END-OF-LIFE ETHICS: AN ECOLOGICAL APPROACH[1]

ÉTICA AL FINAL DE LA VIDA: UN ENFOQUE ECOLÓGICO

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Summary

This paper explores the evolution of Western Ethics from a paternalistic model to a model emphasizing individual autonomy. The paper argues that, as the limits of autonomy become clear, a social ecological model of end-of-life ethics should emerge that is more congruent with both Western spiritual and cultural values.

Keywords: *End-of-life ethics, social ecological model, individual autonomy*.

Resumen

El presente artículo explora la evolución de la Ética Occidental desde un modelo paternalista a un modelo que enfatiza la autonomía individual. El artículo sostiene que, a medida que se definen los límites de la autonomía, nace un modelo ecológico-social de la ética al final de la vida que es más congruente con los valores culturales y espirituales de Occidente.

Palabras clave: *Ética al final de la vida, modelo ecológico-social, autonomía individual.*

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[1] This paper draws from an earlier paper published by the author in Lutheran Ethics.

Introduction

Ever since Childress and Beauchamp (2001) introduced their basic principles of biomedical ethics, they have been widely accepted. Yet, while these basic principles of autonomy, beneficence, nonmaleficence, and justice generally are accepted as a broad ethical frame, the primacy of the concepts has shifted over the years. For many years, beneficence—the principle that the physician should always do what is best for the patients was a dominant ethos in most of Western medicine. In recent years, at least in the United States, the principle of autonomy has become *primus inter pares*. Here the wishes of the patient or surrogate supersede the advice of physicians.

Within the last fifty years, not only has these broad ethical principles waxed and waned but also there have been unprecedented advances in end-of-life care. Hospice and palliative care are now available as options. Technological advances in medical care have been extensive. One result of these technological achievements is that we have lost consensus on when life begins and ends. This has fueled ethical debates in such areas as abortion, end-of-life care, and euthanasia.

In this paper, I explore the shift from a *Rescue Orientation*—supported by the notion of beneficence to that of a more *Individualistic Model* that builds on autonomy. I further argue that Jennings' (2012) concept of an *Ecological Approach* offers an approach that is both ethically sound and more congruent with Western values. Moreover such an approach is validated by research on ethical decision-making at the end-of-life as well as that on the effects of such decisions on the grief of survivors.

The Rise and Fall of the Rescue Orientation

According to Jennings (2012), the Rescue Orientation's underlying premise was that disease and death is the ultimate enemy. In that orientation, the physician's primary role is to rescue the patient from those threats—as well as from the patient's own poor judgment. Based on the principle of beneficence, this orientation spawned a benevolent paternalism. The physician knew best and should operate in the best interests of the patient regardless of the patient's own preferences for care.

Physicians could withhold information or present it in such a way as to direct a decision.

In the US, this position was challenged by *Scholendorff vs. the Society of New York Hospital* in 1919. Here a woman consented to uterine examination. In the course of the examination, the physician decided that his patient needed a hysterectomy. This case placed limits on the physician's discretion by mandating informed consent—that is that the patient had the right to know what medical procedures were recommended, what risks were present in such procedures, and to consent to treatment.

Despite this case, the rescue orientation still was predominant until the 1960's. Then as the Baby Boom came of age, this generation was far less accepting than prior generations on blindly following authority. Baby Boomers value choice and control. Social movements such as death awareness, patient empowerment, and right-to-die movements emphasized the rights of patients to set the conditions of their own end-of-life care. Soon, instruments were developed to assist this process such as Advance Directives. Finally, the rise of hospice offered additional alternatives for end-of-life care.

The Individualistic Orientation

As we moved into the sixties, the rescue orientation gave way to a more individualistic model. In this perspective, the patient is empowered to direct his or her own care. The patient is now considered the ultimate consumer—the disinterested manager of his or her own care. This is seen in surrogacy. New York State's Attorney General Manual, *Planning Your Health Care in Advance,* states, «*Your agent need not agree with all of your wishes, but must be capable of carrying them out, regardless of his or her own feelings*» In fact, current ethical thought suggests that surrogates make decisions based on the clear wishes of the patient (when known), or in other situations where wishes are unknown on the basis of what the patient would be likely to do or what is perceived in the patient/s best interests. The wishes of the surrogate—or even the patient's families—are not considered.

This individualistic orientation has found an apex in physician assisted suicide. Here the patient even retains the right, albeit limited by certain restrictions, to end his or her life rather than continue medical treatment. In states where physician assisted suicide is legal, the patient is empowered to make the ultimate choice of life or death. This may presage another challenge to the individualistic orientation. Sorokin (1937-41) noted that one factor in social change is the *principle of limits*—by that Sorokin meant that any social value inevitably evolves into the more extreme positions that can discredit or cause discomfort, with the value setting the stage for some form of a corrective approach.

While this orientation is still current, there is research that challenges its basic premise.

Generally research has shown that people have poor *affective forecasting*, that is they tend to underestimate their ability to adapt to adversity. They also are likely to exhibit *focalism*—that is that persons focus more on what will change rather than what will remain the same. In addition, researchers found that individuals experience *immune neglect*—failing to foresee how their own coping skills will reduce unhappiness even as illness causes additional disability. Finally individuals f*ail to predict adaptation*. This means that individuals do not recognize how what they value will shift as illness advances (Halporn & Arnold, 2008). The implication is that advance directives, made when an individual is healthy, may have little relationships to the decisions they might make as they struggle with illness.

