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Attention to Caregivers and Hope: Overlooked Aspects of Ethics Consultation

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On occasion when working in my role as an ethics consultant I walk into a situation and think, "Everyone here is *in extremis*, not just the patient but the family and professional caregivers too!" Fortunately it is not always the case, but when it is you can see it in their eyes. And when I recall my clinical years, working in a rehabilitation setting with people who had dementias and traumatic brain injuries, I can bring back the faces of patients and families who slipped away from the professional team's grasp — we who wanted so much to be of some significance in their individual and collective quality of life. I can conjure up, too, a creeping dread, a prickle that started at the base of my spine, that we clinicians were impotent at times to be of much use, even to those who showed great kindness to us for our sincere and arduous efforts.

The narrators of "Margaret's" and her caregivers' stories convincingly convey the extremity into which everyone was cast at one time or another by Margaret's condition, and how those times compromised the ability of professional and family caregivers alike to sustain some modicum of certainty that what they were doing was right for Margaret — or themselves. No reader would conclude that during the months leading up to her transfer to hospice, where she spent the last 10 days of her life, that this was "business as usual," not even for stressed family members or clinically experienced professionals. For example, we are reminded that the institutional context itself — a psychiatric hospital — was an added disorienting factor for clarifying the issues that are usually addressed in end-of-life care.

At the same time, the narrators describe how a family and team of health professionals can show astonishing creativity in their approaches. Woven into the telling of this story are the numerous ways in which this group continued to keep strong links in their human chain of support for Margaret over the course of many months, including instances when professional and family caregivers felt genuine appreciation for each other while struggling with strong differences in judgment.

Many of the ethical issues raised in the long course of Margaret's care are chronicled in the previous pages. This gives me an opportunity to highlight two aspects of Margaret's story that warrant our attention. Because the role of the various (and, in many cases, numerous) caregivers is essential to a fully informed positive outcome, I first want to shine attention on some caregivers' challenges that I believe should be taken into account in deliberations such as the ones that faced the ethics consultant in the story under review. Second, I want to raise some important ethical quandaries that surface when the patient has a chronic and progressively debilitating cognitive condition such as Alzheimer's disease, when there is not only increasing impairment over an indeterminate amount of time, but also an outcome of inevitable death.

Any observer of Margaret's course surely has to appreciate the caregivers' efforts and successes, as well as sympathize with their lingering concerns and queries. As a clinical ethicist, it would be within the scope of my usual and customary practice to affirm them by commending each for bringing his or her skills and involvement to bear on Margaret's onerous and exhausting situation, and leave it at that. Indeed, in many clinical ethics analyses, that is precisely where attention to family caregivers and professional caregivers remains, either as the source of important background information (for example, social or clinical history) as a report on current medical status, or as a crucial instrument to the development of the real story line — that is, what is to become of the patient. In this mode of analyzing a clinical story, Margaret is the main character, and the supporting moral actors exit and enter at various junctures in *her* life. But within clinical ethics, an ever-maturing knowledge and understanding are emerging that this approach, taken alone, often fails to give adequate shape to the core issues, and therefore creates a risk that the consultation may veer off course when a critical recommendation is to be made. The narrators of Margaret's story articulately convey how the contours of the situation finally were fleshed out in the bodies, words, and experiences of Margaret, *but also* those of her children, of the physicians, and other professional team members. A recent book review in *Gerontologist* notes, "six books have been published in such a relatively short time span and all address some level of the psychosocial aspects of Alzheimer's more than the biomedical [aspects, which] symbolizes a reawakening of what makes us all human: the need to relate to others in a meaningful way."¹ In acknowledging the weight under which everyone caring for Margaret was struggling, the narrators of her story were able to raise pertinent questions and begin discernment about what to do, that mattered, in this moment, occasioned by a woman who fell into dire need of professional care.

There are two groups of caregivers, each with their own challenges and essential roles: family and professional caregivers. In some writings, they are referred to as *informal* and *formal caregivers*, but I think these categories can serve to divide their functions into "silos," which may not accurately reflect the web of caregiving that takes place.

