Narrative: A Family Meeting

Dr. and Mrs. Jones are an elderly couple living in the same house where they raised their five children. For the past decade, Mrs. Jones has been increasingly confused, and she now requires in-home assistance most of the time. Recently, Dr. Jones has become more confused as well. Dr. Smith is the primary physician for both Dr. and Mrs. Jones, and, at a recent appointment, the couple’s oldest son, Tim, reported that on several occasions in the past month Dr. Jones became violent towards his wife. Tim asked Dr. Smith to prescribe sedatives for Dr. Jones—not enough to make him sleep, but enough so that he would become less agitated and not lash out at his wife. Dr. Smith considered the request but was uncertain whether prescribing a medication to Dr. Jones for the benefit of Mrs. Jones would be appropriate. Unsure how to proceed, Dr. Smith contacted the on-call ethics consultant at his hospital for assistance.

Nurse Williams was carrying the ethics pager. When she received the call, she discussed the case with Dr. Smith and met with Tim to get further information. Although Nurse Williams was assigned to carry the ethics pager and had attended a one-week “bioethics intensive” course at Johns Hopkins University, she was not sufficiently trained to address such a complex case alone. Accordingly, Nurse Williams contacted the clinical ethicist, Dr. Brown, at a university hospital approximately 100 miles away.

Dr. Brown discussed the case with Nurse Williams and then called Dr. Smith for more information. Based on these discussions, Dr. Brown formed a preliminary recommendation; however, understanding the complexity of the case, he requested a meeting to include Dr. and Mrs. Jones’s five adult children, Mrs. Jones’s in-home assistant, and Dr. Smith. Nurse Williams scheduled the conference in the hospital’s telemedicine suite so that Dr. Brown could participate via videoconference. Prior to the meeting, Dr. Brown and Nurse Williams discussed how best to structure the discussion.

Nurse Williams started the meeting by having everyone introduce themselves. She then asked Tim to discuss his concerns and his ideas for potential solutions. As Tim was talking, Dr. Brown saw an uneasy look come over the face of Sally, one of the couple’s daughters. After Tim finished talking, Mrs. Jones’s assistant affirmed that on several occasions Dr. Jones had been violent towards Mrs. Jones. As the group talked, it seemed
that there was a growing agreement that providing a mild sedative to Dr. Jones might be appropriate. Dr. Brown noted that Sally was looking down throughout this discussion and seemed to be fidgeting. Dr. Brown then addressed Sally directly, asking her opinion. At this prompt, Sally explained that though her father was a physician, he had always been opposed to medications. He refused to give his children aspirin, antibiotics, or any other medications, and he himself refused to take any medications even after developing high blood pressure. She expressed her belief that her father would never take a sedative.

Dr. Brown asked the other children, and they all agreed. Tim said that if Dr. Smith prescribed the medication, they could slip it into his father’s food without him noticing. At this point, the children began arguing. The tension between the siblings increased, and Nurse Williams stepped between two of the siblings to de-escalate the argument. Nurse Williams was thereby able to calm the participants and lead the group back to the discussion.

During the course of the discussion, Dr. Brown and Nurse Williams probed deeper into the risk that Dr. Jones posed to Mrs. Jones. They noted that, if Dr. Jones was indeed violent towards his wife, it would be imperative to contact adult protective services and potentially separate the couple. The children and Mrs. Jones’s assistant stated that these incidents occurred when Mrs. Jones needed help in the bathroom. When she called for help, Dr. Jones would come to assist, and Mrs. Jones often scratched or hit him due to her dementia. Due to Dr. Jones’s confusion, at times he responded to these “attacks” by slapping her. The children and assistant do not believe that these occurrences place Mrs. Jones at risk, and all agree that there is no need for emergent intervention; however, all agree that finding a solution to this problem is essential.