This research underscores a debate about the applicability of advance directives once a patient has dementia. It is argued that persons with dementia are so different than they were before that advance directives are not meaningful, while others would content that the wishes should be honored as dementia was likely a consideration when advance directives were considered (Kapo & Karlawish, 2004).

Other factors too have undermined this individualistic orientation. The development of hospice and palliative care has emphasized the family as a unit of care. This inevitably has highlighted the familial context of ethical decisions—the recognition that end-of-life choices may have implications for family and the larger caring community that extent well beyond the patient's life.

The Rise of an Ecological Perspective

These factors have led Jennings (2012) to propose a *Social Ecology Perspective*—one that roots ethical decision-making in the context of family and community. In effect, it adds a new principle to bioethics—a relational principle that affirms that ethical decisions affect others. In essence, the social ecological perspective believes that ethical decisions at end-of-life should be communal—that is taking into account the effects of varied ethical decisions not only on the patient but also on all in the patient's world that are impacted by those decisions.

Two examples illustrate this approach. When I consider a surrogate, I have two choices. One would be a life-long friend. We have known each other since adolescence. Peers—we have had extensive discussion of our end-of-life choices. I have no doubt that he would follow my wishes fully.

The other choice would be my son. He is reluctant to have conversations about death—typical of midlife adults as they struggle with their own awareness of mortality (Doka, 1995). I strongly suspect that he would keep me alive longer than I wish.

From the individualistic perspective, my choice is clear—my friend should be surrogate. Yet the implications of such a decision would be staggering. It would disenfranchise my son—my last message would essentially be one of distrust. It might alienate him from a person that he would look to for support. It would likely complicate his grief. Hence my son is my surrogate. As to the likelihood that I might live a bit longer than I prefer, as parents, we all make sacrifices for our children. This would be my last sacrifice.

Assisted suicide offers another example. In an earlier work, I described a case of an individual who, at the parent's request, facilitated the suicide of a terminally ill parent. The individual wrote anonymously describing intense grief now effectively disenfranchised. Though he was coping, along with his siblings, with intense guilt and ambivalence over his role in his parent's death, the illegality of the act inhibited any counseling. His parent's own decision deeply complicated his grief (Doka, 2002).

In addition, the social ecology perspective resonates with traditional spiritual emphases on community-emphasizing relationship to others. Our choices and decisions are not made in a social vacuum. Recognizing the needs and welfare of others, sacrificing personal interests to those of others, are values congruent with Western faiths – a common emphasis in Christianity, Judaism, and Islam.

This approach also is sensitive to cultural nuances. Western ethics, particularly in the US, emphasize that the individual is the locus of decision-making and that these decisions should be informed by full medical disclosure. Not all cultures accept these premises. In some cultures, the family is the locus of decision-making. In other cultures, these decisions are still seen as the physician's. In addition, the social ecology perspective is especially sensitive to the value of *familismo*—a value that not only makes the family the locus of decision-making but stresses the primacy of the family good.

Disclosure also may be inhibited. In some cultures the discussion of serious illness, certain diseases, or death is considered inappropriate or disrespectful. In other cultures there may be a belief that disclosure causes depression, anxiety, eliminates hope, and hastens death. Finally, in certain cultures, words have efficacy in and of themselves (Searight and Gafford, 2005). For example, the Inupiaq Peoples, a Native Alaskan group, believe that talking about death, risks, or illness actually brings these events into being. Thus speaking about risks increases the possibility that these risks will occur. In other cultures there may be a sense of fatalism that inhibits advance planning. A social ecology perspective, by recognizing context, acknowledges such cultural nuances.

A social ecology approach also acknowledges the complicated and developmental dynamics that can surround the end-of-life process. Among the realities of the dying process, is the sense of *middle knowledge* (Weisman, 1972)—that is the patients and families drift in out of the awareness of dying, sometimes confronting death while other times ignoring death's nearness. Moreover, families often have mixed feelings even when they acknowledge death's immediacy. Families are conflicted by the desire to remain in the moment with the patient, a hope that death may be forestalled, as well as a desire to find some sort of resolution even in death. Finally families may experience a sense of anticipatory grief as the cope with all the losses associated with the end stage of a debilitating illness. Such emotional conflict can immobilize decision-making. An inherently inclusive process, the social ecology perspective encourages discussion between family members and seeks to enable consensus even if that takes time.

Finally a social ecology perspective facilitates the grieving process. If individuals and staff are troubled by the end-of-life decision, this ambivalence complicates grief while an inclusive process that acknowledges all stakeholders facilitates the grieving process for both families and staff (Jameton, 1993; Doka, 1994, 2012).

Conclusion

In many ways the move toward an ecological system of care is an inevitable result of the limits posed by both technology and an increasingly individualistic model. Patients and families now have an array of bewildering choices that come with considerable personal and economic costs. Seamlessly transitioning patients to palliative or hospice care when cure or meaningful extension of life is no longer viable is best managed in a context where physicians, medical caregivers, families, and patients are freely offered information and discussion in ways respectful of cultural mores, spiritual values, and family dynamics. But it is a model that offers an essential corrective—one that adds a corrective to our current ethical principles by acknowledging that and essential element of our theology—even our basic humanity—is that we exist in relation to others.

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