

Aging and Long-Term Care: Some Ethical Challenges

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Editor's Note: *Msgr. Charles Fahey offers the following reflection as "grist for the mill." Several questions follow his reflection to further the conversation he has begun. We invite readers to share their thoughts with us and with one another. We will publish your responses either in future issues of HCEUSA or on the HCEUSA page on the CHA website.*

Introduction

Reflection on ethical issues in long-term care results in large part from the relative newness and size of an extended "third age," that is, that time in life that is generally characterized neither by reproduction nor production. This third age has become more common only at the end of the twentieth century with so many people living longer as the result of lifestyle changes and medical interventions. Endemic to this part of the life cycle is progressive intermittent frailty (PIF) which, for many, requires long-term care. Hence, the magnitude of long-term care, at least for older persons, corresponds to a reduction in premature mortality.

This reflection will consider underlying causes of the need for long-term care as well as domains where ethically laden issues lurk.

The Third Age and Frailty

The "three ages" and "frailty" framework may require explanation. Understanding the concepts can contribute to developing and evaluating strategies, programs and policies as well as identifying the ethical dilemmas.

The Three Ages

This "three age" phenomenon is found in all living things. It is biologically driven as nature ever renews itself. Historically, there have been high rates of mortality in the first two ages with relatively few survivors into the third

age. However for humans, scientific discoveries, their application and availability have reduced premature mortality, extending life into the third age for most people in developed countries.

During the "first age" — the period in the life cycle from conception until physical maturity — frailty is a reality. Nothing is more vulnerable and in need of external assistance than a child at each stage of its development. However, childhood frailty regresses as a child matures physically, emotionally, intellectually and spiritually. The child gradually moves toward relative sufficiency and acquires the ability to interact positively with his or her environment and to fulfill personal and societal roles. Ideally, the growth of the child is supported by parents and various social structures such as schools.

The "second age" is the period of maximum physiological capacity for reproduction and production. Individuals at this stage are at the height of their capacity to assure the continuation of the species. Ideally, these individuals develop and fulfill their personal life plans even as they, both as individuals and as members of society, contribute to the common good. In this period of the life cycle, frailty may occur, but it is the exception rather than the rule. It is generally a time of maximum cellular organization and balance.

The "third age" — the period after parenting — has become normal in developed countries. Life expectancy continues to lengthen. Improvements in public health, better nutrition, education and medical interventions all contribute to this.

However, the third age is also marked by random cellular disintegration with cellular repair unable to keep pace. In turn this makes individuals vulnerable to illness (some age associated and some not), trauma (such as falls), organic failures (such as failing eyesight and hearing loss) and chronic

and/or accumulated weaknesses and illnesses. Individually or in tandem, these may make the person ever more dependent on medical interventions, prostheses, pharmacological agents and the need for personal assistance or a more supportive physical environment. Medical interventions can ease frailty in some instances and even preserve life. However, they cannot obviate death entirely nor are they sufficient to assure people's ability to perform the activities of daily living.

People in the third age are economically dependent on prior earnings, accumulated wealth and participation in risk sharing mechanisms as well as governmental transfer programs. For most persons, it is period of expending wealth rather than accumulating it.

Throughout life, two realities continually interact—the person and the physical, social and economic environment. Personal capacity and external factors contribute to and/or detract from personal homeostasis. Individuals continually attempt to alter both individual capacities and surroundings in order to maintain the balance necessary for a decent life. In the third age, long-term care becomes a necessity when either fails.

Frailty

Frailty has two meanings. The first is a muscular/skeletal syndrome which is marked by diminished capacity such as in walking, lifting and ascending stairs. The second is social frailty, characterized by difficulties in dealing with the demands of everyday living. The frailty that I am referring to involves, but is not limited to, physiological deficits. It also involves other limitations that make life difficult to negotiate.

Frailty consists in the potential or actual disequilibrium between an individual's internal capacity and external demands coming from the individual's environment. In the third age, frailty tends to be progressive, albeit intermittent (PIF). Its ultimate expression is death. Regarding frailty, we can say:

- It may be viewed as a state or as a process.
- It may be viewed as actual or potential.
- It may be unnoticed or obvious.
- Its progression may be gradual or dramatic.
- It may be relatively benign and personally manageable or

crippling and requiring substantial external interventions.

- The effects of PIF are idiosyncratic since physiological underpinnings, psychological strength or weakness, as well as the social and physical environments will differ from person to person and from time to time.
- It involves continual adaptations on the part of the person and/or his/her environment.
- These adaptations involve costs—economic, and/or psychological.
- Formal long-term care becomes necessary when the disequilibrium becomes so great that it cannot be bridged by personal and social resources.
- PIF often goes unrecognized until it reaches catastrophic proportions and its costs become evident.

Long-Term Care

Long-term care consists of those supports and environments that assist individuals with advanced PIF to deal with the challenges of everyday life.

