to empirical study, to be sure that they are beneficial before we adopt them. I will also discuss an issue that these concerns have in common: each involves different ways that careproviders and/or society may inadvertently treat patients (and others) as though they are invisible.<sup>2</sup> This may leave those persons feeling isolated and may increase their suffering.

I will discuss these three issues in separate sections. In the first section, I will discuss the increased pain that people may experience when they have an invisible genetic risk or an invis-

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ible physical or mental illness. I will use as an example individuals who must decide whether or not to pursue a double mastectomy after they find out that they are at a higher risk for breast cancer. In this issue of *JCE*, Valerie Gutmann Koch, in “Medical Decision Making and the Previvor,” addresses the needs of those with this genetic risk and proposes that careproviders adopt a nontraditional model for informed consent.<sup>3</sup> The word “previvor” refers to individuals who have an increased genetic predisposition to develop hereditary breast and ovarian cancer but who have not been diagnosed with cancer.<sup>4</sup> Because their illness is “invisible,” their suffering may be greater. Their needs may be met to a greater degree when their careproviders find a way to reduce their invisibility.

In the second section, I will discuss the invisibility that people may, without knowing it, bring upon themselves. They may do this because they believe that others can’t or don’t want to understand them. Thus, they don’t even try to tell others what they feel, and their belief that their pain is invisible and can’t be known becomes a self-fulfilling prophecy. In discussing this group, I will consider people who form all-or-nothing conclusions; for example, on the one hand, there are people who loathe those who will not get vaccinated against COVID-19; on the other hand, there are people who loathe those who are vaccinated and insist everyone else should be vaccinated, too.<sup>5</sup>

In the third section, I will explore how society may treat members of some groups as invisible—and may have done so for some time. Members of privileged groups may see others as different and leave them feeling, to some extent, as though they are invisible. I will consider persons who now are referred to as “little people” and who used to be called “dwarves.”<sup>6</sup> I shun both terms because they stigmatize people by regarding them as different, but I will consider these people as members of a group for the purpose of this article. I will relate how careproviders—as anyone—should seek to avoid seeing other persons in any way that results in their feeling less than who they are.

I will consider this group in examining Lo’s third proposal, that we should test our ethical principles empirically. I will use the needs of people in this group to consider whether we should always subject ethical principles to empirical study. I will note briefly before ending the section how careproviders may inadvertently

make patients feel as though they are invisible and suggest how we may best avoid contributing to that feeling.

Overall, I will suggest that when people feel invisible for any of the above reasons, careproviders, and society as a whole, should seek to help them. The extent to which this is possible may be limited, but by recognizing that it can happen, we may be able to reduce its occurrence and help people to feel less alone. I think in this regard of a colleague who was as emotionally devastated as anyone I have ever known after one of her parents died. She was mired in grief to the extent that it probably contributed to the loss of both her life partner and her source of livelihood. I was not her careprovider, but even if I had been, I doubt I could have helped her change these negative outcomes, so dense was her grief. She did, though, in time, recover. At that time, she thanked me. She said my just being with her during that time had made what had been unbearable, bearable. Thus, just being with patients who are in distress may be of help to them.

#### SEEING PAIN THAT IS INVISIBLE

When we are not able to see the inner struggles of previvors and others, we may judge them. For example, we may view those who are experiencing unseen pain as “shirking,” and see them as placing unnecessary, increased burden on us as their careproviders. We may inadvertently show our judgment nonverbally, for example, with a prolonged frown that may convey feelings of contempt. Such interactions, when repeated, may undermine persons’ quality of life.

An example is a person who has a genetic predisposition to breast cancer who is trying to make a decision about whether to have a bilateral mastectomy. The uncertainty she may feel can be excruciating, as Gutmann Koch relates.<sup>7</sup> The needs of persons with a predisposition for genetic illness may be so different than those of most patients that we may need to find better ways to meet their needs. For example, we typically want to reduce risk for our patients, but previvors may be willing to accept greater risk in the present to reduce possible risk in the future. Thus, Gutmann Koch argues, previvors may need to take a stronger lead in making medical decisions than we might anticipate, and this may require different approaches to obtaining their informed consent.

For example, breast cancer previvors may be more likely to request information on risk-reducing surgery and the psychological aspects of treatment than other patients, while those diagnosed with a cancer may be more likely to want to know about treatment and the risk that the cancer may re-occur. There is evidence from preliminary research that some women who receive genetic testing for breast cancer feel their concerns are too readily dismissed.<sup>8</sup>

### Exceptional Struggles that Previvors Face

The risk of carrying a BRCA (BRest CAncer) 1 or 2 mutation is approximately one in 400, and, in one study, five years or so after genetic testing, 16 percent of the women tested had moderate to severe cancer-related distress. The discovery of BRCA1 in 1994 and BRCA2 in 1995 paved the way for more routine genetic testing for cancer, and the use of genetic testing has steadily increased over time. Pathogenic variants in BRCA1 increase susceptibility to breast cancer (55 to 72 percent) and ovarian cancer (39 to 44 percent), with a lower increase in risk for cancers of the prostate, pancreas, and melanoma. Similarly, mutations in BRCA2 increase a woman's susceptibility to female breast cancer (45 to 69 percent).