Family caregivers easily can be taken for granted as simply doing their job in advocating for the patient, no matter the personal cost. No one would argue with Stephen G. Post's observation about the family's role in the care of persons with Alzheimer's disease, that "once care is in place, the issues that emerge in the natural course of the disease can be addressed in an informed manner. Informal family caregivers are vital in the culture and practice of care."² The benefits for Margaret were manifested through the conduct of her three children. Their choices fit the profile of my own previous observation, "When faced with a loved one who shows the debilitating effects of Alzheimer disease, most family caregivers initially rise to the occasion with remarkable courage, good spiritedness and, if all else fails, resignation. They often enjoy the admiration ('regard') of others on the basis of having assumed this new identify."³ However, I believe the "crunch" comes when the need for care perseveres over time, as it did in this situation. Dementia caregivers often find that their personal (including financial) stresses increase as support begins to fall away, leading to isolation. As one wife noted of her husband's worsening condition from Alzheimer's disease, "We no longer meet with our friends. Entertaining became a disaster. Our social life is gone."⁴

In spite of psychological, physical, financial, and social stresses, the peculiar psychology and morality of familial duty persists in the face of unexpected or prolonged caregiving, with sometimes untoward consequences for the caregiver. As I noted elsewhere:

An all-too-often devastating long-term effect is that attention to other vitally important aspects of the caregiver's identity become . . . *disregarded*, with social *disrespect* leading to marginalization quickly ensuing. Neglect over time replaces the initial attention afforded "heroic" caregivers to the point that their own basic needs are ignored and their contributions unappreciated. Study after study reveals that the everyday lived reality of most family caregivers is governed by society's belief that the family member must now accept a role characterized by his or her unbounded obligation toward the affected loved one.⁵

Abel has argued that this societal attitude long has been deeply engraved in social roles and expectations worldwide, especially for women caregivers, and persists to the current day.⁶ Given these patterns of societal expectation, that a family caregiver is expected to shoulder the burden of the other's well-being at all (personal) costs, the clinical ethicist should take uncommon measures to assure that family caregivers do not become unnecessarily marginalized members in the consultant's and clinicians' attention, which can make a patient the sole focus of concern, when the family may be the only window to the patient's wishes and well-being. Disregard for family members need not be expressed directly for them to feel it, but may be expressed through inadvertent slights regarding their comfort, sensitivity to some topics, or an overall tone that suggests, this is "about the patient," not them. For example, I recall one African-American man, the spokesperson for his family in the decision they had to make for their mother, saying quietly as he looked around the room at the consult team, "I'd feel better if I saw at least one Black face among you."

What, you ask, should a clinical ethics consultant do to assure that the family caregivers' situation is acknowledged? Each caregiver needs to be commended by the ethics consultant for doing his or her best. Each needs to be acknowledged as having stayed the course of care under extraordinarily cumbersome and trying conditions. Each needs to be assisted in gaining access to accurate information and assistance such as is available through professional or community-based organizations. Each needs to be seen as someone who may benefit from counseling by a religious advisor, social worker, or other resource available in the health-care setting. The clinical ethicist should not be exempt from joining others in trying to help the family identify such help. At the same time, ethics consultants sometimes can help by verbally acknowledging that a family member may be speaking or acting from exhaustion, by offering encouragement to family members to "hang in there" when they can, and by giving a family member permission to "drop out" for a time to regroup. Weaving these human dimensions into the process of consultation, to avoid family members feeling (or being) marginalized, is as crucial to a successful result as the usual focus on clinical details.

Professional caregivers may face a similar marginalized fate when a crisis of the type facing "Margaret" and her family arises. Generally speaking, the other-regarding morality of due care in professional oaths and codes keeps attention focused on the patient. Selflessness long has been a cardinal virtue of the caring professions. All too often, however, the emotional and physical wear and tear on professional caregivers is ill attended to, at great personal and social cost to them, especially (although not exclusively) in situations such as Margaret's. As O'Brien notes, "Institutional caregivers experience frequent and early burnout dealing with patients with whom they cannot communicate well, who are unappreciative, who resist the caregivers' efforts to help. . . ."⁷

The likelihood that those caring for Margaret for six months were worn down is very high indeed; some reasons are articulated in the narrative. *Six months* of attempts to quell her symptoms, which included lunging, screaming, and falling to the floor as dead weight, while the incessant march of her disease continued to express itself in new sources of clinical concern, right through winter and spring, on days with staff shortages and other patients who needed attention for equally compelling reasons. Professional caregivers also were paying attention to the patient's family. On one side of the coin, their focus on the patient and family is a textbook description of expectations consistent with their professional role. On the other, the underbelly of neglect for the professional caregivers' and aides' needs to cope well over time is exposed, with the negative effect this may have on the whole clinical and moral effort of caregiving.⁸ Difficult-to-manage patients who have troubling symptoms or behaviors may engender feelings of avoidance, dread, or even revenge, hardly the attitude to sustain high-quality caregiving.⁹

A clinical ethics consultant may fear that expressions of sympathy or other attention to the plight of the professional caregiver will appear paternalistic or misplaced. They, after all, are the ones who call in a consultant's assistance, serve as problem-solving partners during the consultation, and often are the ones who take recommendations back to the patient and family to decide on a course of action. But this should not preclude attempts on the part of the ethics consultant to acknowledge the human stresses that the professional caregivers are facing. It may be as simple as a statement to the effect that this is a very challenging situation indeed, even on the end of the curve of situations that require ethics consultation, and that taking

care of each other should be high on the priority list. Some clinical ethicists have worked with psychiatrists or others in more formal sessions designed to allow caregivers to express their frustrations. Follow-up calls or visits after the consultation to see how things are going also may convey the consultant's support.

