

PM R 10 (2018) 90-96

Ethical Legal Feature

www.pmrjournal.org

The Family Caregiving Dilemma

Guest Discussants: Ryan Stork, MD, Marilyn Martone, PhD, Paul Osterman, PhD Guest Editor: Teresa A. Savage, PhD, RN

Feature Editor: Debjani Mukherjee, PhD

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

 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

- Family Caregiver Alliance. National Policy Statement Available at https://www.caregiver.org/national-policy-statement. Accessed October 26, 2017.
- Martone M. Over the Waterfall. Lexington, KY: CreateSpace Independent Publishing; 2010.
- 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

Ryan Stork, MD University of Michigan

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 neurorehabilitation program) following discharge from

inpatient rehabilitation. The state has a duty to fairly distribute its resources.

The productivity losses associated with traumatic brain injury are substantial. Based on year 2000 data, the total annual cost of care related to traumatic brain injury was \$60.43 billion. This includes \$9.22 billion of direct costs and \$51.21 billion of productivity losses [1]. These costs are greater than any other injured body region, including spinal cord injury. It is important for the state to consider what resources it can allocate early on in the rehabilitation course of an individual with traumatic brain injury to minimize disability and lower the costs of productivity losses.

It is well accepted that earlier initiation of rehabilitation and greater intensity of rehabilitation efforts earlier in the course of recovery are associated with better functional outcomes [2]. In Roger's case, if the state was willing to provide more resources early on in his discharge from inpatient rehabilitation, such as adequate transportation services to therapy and either external or paid family caregiver support, this would allow Roger to attend a comprehensive neurorehabilitation program on an outpatient basis with the goal of increasing his level of independence and decrease his lifelong caregiver needs. Taking this consideration a step further, devoting resources to vocational rehabilitation programs as a component to outpatient rehabilitation would likely further decrease Roger's level of disability and help maximize his chances for a return to some form of work. This investment in resources early in the rehabilitation course would likely lead to a decrease in productivity losses associated with Roger's injury. In doing so, the state may ultimately lessen the burden of care and therefore decrease productivity losses associated with traumatic brain injury survivors.

Consideration of the principle of justice is very relevant to Roger's case. The state has an obligation to provide others with what they are owed. Granted, defining what one is fairly owed is a complicated question. In Roger's case, it is reasonable to question whether his access to resources should be limited due to his actions that led to the accident (driving while under the influence and not wearing a helmet). Ultimately, the state must consider the fair distribution of resources to optimize efficiency and access to neurorehabilitation programs for all citizens. Prioritizing resources based on the circumstances that caused an individual to sustain a brain injury (for instance, restricting access to rehabilitation services if someone was injured due to being under the influence of substances) is at conflict with the duty of health care providers to be beneficent. Not uncommonly, health care providers are expected to provide care to patients who may engage in activities or behaviors of which the

health care provider does not agree. A consideration would be to require greater copays or deductibles for individuals who were not wearing a helmet or under the influence when involved in an accident. However, in catastrophic claims, the ability for the patient to afford greater deductibles or copays would be limited. In Roger's case, the state must consider how lack of access to quality rehabilitation and vocational programming may impair Roger's functional recovery and ultimately lead to greater productivity losses for Roger and his family—leaving him more dependent on the state's resources.

When considering the ethical obligations of Roger's girlfriend and family to provide 24/7 care to him, it is important to consider the impact their decisions will have on their own well-being. Caregivers of individuals with traumatic brain injury consistently show increased psychological distress, lower social functioning, and reduced quality of life [3]. It is important to acknowledge the financial and psychological burdens that providing around-the-clock care for Roger may place on his family. Additionally, as Roger's case illustrated, it is not unusual for survivors of traumatic brain injury to have a previous substance abuse history and the patient's family may already have been dealing with a number of financial, legal, and emotional burdens due to the patient's history of substance use. Certainly, the family is not obligated to provide care that would be psychologically, emotionally, or financially damaging to them, particularly if it were to the extent that would ultimately prevent them from providing adequate care to Roger.

It is important for the inpatient rehabilitation team to demonstrate empathy to both Roger and his family as they plan his discharge. Ultimately, the team's first priority should be ensuring a safe discharge for Roger. Second, they should attempt to seek solutions to the barriers that may prevent Roger from accessing the rehabilitation resources that provide him with the opportunity to maximize his functional recovery. Each patient will have a varying amount of social, financial, and emotional resources available to them. Ultimately, the rehabilitation team can only focus on providing the best possible care within the resources that are allotted to them.

References

- 1. Faul M, Coronado V. Epidemiology of traumatic brain injury. In: Grafman J, Salazar A, eds. Handbook of Clinical Neurology. Amsterdam: Elsevier B.V.; 2015, 3-13.
- Teasell R, Bitensky J, Salter K, Bayona NA. The role of timing and intensity of rehabilitation therapies. Top Stroke Rehabil 2005;2: 46-57
- Ponsford J, Schonberger M. Family functioning and emotional state two and five years after traumatic brain injury. J Int Neuropsychol Soc 2010;16:306-317.

