

What at first might seem as a conflict between the patient's benefit and her autonomy turns out to be the question, *What does Ann really want?*

Ann's stated preference for treatment in case of a life-threatening illness from which she could recover seems to support taking the tissue sample, because an accurate diagnosis is a prerequisite for the right treatment. However, this preferred course is in direct conflict with Ann's adamant refusal to undergo diagnosis. Because we have no way to judge whether her interest in treatment or her refusal to undergo a diagnosis best expresses her true will, we are left with a dilemma. There is no unqualified argument for the right course of action in this situation. Nevertheless, with her reference to a previously unhealed spider bite, Ann is obviously grounding her refusal to allow a diagnosis on false beliefs. This irrationality could be seen as a weak justification for not taking her refusal too seriously. Together, Ann's interest in treating a possible life-threatening illness and the opportunity to treat the possible hormone-receptive breast cancer with oral chemotherapy might justify acting according to the principle *in dubio pro vita*: when in doubt, favor life. The opportunity to extend her life-span from 12 months to 10 years through diagnosing and, if necessary, treating a possible cancer might outweigh the possible harm caused by a coerced diagnosis. All these aspects could justify diagnosing Ann without her agreement. However, because a change in German law significantly restricts coerced treatment against even the "natural will" of a patient lacking decisional capacity, as long as Ann refuses to assent, the strong recommendation in our German context would be to seek a legal guardianship through the courts before coercing diagnosis.

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## Commentary: Ethically Important Moments

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One way of approaching this case would be for the ethicist to consider the overriding ethical question of whether Ann is sufficiently competent to refuse to have a tissue sample taken to examine a mass in her breast. The consequences of her refusal are that potentially life-saving treatment may be denied, resulting in her likely death within one year. Reduced to its fundamentals, the ethical conflict concerns a clash between the offer of likely beneficial treatment and respect for Ann's autonomous wishes and choices about her own healthcare. This ethical issue arises from Ann's adamant refusal to undergo testing.

However, I suggest, in this case analysis, that Ann's case raises not just one overriding or fundamental ethical issue on which a decision can be made but rather a number of ethically important moments. Guillemin and Gillam<sup>1,2</sup> define ethically important moments as occurring when an approach to care or decisionmaking appears mundane or uncontentious but nevertheless has important ethical ramifications for a patient or health clinician. In this case commentary, I identify and discuss these ethically important moments to provide a map of moral issues that need to be considered by the ethicist called to consult. This is a deliberate analytic process designed to demonstrate an inclusive process of ethics consultation in which the goals are "to facilitate communication, clarify moral positions and arrange a safe moral space within which differences can be aired, understood and resolved."<sup>3</sup> Such a process is not predictive of the outcome but is designed to generate its own outcome, which emerges from the process itself.

I have selected three ethically important moments:

- 1) Ann's general competence and capacity: A psychiatrist has assessed Ann as lacking decisional capacity for most medical conditions based possibly on her paranoia, which cannot be treated due to her diabetes.
- 2) Ann's decisions and perspectives: Ann appears guarded and possibly paranoid, and she is refusing to allow a tissue sample to be taken. This is not in keeping with her previously expressed wishes to continue to enjoy life.
- 3) The ethicist's role: An ethical consult is called after the health team has failed to persuade Ann to change her mind.

The first ethically significant moment in this case begins with some certainty. *A psychiatric assessment demonstrates that Ann lacks decisionmaking capacity.* However, this specific clinical assessment carries important ethical implications, because it suggests that Ann does not have the capacity to understand relevant information, appreciate her medical situation and its possible consequences, or engage in rational deliberation about her own values in relation to a proposed treatment.<sup>4</sup> If Ann had been assessed as having no decisional capacity in any circumstances, without the possibility of improving this capacity, then it would be ethically appropriate for decisions about her healthcare to be made by a surrogate, in this case, her middle daughter. A surrogate decisionmaker's obligations are well established, especially when a person has previously expressed clear wishes about his or her healthcare. The surrogate decisionmaker relies on the known or previously expressed wishes of the patient to make a substituted judgment. According to

this case, Ann has previously stated that she would want treatment rather than "letting nature take its course."

Uncertainty creeps into this third ethically important moment, however, with the qualification of Ann lacking decisional capacity—for *most* medical conditions—and the fact that Ann's apparent paranoia (which may be contributing to her decisional incapacity) is untreatable due to her diabetes. It is difficult to assess whether Ann's paranoia is impacting on her ability to appreciate the importance of prognostic testing. It is difficult to know how Ann might react to having her wishes overridden in this area of her life, and how her relationship with her middle and other daughters may be affected by surrogate decisionmaking.

The ethical implication of an assessment of decisional incapacity is that a person's stated wishes may be overridden and replaced by another person's assessment of what is in his or her best interests. If this assessment is not accurate, there is a real possibility of harm. The ethics consultant can assist in identifying and promoting further analysis of these possible harms by asking questions about the psychiatrist's assessment of decisional incapacity for *most* medical decisions, including whether Ann's refusal of testing of the breast mass is an example of a medical decision for which she lacks capacity and whether there is scope for treatment of her paranoia other than by psychotropic medication. The ethicist may also ask Ann's family about whether there has been a history of guardedness and paranoia and how it has been previously managed.

The second ethically important moment represents a fundamental divergence between assessment and treatment aimed at promoting and enhancing Ann's interests and well-being and treatment that respects Ann's stated wishes.

