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ETHICS CASE

What Is the Physician's Responsibility to a Patient's Family Caregiver?

Commentary by David Barnard, PhD, JD, and Mark J. Yaffe, MD

Mr. McGuire lives at home with his only child, Jennifer. He is 75, has severe rheumatoid arthritis and a history of atrial fibrillation, for which he takes anticoagulation medication. He can no longer drive and, given his severe arthritis, is dependent on his daughter for his instrumental activities of daily living (IADLs), things like grocery shopping, paying bills, and managing medications, and some of his basic activities of daily living (ADLs), things like bathing, dressing, and walking. Jennifer has been his primary caregiver for two years and has had to cut back on her work hours and significantly decrease social outings.

Jennifer accompanies her dad on a visit to Dr. Peterson, his primary care doctor. As is Dr. Peterson's standard policy, he initially interviews Mr. McGuire alone. Knowing his patient's living situation and ever-increasing needs, Dr. Peterson raises the issue of respite care, as he has before. Mr. McGuire reaffirms his absolute opposition to the idea of leaving his home or having others come to help, even as a temporary measure, despite a long discussion about the potential long-term benefits of such an approach. He also asks Dr. Peterson not to even discuss this with Jennifer. After the initial interview, Dr. Peterson invites Jennifer into the exam room and continues with his interview and exam. As he probes deeper, he realizes that Jennifer is more tired than ever and perhaps depressed.

Dr. Peterson strongly believes that, if Jennifer doesn't get some relief, she may be unable to take care of her dad in the longer term. Forgoing respite care for Jennifer, he believes, could result in Mr. McGuire's placement in a long-term care facility, which is definitely not what Mr. McGuire desires.

Commentary 1

by David Barnard, PhD, JD

On the surface this case raises ethical questions of confidentiality (Dr. Peterson believes it is important to have an open discussion with daughter Jennifer about the growing burdens of Mr. McGuire's caregiving needs, but Mr. McGuire has forbidden him to raise the issue with her), and paternalism (Dr. Peterson believes it is in Mr. McGuire's own long-term best interest to override his refusal to consider additional home care services that would lessen the burden on Jennifer). Underlying both of these issues, however, is a deeper question: How should health professionals view the interests and concerns of their patients' family members who bear the burdens of long-term care for patients with serious illness or disability?

Traditionally, health professionals have seen the patient's family either positively, as a valuable resource in the care of the patient, or negatively, as holders of potentially conflicting interests from which the patient needs to be protected [1]. Either way, from this traditional patient-centric point of view families have no intrinsic value in themselves, but matter only instrumentally, that is, to the extent that they can be deployed as a resource or if necessary circumvented to serve the needs and preferences of the patient.

A common way out of the conundrum of potential conflict between the interests of the patient and his or her family has been to fudge it by declaring "the family as the unit of care." While this perspective—a central tenet of social workers, and particularly prominent in the rhetoric of hospice and palliative care—places important emphasis on the patient's wider social milieu, have we really faced up to the ethical complexities of that mantra? The issue of family caregiver burden is a useful lens through which to examine the question.

When we think of family caregivers, we might think of two contrasting realities. One is the gratification, pride, and self-esteem experienced by caregivers who derive meaning and fulfillment from their caregiving role. Family caregiving, influenced in important ways by culture [2], can express intergenerational reciprocity and mutuality in intimate family relationships. The other reality is the grim daily grind of exhaustion and loss of self that can overwhelm the isolated family caregiver [3, 4]. In thinking about family caregivers, both of these realities are important, and as health professionals weigh their loyalties, roles, and responsibilities in the care of people with serious illness and disability, both must be kept in view.

Mr. McGuire's heart disease and rheumatoid arthritis are typical conditions, but there are many others, e.g., disabling strokes, cancer, dementias such as Alzheimer disease. To mention these conditions is, in fact, to mention the leading causes of death in contemporary society. No longer do most people in the developed world die from infections, accidents, or other short-term catastrophes. We have conquered many infectious diseases; life is generally safer; and we can pull people through the immediate life-threatening aspects of many injuries or acute health problems thanks to our emergency medicine departments and intensive care units.

What happens to those of us who are kept from dying and then sent home needing close attention and care because of severe disabilities or chronic conditions is another matter. Our enthusiasm for life-saving and life-prolonging heroics is rarely matched by our attention or interest in the unglamorous, nitty-gritty work of long-term care [5]. And this poses serious challenges and questions for families, society, and health professionals.

