

## ETHICS CASE

### Who Should Assess the Needs of and Care for a Dementia Patient's Caregiver?

Commentary by Laura N. Gitlin, PhD, and Nancy A. Hodgson, PhD, RN

#### Abstract

Using a clinical case example, we examine whether health and human service professionals have a moral obligation to assess and address the needs of family caregivers of persons with dementia and, if so, the challenges in doing so under current health care and reimbursement mechanisms. We also discuss specific strategies for involving caregivers.

#### Case

It was subtle at first. A missed exit on the turnpike. A puzzled look when running into an old neighbor. A set of car keys in the fridge. Sally attributed it to normal aging at first, but after Hank called to say he was lost trying to drive to his sister's house, she knew something was wrong. During several appointments, other diagnoses were ruled out and the doctor diagnosed Hank with Alzheimer's disease. Sally's and Hank's lives quickly became filled with endless doctor's appointments, which meant less and less time for grandchildren and friends. By the time Sally had Hank dressed, fed, and set up in his chair each morning she was exhausted. She barely had time or energy to shower and curl her hair, something she would never have left the house without doing prior to Hank's diagnosis.

"Who knew our 'golden years' would be over so quickly?" Sally wondered as she organized the prescription bottles that now occupied their kitchen counter. "His and my blood pressure medication. His Alzheimer's medicine. My arthritis medicine. His heartburn medicine. Or was it his arthritis medicine and my heartburn medicine?" It was all becoming so complicated.

At Hank's latest neurologist appointment, Dr. Smith tested Hank's memory and reported that his mini-mental status exam (MMSE) results were similar to those from his previous appointment. Dr. Smith was pleased and convinced they had found the right dosage for Hank's medications, but he felt Sally just didn't look herself. Sally attended all of Hank's appointments, so Dr. Smith felt he knew Sally almost as well as he knew Hank. Over the past year, the impeccably matched outfits and perfectly coifed hair had disappeared. She looked exhausted and jittery, like someone who was constantly on edge. Dr. Smith wanted to ask if she was doing okay, but he didn't want to offend her. "She's not actually

my patient," he told himself, but seeing her look so radically different from the first time they met was nagging at him.

As Dr. Smith finished his examination, Sally squirmed uncomfortably in her seat, mentally preparing herself for another exhausting evening of cooking dinner and then cutting it into bite-size pieces for Hank, bathing Hank, and spending the night with a stranger she felt she barely knew anymore.

Dr. Smith thought to ask, "Before you go, Sally, how are you holding up?" and wondered whether he should.

### **Commentary**

Sally represents the more than 15 million family and other unpaid caregivers of persons living with dementia in the United States [1]. Like Hank, most persons with dementia are cared for in their homes and depend upon family members for complex care needs over the long course of the disease [1, 2]. Tasks associated with caregiving increase in number and complexity with disease progression and can include (but are not limited to) daily, physically challenging, and often intimate forms of assistance with everyday living needs of bathing, dressing, toileting, feeding, moving or transferring the patient, and managing his or her medications. The caregiver must also ensure the patient's safety, well-being, and quality of life; coordinate care and care transitions; negotiate unwieldy and disjointed health and human service systems; accompany the patient to doctor visits; and advocate, protect, support, and comfort the person with dementia, particularly in health care encounters. All this must be done while often juggling other responsibilities such as childcare, caring for another family member, or working full- or part-time [3, 4].

These care tasks accumulate with disease progression and result in significant and well-documented physical, emotional, and financial consequences for families [3-5]. As families provide more than 80 percent of long-term care to older adults [1], and our health care system is therefore dependent upon family involvement, a comprehensive and family-centered approach to managing dementia is required [3, 4]. What this means is that, to ensure quality care and quality of life for Hank, the intertwined medical, social, emotional, physical, behavioral, financial, and familial challenges of Hank's progressing dementia must be carefully considered and addressed for both Hank *and* Sally.

The lack of [family-centered care](#) in current approaches to managing dementia is reflected in Dr. Smith's uncertainty about whether he should ask Sally how she's doing. As Sally is technically not his patient from a health system and reimbursement perspective—and as family-centric dementia care is lacking—Dr. Smith would likely be discouraged from responding to the visible physical expressions of Sally's stress and fatigue.

