



Ethical Issues: Caring for the Caregiver

One of the important details we tend to overlook when taking care of patients with debilitating or life-threatening disease is the welfare of those family members taking care of the patient at home. The burden of providing informal care to patients who are debilitated or dying can be overwhelming, but caregiver burden has historically been underemphasized and is often unrecognized by health care providers who traditionally are more focused on the needs of the patient than the caregiver.^{i ii} When caregiver anxiety increases crisis situations may lead to conflict and imminent breakdown of informal care at a time when it is most needed for the patient, yet when such crises occur there are few targeted services or interventions available for caregivers.

In the United States, over 500,000 deaths are caused each year by cancer, which is the second leading cause of death and the most frequent terminal illness requiring caregiving.ⁱⁱⁱ For those patients with end stage diseases who wish to remain at home nonprofessional caregiving is crucial to respecting the patient's wish and to providing optimal palliative care. Current survey findings indicate that nearly one in four adults provide informal caregiving, much of which requires high-intensity care that is often without instruction or support.^{iv} Nearly two-thirds of primary caregivers are women, half are under the age of 45, most are married, and half are employed full time while at the same time providing more than 20 hours of caregiving a week. Within the next 50 years, the total number of cancer cases in the United States is expected to double.^v This demographic shift, in combination with society's increasing emphasis on controlling health care costs by reducing hospital stays and shifting more care to the outpatient setting, will likely increase the prevalence and need for informal caregiving.

Non-professional caregivers for patients with chronic and debilitating disease are usually family members in the home who become important co-participants in the care of the patient. They often represent the patient when they cannot represent them self, and as the patient's clinical status deteriorates caregivers become one of the most important members of our team. However, to remain a functional member of the medical team caregivers must not only take care of the needs of their patients, they must also deal with their own physical, psychological, and financial needs, which are often substantial and frequently are unmet.^{vi} Not surprisingly these concerns tend to become more critical for the caregiver as their patient nears death. Caregivers and their patients in the palliative care setting often have intense need and expectations of care that, when unmet may lead to distress and conflict.^{vii} When these needs and expectations are effectively addressed, however the sense of conflict and burden tend to be less extreme.

Studies indicate that poor communication with the physician and perceptions of physician inattentiveness to the needs of both the patient and the caregiver contribute to

the burden of caregiving and may damage caregiver trust in the physician.^{viii} Caregivers want and need recognition that they are important and often need assistance in balancing caregiving with other family responsibilities. Caregivers also express a desire for open and honest discussions about clinical findings and the condition of their patient. Poor communication and insensitivity to such needs may contribute to caregiver distress and loss of trust. In particular, caregivers tend to become concerned and mistrustful when there is not full disclosure about medical errors or the condition of their loved one, especially when the patient is deteriorating.

As illness progresses decision-making authority is progressively transferred from the patient to the caregiver, as the patient becomes more dependent and less able to represent them self. In a gradualist sense the caregiver becomes at once an autonomous extension of the patient and an integral partner in the trust relationship forged between the patient and their physician, as well as an important member of the medical team treating that patient. In many ways the patient-caregiver dyad as a unit “becomes” the patient and should be recognized when considering treatment decisions and goals of care. Informal caregiving is today’s expanding world of homecare and hospice is critically important to our patients and to our ability to do our job as health care providers—we need them, and should consider their welfare by welcoming them as equal stakeholders in the relationship we have with our patients.

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