Recent estimates are that 52 million caregivers provide care to adults with a disability or illness [6]; 43.5 million adult family caregivers care for someone 50 years of age or older and 14.9 million care for someone who has Alzheimer disease or other dementia [7]. Our society and our health system depend on this level of

informal caregiving, the economic value of which was estimated at \$450 billion per year in 2009, up from \$375 billion in 2007 [8]. Among the relevant systemic factors in the evolution of this dependence are:

- The massive shift toward outpatient care and deinstitutionalization;
- Pressures for early hospital discharge (the business plan and economic model for the modern hospital is the rapid turnover of beds to maximize reimbursement);
- Reliance on hospitalists who, while managing most hospital-based care, often do not know the patient or the family very well, leading to discharge plans that may reflect little knowledge of the actual situation at home;
- Fragmented social programs for home care that are a patchwork of federal, state, and local programs with barriers in the form of special requirements, preconditions, limitations, and caps;
- The low-status, low-pay, high-turnover nature of home health care (of nearly 2 million home care workers in 2013, almost 40 percent received government benefits, e.g., food stamps or Medicaid [9]), which diminishes the likelihood of a stable home health care workforce with the high levels of professionalism and morale required for this difficult and important job.

All of this shifts the burden of caring for the long-term disabled or chronically ill person to the family at home. Families are required to figure out the health care system, interpret and carry out treatment plans, negotiate with home health agencies and insurance companies, and do literal heavy lifting. Caregiving tasks and burdens can be complex and heavy: bathing or showering, dressing, feeding, toileting, lifting in and out of bed and chair, performing wound care and dispensing medications, maintaining pumps and other machines at the bedside, transportation, making calls to arrange care and services, dealing with insurance forms. One of the most comprehensive national surveys of family caregiving, carried out in 1998, revealed that:

- In 1997 nearly one in four adults provided care to a family member or friend;
- 20 percent of caregivers did so full-time or continuously;
- 41 percent had been caregivers for five years or more;
- One-third had been providing the most intensive kind of care (classified by the number of activities of daily living requiring assistance and hours per day of care needed);
- 26 percent were administering five or more different medications;
- 18 percent who gave meds reported having received no instruction in how to do so; and
- One-third reported no instruction on bandaging, wound care, or use of equipment [10].

Often, as in this case, these tasks come on top of running a household in the usual way (cleaning, shopping, preparing meals) and holding down a job. Furthermore, while gender roles have begun to even out with respect to family caregiving, women—wives, mothers, daughters, daughters-in-law—bear the heavier burden. To

paraphrase Nancy Guberman, in an article aptly entitled, “The Family, Women, and Caregiving: Who Cares for the Caregivers?” [11], it is often more women who initiate, coordinate, and assume many of the tasks of physical care along with housework and dealing with social services; change the diapers and do the laundry; get up 3 or 4 times a night for various tasks of care; comfort others (especially men) in times of crisis; worry that someone with failing short-term memory forgot to turn off the stove and run over to check; are distracted at work by thoughts, worries, and the need to plan complicated arrangements for care; and make excuses for others who do not do their fair share.

Underlying Dr. Peterson’s questions, then, about how to navigate between Mr. McGuire’s preferences and what Dr. Peterson perceives as their impact on Jennifer, are several further questions for families, society, and health professionals.

For Families

What are the obligations for caregiving that come with being a family member? Are there any limits to these obligations? Is it acceptable to say, “I can’t do this”—or “I don’t want to do this”? How should family members distribute the burdens of caregiving among themselves? What about promises to care that begin to be challenged by new realities? Are decisions to assume the unpaid, informal caregiver role genuine choices or the result of social conditioning, the absence of acceptable paid alternatives, or gendered divisions of labor reinforced by social policies or family structures?

For Society

As a society, we must decide what priority we place on the care of the dependent, chronically ill, or disabled? Can and will we organize the health care and social service systems in society with the flexibility, family-centeredness, and affordability required to help families do their part in this care [12]?