In short, what we see in this situation is that the progressive and extreme symptoms of Margaret's Alzheimer's disease occasioned an extraordinarily intense response on the part of key caregivers — responses motivated by love, habit, social pressure, professional duty, moral disposition, and maybe others — but all geared to riveting attention on her for days, weeks, and months. They will feel supported by the ethics consultant's well-placed compliment regarding the contribution they have already made to the patient's well-being and acknowledgment of the specific emotional, physical, or other burdens they may carry in their attempt to care for her. These may be what the caregivers need to gather their energies for Margaret's future care, and give them the courage to take the next step.

These suggestions are set against the backdrop of urgency and a focus on outcomes at the price of process that clinical ethics consultations can easily fall into today. Best practices in ethics consultation, as in other aspects of healthcare deliberation designed to uphold quality of care, require that the press of time be pushed back in the interest of being thorough with issues that matter. Failing to pay attention to caregivers in such situations may compromise the quality of the consult and of the care provided.

In the remainder of this commentary, I invite you to consider some threats to hope in situations of high uncertainty, and to consider how an ethics consultant may help all persons in such situations to maintain hope. My assumption is that hope is an important but sometimes overlooked resource in ethical decision making.

T.S. Eliot wrote that, for many of us, the period between two certainties is one of the most anxiety-producing of human conditions, the place where "falls the shadow."¹⁰ When it is certain that debilitating symptoms will increase and death will come, but there is great *uncertainty* about when the release (of death) will ensue, the shadow falls on everyone involved. It falls longer when caregivers believe it is their duty to create a zone of certainty to guide judgment towards beneficial, morally justifiable action. If we view Margaret as representative of a rapidly growing population of patients whose disease trajectory takes a course of prolonged, progressive debility between diagnosis and death, the situation urgently calls for an ethicist's attention.

In Margaret's story, one critical shadow of uncertainty is the caregivers' lack of knowledge about what Margaret would want. Margaret's advanced directive was not found until after her death, and she had reached the point that she could no longer speak for herself. Another shadow comes from her behavior. Is she suffering? Is there pain? Is she dying? The caregivers aren't sure. They know, yes, she will die from her disease, but the moment that palliative interventions that are appropriate for end-of-life care are suggested, the family and some of the professional caregivers move in one direction — and some in the other.

Certainty helps one to know where to focus realistic hope, using it as a resource for enduring shadow experiences of high anxiety while gathering information and energies to take an informed next step. A basic ingredient in the training of health professionals — that professionals are harbingers of hope — must always be maintained. Health professionals themselves find hope (and take comfort) in their ability to turn their focus solely to comfort and end-of-life measures when recovery is no longer a practical goal, and in knowing that they are proceeding in a manner that is considered to be ethically permissible.

Margaret, her family, and her professional caregivers seem locked in hope-limbo, the latter not knowing or agreeing on where to direct their hope — that emotional light on the right course to pursue. Her situation did not include certainties that would allow morally competent and morally sensitive professionals to proceed with confidence that they were meeting their duty of caregiving, which includes being a source of hope to the family.

The dilemma of "what to hope for" was not simply a matter of a failed attempt at cure: that moment when patient and all caregivers have to check their compasses and gear up for the next climb toward palliation. It was a paucity of footholds as they found themselves slipping down the steep banks of uncertainty. As one social worker put it during a recent seminar on chronic care, while talking about her work with a woman

whose husband was showing signs of serious AIDS neuropathy, "She said they've always been a praying family when trouble hits. But she's having trouble praying! She doesn't know what to pray for because she doesn't know what to *hope* for. And I had to agree it could be difficult. I'm told he could live for several years, or die anytime. The whole encounter left me feeling defeated, because as I tried to think about it, I couldn't say what I thought there was to hope for in that moment either! There's always the religious hope that God will be with you for whatever, but somehow I didn't feel like that was what was called for in that very moment!"

A "hope dilemma" can present a serious challenge to good patient care. Clinical ethicists often experience the tendency of caregivers caught in such a situation to try to reduce the ambiguity and anxiety of the situation by imposing certainty where little exists. One common response among family members is to "go for broke," insisting on every intervention. Didion reflects this stance in her essay, "The Case of Theresa Schiavo," in the *New York Review of Books* when she observes of the parents' position, "There was the unassuageable grief of the parents, the fierce parental need to construe any abandonment of hope [for her continued life-sustaining interventions] as a betrayal of their firstborn child."¹¹ Another is for the family members or health professionals to move towards palliative end-of-life care, often with the anxiety that they have given up prematurely or inappropriately, moving out of the scope of morally permissible action. Recall that this was a concern for some of the professional caregivers in Margaret's situation, which left them with questions while the family members expressed relief.

