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### DON'T I COUNT?

Alice is a seventy-year-old woman with metastatic breast cancer undergoing monthly chemotherapy treatments. Although she lives alone, her granddaughter, Louise, visits her several times a week and helps her do things she can no longer do for herself. Louise usually shops for Alice, washes her clothes, and cleans the house. In addition, she takes Alice to all her appointments. As Alice's treatments continue, Louise finds that Alice requires more frequent help of every kind. Alice seems to have increasing difficulty moving about her house and needs more help with her personal hygiene. Louise discusses with Alice the possibility of hiring someone to look after her and stay with her during the day and some evenings while Louise goes to work. Alice refuses to entertain the suggestion, insisting she is capable of taking care of herself.

Just before a routine office visit Louise tells the nurse, Rebecca, that Alice appears increasingly weak and has difficulty bathing, getting in and out of her wheelchair, and fixing her own meals. Louise explains that she works as a musician in a nearby city and keeps very irregular hours, which makes it difficult for her to help Alice with more than a few simple routine daily activities. She worries constantly that Alice will fall and injure herself. Other family members or friends are either unwilling or physically unable to share the responsibility of Alice's care. Louise's constant worrying and exhaustion have begun to affect her job performance and she occasionally misses rehearsals on days when Alice needs extra help. Rebecca agrees that Louise must have help taking care of Alice, at least

until Alice completes these aggressive treatments. She suggests they approach the doctor about their concern.

The two women explain the predicament to Dr. Ramsey, the oncologist caring for Alice, and ask him to order a consult for a home health nurse and/or meals-on-wheels. Alice immediately protests, "No, absolutely not. I feel well enough to take care of myself. Louise should go to rehearsals and not worry about me. If I fall, it's my problem, not Louise's." Dr. Ramsey asks Alice if she feels positive that she can manage by herself. Alice replies, "I certainly can. I don't want to hear another word about it." Continuing to address Alice, Dr. Ramsey says, "Well, if you say no to home health care the answer is no. My patients have the right to make their own decisions."

Despite Alice's wish to hear no more about this, Louise urges Dr. Ramsey to reconsider, emphasizing that Alice could easily fall and break her hip if left alone, which would set her health back tremendously and force Louise to leave her job to take over Alice's care full time. Dr. Ramsey replies, "I am sorry about your situation, but I cannot, in good conscience, try to persuade a patient to accept a service she clearly does not want." Louise tries to urge Dr. Ramsey again but he ignores her and only acknowledges comments from Alice. Rebecca tries to support Louise's concerns, but the doctor ignores her as well.

Later, after Alice and Louise leave the office, Rebecca tells Dr. Ramsey how frustrated she felt when he would not listen to their concerns about Alice. He reiterates that Alice is competent to make her own decisions and that she has a right to refuse home health care. He says he felt the need to focus on his patient rather than Rebecca or Louise because they seemed to be talking about the patient as if she were a child: leaving her out of the discussion. He says, "Someone in that room needed to show Alice that they recognize she is still in control of her affairs." Rebecca tells Dr. Ramsey that at the very least, he should document Alice's refusal of home health care in the chart in case Alice does injure herself.

Is Dr. Ramsey right to see this decision as belonging solely to Alice?

commentary

by Eileen Amari-Vaught

Dr. Ramsey is very intent on doing the right thing for his patient. He believes, as many doctors would, that treating Alice right means honoring her wishes and not letting the wishes or interests of others thwart her decisionmaking efforts. U.S. physicians overwhelmingly believe that they have an ethical responsibility to respect their patient's autonomy and Louise's requests may be understood to threaten Alice's autonomy. But in his unswerving commitment to Alice Dr. Ramsey may be overlooking important questions of justice.

Louise's position is not unusual. In fact, such cases are becoming much more commonplace as the elderly population increases and the fertility rate declines. There are more elderly people who need care and less younger family members to do the caring. Most of the caregivers are women, since it remains a societal expectation that women take care of domestic work in addition to other responsibilities. Many caregiving women maintain jobs and careers, the primary responsibility for children of various ages, and the care of other elderly or sick family members.