For Health Professionals

How should health care professionals view families? Is the traditional patient-centric ethic of the health professional—“my foremost loyalty is to the patient”—still appropriate? As bioethics scholars such as Hilde and James Lindemann Nelson [1] and John Hardwig [13, 14], have argued, the realities of long-term family caregiving require us seriously to entertain an approach to the ethics of health care that places more weight on family interests. Hardwig [13] argues that an exclusively patient-centered ethics must be abandoned because it is patently unfair to other family members. The patient’s health-related needs are often important enough to override the interests of family members in treatment decisions, but not always. In proxy decision making, Hardwig argues (against the grain of bioethics orthodoxy and the weight of both legislative and judicial precedent), surrogates should be instructed to consider the interests of everyone affected by treatment decisions, including their own. Family members’ interests are relevant in proxy decisions not because the patient may have had them in mind, but regardless of whether he or she had them in mind. Hardwig posits that, while proxies must guard against undue emphasis on their

own interests, undue emphasis on patients' interests should also be avoided [14]. It is irresponsible and wrong for competent patients to make self-centered or exclusively self-regarding treatment decisions if these decisions deny fair and equitable consideration of legitimate interests of all concerned.

Recommendations

Notwithstanding the presumption of professionals' obligation to respect patients' autonomy, it is appropriate for health professionals to argue against patients' choices when patients' exercise of autonomy comes at too great a cost to their families. While we generally allow competent individuals to make their own decisions, including how (short of abuse or neglect of minor children or the elderly) to treat members of their own family, Mr. McGuire's choices in this case are no longer a purely private affair. Mr. McGuire's insistence on continuing to rely exclusively on Jennifer for the care and support he needs at home is placing unreasonable and unfair demands on her, and for Dr. Peterson to acquiesce to Mr. McGuire's insistence that he avoid broaching the subject with Jennifer would make Dr. Peterson complicit in this unfairness. Dr. Peterson should tell Mr. McGuire that, notwithstanding Mr. McGuire's wishes, he cannot refrain from convening a family conference to begin to explore a more sustainable balance between Mr. McGuire's and Jennifer's needs.

We should not assume that Dr. Peterson will know the right answer to a family's question about how much well-being, health, or hopes for the future should be sacrificed for the care of the neediest member. But we should expect that health professionals will be alert to these questions and view it as one of their ethical responsibilities to help families sort out the complicated balancing of interests that come into play when someone is seriously ill, disabled, or dying, as well as to advocate for social policies that might minimize a family's avoidable burdens.

References

1. Nelson HL and Nelson JL. *The Patient in the Family: An Ethics of Medicine and Families*. New York: Routledge, 1995.
2. Hashimoto A. *The Gift of Generations: Japanese and American Perspectives on Aging and the Social Contract*. New York: Cambridge University Press, 1996.
3. Levine C. The loneliness of the long-term care giver. *N Engl J Med* 1999;340(20):1587-1590.
4. Denholm DB. *The Caregiving Wife's Handbook: Caring for Your Seriously Ill Husband, Caring for Yourself*. Alameda, CA: Hunter House, 2012.
5. Relman A. On breaking one's neck. *New York Rev Books*. 2014;61(2):26-29.
6. Coughlin J; Healthways Center for Health Research. Estimating the Impact of Caregiving and Employment on Well-Being: Outcomes & Insights in Health Management, 2010;2(1):1-7. <http://www.healthways.com/success/library.aspx?id=615>. Accessed March 27, 2014.
7. Alzheimer's Association, Thies W, Bleiler L. 2011 Alzheimer's disease facts and figures. *Alzheimers Dement*. 2011;7(2):208-244.
8. AARP. *Valuing the Invaluable: Update, The Economic Value of Family Caregiving*. AARP Public Policy Institute, 2011. <http://www.aarp.org/relationships/caregiving/>

info-07-2011/valuing-the-invaluable.html. Accessed March 17, 2014.

9. Greenhouse S. Wage law will cover home aides. *NY Times*, September 18, 2013, B1.
10. Donelan K, Hill CA, Hoffman C et al. Challenged to care: Informal caregivers in a changing health care system. *Health Aff.* 2002;21(4):222-231.
11. Guberman N. The family, women, and care giving: Who cares for the caregivers? In Dhruvarajan V, ed., *Women and Well-Being*. Montreal, Quebec: Canadian Institute for the Advancement of Women; McGill Queen's Press; 1990: 67-78.
12. Levine C, Murray TH, eds. *The Cultures of Caregiving: Conflict and Common Ground among Families, Health Professionals, and Policy Makers*. Baltimore: Johns Hopkins University Press; 2004.
13. Hardwig J. What about the family? *Hastings Cent Rep.* 1990;20(2):5-10.
14. Hardwig J. The problem of proxies with interests of their own: Toward a better theory of proxy decisions. *J Clin Ethics.* 1993;4(1):20-27.