However, given that Sally's own health and well-being appear to be adversely affected by her increasing caregiver responsibilities, Dr. Smith should honor his impulse to address her visible physical and emotional decline during a clinical encounter by providing Sally with reassurance, support, and education. If Sally's own health declines, she may not be able to effectively care for Hank; that is, Dr. Smith's patient's welfare is at risk and might suffer if Sally's own welfare is compromised.

In deciding whether or not to ask Sally how she is, Hank's physician experiences what has been referred to in the health professional literature as "moral distress" [6]. Moral distress occurs when there is a perceived ethical conflict or "when one knows the right thing to do, but institutional constraints make it nearly impossible to pursue the right course of action" [7]. From a holistic and family-centered perspective, Dr. Smith is obligated to reach out to Sally about her own health and well-being, and he must consider the risks to his patient of not asking Sally how she is.

So, if Sally responds in a way that suggests she's not "holding up" all that well, how should Dr. Smith respond? Which strategies should he use to follow up? More generally, how should professional caregivers be trained to support and respond to the needs of nonprofessional caregivers as they both try to manage the patient's dementia? To understand the nature and scope of Dr. Smith's professional obligation to reach out to Sally, we draw upon classic ethical frameworks and guidelines. We also suggest specific strategies that clinicians can use to guide an interaction with a family caregiver. We conclude that, although there are short-term steps that clinicians like Dr. Smith can take, such as asking Sally how she is doing, changes at the policy, social, and cultural levels must also occur to help Dr. Smith and all professional caregivers offer family-centered dementia care to patients and the family members who care for them.

### **Key Ethical Frameworks**

The situation of Sally, Hank, and Dr. Smith can be examined through the lens of the four foundational values in bioethics: autonomy, beneficence, nonmaleficence, and justice [8]. Although traditionally focused on an individual, these values can also apply to family members providing care to individuals with dementia. This applicability is illustrated by the philosopher Paul Ricoeur, who suggested that one's self should always be considered in relation to others and thus that the person—or, in this case, the patient with dementia—must him- or herself be understood in the context of his or her life space and sources of support (e.g., family caregivers and clinicians) [9]. Ricoeur's ethics of "oneself as another" endorses the value of inclusion, which is critical—particularly for understanding clinicians' obligations to caregivers and to persons with dementia who, at some point in the disease process, will become incapable of autonomous decision making. Table 1 defines each of the four values and indicates how involving family

caregivers in a clinical encounter with patients with dementia is critical to ethical practice.

**Table 1.** Four fundamental values in bioethics and their application to dementia care

Ethical value	Definition	Application to dementia care
Autonomy	Right to self-determination	Clinician needs to evaluate patient's capacity, inform individual and family caregiver of results of assessment, and determine jointly the right balance between safety and well-being, the patient's capability for independent decision making and actions, and when and how to involve the family caregiver.
Beneficence	Making decisions and taking action in best interest of patient	Clinician needs to reach out to family caregiver to assess his or her own health and well-being and capacity to provide ongoing care, as this is in the best interest of the patient with dementia.
Nonmaleficence	Pursuing actions that minimize harm	Clinician needs to reach out to family caregiver and provide education, support, referrals, and resources in order to minimize harm to caregiver and patient.
Truth-telling	Communicating openly and honestly	Clinician needs to inform patient of the importance of involving his or her care partner in decision making and is obligated to share the truth about the capacity of the patient and avoid deception.

Four other ethical frameworks support Dr. Smith in adopting a family-centered dementia care approach and reaching out to Sally. Utilitarian/consequentialist ethics suggest pursuing strategies that produce the greatest happiness for the greatest number of persons or from which the best results for all concerned can be achieved [10]. This perspective would thus support Dr. Smith's assessing and helping to meet Sally's needs, as it would, arguably, do the greatest good for Sally as well as Hank.

A deontological/Kantian framework similarly supports Dr. Smith's reaching out to Sally. In this framework, moral rules are not subjective standards but objective truths that have their source in humanity. Thus, Dr. Smith has a moral duty to reach out to Sally

from a humanitarian perspective [11]; asking about Sally's well-being serves as an act of general goodwill and also fulfills his specific moral duty to his patient.

