examination, stating, "I already know what that is; I was bitten by a spider years ago, and it never healed." When neither family members nor members of the healthcare team could persuade Ann to change her mind, an ethics consult was called.

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Commentary: Denial or Delusion?

Karen Smith

Ann's situation is understandably troubling to both her family and her caregivers. Although she has agreed to hospital treatment to control her diabetes and to go to an extended care facility, she has repeatedly refused to allow diagnostics to confirm or deny a potentially cancerous mass in her breast. Her capacity to make this decision is the ethical question at hand, which focuses the dilemma on the choice between respecting her autonomy and promoting her medical well-being or the value of beneficence. One might understandably guess that the patient is in denial. Perhaps she merely requires further reasoning to allow her to reach the conclusion that biopsy testing is required to allow her to obtain an accurate diagnosis so that she can move forward with her treatment and life plans.

Several clues make me less than willing to believe that this may be so. First, for reasons not provided in the case, Ann has already been deemed by a psychiatrist as lacking in decisional capacity for "most medical decisions." This assessment is especially troubling, as it is not specified as to which ones Ann is capable of deciding. Is it merely the ones to which she agrees—thereby making her unable to decide on the ones with which she disagrees, such as the biopsy? We are not given a psychiatric diagnosis of any mental health disorder; we are merely told that she is guarded, possibly paranoid, but no signs of psychosis are indicated. The concept of capacity to make autonomous decisions remains one of the most difficult-to-assess issues in daily hospital practice and is often done inconsistently. It is difficult to respect a patient's right to make decisions (especially in the case of patients whose abilities vary) without violating another basic principle: the promotion of his or her well-being. This difficult balance was navigated by J. F. Drane in 1984 in developing his three standards for competency.[1] It seems that Ann's situation is well suited for his particular model of evaluation, given her ability to make some—but not all—decisions. It must be noted that the term "competence" is a legal term, and in the field of clinical ethics and medical practice now, the term that is most often used is "decisional capacity."

In this model, the standard for granting decisionmaking capacity goes up as the danger to the patient if he or she were to refuse treatment goes up. This means that for a simple treatment or procedure with clear patient benefit, such as obtaining a temperature, one need only grant *assent* to proceed.[2] There is little harm in refusing, and it is a quick and harmless procedure that requires little thought for consequences. The second level is for chronic conditions (such as Ann's diabetes), when diagnosis is unclear (such as Ann's breast mass), and when treatments are dangerous or uncertain or when alternatives exist for treatments. Then the patient must be able to *understand the alternatives* and make a reasoned choice.[3] The third standard is for when the diagnosis is

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clear, the treatment is effective, and the patient is likely to die from refusal. In this situation, the highest level of capacity is required, and the patient must be able to *provide intelligible reasons* for refusing treatment, even if most persons would choose otherwise.[4]

If we evaluate Ann's situation, we see she is currently caught at the second level, but even then she is confusing. Ann has appeared to understand the implications of not treating her diabetes and has agreed to both hospitalization and placement in an extended care facility for further treatments; this decision is supported by the care team and her family. Where we hit the snag is Ann's refusal to allow the breast biopsy to confirm or deny if the breast mass is cancerous. In denying this procedure, we understand that she could quickly land in the third level, in which death could occur and an effective treatment is available (if her mass is a hormonally treatable malignancy). It is also apparent that her stated reason for refusal, having been bitten by a spider, is not considered an intelligible reason for refusal.

Why is Ann so reluctant to consent to a minor procedure when the risks are relatively low and the benefits (if cancer is confirmed and oral medications can treat it) are so great? This is where I believe we need to discern whether she is suffering denial or delusion concerning her breast mass. Part of respecting our patient is treating him or her as a whole person, not just an illness. Therefore, it is important to know what her reasoning is to allow better treatment of the whole person, rather than just the mass. Denial of a potential cancer diagnosis is a common and rational reaction. Denial is treated by offering compassion, discussing the patient's fears, and allowing her time to assimilate smaller bits of information so that the healthcare team can broach the possibility of surviving both the diagnosis and the treatment of cancer. This said, there are several reasons to believe that Ann may be suffering from a specific delusion regarding her particular breast mass.

