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Marilyn Martone

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Developing New Models to Ensure Autonomy in Home Health Care

by

Marilyn Martone, Ph.D.

The author is Assistant Professor of Theology and Religious Studies, St. John's University, Jamaica, New York.

Autonomy is a key principle in health care ethics. Although there has been much debate as to how to define this principle,[1] there has been overwhelming agreement that autonomy encompasses self-determination, self-rule, freedom of the will , and independence.[2] It can be measured by our capacity to critically reflect on, and then accept or change our preferences, desires, values, and ideals. It entails making choices that lead to the quality of life that we desire.

Recent trends in health care have moved institutions towards recognizing and supporting patient autonomy, so that patients may achieve the desired quality of life during illness and even to the brink of death. However, the home care situation that is rooted in the relationship between the caregiver and the care receiver, or patient, has less to do with ensuring autonomy and more with fulfilling immediate needs of the person who is ill or incapacitated. The personal bond between the individuals in this situation tends to suppress issues of justice and autonomy, and this will remain the prevalent scenario until new models are constructed that recognize the needs, and support the autonomy, of the nonprofessional caregiver as well.

Creating an Environment for Autonomy

Although the fact is fairly obvious that patients are particularly vulnerable to losing their autonomy because of their weakened physical, mental, and emotional states, it is only recently that the issue has been addressed not only in terms of patients' current capacity, but also with a view toward possible incapacity in the future. Patients are encouraged to remain autonomous for as long as possible - to select their physicians, make decisions about the type and duration of health care treatment, and select the individuals who should make decisions for them in the event that the patients become incompetent. Formal guidelines and legal instruments (such as patients' bill of rights, living wills, and health care proxies) have been developed to protect patients' autonomy. These documents help to ensure that patients are treated with dignity and respect and that their specific wishes regarding health care are carried out. Also, the usual documentation for patient registration and consent for surgical and other procedures specify responsibilities as well as waivers for liability. These documents operate as contractual agreements, with both sides freely consenting to abide by the stated terms.

In contrast, when health care is provided in the home by a related primary caregiver, the care receiver and the caregiver have no contractual agreement as to what can be requested and provided. If the responsibility for providing health care, and the expectation of receiving it, is derived solely from the individuals' expertise and conscious decision making about the type of care desired, then the issue is not only whether autonomy is preserved for the patient, but also whether it is preserved for the caregiver.

Comparing the Institutional Setting With the Home Setting

Institutional Setting

In an institutional setting, patients are apt to get the latest in technological assistance and have an entire professional trained staff available to fulfill their health care needs. This care, however, is provided by strangers who may not be familiar with the patients' value systems and the type of health care that patients prefer. Thus, we have seen various legal instruments and formal guidelines put into place in order to protect the patients' self-determination. These guidelines are not always perfectly implemented, but they attest to the fact that patient autonomy is important, and should these documents be ignored, legal action may follow.

In institutional settings, the bond uniting patients and health care personnel is a professional bond that is accepted by patients and professional caregivers and that is directly or indirectly limited to health care needs. Patients have no claims on these professionals' personal lives. Professional health care providers maintain their autonomy, because they freely enter into this relationship and do not compromise their personal self-determination. In fact, they probably enhance it because they are practicing the profession they have chosen to define themselves. They are able to provide care while maintaining a certain professional detachment from their patients because they can limit themselves to the *medical needs* of their patients. Likewise, their professional load can be limited to a certain number of patients, and because they work in conjunction with others they are able to have scheduled time away from the patients in their care. Although they might be truly concerned about their patients' well-being, in most cases, their personal lives will not be altered substantially by whatever their patients' outcomes might be.

Home Setting

The concept of autonomy changes dramatically in a home health care situation. Patients in home health care are in settings where they constructed their visions of well-being and with people who were instrumental in helping them fulfill these visions. The home care setting is representative of how they have chosen to express their autonomy, and it is where they can bestcontinue to live their lives in the ways they have prescribed. Hence, to this degree, their autonomy is most likely to be intact because they are in settings that they have helped to create and with people who understand and share, at least to some extent, their concept of the good life. The fact that courts recognize family members as surrogate decision makers, those best able to represent the interests of patients, supports this belief.

