

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

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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.