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What's Knowledge Got to Do with It? Ethics, Epistemology, and Intractable Conflicts in the Medical Setting

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ABSTRACT

This article utilizes the case of Ms H. to examine the contrasting ways that surrogate decision makers move from simply hearing information about the patient to actually knowing and understanding the patient's medical condition. The focus of the case is on a family's request to actually see the patient's wounds instead of being told about the wounds, and the role of clinical ethicists in facilitating this request. We argue that clinical ethicists have an important role to play in the work of converting information into knowledge and that this can serve as a valuable way forward in the midst of seemingly intractable conflicts in the medical setting.

In "Choruses from 'The Rock,'" T.S. Eliot asks a pair of important questions that clinical ethicists should ponder: "Where is the wisdom lost in knowledge? Where is the knowledge lost in information?"¹ These questions are important because they suggest a helpful distinction of wisdom from knowledge, and knowledge from information. For the purposes of this article, we will adopt a basic definition of knowledge as justified and true belief, whereas informa-

tion may or may not be true and has not necessarily been clearly justified.² Additionally, these questions suggest a helpful hierarchy, in which wisdom is the ideal, followed by knowledge, and then by information. This presents us with a profound task, namely the step-wise conversion of information into knowledge and then ultimately the conversion of knowledge into wisdom. In this article, we are especially interested in the conversion of information to knowledge. That is, how does a spouse, a guardian, a son or daughter, a sibling, or other surrogate decision maker move from hearing all the bits and pieces of *information* about a patient to *knowing* a patient's condition, by which we mean truly understanding and rightly believing certain facts and realities to be the case for a particular patient. If not careful, the ethical doctrine of informed consent has the potential to blur the distinction between information and knowledge. Simply put, the provision of information is not sufficient for knowledge and understanding. Instead, different modes of coming to know and understand a patient's medical condition (of converting information into knowledge) should be considered. In this article, we draw special attention to knowing by verbal testimony versus knowing by direct perception.

To explore this issue, we will present and discuss the case of Ms H. Our focus in presenting this case is on several related questions: First, how do we better navigate seemingly intractable conflicts

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in a medical setting? Second, how does a patient's family or surrogate decision maker come to know and understand a patient's severe medical condition? And third, what role should clinical ethicists have in helping a patient's family come to know and understand a patient's severe medical condition? Or stated differently, we might ask, what does ethics have to do with epistemology, and why does it matter in the medical context?

We suggest that part of the way in which we might better navigate intractable conflicts in a medical setting is by tending more closely to epistemological issues, namely how a family comes to know and understand a patient's medical condition. This is not an *amoral* endeavor, however. Instead, knowing and understanding are facilitated by, and in some cases predicated upon, moral actions such as truth telling, promise keeping, and compassionate support. In addition there are values at stake such as privacy, emotional harm, and trust. As such is the case, clinical ethicists have an integral role in helping a patient's family to know and understand a patient's severe medical condition.

THE CASE OF MS H.

The patient, we will call her Ms H. (this is not her real name), was a middle-aged female. Ms H. was initially admitted to the hospital from another hospital for severe tissue infection. Ms H. had a large number of siblings, no living parents, no children, and no known spouse. Significantly, for several years immediately prior to admission, Ms H. had a chronic, nonhealing sacral decubitus ulcer that extended along her buttocks and perineum.

Ms H. presented to the outside hospital with nonspecific complaints. On examination, the medical team discovered significant worsening of her decubitus ulcer, including maggots in the decubitus ulcer site. Ms H. underwent repeated surgeries for extensive debridement of her wounds and was placed on antibiotics to treat a necrotizing fasciitis infection ("flesh-eating infection") in the wounds. Following her second debridement, the medical team felt Ms H. needed more complex surgery and requested transfer for further services to a more advanced care hospital. When the patient arrived at the advanced care hospital where the ethics consultation process took place, she was sedated, on a ventilator, and full code. Ms H. did not have a health-care power of attorney or living will documents upon admission. Per hospital policy, in the absence of a spouse, adult children, or parent, the patient's siblings would serve as her default surrogate decision

makers. A majority decision amongst the siblings would be considered to be authoritative.