Pathogenic variants of breast cancer genes of unknown significance and benign variants are also mutations.<sup>9</sup> In discussions of genetic test results, the American College of Medical Genetics advises the use of the term "variant" because lay audiences react negatively to the term "mutation." This illustrates the kind of inadvertent stigma that can be associated with breast cancer. Researchers report that previvors who receive benign genetic test results may have survivors' guilt when other family members suffer breast cancer.<sup>10</sup> Should previvors decide to have a breast or breasts removed, it will involve severe body changes. Having surgery may affect their intimate relationships and sexuality. They may face additional, profound stresses, for example, they may fear that they will pass on their breast cancer gene to their children, and that if they inform their family members that they may be at risk, it may negatively affect their relationships.<sup>11</sup> They may fear family relationships will be compromised if they make different choices than family members who are at risk.<sup>12</sup>

Previvors may suffer from socioeconomic inequity. Previvors may need to decide between having a prophylactic double mastectomy or

having ongoing, increased surveillance. This may involve repeated breast magnetic resonance imaging (MRIs) in addition to mammograms, which may be costly. They may have to balance these costs and their health insurance against their best estimate of their quality-adjusted life years.<sup>13</sup> Further sources of inequity include being female, younger, nonwhite, an individual with less social support, and an individual with a lower level of education. People in these groups may have higher levels of distress, regardless of their genetic testing results.<sup>14</sup> "Watchful waiting" is a strategy adopted by 20 to 50 percent of carriers of BRCA mutations. That choice involves ongoing uncertainty and the fear this choice may increase their risk of death from the mutations.<sup>15</sup> Prophylactic bilateral mastectomy provides a 90 percent-plus reduction in the incidence of breast cancer.<sup>16</sup> Even with prophylactic bilateral mastectomy, there remains a small but nonetheless residual risk of acquiring breast cancer from leftover breast tissue. Unanticipated repercussions may surface; for instance, after surgery, previvors may not be satisfied with their new body image or with changes in how they experience sexual intimacy.

Gutmann Koch recommends that we be prepared to discuss all of these factors with previvors. Particularly, we should tailor communication about risk to previvors' possible *a priori* knowledge regarding genetic testing, their worries about cancer, their tolerance for uncertainty, and their psychosocial needs.<sup>17</sup> Many patients find it easier to consider risk by category rather than by percentages; that is, they might prefer to hear that they are at high risk or at low risk, rather than be advised about percentages of risk. For example, we might tell a previvor that she is at higher risk than most women in the general population, or that she is at lower risk.<sup>18</sup>

As a further example, we could tailor our discussions of risk to previvors' self-reported level of pre-counseling worry. That is, some previvors may overestimate their risk even after counseling, and when that happens, their level of worry after they receive counseling may remain at the level it was before counseling.<sup>19</sup> Talking with previvors about their level of risk may help them to see and assess their risk more accurately.

### How this Suffering May Be Invisible

The pain these patients experience may not be clear to others. I have discussed previvors'

pain in detail to illustrate how extensive their unseen inner turmoil may be. Those who are not aware of this pain may judge these patients, and their misunderstanding may add to patients' pain. Such judging and blaming may affect anyone who has hidden physical or emotional illness. This population is enormous. I will describe two specific examples, one of a physical illness, the other emotional. The patient with a physical illness is a woman who has difficulty swallowing after she was treated for cancer. She must lie upside-down on an inclined table after every sip of liquid or bite of food. She must do this to reduce the risk of aspirating food and drink—she uses gravity to reduce her risk. This is not evident to others. She tires easily. When she cannot do what others think she should be able to do, they frown. A patient who has an invisible emotional illness saw a man shot in front of him by a street gang as he walked down the street. He was so terrified he found it difficult to leave his house. Others couldn't know this, and judged him for not going out when he was afraid, and because they thought that he could and should be able to leave his house.

Patients who suffer invisible pain like those described above may suffer more than patients whose source of pain is visible. Thus there is a need to reduce this inequity. Lo notes, "One important difference from my earlier work on allocating intensive care resources is greater attention to equity. The COVID-19 pandemic has had the greatest impact on communities and groups who already faced multiple disadvantages and discrimination."<sup>20</sup> To increase equity for previvors and others who may suffer in ways that are not easy to detect, we can try to recognize when they feel pain, and, if they are suffering, ask them about it. As Gutmann Koch suggests, they may need increased interventions to help them feel less alone. Our efforts may help make what is for them unbearable, bearable.