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Commentary 2

by Mark J. Yaffe, MD

This case describes a common occurrence in the management of chronic illness, specifically the ability to address the needs of both the care receiver and the caregiver. When they are both looked after by the same primary care physician (PCP), the doctor has a fiduciary responsibility to each one, despite the possibility of conflict of interest. Since a comparable dilemma exists when a PCP provides care to spouses who may be in conflict for any reason, some PCPs have acquired a spectrum of strategies they hope will be useful in such delicate (and stressful) situations.

When a PCP looks after a care receiver and not the caregiver, given the possible enmeshment of the two, the PCP may not be able to provide comprehensive care to the former without some interaction with the latter. Or, framed another way, why wouldn't it be good medical practice to routinely involve the caregiver? Indeed, in the United States the Health Insurance Portability and Accountability Act (HIPAA) of 1996, while protecting the privacy of patients, permits family members or others directly involved in the patient's care to be present during medical visits or informed about a diagnosis, treatment, or future plans, unless the patient specifically objects [1, 2].

Given the potentially complex nature of the doctor-patient-caregiver triad, however [3], a challenge exists in ensuring patient autonomy in such cases. As discussed below, addressing this goal does not, however, preclude respectful attempts by a PCP to provide patients with opportunities to see the perspectives, viewpoints, or needs of others.

In a study of Canadian urban-based family physicians (FPs) that Jacqueline Klvana and I conducted, 81 percent of the FPs surveyed reported finding encounters with

family caregivers stressful. As few as three such encounters per day were sufficient to result in reported stress [3]. In that study, when the FPs were asked to rank 17 factors that impact on the doctor-patient-caregiver triad, the second most commonly cited concern about the “triad encounter” was caregivers and care receivers with differing agendas and needs. This was a concern for 63.4 percent of the FP respondents. Hence it is easy to imagine the feelings of Dr. Peterson in the aforementioned case.

It has been suggested that physicians require more and broader training about issues pertaining to caregiving [4]. This would include the general principle that visits that incorporate both caregivers and care receivers might flow better if PCPs encouraged them to try to discuss beforehand the matters that will be brought up during the medical encounter. In the case of Mr. McGuire and Jennifer, such an approach may not be helpful initially, since we are given no indication that Jennifer is aware of her growing need for respite.

Dr. Peterson might consider structuring his encounter with Mr. McGuire and Jennifer around the goal of defining care more broadly. He could summarize Mr. McGuire’s health status and limitations, but reframe them by introducing the concept of the Chronic Care Model (CCM), explaining that in this approach both patient and family member(s) join him as part of the treating team [5-7]. Dr. Peterson might elaborate on some advantages of this model, including the opportunity for expanded input on care options and for hearing different perspectives on a treatment plan.

Dr. Peterson could acknowledge that in the CCM there is potential for conflict arising from differences of opinion, feelings, or needs, and that he is comfortable hearing such conflict. While the doctor might in fact not be so comfortable early on, as a member of a collaborative care team he should strive to be as open to different approaches as he would like the caregiver and care receiver to be. Following this sort of overture, Dr. Peterson might close the visit by suggesting that caregiver and care receiver try to reflect, between then and the next visit, what the CCM might mean for each of them.

Dr. Peterson might schedule the subsequent visit a little sooner than usual in order to follow-up on the discussion. At that encounter, initially with Mr. McGuire alone, Dr. Peterson might ask for his reflections on the last visit. Given Mr. McGuire’s previous resistance to the idea of respite care and the reasons for it, one might expect him to verbalize some appreciation for certain aspects of the CCM, but to assert his right to control and decision making. Dr. Peterson should validate this feeling, but perhaps note that Mr. McGuire’s permitting his daughter to be present for the second part of each visit suggests his tacit acknowledgement of the importance of her involvement. This would provide an opening for Dr. Peterson to say to Mr. McGuire, “I am actually worried about your daughter. The last few times you two have been here, she has not been looking well. What do you think?”