The Ethics Consultation Service was consulted by members of the medical team caring for Ms H. during the first week of her admission at the advanced care hospital. Initially, Ms H. was judged by the medical team not to be a candidate for surgery due to the extensive nature of the infected wounds and a very poor prognosis. Consequently, the medical team was pursuing discussions with the patient's large family about the goals of the patient's care. Ms H.'s siblings were not in agreement about the right or best course of action regarding end-of-life care for Ms H., however. Citing religious belief and the patient's tenacity, some members of the family insisted on further curative and life-sustaining medical treatments, while others were considering the medical team's recommendation to discontinue or to not escalate some medical treatments and shift to a focus on treating the patient's symptoms and prioritizing the patient's comfort. The medical team initially asked the Ethics Consultation Service for guidance in resolving intra-family conflict regarding goals of care for the patient.

The case became further complicated, though, shortly thereafter, when the surgical team decided that the patient was a surgical candidate and offered the patient's surrogates the option of pursuing further surgical debridement of Ms H.'s wounds. The family was in support of the surgery, despite the surgeon's candid warnings that there was a real possibility that the surgery would cause more pain and suffering, serious debilitation, and would likely require a long and difficult recovery marked by a diminished quality of life. As the family would emphasize repeatedly throughout this case, they claimed that the patient was a fighter and would want to live. The patient then underwent surgery to further debride her extensive wounds.

Although Ms H. survived the surgery, it was even clearer to the medical team afterwards that her prognosis was extremely grim. Nonetheless, over the next several days, there were repeated reports that her family was divided on whether to transition to comfort care or to pursue aggressive medical treatment. The majority seemed to favor pursuing aggressive medical treatment. The conflict between the medical team and the family showed signs of becoming more entrenched. The medical team was more and more convinced that Ms H. would not survive her current medical condition and would not benefit from various medical treatments. But most of her family advocated for maximal medical treatment, despite the possibility of causing pain and suffering

without clear benefits. Further exacerbating the tension, some of the family made bold statements that if the medical team did not do everything for Ms H., the medical team would be murdering her.

Over the ensuing days there were continued struggles (for example, regarding resuscitation status) within the patient's family and between the family and the medical team. Nonetheless, the patient's chances of survival at this point were considered to be very low. The medical team met with members of Ms H.'s family to clearly explain her severe medical condition and poor prognosis with no definitive cure available, expressed that further medical and surgical interventions would be futile, and recommended withdrawing life-sustaining treatments and moving to comfort care. Nonetheless, various family members were adamant that the patient would not want anything withdrawn and insisted on continuing with medical treatment.

We cannot know what the medical team wondered in their own minds, but we can plausibly imagine that some might have been thinking at this point: "Does this family hear what we are reporting to them about the patient's condition? Do they really know and understand the severity of her condition?"

A REQUEST

In the midst of this seemingly intractable conflict, members of the Ethics Consultation Service were able to meet with several of the patient's siblings and hear their version of what had taken place, their reasoning process about medical decisions, and their concerns and questions. The meeting served to build rapport between the Ethics Consultation Service and the patient's family. During the meeting, some of the family expressed understanding of Ms H.'s dire medical condition, but also voiced their general hope that the antibiotics would treat her infection, given enough time. There were indications during this conversation that some of Ms H.'s family did not know, or believe, precisely how severe the patient's wounds were, or the limitations of the antibiotics, given her extensive wounds. The family expressed distrust in the information provided to them because of their perceived shifts in the medical team's language, as well as the team's shift from judging the patient not to be a surgical candidate initially to then saying that she was a surgical candidate following further monitoring and review.

During the meeting, an important request was made. Several of family members expressed that they would be interested in seeing pictures of the patient's wounds in order to better understand the severity

of her condition, because they claimed they had no way of knowing that the wounds really had become worse. Initially, one might wonder why the family needed to see the wounds (or pictures of the wounds) in order to know or understand the patient's condition, when the medical team had been repeatedly describing in detail the extent and severity of Ms H.'s wounds and overall medical condition throughout her hospital stay. In short, why did the family not know and understand the patient's severe condition on the basis of the medical team's verbal testimony or report about her condition?