At the end of the meeting, Nurse Williams thanked everyone for coming and thanked Dr. Brown for participating. She and Dr. Brown spoke about recommendations. Based on the conversation, they gathered that medicating Dr. Jones would be contrary to his longstanding beliefs and practices and would feel deceitful for his children and caregivers. As such, Dr. Brown advised that such a course of action would not be ethically permissible. He and Nurse Williams discussed other potential solutions (e.g., increased in-home assistance, relocating the couple to an assisted living facility, separating the couple, contacting adult protective services), and Nurse Williams drafted a note addressing the history, ethics background, ethical analysis, and recommendations. She sent the draft to Dr. Brown (via Health Insurance Portability and Accountability Act [HIPAA]-compliant email), who made several recommendations for editing the note and sent it back. Nurse Williams then finalized the note, placed a copy in the patient’s chart, and discussed the recommendations with Dr. Smith.
Remote HCEC
Competency in health care ethics consultation (HCEC) requires significant training and experience. Although the American Society for Bioethics and Humanities (ASBH) has published core competencies necessary for those who provide HCEC [1], most organizations continue to rely on untrained or minimally trained volunteers (such as those who have attended a one-week intensive course) for such services. A survey of 40 Maryland hospitals with ethics committees found that only 11.4 percent required any training or apprenticeship for personnel performing HCEC [2], and two surveys found that less than half of people who perform HCEC had formal training in clinical ethics [2, 3]. As such, it is not surprising that many clinicians believe that their ethics consultants are unqualified and, therefore, do not request consultations [4]. In response to the lack of local HCEC expertise, some organizations now contract with larger hospitals or universities to provide support for HCEC, which has paved the way for remote HCEC.

Modes of Remote Health Care Ethics Consultation
In our experience, remote support for HCEC can be provided in several ways: email, telephone, or telemedicine (two-way audiovisual conferencing, often augmented by electronic access to medical records including laboratory and radiological studies) [5]. Several vendors sell prepackaged telemedicine systems (e.g., GlobalMed, AMD Global Telemedicine, Rubbermaid Healthcare), and experts have published recommendations for centers that wish to develop such programs [6]. When developing any telemedicine program, however, centers must be cognizant of measures necessary to protect private health care information (PHI), and, in the United States, such systems must be compliant with HIPAA [7].

In considering each of the above modalities for providing remote HCEC support, it is necessary to reflect on the overall goals of the HCEC process. According to ASBH:

The general goal of HCEC is to improve the quality of health care through the identification, analysis, and resolution of ethical questions or concerns. This general goal is more likely to be achieved if consultation accomplishes the intermediary goals of helping to: (1) identify and analyze the nature of the value uncertainty or conflict that underlies the consultation; and (2) facilitate resolution of conflicts in a respectful atmosphere with attention to the interests, rights and responsibilities of all those involved. Successful HCEC will also serve the goals of helping to promote practices consistent with ethical norms and standards; informing institutional efforts at policy development, quality improvement, and appropriate utilization of resources by identifying the causes of ethical concerns; and assisting individuals and the institution in handling current and future ethical problems by providing education in health care ethics [8].
Each modality for providing remote HCEC support has strengths and weaknesses with respect to these goals, and we (both authors) have employed each at various times depending on the situation, resources available, and needs of those requesting assistance with complex HCEC.

**Email.** Email is often extremely helpful because it enables those requesting a consultation to do so at any time on any day and the expert consultants to respond when they are able. Although this method of communication might be the most flexible, in our experience it can be difficult for those requesting consultations to explain the nuances of an ethically and clinically complex case in an email, and it can also be challenging for the requester and expert to have an effective dialogue about the case. Further, PHI can only be sent over an encrypted, secure system but, because some requesters might not use that type of email, it can be impossible to provide sufficient detail. As such, we find that email alone is generally a suboptimal system for such support in most cases.

**Telephone.** Telephone is perhaps the most common form of communication for remote consultation assistance. With the ubiquity of cell phones, requesters can immediately access experts. Furthermore, because it doesn’t require the same kind of encryption technology as email, telephone communication allows more detailed discussion of clinically and ethically complex issues and nuances of a case regardless of an individual’s technological resources. Such communication may be augmented with HIPAA-compliant email, which facilitates the transmission of background case materials to and from the expert and also allows the expert to send a note that can be placed in the patient’s chart.