Increasingly today, the hope dilemma is being articulated in ethics consultations. Some comments I've heard in recent weeks include, "One of the problems is that the family is still clinging to the hope that she will not linger, but go quickly," or, "They can't let go of hope [for her recovery]." The rub is that the ethics consultant, too, does not know what to *do* in many situations when hope is elusive. Occasionally, bringing caregivers and family together for an ethics consultation will reduce uncertainty because additional information is obtained, or values are expressed, or new goals offered, as the health professionals and family have a more concentrated exchange. Often participation in the consultation process is a source of comfort to all, even though the clinical diagnosis and prognosis remain unknown or uncertain. I believe that while increased clinical certainty and a deeper understanding of the issues always help to sustain and focus hope, the personal interaction that takes place in ethics consultation may support hope when one result is reassurance that family caregivers and their loved one will not be abandoned by the healthcare team during their time of difficult decision making, while they are under a shadow of uncertainty.

Everyone knows that consultations take time in an environment where time is literally money. I learned a lesson about the power of taking time while visiting an Alzheimer's Unit of a local hospital. A social worker was hurrying down the corridor ahead of me, but stopped upon seeing a very worried-looking family huddled near the lounge. "Is something the matter?" I heard her say. A young woman replied, "We don't know what's happening and everyone is too busy to tell us." The social worker pulled up very tall and responded reassuringly, "*I have time*. I may not be able to answer your questions, but *I have time* to hear them." There was visible relief on every face. Taking time, making time in an ethics consultation for the concerns of professional caregivers and families to be heard in one place, for as long as it takes, may also serve as a means of discovering where they can place hope.

Margaret's story reminds me that the traditional sources of hope that come from a predictable progression of symptoms and a clear prognosis often are not available to a family or to professional caregivers. Should the clinical ethicist offer reassurances that support hope? I believe the answer is yes. Acknowledging that it's hard to know what to hope for in some situations may help a health professional or family caregiver to place a portion of his or her anxiety into perspective. Reassurance that an ethicist or the ethics team will abide with the patient, family, and health professionals may help maintain their hope that they will not be abandoned.

The depletion of hope among caregivers is relevant information in an ethics consultation, and vigilant sensitivity to their hope and hopelessness can become an essential part of ethics consultation.

NOTES

1. L. Levy-Storms, "Book Review: Connecting informal and formal caregivers to older adults with Alzheimer's and related dementias," *Gerontologist* 445 (2005): 135-9.
2. S. Post, *The Moral Challenge of Alzheimer Disease: Ethical Issues from Diagnosis to Dying*, 2nd ed. (Baltimore: Johns Hopkins Press, 2000), 298.
3. R. Purtilo, "Social marginalization of persons with disability: Justice considerations for Alzheimer Disease," in *Ethical Foundations of Palliative Care for Alzheimer Disease*, ed. R. Purtilo and H. ten Have (Baltimore: Johns Hopkins University Press, 2004), 290-304, p. 298.
4. C. Withoute and M.T. Buschmann, "Alzheimer Disease: Diary of a caregiver," *Nursing Forum* 26, no. 2 (1991): 17-22, p. 18.
5. See note 3 above, p. 298.
6. E.K. Abel, *Hearts of Wisdom: American Women Caring for Kin, 1850-1940* (Cambridge: Harvard University Press, 2000).
7. R. O'Brien, "Darkness cometh: Personal, social and economic burdens of Alzheimer Disease," in *Ethical Foundations of Palliative Care for Alzheimer Disease*, see note 3 above, pp. 7-23, p. 12.
8. J.A. Breeze and J. Repper, "Struggling for control: The care experiences of 'difficult' patients in mental health services," *Journal of Advanced Nursing* 28, no. 6 (1998): 1301-11.
9. A.M. Leon, J.A.S. Altholz, and S.F. Dziegielewski, "Compassion fatigue: Considerations for working with the elderly," *Journal of Gerontological Social Work* 32, no. 1 (1999): 43-62.
10. T.S. Eliot, *The Complete Poems and Plays 1909-1950* (New York: Harcourt Brace and World, 1962).
11. J. Didion, "The Case of Theresa Schiavo," *New York Review of Books*, 9 June 2005, 60.

Note: Throughout this case, the names of the patient and her children have been changed. Quotation marks have been used around these changed names at their first appearance in an article. No other information has been masked or changed in this case. The information presented in this case is used with the permission of the patient's children and the other parties involved.