Caring for the Most Vulnerable Members of Society

Marilyn Martone, PhD St John's University

When moving from an institutional setting to a home setting, there are major adjustments that need to occur. Much of our ethical decision-making has been formulated by professionals. It is usually principle based. We examine such principles as autonomy, beneficence, nonmaleficence, and justice and then try to determine how these principles should be applied in a particular situation. There is also an emphasis on the individual. For instance, when there is more than one individual involved, the issue becomes whose autonomy takes precedence. When one no longer has the capacity to make decisions for oneself, someone is appointed to express that person's wishes. But making one's wishes known and having someone carry out those wishes when one can no longer do it for oneself are 2 separate considerations.

In a home setting, one seldom uses principles to determine what should be done but instead applies practical reasoning. What is the right thing to do in this particular case with these particular persons? It is contextual. It is relational. Many more factors than individual autonomy need to be considered. What we do for each other in a home-care setting is often based on what bonds we have to each other. This care giving is not based on a contractual, mercurial relationship between separate individuals but on personal relationships among individuals. Sometimes this caregiving is done out of duty. Sometimes it is done out of love. And sometimes it is not done at all.

In the case presented, there are many individuals involved, and although there is much we don't know, the bonds between these individuals seem somewhat in flux. For example, the young man who suffered the injury is not married to the mother of his children. They do not have their own residence. The twins have not yet been born. The parents of the injured man appear somewhat annoyed at his behavior, and their relationship with him appears strained. He is an adult but still living in their home. We do not know the age and the health conditions of the parents or whether they are caring for other individuals such as elderly parents or other children. They are reluctant to take on the enormous caregiving responsibilities that would be involved in caring for their brain injured son, his partner, and their twin grandchildren.

Although the young man does not wish to go to a nursing facility, are there other places he could go besides his parents' home? Does he have other siblings who would welcome him? Is he in a position to set up residence with the mother of his children? Would she want to care for him as well as the twins? The solution seems

to rest on what kind of relationship exists among all of them and how deep the bonds of concern are. This is not a decision that can be easily forced on anyone.

Society has a role to play as well. As medical facilities discharge patients earlier and earlier, and as insurance companies encourage more and more patients to go home rather than to acute or subacute facilities, families are put under tremendous stress. Many families are splintered and overworked even before illness strikes. They are ill equipped in many cases to do this caregiving, and there are few resources available to help them. As a society we do not do well with long-term, chronic care and, unfortunately, often the only solution society has to offer families is a skilled nursing facility. Institutions are concerned with discharge, but families are often riddled with guilt at putting their loved one in a skilled nursing facility and are left doing the long-term tedious and often strenuous care with few resources to assist them.

As a society we must do better. Rather than present families with an either/or dilemma—skilled nursing or overwhelming home care—we must bring more resources into the home to assist families or establish other places of care besides skilled nursing facilities. Many families are willing to bear a portion of the responsibility of caring for their ill family member but realize that total caregiving might actually destroy the family and those who do the caregiving.

Studies show that the need for home health care workers is phenomenal. Experts estimate the need for 1.8 million additional workers in the next decade [1]. Home care is the fastest-growing of all occupations in the nation, and by 2018 the demand for home care workers will increase by more than 90%, but health insurance, including Medicare, provides little, if any, support for home-based care. Although Medicaid does pay for some home health care aides, it is often very difficult to find workers who will work for the Medicaid wages. Home health aides are paid low wages, and many families cannot afford to self-pay for the help they desperately need. As a result, family members often do this work themselves. However, 61% of family caregivers also are employed. Most family caregivers are women, and statistics show that if one is a caregiver, there is a loss of \$303,800 in income over a lifetime. Even if there are strong bonds between family members, taking care of a loved one at home has severe consequences for the caregiver. When dealing with home care, we cannot think only of the individual who needs care but of the entire family structure.

As a society we need to appreciate the value of caregiving and to offer more choices. We need to think creatively about ways of supporting families in their caregiving capacities and build on what is already present in the family structure. One size does not fit all. We need to properly compensate those professionals who do this work and move more of society's resources into this area. It is unethical to force a family to do this work when they have few resources available to help them. We must face our national caregiving problem and assist

families in doing this work. Societies will be judged by future generations on how they care for their most vulnerable members.