### **Some Possible Interventions**

There are several ways that we can at least try to help meet the needs of these individuals. I will use previvors as an example. These individuals may be greatly helped by their peers. One previvor, post-mastectomy, said, "To see real people in your community tell you they are so happy [you] did this, and [you] feel and look great just makes a huge difference."<sup>21</sup> We may help previvors greatly by asking them, whenever we see them, whether they would be will-

ing to have another previvor contact them in the future for peer support. Most careproviders may feel reluctant to do this, but when patients are asked to do this, they may welcome the invitation. As one previvor said, "how nice it would be if providers would ask their current previvor patients if they would be willing to serve as a contact for other previvor patients."<sup>22</sup>

Another new initiative would be to ask previvors whether they want to bring family members to their appointments. At present, there are legal and ethical barriers to this approach; for example, HIPAA (the Health Insurance Portability and Accountability Act of 1996) may exert a deterrent effect. Ethically, we place a priority on patients' privacy. Yet, when previvors must decide whether or not to have a bilateral mastectomy, having family members with them may greatly reduce their stress. For example, one previvor shared that "Our genetic counselor was amazing. I mean she was a wealth of information! When we got our test results, my mom, my sisters, and I all went to get our results together, and she spent probably an hour with us talking about what our next steps were and things we needed to be doing, and what doctors we needed to be seeing. It was just so, so helpful."<sup>23</sup> One website offers sample letters that previvors can use to share their genetic results with family members.<sup>24</sup> The authors who reported the statements of this previvor write that it was important that "the genetic counselor not only spoke with [the previvor] but also included her family members in the conversation. Communicating information about living with BRCA to her family support structure enabled [her] to feel supported and better manage her uncertainties."<sup>25</sup>

Presently, neuroscientific studies unequivocally document the beneficial brain effects of positive interactions with family members.<sup>26</sup> These beneficial results also apply in many other medical contexts.<sup>27</sup> We can benefit previvors, and our other patients, by taking the initiative to discuss their emotions with them, including feelings of invisibility, if they want to do this. For instance, one previvor described how her plastic surgeon helped her to cope with the emotions she felt were the result of learning that she was at a high risk for breast cancer. He took the initiative to ask her about her feelings, which she saw as an expression of his exceptional concern. She says, "He wasn't the nose job plastic surgeon. . . . He was concerned for my full well-



being not just his little part of the job. That was helpful. I mean you have your support from your family and friends, but on the medical side, it felt really good to be supportive on that end as well. . . . He showed an absolute sensitivity.”<sup>28</sup>

She added, more notably, an additional, less common intervention that her surgeon made: “when my husband was with me, [the surgeon] wanted to know how he was doing, and then when he wasn’t with me, [the surgeon] wanted to know how our relationship was doing . . . so totally above and beyond. . . . He was just completely aware of how emotional this whole process is for a woman.”<sup>29</sup> This previvor managed her uncertainty better because her surgeon took the initiative to repeatedly check with her to see not only how she was doing, but how her husband was doing.

We should consider telling previvors and other patients what we personally would do, should they ask. The response of a third previvor may be telling: her “breast surgeon helped her manage her uncertainty because she gave [the previvor] ‘real answers’ to her questions about deciding whether or not to undergo a preventative bilateral mastectomy. [The previvor] explained that her surgeon’s personal answers to what she would do if she were in [the previvor’s] position made [her] feel like her surgeon was a ‘real person’ and understood her situation.”<sup>30</sup>

Such a personalized response may be particularly helpful when a patient feels invisible. Even if previvors and other patients do not ask us what we would do, they may still want to know. To avoid possible discrimination against those who have not asked but still would be grateful to know, we might ask whether the previvor or patient would want to know what we would do. While some may indicate they are interested in this information, some may indicate that they are not interested. Asking them may make it easier for them to indicate what they would find helpful, either way.

There is yet another way we may help those who experience invisible pain. In 2005, Lo and Rubinfeld wrote that careproviders could urge loved ones to touch patients who were unconscious and at the end of life, to let them know their loved ones were close by, to help alleviate any unexpressed pain they may be feeling.<sup>31</sup>

Such touching may also dispel feelings of invisibility in patients who are conscious. We may need to be more delicate when we consider

touching another person, because if such touching is not wanted, it may be a crime and a legal tort. But risking touching, notwithstanding this, may move patients emotionally, and present a negligible risk. For example, a fourth breast cancer previvor reported her response to her surgeon’s touching her just prior to her undergoing surgery. “[The previvor’s] most memorable moment during her health journey was when her breast surgeon held her hand before she went under for her preventative mastectomy. Through this simple act, [the previvor] felt she was not alone and was supported.”<sup>32</sup>

### SEEING AND UNDOING PAIN THAT PATIENTS CREATE FOR THEMSELVES

Lo writes about the importance of using the right words; he states that we should seek ways to communicate more clearly, without medical jargon, so that patients can better understand us and make better choices. He writes, “Bioethics scholars need to think about how to reach beyond academic audiences and beyond those who already agree with them or are inclined to do so,” and that narratives capture the attention of readers.<sup>33</sup>

Some individuals who feel invisible also feel isolated. Some individuals are even still worse-off because they so distrust others that they create their own invisibility. Here are two examples.