In contrast, care ethics [12] seeks to promote well-being by emphasizing the importance of interdependent social relations. Assessing Sally's well-being is justified from a care ethics perspective that recognizes and honors Hank's and Sally's interdependence and mutual vulnerabilities.

One can also query the ethics of Dr. Smith's *not* approaching Sally and the health risks that no action might pose to her and Hank. Arguably, Dr. Smith's reaching out to Sally about her health would be unethical—and could possibly result in harm—if he is not prepared to responsibly follow up if she reveals that she is not doing well. Harm might result in this instance since Sally would not be provided viable recommendations or solutions and thus might conclude that nothing could be done to help her and relieve her care situation. Moreover, Sally would be deprived of care strategies that could be beneficial to her, Hank, or both of them. As a result, Sally's distress might increase and possibly harm Hank. However, this is a worst case scenario. The four fundamental ethical values guiding clinical encounters as well as several common ethical frameworks all point to and reinforce Dr. Smith's moral obligation to reach out to Sally *and* follow up with her if indicated.

In sum, from a family-centered care perspective, asking about how a patient's caregiver is doing and about his or her needs during a clinical encounter is the only ethical and moral stance that a clinician can assume [13, 14]. Although Dr. Smith's underlying concern that Sally's well-being poses a risk to his patient may be the cause of his moral distress, he also demonstrates empathy and moral sensitivity towards Sally's situation, which may help to mitigate his moral distress [15]. Regardless of his level of moral distress, he is obligated to ask how she is doing.

### **Barriers to Reaching Out to Caregivers**

There are several barriers to clinicians' reaching out to caregivers. With few exceptions [16], the codes of ethics for physicians, nurses, and other health care professionals typically emphasize obligations toward individual patients and thus offer little guidance as to how to effectively involve caregivers. Electronic health records and reimbursement structures also focus on individual beneficiaries, thereby limiting potential to extend care to family caregivers. Furthermore, because medical training focuses on diagnosis and treatment, physicians can sometimes be ill-prepared to reach out to family members [14]. As Kleinman, the American psychiatrist and medical anthropologist, argues, there is a compelling need for serious discussion about caregiver needs and for reconsideration of medical education, practice, and research to address how to protect the autonomy and dignity of patients while effectively including family caregivers and addressing their needs [17, 18]. Lack of training combined with restrictions imposed by health insurers or

reimbursement incentives conspire to keep clinicians narrowly focused on patients with little attention to or understanding of their caregivers.

### **Strategies to Support Caregivers**

While health systems will need to evolve and change to become family-centered and offer comprehensive [dementia care](#), there are strategies clinicians can use now [19]. A common complaint of caregivers is that no one asks how they are doing or what they do [4]. Thus, caregivers could benefit from simply being asked about themselves and having a compassionate listener who provides reassurance, support, education, and referral. As part of routine care of a patient with dementia (or if the caregiver is the direct patient), clinicians can ask how the caregiver is managing. They can also initiate discussions with the caregiver concerning the scope and nature of his or her care responsibilities, sources of appropriate support and assistance, and self-management of stress and health. Based on these discussions, clinicians can emphasize the importance of the family caregiver's managing his or her own health and stress and make recommendations to connect with local resources (e.g., the Alzheimer's Association, adult day services, the National Family Caregiver Support Program offered by the local Area Agency on Aging) for respite, support, and other services. Thus, clinicians can help forge stronger alliances with patients' caregivers by asking strategic questions and encouraging family caregivers to share their challenges [20, 21].

Another approach found to be helpful for some caregivers is the use of a written or recorded oral diary [22]. This strategy has been shown to help caregivers maintain their self-identity and enables them to pinpoint ethically complex challenges to inform discussion of possible solutions [23].

Health care professionals should also recognize that dementia caregivers (professional and nonprofessional) struggle, as they do, with ethical ambiguities in balancing the dementia patient's autonomy and right to self-determination with his or her safety and well-being [24]. These moral challenges, in the absence of support and guidance from health professionals, contribute to the burden of and a sense of isolation among caregivers [24]. Recognizing caregivers' ethical and care challenges is an important step in supporting the caregiver and helping him or her identify effective care strategies.