Reference

1. Poo A. The Age of Dignity. Hyde Park, NY: New City Press; 2015.

How to Improve Long-Term Care: Respect the Home Care Aide

Paul Osterman, PhD

Massachusetts Institute of Technology (MIT) Sloan School of Management

Excerpted with permission from Who Will Care for Us? Long Term Care and the Long-Term Workforce. New York: Russell Sage Foundation; 2017

In 2015, nearly 19 million people younger than the age of 65 years and nearly 14 million people older than the age of 65 years reported that they had difficulty taking care of themselves or living independently [1]. Thirty-three million is a big number but is nothing compared with what will come as the Baby Boomers age. The number of adults age 65 and older who need assistance is predicted to nearly double in the next 25 years. Population growth in younger cohorts will also increase demand for services for the nonelderly people with disabilities.

Who will care for the aged and younger people with disabilities such as the 25-year-old man in the case example? Ask any adult with an elderly parent or any younger person with disabilities about who is central to quality of life and physical well-being of their loved one and the answer will be home care aides.

In 2015, there were 2.2 million aides working "above the table." Nationally the median wage is a mere \$10 an hour, and they receive little respect. Decision-makers—doctors, hospitals, state regulators, state legislators, insurance companies, Federal bureaucrats—typically do not think that home care aides can be real members of a care team. Home care aides are seen as unskilled companions, as glorified babysitters, with little education and little potential. Typical comments by insurance executives and senior public policy makers were that they are "minimum wage people" who perhaps "cannot tell the difference between the cat's eye-drops and the eye-drops for their client" [1].

It need not be this way. Imagine that you were designing a system of care from scratch. Given people's preferences and needs, what are your goals? You know that people want to stay in their homes and remain connected to their communities and you also know that (in most cases) home and community-based care is more affordable than institutional care. You also know that

the people who spend the most time with the elderly and younger people with disabilities are home care aides. What would you do?

The most fundamental change is to reconceive longterm care so that it is not the stepchild of the health care system but instead is seen as central to the quality of life for the millions of people who need it. This means raising the profile of the field within health care and incorporating home care aides into health care teams.

When it comes to home care aides, one would seek to maximize their contribution to the well-being of those for whom they care. You would also worry about how to pay for improved wages and working conditions for home care aides so you would look for strategies to improve their productivity and enable them to help save medical costs through decreasing emergency department visits and hospital readmissions. And these 2 objectives—assuring that the home care aides are as helpful and productive as possible, and finding ways to economize on the cost of care—are complementary and point in the direction of new thinking about the delivery of care.

The central idea is to reconceive of the role of home care aides. It is important to be realistic: not all aides are interested in or capable of undertaking an expanded role, but many in fact are. For these aides, you would train them in skills ranging from observation of health conditions, to wound treatment, to health coaching, and to physical therapy assistance. Home care aides would assist in transitions as people leave hospitals and hopefully return home rather than to an institution. You would assure that there is regular communication between the home care aides and other members of the health care team; in fact, the home care aides would be members of the health care team.

This is far from today's reality, but it is consistent with emerging ideas about how to deliver health care. In recent years new approaches for delivering medical care have begun to percolate through the system and gain traction. The focus has been on 3 key pressure points: preventative care, treatment of chronic conditions, and transitions from acute care (in hospitals) to home. The core idea is to manage these 3 needs using nonphysicians who work to "the top of their license." My argument is that home care aides can also be part of this transformation.

The message is also that improving the quality of life for the elderly and people with disabilities is not about high tech medicine, but is about quality care and attention to managing chronic conditions. Home care aides see their clients every day for hours. No one is in a better position to help with these challenges than they are.

The vision just laid out holds real promise for offering better care and for improving the quality of jobs for those who do the work. But achieving this vision will be very difficult. The primary funder of long-term care, not just for poor people but on occasion for working people and the middle class, is Medicaid. This reliance is in itself a problem because Medicaid is widely seen as a part of the welfare system, indeed its origins are precisely that, and the consequence is that Medicaid funding, unlike Medicare, is constantly under attack and the program enjoys few powerful allies. Compounding the problem is that the incentive structures are not properly aligned. Most elderly patients whose long-term care is paid by Medicaid are also covered by Medicare, but the Medicaid system, with state contributions and sate policy making, has no incentive to save Medicare costs (for example, by enhancing the role of sides) because it is entirely Federally funded. Fixing these incentives—and there are some efforts to do so—is essential.

It is easy to go through the litany of challenges, but there are also reasons to think that progress is possible.

Simple demographics will push us towards a solution. As the numbers of people who need care rises and as the reservoir of family caregivers shrinks because of smaller family size and geographic dispersion, pressures will build and likely be translated into politics. Adding to this are shifts in the structure of the industry. Everywhere, states are moving their Medicaid long-term care into managed care insurance (as opposed to the traditional fee-for-service systems), and there are also increasing moves to integrate Medicaid and Medicare systems for the elderly. State budgets are under pressure, and the state share of Medicaid long- term care costs is a big part of the problem. We can therefore hope that both insurance companies and the states will look at the relatively less expensive home care aides and think about how they could reduce the costs of chronic care if they were trained better and had a broader set of duties. In some states, unions are pushing to expand the role of home care aides. Add this all up and the potential is there to shake up what has been a stagnant system and improve the options for those who need assistance and in the process make far better use of the human capital and potential of Home Care Aides.