Significantly, there are multiple ways of coming to know and understand a particular situation. The family's request reflected an effort to come to know the patient's condition by way of directly seeing or perceiving her reportedly severe wounds, rather than know about her condition, strictly based on the verbal testimony/report of the medical team. For the purposes of this article, then, it is useful to distinguish (1) knowing based upon verbal testimony and (2) knowing based upon direct perception. Knowing based upon verbal testimony is likely the typical practice and goal in most medical settings, whereby medical teams provide verbal reports about the patient's medical condition to the patient's spouse, family, or friends, to help them to come to know the patient's medical condition. Knowledge based upon direct perception, by contrast, involves a spouse's, family's, or friend's coming to know and understand the patient's medical condition by way of actual, firsthand experience of the patient's body (for example seeing the patient's wounds, hearing groans, touching an amputated limb). Therefore, Ms H.'s family was not necessarily trying to be difficult in requesting to see her wounds, but instead appeared to be asking for a categorical shift in how they could come to know and understand the patient's medical condition. Instead of being limited to knowing by verbal testimony, the patient's family sought to know by direct perception of the patient's wounds. Such a request represents a commendable effort on the family's part to know the patient's medical condition more surely, directly, and perhaps comprehensively.

ETHICAL ANALYSIS OF THE REQUEST

It is worth pausing to consider at this point why a request to see a patient's wounds might be ethically significant. There are at least three clear moral benefits that may result. First, the family might be able to engage in better decision making for the patient if they are able to more fully know and under-

stand the patient's medical condition. Second, honoring their request may increase the sense of partnership between the medical team and the surrogates. In particular, it would help to avoid a Wizard of Oz type effect, whereby the medical team seems to work behind a curtain and ask the surrogates to simply trust verbal reports. Third, if family members are provided with greater insight into and understanding of a patient's medical condition, then they and the medical team might come to greater agreement, and thereby potentially diffuse or resolve previous conflicts, as well as thwart future conflicts.

The family members' request to see Ms H.'s wounds was not without moral concerns, and it was important to address several issues and questions before the family saw pictures of Ms H.'s wounds (or even her actual wounds). For example, it is vital to maintain respect for a patient's privacy when family members are shown the patient's wounds or other injuries. In the case of Ms H., this was especially important, given the location of her wounds. Therefore, in these cases, it should be clearly addressed who will be allowed to see a patient's wounds. Should anyone in a family be allowed, or only those most directly involved in surrogate decision making? What would the patient want, if the patient could speak on his or her own behalf?

Bound up in a concern for patients' privacy is a deeper ethical commitment to respect patients as persons. Thus, it is important to critically assess family's motivations for requesting to see a patient's wounds. Is this for the sake of better understanding a patient's medical condition, or a matter of curiosity and voyeurism? Voyeurism disrespects patients and has no place in the clinical setting.

An additional consideration, when the patient is alert (although still lacking decision-making capacity), is whether the patient is agreeable to surrogate decision makers seeing her/her wounds. In thinking through such requests from family members, a patient's wounds should never be considered separately from a consideration of the patient as a thinking and feeling person who possesses those wounds. Such considerations may constitute a reason to not utilize photographs of the wounds, which may have a greater potential (when compared to seeing physical, bodily wounds) to isolate the wounds as an abstract feature separate from the patient.

If the family's motivations to see a patient's wounds/injuries derive from the morally laudable effort to better understand the patient's condition, so as to make better decisions, then it is important to consider whether the family will simply be shown

the wounds, without explanation, or whether a medical professional will be present to explain the nature, significance, and severity of the wounds. Trained medical professionals can play an important role in these situations by augmenting the ways in which family members perceive a patient's wounds, which, in turn, may have the salutary effect of increasing and deepening the family's understanding. Without this framing or contextualization of what is being seen, there is the risk of actually misinforming surrogate decision makers and thereby failing to achieve knowledge and understanding.

During a magician's performance, the audience "sees with their own eyes" someone disappear, as if by magic, even though this is not what actually occurs. Similarly, the very strong visual display of wounds or other injuries might lead away from understanding, if not provided in a responsible framework or context that gives greater meaning and clarity to what is seen. That is, showing family members the wounds themselves, especially if done without any medical contextualization, has the real potential to confuse and distort surrogate decision makers' understanding of the patient's condition. In particular, surrogate decision makers may judge the wounds to be even more severe than they are or even less severe than they actually are.