The default place of care for the frail is the community; only with intense frailty do long term-care facilities come into play. For some, the “community” is supportive. A degree of dignity can be maintained despite personal losses. For others, frailty is held in check at substantial emotional and economic costs to self and others. Currently, at both the federal and state levels there are efforts to increase “home and community” based services to relieve care-giver burden and to rein in costs associated with nursing homes.

These efforts include:

- Access to appropriate medical and rehabilitative services.
- Encouragement for early decisions about saving and risk sharing to deal with frailty.
- Health promotion and prevention of disease/trauma.
- Management of chronic illness.
- Attention to and modification of physical environment as necessary.
- Assurance of adequate nutritional services.
- Assistance with activities of daily living (ADLS) and instrumental activities of daily living (IADLs).
- Stimulating social, spiritual and intellectual opportunities.
- Care management.
- Better support of informal primary care givers.
- Provision of cash and counseling.

Implementation of these efforts is uneven among the various states.

Areas of Special Ethical Concern

People needing help over long periods of time present common ethical challenges. However, just as regressive frailty is endemic to childhood so PIF is normal in the third age. In both instances, the universality of frailty in a definable part of the life cycle creates a predictable ethical agenda for individuals as well as for society. In the first age, this agenda includes evolving and reciprocal parent/child moral claims, while society recognizes the need to help parents and, in some instances, substitute for them through both voluntary and public efforts. The basis of concern and response is primarily the well-being of the children, but also enhancing their potential to become contributing members of society.

The physical, emotional and often financial vulnerability of those in the third age entails serious moral issues for the frail individual, those who care for them and for society as a whole. The individual and society must be engaged in confronting the issues particular to this part of the human journey.

There are four foci that individually and interactively pose ethical issues in a special way in the third age:

- The individual.
- Significant others with moral/emotional/legal ties to frail persons.
- Providers — individual and group.
- Public policy.

The Individual

An ethical analysis of frailty in the third age begins with the individual. While not endorsing a “blame the victim” approach, it must be noted that individuals can in some instances affect the course of frailty. Exacerbating or ameliorating factors can be traced to the individual’s behaviors in the area of health, interpersonal relationships, finances and spiritual development. Risky health behaviors can intensify frailty. The development and maintenance of close personal relationships can spell the difference between loving care and isolation. Frailty entails costs ranging from medical interventions and prosthetic devices to personal care and support. Some frail persons have never had the

capacity or the opportunity to save or participate in risk sharing mechanisms in order to have resources in times of need. Others may be quite imprudent in making life style choices and become dependent on the largesse of others or the government.

Individuals react differently to losses and limitations. A lifetime of spiritual development and character building, or a lack thereof, sets the stage for how persons will deal with these losses, either with or without some equanimity.

No human event is more personal than dying. However, dying is also a social event that involves others, both loved ones and professionals. For the person, loved ones and providers, there are often excruciating decisions to be made about what are appropriate medical interventions. Unfortunately, the understanding of and commitment to palliative care is still in early stages of development.

Significant Others

The social nature of PIF, especially in its most debilitating phases, creates demands on individuals and society.

Frailty within the “traditional” family entails demands on spouses and children. Four and five generation families, single parents, grandparents caring for grand children, the divorced and remarried all challenge the ties that bind and make for difficult moral choices involving competing demands. The intra-familial realities spill over into the policy sector as decision makers attempt to sort out what are private/personal responsibilities and public/governmental duties. What are the affective, instrumental and financial responsibilities in such a confusing set of circumstances?

Providers of Services

The professionalization and monetization of caring create new moral and legal, i.e. explicit contractual relationships among the parties. These often involve considerable power imbalances. The frail person is vulnerable to the quality and sensitivity of providers, both individuals and agencies. In both instances, respect for the individual, including that person’s wishes, as well the provision of quality services are essential elements in the legal and moral exchange. To the degree that the frail person is infirm and to the degree the provider is charged with the overall care of the individual, as in the instance of an institution, the greater the moral

bond and the greater the necessity to exercise careful oversight and to respond sensitively.

The institutional provider should empower the person and significant others, especially surrogate decision makers, with information as well as psychological and spiritual support to make difficult decisions and to live with them.

Public Policy

Public policy involves politics. However, “the will of the people” is rooted in their values. Ideally, fundamental option for the poor and vulnerable, maintenance of reciprocity and solidarity and promotion of the common good should be part of the calculus. Unfortunately, it is easier to articulate these concepts in theory than it is to translate them into fair and effective policies and programs.

The ethical/policy decisions will become more acute and more contentious in a period of ever greater national debt, an uncertain economy and growth in the numbers of those in the third age.

Conclusion

These reflections are designed to be “grist for the mill.” The idiosyncratic and painful nature of PIF demands attentiveness, ethical sensitivity and sound spirituality on the part of all significant actors, as well as a generous and just response of the body politic.

Questions to further the conversation:

1. Msgr. Fahey identifies four areas of ethical concern. What specific ethical issue or issues do you see or encounter in one or more of these areas? How are you or your organization addressing it?
2. What is your organization doing to respond to the needs of the frail elderly now and into the future? Are there practices or programs that you would like to share with the ministry?