This sort of approach would generally provide a doctor a natural opportunity to accentuate the significant contributions made by caregivers. Without specifically raising the issue of respite care, introducing the topic of caregiving could facilitate a discussion about the common problem of what is called “caregiver burden,” which may have negative implications for both caregiver and care receiver [8]. If Mr. McGuire did not agree with Dr. Peterson’s concerns about Jennifer, the doctor might broach having Jennifer take the Brief Assessment Scale for Caregivers (BASC), an empirically derived measure of caregiver burden with good internal reliability and both construct and criterion validity [9]. He could say something like, “Given how common it is for caregivers to get run down and exhausted, I’m wondering whether this may be happening to Jennifer. There is a short paper test to find out. What would you think if I asked Jennifer to fill out this questionnaire?”

Dr. Peterson’s more direct approach in bringing up Jennifer’s health might prompt Mr. McGuire to voice worries, fears, or misconceptions about respite care (e.g., that it might open the door to long-term placement). Each specific concern could then be validated and addressed with specific patient-centered solutions, which may require the assistance of a social worker familiar with respite care. It may be necessary to appeal to Mr. McGuire’s self-interest by reminding him that Jennifer may be able to provide better and longer-term care if her needs are respected and addressed. If Mr. McGuire continues to refuse to acknowledge the possibility of strain on Jennifer, it might help to put him in contact with a care recipient from his or a colleague’s practice who had been in a similar position and had benefited from respite care.

Another approach would be one that draws on principles of couples’ therapy, asking Mr. McGuire if Dr. Peterson can facilitate a discussion about each party’s needs. If he consents, and Jennifer is forthright, this would allow the father to hear his daughter’s own words of distress. Many caregivers need a structured, supportive forum in which to openly vent that, despite their love and commitment to caring, there may be limits to their abilities to support some of the care recipients’ needs or wishes. The honest expression of feelings and needs sometimes becomes the stimulus to a more open recipient-caregiver relationship in that other issues not previously discussed may more easily come to the surface [10].

Should Mr. McGuire continue to refuse any discussion of Jennifer’s situation, Dr. Peterson might send Jennifer a note with a list of community resources for family caregivers and the suggestion that she seek help from her own PCP, a social worker, a psychologist, or other therapist.

The aforementioned interventions may be time-consuming or stressful for PCPs. Some may argue that a social worker should handle all these discussions. However, the potential to be an instrument of growth for a person with chronic illness, the opportunity to foster a more realistic and open dialogue between caregiver and care receiver, and the possibility of a richer doctor-patient relationship should encourage PCPs to address these issues to the extent of their skills and time availability.

References

1. US Department of Health and Human Services. A patient's guide to the HIPAA Privacy Rule. http://www.hhs.gov/ocr/privacy/hipaa/understanding/consumers/consumer_ffg.pdf. Accessed March 31, 2014.
2. US Department of Health and Human Services. A health care provider's guide to the HIPAA Privacy Rule: communicating with a patient's family, friends, or others involved in the patient's care. http://www.hhs.gov/ocr/privacy/hipaa/understanding/coveridentities/provider_ffg.pdf. Accessed March 31, 2014.
3. Yaffe MJ, Klvana J. Physician perspectives on the elderly patient-family caregiver-physician encounter. *IMAJ*. 2002;4(10):785-789.
4. Yaffe MJ, Jacobs BJ. Educating about family caregiving: advocating more family physician involvement. *Can Fam Physician*. 2008;54(10):1359-1360.
5. Bodenheimer T, Wagner EH, Grumbach K. Improving primary care for patients with chronic illness. *JAMA*. 2002;288(14):1775-1779.
6. Hindmarsh M. The chronic care model. In: Dorland J, McColl MA, eds. *Emerging Approaches to Chronic Disease Management in Primary Care*. Montreal, Quebec: McGill-Queen's University Press; 2007.
7. Wagner EH, Austin BT, Von Korff M. Organizing care for patients with chronic illness. *Milbank Q*. 1996;74(4):511-544.
8. Yaffe MJ. Implications of caring for an aging parent. *CMAJ*. 1988;138(3):231-235.
9. Glajchen M, Kornblith A, Homel P, Fraidin L, Mauskop A, Portenoy RK. Development of a brief assessment scale for caregivers of the medically ill. *J Pain Symp Manage*. 2005;29(3):245-254.
10. Jacobs BJ, Yaffe MJ. "Help" is not a dirty word. *Take Care*. 2009;18(1):3-4.

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