A careprovider sought to reassure a patient that the patient’s response to trauma that the patient had experienced was not uncommon. The patient was not reassured; rather, he became enraged: “I am not someone else,” he railed. “My doctor trivialized me and my experience. He thinks I am no different from others, but I am unique.” This patient shared his history with me when he came to me for help, after choosing not to see this careprovider again after the above exchange. When we try to reassure such patients by “normalizing” what they experience, we may fail, no matter what we do. These patients may see us as trivializing them and/or their pain, as this patient did.

This same kind of “no-win situation” may exist in regard to the words we choose. We can, for example, describe the pain that patients feel as “pain” or as “discomfort.” The former, some believe, risks validating and thus reinforcing patients’ pain so that it may become greater than it is. But referring to pain as “discomfort” may lead patients to see us as trivializing their pain.

I choose to use words like “pain,” even when the hurt that patients feel may be less than “pain.” I hope that by doing this I will convey that I “get” that they are hurting, and thereby work to keep our relationship intact.

A second example of a patient who created his own isolation is one who maligned his mother at every opportunity. He recalled that a pet guinea pig died when he was a young child, and his mother did not tell him, but instead bought him a new guinea pig she thought looked the same. Unfortunately, it did not look enough the same, and the patient saw through her attempt. I asked him if he thought it was possible that his mother might have done this because she cared about him. He absolutely denied that possibility. “No,” he said, with angry emphasis. He insisted that she did it only for herself, so that she would feel better.

While there have long been discussions about the source of altruism that echo the suspicions of this patient—that people who appear to act altruistically are acting in ways that benefit themselves—a conclusion in this case may not be possible.<sup>34</sup> What the anecdote illustrates, however, is that when such irresolvable, different ideas on altruism are present, some patients will always see their glass as half full, or even as always empty. Our challenge is to get through to them, in spite of their responding in this way.

The tendency of some patients to completely reject everyone else, out of hand, can lead them to feel as though they are invisible and alone. This may underlie many of the emotionally charged views we see today that cause individuals to end relationships they have had, even for decades. I have seen this happen among people who are for or against COVID-19 vaccination. Why might this happen? I will consider one possible explanation, since it may help us to reach patients, giving them a possible way to escape their invisibility, even when it is self-imposed.

### How This Occurs

Patients may reject others and see doing so as rational, even though it may result in calamitous outcomes for themselves. For example, the patient who mourned his guinea pig saw his mother as not caring for him for his whole life, although in other instances he reported, it was clear that she did. Why can't this patient, and others like him, see this? One answer may lie in how our brains sometimes work. We may feel feelings first and then find reasons to support

them, and we may do this selectively and not know we are doing it. An experience may evoke hurtful feelings in us, and we may find reasons to support our reaction. Then the reasons may become entrenched in our mind, and we may use them to protect ourselves, because doing so may enable us to hold onto even tenuous positions that we adopt. Should we feel our positions are threatened, we may become even more rigid in our responses to protect them.<sup>35</sup>

This possibility has far-reaching implications for how we may best reach patients. Namely, our approach cannot be direct, because being direct may trigger greater rigidity. Not being direct may require that we engage in a degree of implicit deceit: deceit by omission. For example, we might tell patients a story to make a point that we don't explicitly reveal. Or we may ask questions when we think we already know the answers, but we don't disclose this. Here are some examples.

### Reaching these Patients

We might initially ask why we might be willing to and even want to engage in such deceit. Mervyn Conroy and colleagues queried 131 doctors regarding their ethical practices, and their findings are illustrative. One respondent said, “I felt very sorry for the patient, and a little disturbed at the idea that this was almost certainly going to kill her. . . . I therefore found it difficult to reconcile my wish to respect her autonomy and her decision making, and the horrific consequences of her choice.”<sup>36</sup> Another said, “a patient doesn't understand the severity of the decision they're making, and perhaps only when they've seen people who don't have the procedure done or don't have an operation might they learn . . . the actual nature of the decision they're making, because we see it, whereas they don't.”<sup>37</sup>