Finally, caregivers need concrete strategies for managing patients' psychosocial and behavioral changes and functional decline and would benefit from clinicians' attention to these clinical aspects of the dementia process [25]. Family caregivers face a broader array of daily care challenges—from the daily routines of physical care to existential and moral considerations—than physicians, who see patients typically only in clinical settings for acute medical issues and on a time-limited basis [26]. As clinical encounters tend to be short, it may not be possible for physicians to help family caregivers learn and practice care strategies. However, [referral](#) to other resources and health professionals

could be helpful. For example, based on Sally's description of her daily challenges, Dr. Smith could make a referral for an occupational therapist to conduct a home safety assessment, help Sally learn effective communication strategies to minimize Hank's behavioral symptoms, and modify the home environment to support Hank's daily function [27]. A referral for a home care nurse could provide important information to Sally about pain detection and ways to ensure proper hydration and, in addition, identify medication issues and address other common medical concerns family caregivers like Sally may have [28].

Nevertheless, physicians cannot meet their ethical obligations to families, and health care systems cannot deliver adequate dementia care, without policy-level changes that might influence social and cultural trends at the health care organizational and practice levels. With rare exceptions, discussions about supporting family caregivers of patients with dementia have been all but absent from current discourse on health care [29]. Rather, concerns about self-sufficiency, autonomy, and individual patient needs continue to influence policy discussions. Such concerns may be reinforced by the stigma associated with receiving help and the viewpoint among older people that dependence on others is burdensome [29, 30]. One reason that support for family caregivers is absent from the discourse on health care is that the work of family caregivers is largely undervalued and ignored, although ironically the health care system fully depends upon families for providing long-term care to older adults [4].

Clinicians must also be actively engaged in national discussions and [advocate](#) for the needs of patients with dementia and their family caregivers. One step would be to integrate into clinical practice quality indicators for dementia care that have been previously developed by the American Association of Neurology and other medical bodies [31] and the International Consortium for Health Outcomes Measurement for dementia [32]. Both offer quality indicators for dementia care that recognize the need for outreach to, and provision of education and support for, family caregivers as part of routine care of a patient with dementia. Another step might be to apply new reimbursement codes for care coordination. The Centers for Medicare and Medicaid Services now recognizes that care coordination of chronic conditions in primary care is critical and offers billing codes to offset clinical time in coordinating care and making referrals [33].

At a policy level, findings from current dementia care demonstration projects supported by the Center for Medicare and Medicaid Innovation [34] may yield new family-centered care models that can be adopted by clinical practices and supported through bundled or other payment structures. New payment models may be forthcoming if projects demonstrate better care at reduced costs. The various strategies for supporting caregivers—at the individual, organizational, and social level—are summarized in Table 2.

**Table 2.** Strategies for reaching out to family caregivers

Domain	Specific Strategies
Ask strategic questions about caregiving	<p>Ask about caregivers' own health and well-being (e.g., if they have respite opportunities and a support network in place, what are their specific daily care challenges).</p> <p>Recommend keeping a journal of care and listing decision-making challenges that can be discussed in future encounters.</p>
Engage in active listening	<p>Provide reassurance.</p> <p>Validate caregiver efforts.</p> <p>Show empathy.</p> <p>Reaffirm the ethical dilemmas (e.g., autonomy versus safety) caregivers experience and explore whether they view the patient as suffering.</p>
Offer resources	<p>Provide ongoing education about the disease and its clinical symptoms.</p> <p>Explain that behavioral symptoms (e.g., agitation, rejection of care) are part of the disease process, are not intentional, and may be expressions of unmet needs including pain, hunger, fatigue, and discomfort).</p> <p>Recommend that caregivers discuss their situation with their own physician.</p> <p>Refer caregivers to specialists (e.g., counselor, geriatric care manager) as needed.</p> <p>Refer caregivers to Alzheimer's Association for support groups, information, and access to the help line.</p>
Prepare office and office staff	<p>Integrate family education and support into office practices.</p> <p>As part of medical history taking, ask if a patient receives help from a family member, and, if so, ask the family member what care responsibilities he or she has and how he or she is doing.</p> <p>Provide readings and education to office staff about dementia and caregiving.</p> <p>Develop office protocol that recognizes and includes caregiver as part of the medical encounter.</p>
Advocate through medical organizations	<p>Advocate for changes in reimbursement to accommodate time spent with family unit.</p> <p>Support upcoming legislative changes to the Health Insurance Portability and Accountability Act (HIPAA) that may serve as a barrier to including families in decision making about the patient's care and their own health and well-being as well as other policies that recognize and support the role of family caregivers.</p>