It is also the case that verbal reports about a patient's condition can confuse and distort surrogates' understanding of the patient's condition. For example, medical professionals may use euphemism to talk around the plain facts of a patient's condition. Or an inexperienced clinician with limited medical experience may present a patient's condition as more severe than it is, or otherwise may use language that surrogates cannot understand. The possibility that a surrogate may misunderstand a patient's condition is not, on its own, a sufficient reason to reject one course of action over another. Instead, what should be guiding is whether the medical team has the patience, knowledge, and communication skills to assist surrogates in the process of seeing a patient's wounds, so as to be properly attuned to their medical meaning and significance.

Finally, seeing a loved one's wounds or injuries can be deeply distressing, and it is important, therefore, to consider how family members should be prepared and supported by the healthcare team to reduce the distress that they might feel. For example, it might be helpful to clearly explain to family members what they are going to see, before they are shown a patient's wounds/injuries, to enable them to be better prepared for what they will see. It also may be beneficial, especially if family members request

it, for a member of the healthcare team to be present with the family when they see the patient's wounds so as to provide a comforting and supportive presence during a potentially distressing experience. In similar fashion, it is important that members of the healthcare team are prepared for and equipped to handle potential distress from seeing a patient's wounds. This is especially important in the case of healthcare team members (for example, ethics consultants) who are not regularly involved in tending to and caring for a patient's wounds. In the effort to sufficiently support family members who request to see a patient's wounds, it is also important to support members of the healthcare team who may be deeply distressed by seeing particular wounds. In the same way, there should be support for members of the medical team who may object to showing a patient's wounds to surrogate decision makers.

Suffice to say, the request to see a patient's wounds is not a simple request, ethically speaking. While there is good to be gained from a respectful process of showing a patient's wounds, there are also moral concerns that need to be considered. In particular, we have highlighted several concerns relating to the privacy and dignity of patients, the possible distress of surrogate decision makers and medical team members, and the potential that an uninformed perception of wounds may distort surrogate decision makers' understanding of a patient's condition. Undoubtedly, different situations will warrant different courses of action. Part of the role of a clinical ethicist is to acknowledge and assess the various ethical considerations relative to the situation, to present the stakeholders (surrogate decision makers, members of the medical team) with the positives and negatives of a request to see a patient's wounds, to offer a recommendation, and to continue to work with the various stakeholders to arrive at a morally defensible decision.

THE CASE OF MS H. (CONTINUED)

In the case of Ms H., members of the Ethics Consultation Service reported her family's request to see pictures of her wounds to the medical team. Members of the service also conveyed the family's concerns about Ms H.'s privacy, and their desire that only immediate family be able to see the patient's wounds. At the end of the week, a significant number of Ms H.'s family were able to be present for a family meeting with the medical team to revisit the goals of care. While the plan had been to show the surrogates pictures of Ms H.'s wounds, the medical team instead offered to show the wounds them-

selves, while performing a necessary change of dressings. Several family members chose to see Ms H.'s wounds. Before seeing them, though, they were clearly and compassionately warned about the potentially disturbing sight of the wounds. Additionally, the family requested that one of the ethics consultants be present while they viewed Ms H.'s wounds. Afterwards, a number of the family members were visibly distraught by what they had seen and needed time to recover before eventually taking part in the family meeting.

We wish that we could say that this was a clear, game-changing moment, and at this point the family and the medical team were able to agree on the best course of action for Ms H. That was not the case. Seeing her wounds had a considerable impact on the family members who chose to see the wounds, but these were some of the same family members who were already more sympathetic to the medical team's recommendations. The majority of the patient's siblings remained fixed in their resolve not to withdraw any medical treatments. Perhaps if the entire family had seen her wounds, they might have decided differently, but forcing such an experience on anyone would arguably constitute a wrong. Therefore, the conflict between the medical team and Ms H.'s family persisted for several more weeks until Ms H. underwent respiratory arrest and died.

