



Ethical Legal Feature

The Family Caregiving Dilemma

Guest Discussants: Ryan Stork, MD, Marilyn Martone, PhD, Paul Osterman, PhD

Guest Editor: Teresa A. Savage, PhD, RN

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Introduction

We often assume that, on discharge from inpatient rehabilitation, families will provide caregiving for their loved ones. The discharge process involves assessing the intensity and skill level of assistance needed by the patient, and decisions about placement recommendations often hinge on the intensity and availability of caregiving resources. This responsibility often falls on family members, and there are ethical issues involving allocation of resources, family duties, and potential harms, among others. To explore this topic, I have invited Dr Teresa A. Savage, PhD, RN, to guest edit a column on ethical issues of family caregiving.

Dr Savage is a Clinical Associate Professor in the Department of Women, Children and Family Health Science at the University of Illinois at Chicago College of Nursing. She is also a consultant to the Donnelley Ethics Program at the Shirley Ryan AbilityLab and an adjunct Associate Professor in the Department of Physical Medicine & Rehabilitation and in the Center for Bioethics and Humanities, both in the Feinberg School of Medicine of Northwestern University. Dr Savage's expertise includes developmental disabilities, neonatal ethics, and

disability ethics. Her research has explored end-of-life care for people with intellectual and developmental disabilities and also life-support decisions for infants born extremely premature. She is the author of numerous articles and coauthor of an ethics textbook, *The Ethical Component of Nursing Education: Integrating Ethics Into Clinical Experience* [1]. Dr Savage has worked as a clinical nurse specialist in pediatric neurology, where she coordinated services for children with multiple and complex health care needs. Through her work with families of children with significant disabilities, she became familiar with issues of the family caregiver, and she brings her experiences and expertise as a guest editor.

This column raises complex issues about the role of families, caregivers, and society in responding to the sequelae of traumatic injury. As always, I welcome comments and ideas for ethics/legal columns at dmukherjee@sralab.org.

Reference

1. Bosek MSD, Savage TA. *The Ethical Component of Nursing Education: Integrating Ethics Into Clinical Experience*. Philadelphia, PA: Lippincott Williams & Wilkins; 2007.

Guest Editor: Teresa A. Savage, PhD, RN

In 2016, there were 44 million family caregivers in the United States [1]. On discharge from acute care and/or acute inpatient rehabilitation, family members face the dilemma of assuming the care of their loved ones with disabilities or placing the loved one in a skilled nursing facility. Many times, families will sacrifice their health and financial well-being by becoming the caregiver for their disabled loved one. The work becomes even more challenging when that loved one has sustained a traumatic brain injury that affects behavior and ability to

perform activities of daily living. Often the person with the disability, if capable, expresses a desire to be at home and refuses nursing home placement. Caregivers desire to provide the best care that they can but often find the work overwhelming. They may find few resources to assist them in their ability to balance caregiving with other responsibilities.

What are the ethical obligations, if any, for the family to become the caregivers? How much must the family be expected to sacrifice? How does the

rehabilitation team reconcile the patient's refusal for nursing home placement with the reluctance of the family to assume the care? Are there ethical and economic arguments to be made in support of the state paying family members who must give up paid employment to provide a loved one's care, rather than pay for nursing home care?

I have asked 3 commentators to review the case herein and offer their thoughts on the situation of the unpaid caregiver. The first case commentator is Dr Ryan Stork, a physiatrist and Assistant Residency Program Director in Brain Injury Medicine and Rehabilitation at the University of Michigan. Dr Stork focuses on the challenge to the rehabilitation team to provide for a safe discharge, but one in which he has potential for his maximal recovery within available resources. Next, Dr Marilyn Martone, a theologian and ethicist, retired associate professor from St John's University in Jamaica, NY, who has personal experience with providing care for her daughter, presents the issues the family faces in making the difficult decision to provide caregiving. Dr Martone shares her caregiving story in her book *Over the Waterfall* [2]. The third commentator, Dr Paul Osterman, economist and professor at Massachusetts Institute of Technology Sloan School of Management, proposes a possible solution to the crisis of unpaid caregivers and the increasing need for caregivers in long-term care. For more detail about his proposal, see *Who Will Care for Us? Long Term Care and the Long-Term Workforce* [3]. These 3 commentaries illuminate the ethical, social, political, and personal forces in play surrounding the caregiving decisions.

Hypothetical Case

Roger, a 25-year-old auto mechanic, was injured while riding a motorcycle that hit a truck. He was not wearing a helmet and was ticketed for driving under the influence. Roger sustained a traumatic brain injury, leaving him with a right hemiplegia. He is impulsive, emotionally labile, and lacks insight into his deficits. He uses a wheelchair at this time. He and his girlfriend, Maria, are expecting twins in 3 months. Roger and Maria moved in with his parents when she became pregnant, and they planned to stay there until after delivery. On

discharge, he will require 24-hour supervision and assistance with activities of daily living. Plans are for him to have weekly outpatient occupational therapy, physical therapy, and speech therapy at a facility located 30 miles from his home. Maria's car is a subcompact and probably not suitable for transporting Roger to and from his appointments; his parents have a pick-up truck.

At the discharge meeting, his parents expressed their frustration with Roger's behavior that resulted in his injuries and current situation. They believe he has acted irresponsibly throughout his teenage years and early adulthood, and they are tired of "cleaning up after him." They are angry that their life plans must change to care for their son. Although his parents live from paycheck-to-paycheck, his mother suggests that she will quit her job when the twins are born and will take care of Roger and the twins while Maria works 2 jobs, as a waitress during the day and a telemarketer in the evening. They will let Roger, Maria, and the twins stay at their home until he recovers and can return to work. His rehabilitation team cannot predict whether he will ever be able to return to work at this point.

Maria is considering taking the twins and moving in with her parents, who live in another state. Roger's extended family, although not fond of Roger, offered to help "babysit" Roger so his parents can have a break once in a while. A few of Roger's relatives have also offered to make the structural changes in his parents' home to accommodate Roger's wheelchair and safety needs. The team offers the option of transferring Roger to a skilled nursing facility about 75 miles from his parents' home. The parents and Maria want to explore that option, but Roger has stated he would rather die than go to a nursing home.

References

1. Family Caregiver Alliance. National Policy Statement Available at <https://www.caregiver.org/national-policy-statement>. Accessed October 26, 2017.
2. Martone M. *Over the Waterfall*. Lexington, KY: CreateSpace Independent Publishing; 2010.
3. Osterman P. *Who Will Care for Us? Long Term Care and the Long-Term Workforce*. New York: Russell Sage Foundation; 2017.

Maximizing Functional Recovery With Limited Resources

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The difficult questions that surround Roger's discharge plan represent a common scenario that the family and members of the rehabilitation team

encounter while preparing to discharge survivors of traumatic brain injury from inpatient rehabilitation. Roger's situation emphasizes a number of barriers that one may have with accessing the most appropriate services (a comprehensive outpatient neuro-rehabilitation program) following discharge from

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