Ann is refusing to allow tissue testing to take place, and without conducting that test, potentially beneficial and, in the case of breast cancer, life-saving treatment will not be provided. The outcome could be that Ann may develop breast cancer and die as a result of this preventable clinical condition. The questions posed by the ethics consultant would likely include the following: Has Ann refused treatment before? How much does she value her independence? How has she demonstrated this value? What reasons might there be for her developing a guarded view about medical practice and interventions? How can Ann be best supported to enable her to further explain her beliefs about the spider bite? What does the testing involve? Is it likely to be frightening for Ann? Can it be conducted with minimal disruption for Ann? What are the risks of overriding Ann's refusal for testing? How is Ann likely to respond if her daughter overrides her refusal? What effect will this have on family relations? What are the benefits of testing? How burdensome is the likely treatment for breast cancer?

These "ethics" questions are aimed at assisting clinicians to examine and clarify their clinical goals. They would also help clinicians and Ann's family to better understand and consider approaches to minimize the apparent clash between providing a benefit and respecting Ann's stated choice to refuse testing.

The third ethically important moment concerns the timing of the request for an ethics consult. The request is made when conflict or uncertainty is obvious and when clinical decisionmaking is being restricted. This timing raises questions about whether ethics consultation is best seen as a reactive intervention or whether there may be a possible role for ethics consultation as preemptive work. Agich<sup>5</sup> suggests that the authority of ethics consultants emerges from their

ability to construct a basis for cooperation and engagement in dialogue among individuals who have diverse values, beliefs, and moral understanding; from their ability to identify shared values among this group of people; and from their ability to facilitate a rational discussion of the case. For Ann, this means that the ethicist has a responsibility to probe, encourage reflection, and promote ethical reasoning, opening up rather than closing down possibilities. Such questions can identify gaps between ethical and clinical values and can highlight ways to better align them so they are mutually supportive. In Ann's case, this means recognizing and discussing all ethically important moments, not just the moments that raise conflict.

I suggest that the process of identifying, posing, and then responding to these questions will yield the most ethically appropriate response. Based on the information provided by the case, there are good ethical reasons for overriding Ann's refusal of treatment. She is relatively young, and her conditions appear treatable. Conducting a breast biopsy is not, in itself, an overly invasive procedure, and Ann's previously expressed wishes are in contrast to her current guardedness and apparent paranoia. She is likely to value treatment if it will enable her to continue to enjoy her life.

However, as I have sought to demonstrate in this commentary, the ethicist's role is not only to reduce the complexities to one likely ethically appropriate outcome, although this is often important. A further aspect of an ethics consultation is to acknowledge the realities of clinical practice, the complexity of family and therapeutic relationships, and the history and fragility of a person's expressed healthcare wishes. A fine-grained approach that identifies ethically important moments

and the questions that these moments raise may support clinicians, patients, and their families to formulate their own ethically appropriate responses, which will emerge as a result of the process.

### Notes

1. Guillemin M, Gillam L. *Telling Moments: Everyday Ethics in Health Care*. Melbourne: IP Communications; 2006.
2. Guillemin M, Gillam L. Ethics, reflexivity, and “ethically important moments” in research. *Qualitative Enquiry* 2004;10(2):261–80.
3. Casarett D, Daskal F, Lantos J. The authority of the clinical ethicist. *Hastings Center Report* 1998;28(6):6–16, at 2.
4. Jonsen AR, Siegler M, Winslade WJ. *Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Medicine*. 7th ed. USA: McGraw-Hill Medical; 2010.
5. Agich G. Authority in ethics consultation. *Journal of Law, Medicine & Ethics* 1995;23(3): 273–83.

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## What Actually Happened

Multiple attempts were made to encourage Ann to allow a biopsy, including using words like “tissue sample” and “test” to talk about the procedure. Explanations that she might have cancer or some other life-threatening but treatable illness failed; Ann merely said that she knew the lesion was a spider bite and did not want to hear any more foolishness about it. Attempts to elicit why Ann was reluctant to have the biopsy done got the same response.

Jayne and her sisters had been approached about consenting to the biopsy on Ann’s behalf, because Ann had been assessed as decisionally incapacitated. Initially they thought this would be best, even if Ann had to be sedated before the procedure in order for it to happen. They believed that if she did have breast cancer that could be treated with oral chemotherapy, she would take the medication with her other medications without distress. They also believed that she would rather live 10 more years having had the biopsy and treatment than 1 year without the biopsy and no treatment. However, they were unwilling to sign a consent form for their mother to have a diagnostic procedure that she clearly said she did not want, even though they thought she would want it if she could understand. They could not offer an explanation as to why Ann was so adamant about not having cancer or for her resistance to the biopsy, except that she has always been profoundly distrustful, especially when it came to healthcare.

Indeed, during the time it took to find a bed in an extended stay facility, Ann began to say that she “would not go to a nursing home,” and that she would only be willing to go back to her own apartment. Her daughters and care providers all believed that home would not be a safe discharge for Ann, and her daughters thought it best not to push her into several things she did not want to do at once. They focused on making her comfortable with discharge to a facility and requested that care providers not address diagnosis or treatment for her breast mass for the time being. She was discharged to an extended care facility for physical therapy. Her daughters planned to make an appointment with the oncologist to address her breast mass. Several months later, no appointment had been made, and Ann was considered lost to follow-up.