## Conclusion

The ethical dimension of providing medical care to patients with dementia and their caregivers is rarely discussed [35, 36]. The moral distress experienced by Hank's physician, Dr. Smith, is largely due to the restrictive context of health care delivery, which permits only a narrow focus on patients. However, the complexities of dementia require that health care assumes a social ecological perspective encompassing an understanding of the medical, social, financial, caregiver, and environmental contexts and needs of families living with dementia and that makes it possible for clinicians to help families meet those needs. Our health care system is not dementia ready, resulting in the experience of moral distress among practitioners as well as unethical practices (e.g., not reaching out to a family caregiver).

We suggest that, in dementia care, attention to family caregivers should be mandatory as their health and well-being are a critical part of the context of providing care to a patient with dementia. We show that regardless of the ethical framework employed, the resounding conclusion is that Hank's physician is obligated to reach out to Sally even in our current health care system. She is integrally bound to the health and well-being of her husband; thus reaching out to her would also help him. There is as well the moral obligation of justice to assure the health and well-being of family members who are intimately involved in caring for a patient with dementia.

## References

1. Alzheimer's Association. 2015 Alzheimer's disease facts and figures. *Alzheimer's Dement.* 2015;11(3):332-384.
2. Callahan CM, Arling G, Tu W, et al. Transitions in care for older adults with and without dementia. *J Am Geriatr Soc.* 2012;60(5):813-820.
3. Gaugler JE, Kane RL, eds. *Family Caregiving in the New Normal.* London, England: Academic Press; 2015.
4. National Academies of Science, Engineering, and Medicine. *Families Caring for an Aging America.* Washington, DC: National Academies Press; 2016.
5. Hurd MD, Martorell P, Langa KM. Monetary costs of dementia in the United States. *New Engl J Med.* 2013;369(5):489-490.
6. Berger JT. Moral distress in medical education and training. *J Gen Intern Med.* 2014;29(2):395-398.
7. Jameton A. *Nursing Practice: The Ethical Issues.* Englewood Cliffs, NJ: Prentice-Hall; 1984:6.
8. Beauchamp TL, Childress JF. *Principles of Biomedical Ethics.* 5th ed. New York, NY: Oxford University Press; 2001.
9. Ricoeur P. *Oneself as Another.* Blamey K, trans. Chicago, IL: University of Chicago Press; 1994.
10. Barrow R. *Utilitarianism: A Contemporary Statement.* London, England: Routledge;

2015.