In fact, family caregivers deliver more care to the elderly and the chronically ill than nursing home aides or other health care providers. Whereas health care providers have

professional standards and codes to protect them from taking on too many caregiving responsibilities, family caregivers have no social norms or historical precedents to appeal to for such guidance. Family caregivers are vulnerable to harm because they care about maintaining the health and independence of their loved ones, and far too often the amount of assistance they must provide overwhelms them. As the elderly population continues to increase and more women find themselves caring for their elderly relatives, this injustice may gain momentum, unless society and the medical profession rethink their ethical commitments so family caregivers are given moral consideration in treatment decisions.

Both Dr. Ramsey and Alice need to appreciate Louise's position. Although Alice does give Louise the option of releasing herself from caregiving responsibilities, this "option" is hardly a genuine one. Louise has a history with and an emotional attachment to Alice; her relationship is not a contractual one that she can walk away from feeling that she is free at last of a burdensome responsibility. Louise could be emotionally harmed if Alice hurt herself, despite Alice's "dismissal."

Dr. Ramsey should explain to Alice that her decision poses risks to her granddaughter. He should fully explore Louise's dual responsibilities and emphasize to Alice that she must factor Louise's lifestyle and emotional attachment to Alice into her decision regarding home health care. Many physicians might fear that this degree of mediation is inappropriate and would not feel comfortable in this role. However, with the proper training and understanding of the social situation between family caregivers and their elderly relatives along with a broadened understanding of their moral responsibility, physicians could facilitate discussions, strongly emphasizing to their patients that the interests of their family caregivers should also count.

commentary

by Wyne Vaught

This case presses us to consider the scope and nature of physician responsibility. While we may believe that Alice ought to think of Louise's well-being when making her treatment decisions, can we ask Dr. Ramsey to play a role in persuading Alice of this? There are several reasons why we should not.

Dr. Ramsey's primary commitment ought to be to Alice's health and well-being. This commitment entails not only providing her the best care possible, but respecting her values and expressed preferences. It is widely accepted in the United States that competent patients have a right to make their own decisions, including the right to decide who gets to participate in those decisions. This may be especially important in the case of patients like Alice, who is frail and elderly. In addition to showing respect for her autonomy, allowing Alice to make her own treatment decisions may bolster her self-esteem and will to take care of herself. Such a boost in self-esteem may contribute to her health and well-being.

Another issue raised by considering whether physicians ought to take on family mediation is that of expertise. Functioning as a family mediator requires familiarity with the caregiver's and patient's motives and values, their priorities and commitments. While family members most likely have their loved one's best interests at heart, as surely Louise does, this may not always be the case and it may not be easy to determine. Physicians are in no way especially trained to make such determinations. Indeed, it might be better for someone else on the health care team, perhaps a clergy member or social worker, to function as a mediator. Someone who has more contact with all the players and perhaps

more distance from the conflict may be better suited to negotiate disagreements.

Finally and importantly, constraints on physicians' time limit just how broadly their sphere of responsibility can be drawn. This is especially true in the era of managed care, which limits contact time between patients and physicians. Dr. Ramsey would need a considerable amount of time to explore the legitimacy of Louise's concerns, share those concerns with Alice, and work toward a reasonable compromise. While physicians certainly need to be sensitive to their patients' familial circumstances and concerns, their time and role in patient care should be guided by patient interests. If Alice, a competent patient, does not want to use her allocated time with Dr. Ramsey to discuss home health care, nor wants his assistance in mediating a family dispute, then Dr. Ramsey ought not require Alice to do so.

This case helps us to recognize the moral responsibilities that exist between patients and family caregivers. Louise's question "Don't I count?" is appropriate and important, but the question is to whom her interests count. Dr. Ramsey may well sympathize with Louise, and may even ask Alice if she would like to include Louise in the discussion of her treatment plan. But if Alice, for whatever reason, decides not to discuss the issue, then Dr. Ramsey should not require Alice to do something she does not want to do. He should accept the decision as belonging solely to Alice, in spite of the fact that she may be treating her granddaughter unfairly.

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By Eileen Amari-Vaught and Wayne Vaught

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