L.A. Paul has written about transformative experiences that result in knowledge that we could not have gained without those experiences.<sup>38</sup> But it is not possible for patients to gain such knowledge prospectively. But we, as their careprovider, may help them gain such insight by asking them to imagine themselves as having made the choice they want to make, and then looking back 20 years later to see whether they made the right choice. This imaginative leap may provide them with new insight. Our task is, when our insights are sound and our patients' insights are horrific, as the first physician expressed above, to find a way to help patients to

see other options without alienating them. An overarching priority is that patients remain willing to return to us for care. A good illustration is that of patients who have a political stance that we oppose, and perhaps can't even fathom. It may seem that we should point out why we believe they are wrong. But doing this may destroy our capacity to help them. Thus, it may be best that we remain silent. We could, however, ask them, "Do you want to know what I think?" If we do ask them this, we can add, "I fear, though, that if I do tell you my view, if we differ, this could harm our work together. So it may not be worth taking that risk. What do you think?" If patients say, "Please go ahead," the risk of sharing our views may be lessened.

Another approach would be to tell a story. In the instance of opposing political stances that could affect treatment, we might want to tell a "counterstory" when a patient's view has become fixed as a result of exposure to another story.<sup>39</sup> People who refuse to be vaccinated against COVID-19, for example, may have made their decision because they heard a horror story about someone who was vaccinated and then died. We could ask the patients if they would want to know about a counterstory, since this might influence their decision. Doing so may be important, because, as Lo writes, there is power in narrative. For example, we could tell a patient who chose not to be vaccinated a counterstory about a patient who didn't get vaccinated and died. We might not share why we do this, although this could be seen as deceit by omission—which might negate the desired effect of telling a counterstory.

Should we do this? We could indicate that we want to tell a counterstory because it might help patients to make decisions that more fully further their best interests. Telling a counterstory can be seen as balancing a story that patients have already heard, and, in this sense, it could be seen as ethically justifiable. This approach may also be seen as ethically justifiable because it ultimately may enhance patients' autonomy. On the other hand, it's generally seen as ethically optimal to explain to patients in advance what we will do and why. As a way to limit deceitfulness as well as to benefit patients to the greatest extent possible, we could ask patients if they would like to hear a counterstory. But this could prompt patients to think that we are correcting their views, and they may feel infantilized and offended. This should be avoided at

all costs. Research indicates that some of the language that we use that most notably offends patients are that the patient "complains," "is non-compliant," and even "rejects treatment."<sup>40</sup>

A second possible approach, one that is often used, is motivational interviewing.<sup>41</sup> In this approach, interviewers do not give out all of the information they know or believe all at once, but rather they give out information bit by bit, and only to the degree that the persons who are being interviewed, as best the interviewers can tell, can accept the information. The example I described above, of asking patients to imagine how they would view a current decision 20 years from now, is an example of this approach. This approach also involves implicit deceit, and there are ways that we can seek to reduce the deceit. Should we choose to use a motivational interview approach, we could begin by asking a patient if it is okay with the patient that we ask what could be some difficult questions. We can point out that if we do this, and the patient accepts this, the added answers, like any new insight, may benefit the patient in the long run. We can say that we will go slowly, as slowly as the patient requires, and we will take our cues solely from the patient. These last statements explain, to some degree, our underlying purpose: this may help to offset the stress our questions might otherwise evoke, and to the degree that the added information shares what we intend, it may reduce our deceit. Taking this tack may convey that we think we know what is best for the patient, more than the patient does. We will have explained, however, why we are going slowly—because it will most benefit the patient.

A third approach is to use language that may help a patient answer questions more easily and truthfully, although we would not say this, nor would we say why we are doing this. For example, when we ask a patient about alcohol consumption, we may ask not *whether* the patient drinks, but *how much*. The latter question may be less threatening to a patient who drinks and may make it easier for the patient to respond more truthfully. For some patients, we may already know or suspect that, due to their drinking, they have lost the things that are most precious to them, for example, their family or their job. We can acknowledge that the main reason we ask this question in this way is that this makes it easier for patients to answer truthfully.

It might appear that adding this additional explanation could wholly negate the ends our

deceit was intended to achieve. That would be a logical conclusion. Paradoxically, however, it may not apply. Our feelings may not work logically. Patients who are given these extra explanations may still respond truthfully. Although all paternalistic interventions involve a degree of deceit, the benefit these interventions offer to patients may allow us to lessen their inherent deceit, at least to some extent.

Another approach to increase our chance to reach patients is to point out that what they may see as a weakness may be a strength. For example, a man was deeply bereft when his preschool son had a meltdown. He felt that his son would have to be tough when he became a man, and his son's meltdown indicated that he was failing as a father. I pointed out to him that his son's having a meltdown might suggest that his son had a gift—an emotional strength—of being sensitive to feelings he had, and also to the feelings of others. His son might have been more able than most to empathize. I said that we can't have one without the other: we can't have empathy initially without our also hurting too easily and too much. Our task, I said, is to maintain our gifts while reducing our liabilities. The man, hearing this, said that he felt much better.