Reference

 Osterman P. Who Will Care for Us? Long Term Care and the Long-Term Workforce. New York: Russell Sage Foundation; 2017.

Concluding Remarks: Teresa A. Savage, PhD, RN

From the time of admission, the rehabilitation team strives to achieve a safe discharge consistent with the patient's preferences and resources. Often, the patient and the team struggle to find the ideal placement. Nearly all patients want to return to their home, but they often lack the resources to make the necessary structural accommodations to the home. Despite the desire to provide the direct care that the patient needs, the family may not realize the magnitude of the commitment of time and effort. Yet, they have limited options because many patients resist the plan to be transferred to a skilled nursing facility, especially one that is a considerable distance from their family, as in the aforementioned case. There is also a lower ratio of caregiver-to-patient and a lower intensity of direct therapies at skilled nursing facilities compared with the acute inpatient rehabilitation hospital. This sets up a strong preference for the patient to return home.

Home care involves training family to provide direct care, such as giving medications, assisting with activities of daily living, including intimate care involving bathing and attending to bladder and bowel function, and monitoring the patient for complications. They also may be involved in exercising and positioning the

patient or placing and removing orthotics. If a Medicaid transport vehicle is not available, they may also need to transport the patient to medical appointments and outpatient therapies. These activities, as well as routine activities such as preparing meals, doing laundry, grocery shopping, and housekeeping, must be done as well. There may be extended family to help, but they may not be comfortable in giving direct care. Further, the behavior of survivors of traumatic brain injury can be challenging even for professional caregivers and may deter extended family from giving direct care. As each of the commentators point out, caregiving can be allconsuming, and even with the most ardent commitment, be impossible for family members to sustain. Dr Martone characterizes the sense of duty the family owes to their loved one, yet, as illustrated in the case, there is some ambivalence about owing duty to Roger, whose irresponsible behavior caused his accident.

All 3 commentators recognize the need to provide families with financial support at a level that would secure well-trained, dependable, committed paid caregivers. Dr Stork observes that regardless of the reason for Roger's injuries, the health care professionals are obligated to provide care that will maximize his

health and function as much as possible. Economist Osterman argues that the caregiver should be the inhome link to the hospital and clinic-based health care team, and should have the skills and motivation to fulfill the role by being recognized as a vital part of the team. The pay for the caregiver should be commensurate with the level of responsibility and education to attract the best people. There have been experiments in creating a new level of unlicensed assistive personnel, such as the Registered Care Technologist, created by the American Medical Association in the late 1980s [1], which failed because of resistance from the American Nurses Association.

The Family Caregiver Alliance in their National Policy Statement calls for these 8 initiatives:

- Authorize and fund a National Resource Center on Caregiving;
- Modernize Medicare and Medicaid to better support family caregivers;
- Commission an Institute of Medicine study on family caregiving;

- Provide adequate funding for programs that assist family caregivers;
- Expand the Family Medical Leave Act;
- Promote policies that expand the geriatric care workforce;
- Enact legislation providing refundable tax credits for family caregivers and employers; and
- Strengthen Social Security by recognizing the work of family caregivers [2].

Movement toward enacting these initiatives may help to solve the dilemma facing the caregiver. Unfortunately, until that time, health care professionals, patients, and families are left with often inadequate solutions to this very important issue.

References

- Perry L. Nurses win RCT battle, but war isn't over. Modern Healthcare 1990;20:36.
- Family Caregiver Alliance. (n.d.). National Policy Statement. Available at https://www.caregiver.org/national-policy-statement. Accessed October 26, 2017.

Disclosure

R.S. Brain Injury Medicine and Rehabilitation, University of Michigan, Ann Arbor, MI

Disclosure: nothing to disclose

M.M. St John's University, Jamaica, NY Disclosure: nothing to disclose

P.O. Sloan School of Management, Massachusetts Institute of Technology (MIT),

 ${\it Cambridge,\,MA}$

Disclosure: nothing to disclose

T.A.S. Department of Women, Children and Family Health Science, University of Illinois at Chicago College of Nursing, Chicago; and Donnelley Ethics Program at the Shirley Ryan AbilityLab and Department of Physical Medicine & Rehabilitation, Center for Bioethics and Humanities, Feinberg School of Medicine, Northwestern University, Chicago, IL

Disclosure: nothing to disclose

D.M. Shirley Ryan AbilityLab, Northwestern University, Chicago, IL. Address correspondence to: D.M.; e-mail: dmukherjee@sralab.org

Disclosure: nothing to disclose