**Please share your thoughts at
HCEUSAeditor@chausa.org**

Tools for Discernment on Health Care Reform

In an article in the January-February 2008 issue of *Health Progress*, Jack Glaser, senior vice president for theology and ethics at St. Joseph Health System, Orange, California, writes:

Ethical wisdom is the gift not of ethical experts, but rather, as I have argued in a previous *Health Progress* article, the gift of the right community—the “community of concern.” Different ethical issues require different communities of concern, I noted. “Gathering the community of concern requires people who command essential perspectives on the issue at stake and also share an overarching concern for the common good.” (“The Community of Concern,” *Health Progress*, March-April 2002, pp. 17-20).

However, in generating ethical wisdom, “communities of concern” consistently need further tools. This article suggests some tools for the moral/ethical challenge of health care reform (“Tools for Ethical Discernment,” *Health Progress* January-February 2008, p. 51).

Ethics committees, boards, executive teams, departments and staff can all constitute “communities of concern” in addressing the reform of our health care system.

In addition, in a CHA resource, *Building Consensus for Change: A Guide to Organizing Roundtable Discussions on Health Reform*, Sr. Carol Keehan, D.C., president and CEO of the Catholic Health Association, writes: “[T]he Catholic Health Association is urging individuals and organizations to take a moment to consider the values and priorities that should drive health reform in America—and how we can build and sustain consensus for productive change” (p.2).

We provide here two resources that can be used to foster discussion about health reform in your organization, parish or community. One is a survey tool from Jack Glaser’s *Health Progress* article which focuses on identifying priorities that should shape a reformed health system. www.chausa.org/hpsurveytool.

The second resource is a study tool to help you assess various reform proposals. It is on the CHA website at www.OurHealthCareValues.Org.

Additional resources for dialogue and discussion about health care reform are listed in the Resources section of this newsletter.

SURVEY

**Values for Shaping the U.S. Health Care System:
What Priorities Should Shape the Future?**

Health care is an important concern for most people and is an important topic in our government at the national, state and local levels. We want to know your opinion of what should shape the future of the U.S. health care system. From the 15 items below, please select the five priorities that you believe should be shaping the future U. S. health care system. **FIRST, PLEASE READ THROUGH ALL 15 OF THE ITEMS.** THEN PICK YOUR TOP FIVE PRIORITIES IN ORDER OF IMPORTANCE.

1. My top priority is: 3. My next priority is:

2. My next priority is: 4. My next priority is: 5. My next priority is:

- 01 - Advances in research:** The U.S. health care system should spend more money on research to prevent and treat health problems than it does now.
- 02 - Universal access:** The U.S. health care system should make needed services available to all regardless of ability to pay.
- 03 - Build on the current system:** The U.S. health care system should expand and improve on the current system -- job-based insurance and public programs like Medicare and Medicaid.
- 04 - Comprehensive services:** The U.S. health care system should provide access to a broad range of health care -- prevention, emergency services, trauma, and care for on-going illnesses, as well as care for dental, vision and mental health problems, with the care provided and supported at the most appropriate facilities and locations, including the home.
- 05 - Consumer good:** The U.S. health care system should treat health care like other goods and services; it should be available to the extent that you have money to buy it.
- 06 - Health care as a business:** The U.S. health care system should allow health care businesses -- such as hospitals, insurance, drug and supply companies -- to make as much profit as they can within tax and other relevant regulations.
- 07 - Health care as a national concern:** The U.S. health care system, like homeland security and interstate freeways, needs national planning and financing.
- 08 - Minimize the role of government:** The U.S. health care system should reduce the role of government in financing health care (e.g., through Medicare, Medicaid and tax benefits) and providing health care (e.g., through public clinics and the Veterans' Administration).
- 09 - Patient choice:** The U.S. health care system should give patients as full a choice of doctors and other providers, settings and treatments as possible.
- 10 - Prevention:** The U.S. health care system should give priority to services and programs that promote health and keep people from getting sick, such as smoking prevention and nutrition/diet education, childhood immunizations and cancer screenings.
- 11 - Public participation:** The U.S. health care system should have effective ways for the public to help set priorities for health care, influence decisions about important health care issues, and improve the health care system.
- 12 - Quality of health care:** The U.S. health care system should have a more effective way of improving the quality of care and reducing medical mistakes.
- 13 - Spend health dollars for direct patient care:** The U.S. health care system should spend as much as possible on direct patient care and as little as possible on administrative costs.
- 14 - Stable costs:** The U.S. health care system should keep health care costs from rising faster than the costs of other goods and services.
- 15 - Uninterrupted care:** The U.S. health care system should reduce to a minimum the need to change doctors, hospitals, insurance companies and levels of coverage.

Sample Questions for Discussion

1. Working individually, consider your reaction to the survey results. Compare your priorities with those of the group. What do you notice? What surprises you?
2. In small group discussions, create a dialogue in which each person shares an idea or two from his or her reflection on the survey results. As you listen to the conversation at your table, what do you notice?
3. To what extent does the current health care system reflect the priorities of the group?
4. What would need to happen for our current health care system to better reflect the priorities of the group?