11. Steinbock B, Arras J, London J, eds. *Ethical Issues in Modern Medicine: Contemporary Readings in Bioethics*. 7th ed. Boston, MA: McGraw-Hill; 2009.
12. Tronto JC. *Moral Boundaries: A Political Argument for an Ethic of Care*. New York, NY: Routledge; 1994.
13. Barnard D, Yaffe MJ. What is the physician's responsibility to a patient's family caregiver? *Virtual Mentor*. 2014;16(5):330-338.
14. Cohen CA. Caregivers for people with dementia. What is the family physician's role? *Can Fam Physician*. 2000;46:376-380.
15. Rushton CH, Kaszniak AW, Halifax JS. Addressing moral distress: application of a framework to palliative care practice. *J Palliat Med*. 2013;16(9):1080-1088.
16. Mitnick S, Leffler C, Hood VL; American College of Physicians Ethics, Professionalism and Human Rights Committee. Family caregivers, patients and physicians: ethical guidance to optimize relationships. *J Gen Intern Med*. 2010;25(3):255-260.
17. Kleinman A. Care: in search of a health agenda. *Lancet*. 2015;386(9990):240-241.
18. Kleinman A. Caregiving as moral experience. *Lancet*. 2012;380(9853):1550-1551.
19. Holmes SB, Adler D. Dementia care: critical interactions among primary care physicians, patients and caregivers. *Prim Care*. 2005;32(3):671-682, vi.
20. Rydeman I, Törnkvist L, Agreus L, Dahlberg K. Being in-between and lost in the discharge process—an excursus of two empirical studies of older persons', their relatives', and care professionals' experience. *Int J Qual Stud Health Well-being*. 2012;7(0):1-9.
21. Cohen CA, Pringle D, LeDuc L. Dementia caregiving: the role of the primary care physician. *Can J Neurol Sci*. 2001;28(suppl 1):S72-S76.
22. Parks SM, Novielli KD. A practical guide to caring for caregivers. *Am Fam Physician*. 2000;62(12):2613-2622.
23. Sorrell JM. Deciding for others: surrogates struggling with health care decisions. *J Psychosoc Nurs Ment Health Serv*. 2014;52(7):17-21.
24. Breitholtz A, Snellman I, Fagerberg I. Carers' ambivalence in conflict situations with older persons. *Nurs Ethics*. 2013;20(2):226-237.
25. Roland KP, Chappell NL. A typology of care-giving across neurodegenerative diseases presenting with dementia. *Ageing Soc*. 2015;35(9):1905-1927.
26. Glasser M, Miller B. Caregiver and physician perspectives of medical encounters involving dementia patients. *Am J Alzheimers Dis Other Demen*. 1998;13(2):70-80.
27. Gitlin LN, Winter L, Dennis MP, Hodgson N, Hauck WW. A biobehavioral home-based intervention and the well-being of patients with dementia and their caregivers: the COPE randomized trial. *JAMA*. 2010;304(9):983-991.
28. Hodgson NA, Gitlin LN, Winter L, Czekanski K. Undiagnosed illness and neuropsychiatric behaviors in community residing older adults with dementia. *Alzheimer Dis Assoc Disord*. 2011;25(2):109-115.
29. Bursch HC, Butcher HK. Caregivers' deepest feelings in living with Alzheimer's

- disease: A Ricoeurian interpretation of family caregivers' journals. *Res Gerontol Nurs*. 2012;5(3):207-215.
30. Kittay EF. *Love's Labor: Essays on Women, Equality, and Dependency*. New York, NY: Routledge; 1999.
  31. Odenheimer G, Borson S, Sanders AE, et al. Quality improvement in neurology: dementia management quality measures. *Neurology*. 2013;81(17):1545-1549.
  32. International Consortium for Health Outcomes Measurement (ICHOM). Dementia. <http://www.ichom.org/medical-conditions/dementia/>. Accessed October 18, 2016.
  33. Centers for Medicare and Medicaid Services. Chronic care management services. <https://www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNProducts/Downloads/ChronicCareManagement.pdf>. Published May 2015. Accessed October 16, 2016.
  34. Centers for Medicare and Medicaid Services. The CMS Innovation Center. <https://innovation.cms.gov/>. Accessed October 16, 2016.
  35. Breheny M, Stephens C. Negotiating a moral identity in the context of later life care. *J Aging Stud*. 2012;26(4):438-447.
  36. Barber CE, Lyness KP. Ethical issues in family care of older persons with dementia: implications for family therapists. *Home Health Care Serv Q*. 2001;20(3):1-26.

**Laura N. Gitlin, PhD**, is a professor at the Johns Hopkins University School of Nursing and School of Medicine in Baltimore, where she is also the director of the Center for Innovative Care in Aging. Her clinical and research expertise is in caregiving and nonpharmacological approaches in dementia care.

**Nancy A. Hodgson, PhD, RN**, is an associate professor and the Anthony Buividas Endowed Term Chair in Gerontology at the University of Pennsylvania School of Nursing in Philadelphia. Her clinical and research expertise is focused on the area of dementia caregiving.

#### **Related in the *AMA Journal of Ethics***

[Ethical Issues in Early Diagnosis of Alzheimer Disease](#), December 2011

[The Legal Implications of Detecting Alzheimer's Disease Earlier](#), December 2016

[Managing Difficult Behaviors in Patients with Dementia](#), June 2008

[Patient- and Family-Centered Care: It's Not Just for Pediatrics Anymore](#), January 2016

[What Is the Physician's Responsibility to a Patient's Family Caregiver?](#), May 2014

The people and events in this case are fictional. Resemblance to real events or to names of people, living or dead, is entirely coincidental.

The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

**Copyright 2016 American Medical Association. All rights reserved.**

**ISSN 2376-6980**