### When these Approaches Fail

How should we continue when these approaches fail to reach patients? In this regard, I think of an account by Amanda C. Garfinkel, an internal medicine resident at Brigham and Women's, about how she struggled emotionally after treating a patient who died due to COVID-19. "While [the patient's] family felt sadness," she admits, "I felt anger." She says she felt "enraged" because "an unvaccinated person—not me—should have had to call this patient's family to tell them she was dying of a preventable disease."<sup>42</sup> She describes how she then dreaded going to treat another unvaccinated patient:

But whereas I'd prepared to encounter an opponent—a face to represent the faceless mass of "the unvaccinated"—I met a man who lay prone and powerless against this disease, whose breathing quickened and whose lips quivered as we discussed the progression of his illness. When I suggested that he and I call his wife together to share an update, he failed to stifle a pained, knowing sob. My shoulders relaxed, and my wall began to crumble. Disarmed, I knelt by his bedside and reached out my gloved hand to

hold his. . . . As he rested his cheek on the pillow, twisting his neck to meet my gaze, his eyes betrayed the fear I hadn't allowed myself to see, too blinded by my anger to perceive him in his individual humanity.

. . . Like me, these humans will be imperfect. Like me, they will be biased, at times irrational, at times blinded by anger or fear. My role will always be to bridge the gap between scientific knowledge and lived experience, and the patients for whom the gaps are widest will be those whose lives I might affect the most.<sup>43</sup>

Before this encounter, Garfinkel had seen patients who had not "vaxxed" as invisible. This is a risk that we must keep in mind. When we are outside our medical role with a patient, we are two people who meet as equals.

### SOCIETY RENDERS SOME OF ITS MEMBERS INVISIBLE

Lo urges us to study the practical benefits (or lack thereof) of our actions that are based on moral principles we cherish and espouse, by testing them empirically. Surely, we should subject moral principles to empirical study, but must our cherished moral principles always be tested? Perhaps, in some cases, not.

This is a question I will briefly address in considering the moral principles that can be applied to the treatment of a group of people whom society has mostly treated as invisible.<sup>44</sup> In their article, " 'Nobody Tosses a Dwarf!' The relation between the empirical and normative reexamined," Carlo Leget, Pascal Borry, and Raymond De Vries use the example of "dwarf tossing" to analyze the bioethical principles of human dignity, autonomy, and the protection of vulnerable people "with fresh eyes."<sup>45</sup> (The authors explain that the title of their article is taken from the movie *The Lord of the Rings: The Fellowship of the Ring*, in which the mighty dwarf Gimli shouts, "Nobody tosses a dwarf!" as he jumps across the chasm at Khazad-dûm, rather than be tossed over it.<sup>46</sup>) In their consideration of the ethical principles that could be used to analyze the ethicality of this activity, the authors conclude, "The critical applied ethics approach is the only one . . . that allows this necessary dialogue between empirical and normative ethics. Our five-step application of this approach allows fruitful and necessary conversation be-



tween facts and values, that can help create innovative, practical, and useful solutions to the moral dilemmas of medicine, medical science, and yes, dwarf-tossing.”<sup>47</sup> This article, published in 2009, is now dated; for example, the terms “little person” and “person of short stature” are now used. Further, unless physical stature is of relevance in a conversation, using a person’s name, rather than a descriptor, is more appropriate.<sup>48</sup> Leget, Borry, and De Vries consider whether *all* ethical principles should be tested empirically, and come to ask whether “dwarf tossing” anywhere, ever, should be allowed.

Dwarf tossing, to use that term just for the present discussion, is the “ancient art” of throwing a small person as far as possible,<sup>49</sup> an activity that is, incredibly, still practiced in the modern day, although three courts, two in the United States and one abroad, have outlawed it.<sup>50</sup> It is said to be safe because the people who are tossed wear a helmet. In my view, this activity violates the dignity of these people horrifically. Yet, some ask, “What about dwarves who make their living by strapping on a helmet and allowing themselves to be launched into the air by burly, slightly drunk men and women?”<sup>51</sup> One individual argues that persons who are unusually tall play basketball to entertain others; why, then, shouldn’t smaller persons similarly be permitted to make their livelihood in a safe way?<sup>52</sup> This individual asserts that banning the practice is discriminatory and limits the personal autonomy of persons of small stature.<sup>53</sup>