INTRACTABLE CONFLICTS, EPISTEMOLOGY, AND ETHICS

Despite the persistent disagreement and conflict in this case, the decision to allow family members the opportunity to see the patient's wounds was ethically important, and is worth reflecting on more generally now, by returning to several questions that were introduced at the beginning of this article. First, how can we better navigate seemingly intractable conflicts in a medical setting? As evidenced by the case of Ms H., we suggest that, sometimes, part of what is contributing to the intractability of conflicts in the medical setting are gaps in a surrogate decision makers' knowledge and understanding of a patient's condition. By attending to or minding the gaps in knowledge, so to speak, we can better navigate seemingly intractable conflicts. This prompts us to ask, secondly, how do a patient's family members or surrogate decision makers come to know and understand a patient's severe medical condition? Perhaps most typically, surrogate decision makers come to know and understand on the basis of the medical team's verbal testimony/report about the patient. As this case reveals, however, there are other,

important ways of helping to convert the pieces of information that surrogate decision makers hear into knowledge and understanding of a patient's condition. In particular, sometimes knowing by direct perception will be important.

At this point, though, a skeptic might ask, "Okay, this is all well and good, but what does it have to do with ethics? What role should a clinical ethicist have in helping a patient's family come to know and understand a patient's severe medical condition? Or, stated differently, what does ethics have to do with epistemology, and why does it matter in the medical context?" To answer this question, it is necessary to address two additional questions. First, are there moral conditions/foundations that are necessary for the possibility of knowledge and understanding? Second, are there moral consequences that result from knowing and understanding?

Regarding the first question, there are moral conditions/foundations that must be in place for knowledge to be possible. For example, there must be access to not just any source of information, but a trustworthy source of information (especially in cases of knowing by verbal testimony). This requires that the source is well informed, accurate, and sufficiently precise. Additionally, the source should be such that he or she tells the truth and keeps promises.

As a second example, and perhaps less obviously, an individual must have the will and courage to know in the face of some difficult truths or realities. A distinctive feature of human rationality is that some truths are harder to face and accept than others (an intelligent computer, by contrast, would not likely experience this burden). As a result, human knowing not only requires certain faculties of reason, logic, and perception, but also strength of will and the courage to encounter and engage with difficult realities and situations.

Regarding the second question, there are a number of important moral consequences that result from knowing and understanding, several of which have already been mentioned in this article. First, knowing and understanding facilitate better decision making by the patient's surrogates. Decisions made on the basis of justified and true beliefs (that is, knowledge) are likely to be more sure, consistent, and defensible than decisions that are based on incomplete or inaccurate bits and pieces of information. Decisions that are based on fragmented and inaccurate information increase the risk of doing serious wrong to the patient. Further, when surrogates learn that they have been working with incomplete or inaccurate information, they are likely to feel regret and/or anger, and may second guess de-

isions, which can result in additional confusion and protracted conflict.

Human knowledge and understanding are imperfect and limited. But an effort to move from decisions that are based upon fragmented and potentially inaccurate information to decisions that are based upon knowledge and understanding of a patient's condition is a substantial and valuable improvement that can help to minimize the harms and wrongs associated with inadequate decision making by surrogates. As a result, the effort to better facilitate surrogates' decision making through increased knowledge and understanding shows greater respect for surrogates, and also for the incapacitated patient for whom decisions are made.

A second major consequence of knowledge and understanding is the possibility for an increased sense of partnership and/or solidarity between the medical team and surrogate decision makers. This partnership and sense of solidarity can result from two sources: (1) due to working from a common/shared set of facts and understanding about a patient's medical condition, and (2) due to surrogates' appreciation for the medical team's efforts to ensure knowledge and understanding.

A third moral consequence is that, either because of or independent of the above two moral consequences, knowledge and understanding may facilitate the resolution of conflicts between surrogate decision makers and members of the medical team, or otherwise thwart future conflicts. While not sufficient to ensure agreement between members of the medical team and surrogate decision makers, knowledge and understanding of a patient's medical condition enhances the possibility for agreement between the various stakeholders in a patient's care.