In home health care, patients and primary care providers are intimately connected. Their lives are intertwined and their self-determination is enmeshed in their relationships to each other. Professional boundaries and competencies are lacking. Unlike professionals who have chosen the health care field as the role through which they define themselves, these health care providers find this role thrust on them. As a result, some caregivers are competent; some are not. Some are grateful to be able to give care and find it fulfilling; some resent finding themselves in a caregiving situation. Some are eager; some are fearful. In addition, these primary caregivers usually have only limited periods of time away from their ill family members, and often they are not medically trained to handle health care emergencies. They are constantly on call and work in an atmosphere of uncertainty and isolation. Caregiving in this setting requires great expenditures of time, energy, and emotional support; is personal; and extends beyond tending to physical needs. Providing such care usually substantially alters the life patterns of the caregiver and, because of the structure of our society, also makes the caregiver vulnerable to many economic and social pressures.[3]

Overwhelmingly, caregivers are women.[4] Statistics show that more and more caregiving winds up in fewer and fewer hands, and these are usually female hands. Historically, society has paid little attention to this work because it is unpaid labor and usually part of the domestic realm. Likewise, many religions that encourage supererogation would espouse the labors of caregiving as selfless charitable works. In this framework, caregivers can easily be exploited, and they may be hesitant to express any desire for self-determination other than their caregiving activity. Any considerations of autonomy as they relate to the caregivers in these settings are frequently overlooked.

Not only then do we need to be concerned with the autonomy of the patient, but we also need to be concerned with the autonomy of nonprofessional caregivers in a home setting. How does autonomy function in situations where both the patient and the caregiver are at risk, and where it is their very relationship that puts them at risk? This is a question that has seldom been asked because our present concept of autonomy stems from viewing individuals as independent and detached rather than as dependent and connected, and as operating outside of the personal realm.[5] When autonomy is discussed from an individualistic perspective, as is usually the case in an institutional model, it is suggested that the goal here is independence so that we can carry out our wishes either by ourselves or with the usually contractual assistance of others. Autonomy from a relational perspective, however, involves considering our own best interests as they relate to the best interests of others. It recognizes that we define ourselves as persons in relationship to others while maintaining our individual identity in the process.

The relational approach to autonomy does not focus on the legal instruments (e.g., living wills and durable powers of attorney) that ensure that issues of health and welfare are handled as the affected individuals determine they should be handled. Rather, it offers a model that acknowledges the dependency of the patient but recognizes the needs of the caregiver as well. Under this approach, caring for others is much more than attending to the overt needs of the patient and facilitating that individual's self-directed strategy for medical treatment and care. Instead, it must include some reasonable reflection as to what best serves not only a particular patient but also a particular caregiver in a specific situation.

The problem in home health care situations, however, is that in many cases the patients are incapable of considering the well-being of the caregivers, and without the professional boundaries that we find in institutions, caregivers may easily be neglected. Autonomy for caregivers may mean knowing when it is necessary to call nonrelated parties to take over some of the caregiving responsibilities.

Professional At-Home Health Care Workers

There is a third party that is often involved in home health care: professional, home health care workers. As more and more health care moves to the home, we find many professional teams established to do this medical caregiving. Like their peers who provide services in institutions, home health care workers are professionally trained and licensed, are familiar with the latest technology, and are united to their patients through a professional, rather than a personal bond. As a result, they too can maintain a certain degree of detachment.

The difference lies in the settings in which these two groups of health care workers provide their services. The health care workers who work in the patients' homes daily bridge the gap in our society between the public and private realms. Although home health care workers are trained in the public, professional realm of medicine and are held accountable to the norms and rules that govern that realm, the bulk of their work takes place in a domestic setting. An although they have been trained to respect the autonomy of patients, they usually find that patients are not single, independent moral actors but are enmeshed in family situations (too often dysfunctional situations).

In home settings, professionals do not only help make decisions about appropriate care but usually need the assistance of family members to carry out these decisions. In this way, they too are dependent because they need the cooperation of people who are not professionally bound to give it and who cannot be held legally accountable for refusing to give it. The irony that has recently developed is that in the institutional setting concerns about autonomy have centered on overtreatment and whether or when treatment should be withdrawn or withheld; in a home setting, focus is on possible undertreatment and whether the patient will receive appropriate care. Home health care professionals, therefore, need to consider patients' family situations as well as their patients' medical needs. Thus, although their bonds to their patients are professional bonds, home health care workers are much more likely to be drawn into personal situations than are institutional workers.

Because it is necessary for professional home care workers to become somewhat involved in the context of patients' family and other relational experiences, these professionals' autonomy may be endangered. When caregivers enter patients' homes, caregivers may be treated more as employees who are there to do patients' bidding than as professionals who have competencies and values of their own to fulfill. The boundaries are much more fluid, and the needs are frequently so overwhelming that home health care workers often find themselves in situations that their medical background has not trained them to handle. For example, they may understand pain control but in a home setting, they might be faced with neglect or even abuse.