A significant limitation of telephone communication, however, is the inability of the expert to “be present” in a family meeting. As noted in the case presented above, Dr. Brown’s ability to observe affective cues was integral in revealing and exploring essential elements of the case. Therefore, although telephone communication can be an excellent way for requesters and experts to communicate one-on-one, the telephone is unhelpful when careful discernment of affective cues from participants is needed.

**Telemedicine.** Telemedicine provides many of the benefits of telephone consultation, but it also allows the expert to see all participants in discussions. In our experience, the ability to see who is talking and observe nonverbal cues of the speaker and others present can be essential in such cases. As noted in the case presented here and in cases we have presented previously [9], seeing participants’ physical state (facial expressions or posture, for example) is often critical.

Although telemedicine has significant advantages, there are also significant barriers to using such technology. In our experience, telemedicine systems are expensive and require ongoing technical support and expertise. Local and remote telemedicine systems
must be compatible, and such communication must be HIPAA-compliant. Systems require high-speed connections, which can be difficult to guarantee in some remote locations. Furthermore, in many areas of the world, the necessary bandwidth can be impossible to procure without integrating satellite communication, which raises further privacy concerns.

**Recommendation**

In our experience with facilitating family meetings (both in-person and remote), we would argue that the use of a remote expert cannot replace having someone physically present at the location. We therefore believe tele-HCEC should be considered as a tool to link a local consultant or meeting facilitator with a remote expert in clinical ethics.

Firstly, we believe it would be difficult for an expert clinical ethicist to effectively facilitate a family meeting via telemedicine. There are times when the meeting facilitator’s physical presence is critical. As noted in the case presented here, the ability of Nurse Williams to physically insert herself between the siblings de-escalated the conflict. In family meetings, a facilitator might place a hand on a sibling’s shoulder, give a patient’s spouse a hug, help support a swooning parent, or otherwise provide physically demonstrable support to family members. These powerful gestures are impossible without physical presence. As such, we believe that, whenever possible, such meetings should be facilitated by someone who is physically present and that the expert should participate (but not facilitate) via telemedicine. However, when a remote location has no one sufficiently skilled and experienced to facilitate a family meeting, the only option may be to rely on an expert clinical ethicist to act as facilitator via telemedicine.

Secondly, HCEC involves reviewing medical records; talking with clinicians, nurses, and other staff members; seeing patients and talking with them as well as with family members; and organizing and scheduling meetings with staff or with family members. Such tasks can be more easily executed when someone is on-site to gather significant data prior to, or in tandem with, expert assistance. Prior to a consultation via telemedicine, a local consultant should provide significant background material to the expert [9].

Furthermore, ethics consultants doing remote consultations must be cognizant of legal and ethical issues that can vary by location and culture. For example, because laws regarding the unilateral withdrawal of life-prolonging interventions over the objection of the surrogate decision maker vary by state and country, an expert clinical ethicist must be well versed in the relevant norms and laws when providing support to clinicians in another state or country. Similarly, if a clinical ethicist were to provide HCEC support for a case in another country, local norms and laws could be significantly different than the norms and laws that the expert usually relies upon. Because HCEC relies heavily on cultural norms, statutes, and case law, a clear understanding of the relevant customs
and laws is essential. For example, all states in the US recognize death by neurological criteria, but many other countries and cultures do not accept such patients as dead; therefore, if an American clinical ethicist were to assist with a case in such a country, the consultant would need a good understanding of the local laws and customs regarding patients in permanent coma. As such, whenever expert clinical ethicists provide support to a remote location, knowledge and understanding of local norms and laws is essential.

**Conclusion**

HCEC via telemedicine offers a unique opportunity to enhance access to qualified clinical ethicists, provide support for medical professionals, and improve care for patients and family members. There is growing interest in the professionalization of HCEC, and ASBH is moving toward development of a national certification process for trained and qualified HCEC consultants [10]. As tele-HCEC support is increasingly deployed, it will be essential to perform well-designed research to help clarify how such services can be enhanced to meet the needs of health care professionals and the patients and families they serve.

**References**

8. American Society for Bioethics and Humanities, 3.
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