The concept of a patient who is sane and lucid on some subjects—such as Ann stating that she would want treatment for a life-threatening illness that could be treated with oral medication—but who then states an irrational reason to refuse a procedure to promote her best interests is not unique. In some ways, the 1978 case of *State of Tennessee Department of Human Services v. Mary C. Northern*[5] is eerily and frustratingly similar. Mary was admitted to the hospital with severe gangrene of both feet and needed surgical amputation in order to save her life. Mary was alert and oriented to person, place, time, and event at all times, and intelligent in conversation but adamantly refused amputation, stating that her feet had soot on them due to her oil heating and that she would improve without surgery. This patient, similar to Ann, did not express a desire to die but also would not accept that refusing surgery would result in her death. In this situation, the diagnosis and treatment were more clearly evident than in Ann's situation. The patient was found by the psychiatrist to be lucid, sane, and "functioning on a psychotic level with respect to ideas concerning her gangrenous feet."[6]

A more current evaluation of such episodic or specific areas in which patients appear to be convinced of an illogical belief or delusion, beyond what rationality can endorse, has been done recently by Jann E. Schlimme.[7] Because we are told that Ann "adamantly refuses" and that she is unable to be persuaded that it is not a spider bite, it appears that this belief is enduring. Schlimme states:

> Delusional convictions can be understood as highly private, explicitly known and incorrigible convictions which have

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> gained the status of a "justified belief," although being unjustifiable (and non-falsifiable) in discourse. According to the German tradition of phenomenological psychopathology two criteria can be named for delusional convictions: a) the extraordinary degree of conviction concerning particular ideas; and b) the outright rejection of alternative explanations, the so called *Unkorrigierbvarkeit* (incorrigibility) of these convictions (ideas).[8]

Although we do not have a psychiatric evaluation to confirm, it appears that Ann may be suffering from a delusion that she merely has a spider bite. If this is the case, per Schlimme, "the deluded person is ('*per definitionem*') ineffective and helpless with respect to altering these convictions."[9] If Ann has such a specific delusion, it would then significantly hamper her ability to pursue her stated goals of "enjoying life and wanting to continue living." The confirmation of wanting and pursuing treatment for her diabetes seems to be an autonomous (self-directed and chosen) true value, wherein the refusal of the biopsy is a specific aberration. Furthermore, if this is correctly a delusion, then she is not acting with true autonomy in refusing the biopsy, because she is unable to rationally review the conviction that she has a spider bite and to consider that not allowing the biopsy may cause her harm. Therefore, her autonomy to make this decision is impaired and a surrogate is required.

In this situation, her daughter Jayne is the appropriate decisionmaker to consent or deny the biopsy. It ought to be explained to the patient that the only way to confirm or deny if the mass is a spider bite is to complete the biopsy and that the healthcare team will use all medications required to minimize her discomfort during the procedure. Ann both fails to meet Drane's evaluation of capacity to refuse treatment and, more specifically, may have her autonomy impaired by the delusion of a spider bite. Overall, the psychological discomfort of going against a patient's autonomy may be mitigated by the knowledge that her capacity to make a choice, in this decision, is lacking due to a delusion, and overall beneficence will be greater once the results of the biopsy are known and once appropriate treatment may be started (or not, if the biopsy is negative).

Notes

1. Drane JF. Competency to give an informed consent: A model for making clinical decisions. *JAMA* 1984 Aug 17;252(7):925–7.
2. See note 1, Drane 1984.
3. See note 1, Drane 1984.
4. See note 1, Drane 1984.
5. *Northern v. Tennessee Department of Human Services*, 435 U.S. 950 (1978); available at http://law.justia.com/cases/tennessee/court-of-appeals/1978/563-s-w-2d-197-1.html (last accessed 14 February 2013).
6. See note 5, *Northern v. Tennessee Department of Human Services* 1978.
7. Schlimme JE. Is acting on delusions autonomous? *Philosophy, Ethics, and Humanities in Medicine* 2013;8(14); available at http://www.peh-med.com/content/8/1/14 (last accessed 3 Apr 2014).
8. See note 7, Schlimme 2013.
9. See note 7, Schlimme 2013.

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Commentary: What Does Ann Really Want?

Jens Clausen

Ann's "only a spider bite" case presents a challenging situation for clinical decisionmaking. In order to provide advice in an ethics consultation, the first step after summarizing the facts about Ann's medical condition would be determining possible alternatives of action. Because no safe treatment is possible without a prior diagnosis, a prophylactic treatment of the possible cancer is not recommended. So, if Ann does not change her mind and refuses to allow a diagnosis, what alternatives remain?

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