Therefore, to return to the question of what ethics has to do with epistemology, ethics has everything to do with epistemology. Ethics is vital for elucidating and prescribing certain moral conditions (for example, truth telling, promise keeping, and so forth) that are necessary for coming to know and understand. As such, clinical ethicists should be amongst those individuals advocating for and helping to promote these conditions in clinical settings. Additionally, ethics serves to illuminate certain moral goods (for example, respect for persons, mutual cooperation and collaboration, and the resolution of fractious conflicts) that flow from increased knowledge and understanding of a patient's condition. Clinical ethicists, in turn, should strive to promote, highlight, and commend the moral goods that result from increased knowledge and understanding during ethics consultations.

Clinical ethicists need not be epistemologists, but they have a crucial role to play in promoting the moral conditions for knowledge and understanding, and in promoting the good consequences that can result from knowledge and understanding. To promote those good consequences, sometimes clinical ethicists will have to get into the epistemological trenches, so to speak, and actually assist with converting information into knowledge and understanding of a patient's condition. Nor is this necessarily a singular occurrence. Instead, the conversion of information into knowledge and understanding needs to be attended to at each phase of discovery during a medical encounter.

One of the ways that clinical ethicists can do this is to highlight and make room for the different ways of coming to know and understand a patient's medical condition. While sometimes verbal testimony from the medical team about the patient's condition will be sufficient, at other times coming to know by way of direct perception of a patient's present medical condition will be necessary. Clinical ethicists can serve a valuable role in distinguishing these ways of knowing and advocating for them, as appropriate to the situation. Part of determining what is most appropriate in the situation will be an evaluation of which route is most likely to promote actual knowledge and understanding of a patient's condition, along with respect for particular patients with their own values and preferences.

In the case of Ms H., there are several ways in which clinical ethicists in this case performed valuable actions that may have contributed to surrogate decision makers' knowledge and understanding:

1. Met with surrogate decision makers, listened to questions, and developed a trusting rapport.
2. Advocated for the surrogates' ability to know and understand the patient's medical condition by direct perception, instead of only knowing by testimony.
3. Helped to prepare surrogates for the distressing nature of seeing the patient's wounds.
4. Literally stood with the surrogates while seeing the patient's wounds and provided a comforting and supportive presence. This was likely key to augmenting the courage that family members needed in order to view Ms H.'s wounds and thereby come to know and understand her condition better.
5. Encouraged and supported the medical team in providing compassionate but candid assessments of the patient's condition to the patient's family, as well as transparency about what medical treatments would and would not be offered at various points.

A CONCLUDING QUALIFICATION

Unfortunately, even if surrogate decision makers genuinely know and understand a patient's severe medical condition, this will not necessarily lead them to agree with the medical team's recommended course of action. In addition to what individuals know about a situation, there may be a range of diverse and divergent value judgments such that surrogate decision makers and the medical team ultimately part ways on what they believe to be the good or right course of action for a particular patient. However, what we have been at pains to convey here, is that before trying to fully adjudicate between different moral perspectives on what is good and right, it is vital to address the issue of converting information about a patient's medical condition into knowledge and understanding of the patient's medical condition. Clinical ethicists must mind the gaps in surrogates' knowledge and understanding of a patient's condition. This attention to knowledge is foundational for the subsequent work of generating a constructive and meaningful dialog around differing moral perspectives. Perhaps ultimately, in order to achieve this next step—to better mediate and resolve moral difference and conflicts—we will need to consider T.S. Elliot's questions again and seek to find the wisdom we have lost amidst knowledge.

CONFLICTS OF INTEREST

The authors have no relevant conflicts of interest to disclose for the publication of this article.

NOTICE ABOUT CASE PRESENTATION

Some details of the case presented in this article were intentionally omitted or left vague in order to protect the privacy of the patient and the patient's family, as well as the privacy of caregivers. Written informed consent by the patient or patient's surrogates was not obtained for the presentation of this case.

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NOTES

1. T.S. Eliot, "Choruses from 'The Rock,'" in *The Complete Poems and Plays: 1909-1950* (New York: Harcourt Brace, 1980), 96.
2. For a fuller articulation and analysis of the limitations of this basic definition, see E. Gettier, "Is Justified True Belief Knowledge?" *Analysis* 23, no. 6 (1963): 121-3.