Beyond this discussion, there is an overarching need for society—for all of us—to stop viewing people based only on one characteristic that they have in common. We should not characterize groups of people as “schizophrenic” or “diabetic” and so on. If we see only this part of persons, we make them, to a degree, invisible, and it may blind us to seeing who they really are. This is a concern that can be fed by horror movies in which we see actors who are made up to be frightening. People with craniofacial conditions are another group that is subject to invisibility, and subject to hate crimes. The British Film Industry, consequently, will no longer fund moves that use facial difference as a sign of evil.<sup>54</sup>

## CONCLUSION

In this article I have discussed three concerns that Lo raises in his article in this issue of *JCE*: equity, communication, and testing ethical

principles. I have discussed ways that previvors and patients who have hidden physical and emotional conditions may be “invisible” to others. I have discussed how society may render people invisible by viewing them as “different.” I have suggested ways that we may seek to better reach previvors and patients.

Guttman Koch provides a path for us to better reach previvors and others in her article in this issue of *JCE*, and we must do whatever we can to try to better meet their often extreme needs. Society, in turn, must try to never see any of its members primarily as persons who have a characteristic that others lack. Society must strive to see its members as people who only happen to have one characteristic or another, so that one characteristic or another does not render those persons invisible.

## NOTES

I wish to thank Norman Quist for his profound, insightful suggestions regarding numerous aspects of this article.

1. B. Lo, “Clinical Medical Ethics: How did we Start? Where Are We Heading?” in this issue of *The Journal of Clinical Ethics* 33, no. 2 (Summer 2022).

2. This experience is depicted in Ralph Ellison’s novel, *Invisible Man* (New York, N.Y.: Random House, 1952).

3. V. Gutmann Koch, “Previvorship’s Challenges to the Law of Medical Decision Making,” in this issue of *The Journal of Clinical Ethics* 33, no. 2 (Summer 2022).

4. M. Dean and L.G. Davidson, “Previvors’ Uncertainty Management Strategies for Hereditary Breast and Ovarian Cancer,” *Health Communication* 33, no. 2 (February 2018): 122-30, doi: 10.1080/10410236.2016.1250187.

5. D.M. Amodio, “The Neuroscience of Prejudice and Stereotyping,” *Nature Reviews Neuroscience* 15 (October 2014): 670-82, doi: 10.1038/nrn3800.

6. C. Leget, P. Borry, and R. De Vries, “‘Nobody Tosses a Dwarf!’ The relation between the empirical and the normative reexamined,” *Bioethics* 23, no. 4 (May 2009): 226-35, doi: 10.1111/j.1467-8519.2009.01711.x.

7. E. Anthony, K. Files, and S.C. Danhauer, “Leaning Into Uncertainty and Discomfort With Hope,” *JAMA Oncology* 7, no. 8 (August 2021): 1117-8, doi: 10.1001/jamaoncol.2021.1496. See also, T.Y. Chen, C.W. Kao, S.M. Cheng, and Y.C. Chang, “Uncertainty and Depressive Symptoms as Mediators of Quality of Life in Patients with Heart Failure,” *PLoS One* 13, no. 11 (November 2018): e0205953, <https://doi.org/10.1371/journal.pone.0205953>.

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women attending French, German and Spanish genetics clinics before and after targeted or multigene testing results: an observational prospective study,” *BMJ Open* 9, no. 9 (2019): e029926-e, doi: 10.1136/bmjopen-2019-029926

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10. S. Makhnoon, B. Arun, and J. Bedrosian, “Helping Patients Understand and Cope with BRCA Mutations,” *Current Oncology Reports* (18 March 2022): 1-8, doi: 10.1007/s11912-022-01254-8.

11. Dean and Davidson, “Previvors’ Uncertainty Management Strategies,” see note 4 above, p. 123.

12. *Ibid.*

13. K.E. Clift, S.K. Macklin, and S.L. Hines, “Patients with Pathogenic Variants for Breast Cancer Other than BRCA1 and BRCA2: Qualitative Interviews about Health Care Experiences,” *Hereditary Cancer in Clinical Practice* 17, no. 1 (2019): 32, doi: 10.1186/s13053-019-0132-6.

14. *Ibid.*

15. *Ibid.*

16. *Ibid.*

17. *Ibid.*

18. *Ibid.*

19. *Ibid.*

20. Lo, “Clinical Medical Ethics,” see note 1 above.

21. Dean and Davidson, “Previvors’ Uncertainty Management Strategies,” see note 4 above, p. 127.

22. *Ibid.*

23. *Ibid.*, 125.

24. BRCA Exchange, <https://brcaexchange.org/>; Stanford Medicine, Cancer Institute, “Decision Tool for Women with BRCA Mutations,” 1 December 2011, <http://brcatool.stanford.edu/>.