It is also much more difficult to reason with noncompliant patients in their homes than in a hospital setting where there is an institutional background to support the professionals' recommendations.

In a hospital setting, if a patient is totally noncompliant, one has the possibility of declaring the patient incompetent in order to circumvent what seems to be unreasonable behavior. It is difficult to enforce this method in a home care situation, because professionals do not have easy access to the patient nor do they have extended periods of time in order to make their observations. Even if they should be able to declare the patient incompetent, it would be difficult to enforce what they consider reasonable measures onto the patient. In home care, the professionals are the outsiders to a value system that may be foreign to theirs, yet they are asked to provide care within this setting.

Using a Relational Approach

New models must be created for issues of autonomy as they relate to home health care. These models must be able to handle issues of autonomy as they relate to individuals who are living in personal, dependent relationships and who have a vested interest in the patients' care. They must also include the concerns of professional health care providers who bring their medical expertise into the home setting. The new models for autonomy must begin with a recognition that people are connected and that health care decisions affect not only the individuals, but also their relationships. They must include viewing the limitations of the situation and addressing questions of what is reasonable in this specific situation. As a result, they will be much more particularized and personalized. Several guidelines might prove helpful.

- Establish trust. For effective health care delivery, all parties involved must provide care in an atmosphere of sincere concern and good will. The patients need to trust that the caregivers, both professional and nonprofessional, are acting on their behalf. Family members need to understand that the professionals are there to assist them and not to co-opt their existing value systems. Professionals need understanding from the patients and their families that they too have responsibilities and values that they must uphold. Everyone also needs resources and support from society for their projects. Without this atmosphere, all will be fearful to trust themselves to the care of others.[6]

- Consider the autonomy of others. Everyone's autonomy must be respected. The relational aspects of home health care must be accepted, for if it is assumed that only the patients need help in fulfilling their autonomy, others may easily find themselves in situations where their autonomy is greatly compromised. Patients do have serious concerns regarding their care, but because of their contextual nature these concerns must be balanced against the needs of those involved in the caregiving. We might refer to this as "just care". Just care centers on fulfilling needs yet allows sufficient room for all involved in the care to express their concerns and have them met to a reasonable degree. Situating autonomy amidst concern for the needs of others, rather than regarding it from an individualistic perspective of establishing rights, should also lead to a less confrontational model of decision making and towards more of a compassionate one. This, of course, depends on the fact that an atmosphere of trust has been established.

- Encourage open communications. If the parties involved trust one another, they should be able to have an open dialogue and show mutual respect. To properly assess an individual's needs, it is essential to have dialogue that is free of manipulation and coercion. Conditions change, attitudes change, and without open dialogue and the encouragement of such dialogue, proper evaluations of the situation can be difficult, if not impossible. In using a relational approach to autonomy in a home health care setting, the focus is not on exotic methods of treatment, or on the withholding or withdrawal of such treatments, but on issues of presence, concern, and faithfulness - issues that transcend professional medical training and return us to the core of our humanity. What could be more appropriate than to ensure that patients' whose life plans are drawing to an end are attended to by persons who were an integral part in helping them formulate those plans. This is health care at its best and the appropriate completion of relational autonomy.

References

1. See, for instance, Thomas Hill, Jr., *Autonomy and Self-Respect* (New York: Cambridge University Press, 1991) or Gerald Dworkin, *The Theory and Practice of Autonomy* (New York: Cambridge University Press, 1988).

2. Dworkin, p. 6.

3. Joan Tronto in *Moral Boundaries* (New York: Routledge, 1993) deals in detail with the problem that caregivers face in giving care as it relates to autonomy. She stresses that the subordinate position given to care in our society is not inherent in the nature of caring but has been given that position from a political point of view, pp. 63-64.

4. Helen O'Connell in "The Caring Career," *Women and the Family* (New Jersey: Zed Books, Ltd., 1994), pp. 37-54, points out how "it is widely assumed that within families women provide most, if not all, of the practical and emotional support and nursing, as well as general care required by young children and by family members who are ill, disabled or elderly," p. 37.

5. Eva Fedder Kittay, "Taking Dependency Seriously: The Family and Medical Leave Act Considered in Light of the Social Organization of Dependency Work and Gender Equality," *Hypatia* 10 (Winter 1995): 8-29.

6. Annette Baier, "Trust and Antitrust", *Ethics* 96 (January 1986): 235.