25. Dean and Davidson, “Previvors’ Uncertainty Management Strategies,” see note 4 above, p. 125.

26. A.M. Heru, “The Context of Our Lives: Neuroscience Expands Our Knowledge of Relational and Social Worlds,” *Clinical Psychiatry News* 50, no. 4 (April 2022): 10-1. See as an example, also, T.H. Lee, M.E. Miernicki, and E.H. Telzer, “Families that fire together smile together: Resting state connectome similarity and daily emotional synchrony in parent-child dyads,” *Neuroimage* 152 (15 May 2017): 31-7, doi: 10.1016/j.neuroimage.2017.02.078.

27. A.M. Heru, *Working With Families in Medical Settings: A Multidisciplinary Guide for Psychiatrists and Other Health Professionals* (New York, N.Y.: Routledge, 2013).

28. Dean and Davidson, “Previvors’ Uncertainty Management Strategies,” see note 4 above, p. 127.

29. *Ibid.*

30. *Ibid.*, 123.

31. B. Lo and G. Rubenfeld, “Palliative sedation in dying patients: ‘we turn to it when everything else

hasn’t worked,” *Journal of the American Medical Association* 294, no. 14 (12 October 2005): 1810-6, doi: 10.1001/jama.294.14.1810.

32. Dean and Davidson, “Previvors’ Uncertainty Management Strategies,” see note 4 above, p. 126.

33. Lo, “Clinical Medical Ethics,” see note 1 above.

34. J. Lichtenberg, “Is Pure Altruism Possible?” in *Modern Ethics in 77 Arguments*, ed. P. Catapano and S. Critchley (New York, N.Y.: Norton, 2017), 59-63.

35. J.E. LeDoux, *Anxious* (New York, N.Y.: Viking, 2015).

36. M. Conroy et al., “Using Practical Wisdom to Facilitate Ethical Decision-Making: A Major Empirical Study of Phronesis in the Decision Narratives of Doctors,” *BMC Medical Ethics* 22, no. 1 (February 2021): 6, doi: 10.1186/s12910-021-00581-y.

37. *Ibid.*

38. L.A. Paul, “Teaching Guide for Transformative Experience,” <https://lapaul.org/papers/teaching-guide-for-transformative-experience.pdf>. I wish to thank Norman Quist for this reference and his many other contributions to this article.

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40. C. Cox and A. Fritz, “Presenting Complaint: Use of Language that Disempowers Patients,” *BMJ* 377 (27 April 2022): 1-4, 2, doi: 10.1136/bmj-2021-066720. I thank Norman Quist for this reference.

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42. A.C. Garfinkel, “From Resentment to Reconnection: Reflections on Caring for the Unvaccinated,” *New England Journal of Medicine* 386, no. 1514 (14 April 2022): 1394-5, doi: 10.1056/NEJMp2119720.

43. *Ibid.*

44. See, e.g., Diego de Silva Velazquez’s *Las Meninas*, c. 1656, Museo del Prado, Madrid, Spain, <https://www.museodelprado.es/en/the-collection/artwork/las-meninas/9fdc7800-9ade-48b0-ab8b-ede94ea877f>. In this painting, a young princess has several small people with her. We should ask, “Why? How were these people seen by royalty, and by all of those who have viewed this picture since that time?”

45. Leget, Borry, and De Vries, “ ‘Nobody Tosses a Dwarf!’ ” see note 6 above.

46. *Lord of the Rings: The Fellowship of the Ring*, directed by Peter Jackson (2001; Burbank, Calif.: New Line Cinema).

47. Leget, Borry, and De Vries, “ ‘Nobody Tosses a Dwarf!’ ” see note 6 above.

48. Disabilities, Opportunities, Internetworking,

and Technology (DO-IT), “How are the terms ‘dwarf,’ ‘little person,’ and ‘person of short stature’ commonly used?” [www.washington.edu/doi/](http://www.washington.edu/doi/), updated 8 April 2021, <https://www.washington.edu/doi/how-are-terms-dwarf-little-person-and-person-short-stature-commonly-used>.

49. Ibid.

50. Ibid.

51. Ibid.

52. Writing in *New Republic*, Steven Pinker notes his concern about the use of dignity “as an *a priori* norm for making ethical judgments.” Until we have evidence, Pinker argues, we do not know how dignity operates. He uses the case of dwarf-tossing, among others, to illustrate his point. S. Pinker, “The Stupidity of Dignity: Conservative Bioethics’ Latest, Most Dangerous Ploy,” *New Republic*, 28 May 2008, note 5, <https://newrepublic.com/article/64674/the-stupidity-dignity>, cited in Leget, Borry, and De Vries, “‘Nobody Tosses a Dwarf!’ ” see note 6 above.

53. Ibid.

54. A. Henley, “Hollywood Should Know Better: You Can’t Tell Evil Just By Looking,” *Washington Post*, 20 February 2019, A21.