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On Being Mortal, Medicine and What Matters in the End: A Book Review

by

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Atul Gawande's On Being Mortal, Medicine and What Matters in the End (New York: Metropolitan Books 2014) is truly an extraordinary book about our care of the aged, and our care of the dying. In this book Gawande, MD, MPH, a surgeon and public health researcher as well as a writer, deals with major issues facing the elderly and dying: safety vs. independence, control vs. autonomy, and living a meaningful life. For the elderly, their salient status is their age. It does not matter if they are male or female, short or tall, rich or poor – what matters is that they are old. Attached to being old are stereotypes: They are frail; they can't reason properly; and they should not make their own decisions. (For example, if you take an elderly friend or relative to the doctor, who does the doctor address, you or the patient?)

We tend to define the elderly in terms of their frailties, e.g. poor eyesight and hearing, muscle loss, arthritis, loss of balance, memory loss. Care revolves around taking care of these various ailments rather than seeing the whole person. An emphasis is placed on safety and survival rather than autonomy and independence. Yet, independence is very important to the elderly. In their research with focus groups of elderly persons, Spitz and Gallant (2004) found that, although older persons want to remain connected with their adult children, they also want to remain independent. They appreciate their children's concern, but do not like their children's over protectiveness. Gawande gives numerous examples of this. He tells of Harry Truman who at age eighty had

been shoveling snow off his roof, and fell off and broke his leg. The doctor called him a fool. Truman's reply: I am eighty years old and I have the right to make up my mind and do what I want to do (p. 66). Or as the manager of a subsidized apartment building for low-income elderly people put it: "They (the tenants) live like they would live in their neighborhood. They still get to make poor choices for themselves if they choose." (p. 135)

The major threat to the elderly's independence is falling. According to the Centers for Disease Control (2016) in 2014 over one quarter of Americans aged 65 or older fell; that is forty-seven million people. Seven million required medical attention and/or restricted activity; and seventy-four older adults died every day because of falls. Yet, most doctors look at the elderly's specific illnesses, not the potential cause for their loss of autonomy. Gawande tells about one special geriatrician who was examining an eighty-five-year-old woman who had arthritis, glaucoma, high blood pressure and possibly metastasis from colon cancer. Rather than focus on these issues, the doctor spent a great deal of time watching her walk, speaking with her, and examining her feet. Why? This way he could assess her mental abilities, her nutrition, and most importantly the risk of her falling. As the doctor told Gawande: "The single most serious threat she faced was not the lung nodule or back pain. It was falling." (p. 40) The doctor was more concerned with the woman maintaining her

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independence, than treating all her various maladies. As a result, a year later, the patient was still living on her own and doing very well. She had not fallen.

The majority of the aged want to remain in their own homes. According to a 2011 AARP study, 90 percent of seniors want to stay in their own homes as they age and 80 percent believe their current residence is where they will always live. The want to "age in place," which is "the ability to live in one's own home and community safely, independently, and comfortably, regardless of age, income, or ability level."(p. 1). A survey by Gallup and Robinson (2012) for Pfizer found that only 25 percent of those over 65 would want to live with a younger relative if they could no longer care for themselves. But, as Gawande points out: "Our reverence for independence takes no account of the reality of what happens in life: sooner or later, independence will become impossible. Serious illness or infirmity will strike. It is as inevitable as sunset. And then a new question arises: If independence is what we strive for, what do we do when it can no longer be maintained?" (pp. 23-24). Parents may move in with children. However, with adult children working, it becomes difficult to care for their parents adequately. Thus, there are assisted living housing and nursing homes.

Gawande discusses the different types of living arrangements available for the elderly who can no longer maintain their independence. Assisted living housing was started so that elderly people could maintain control of their lives while receiving the help they needed. It was an attempt to solve "a deceptively simple puzzle: what makes life worth living when we are old and frail and unable to care for ourselves?" (p. 92) However, as he points out, concerns for safety have limited the control the elderly have over their lives even in assisted living.

Nursing homes are by and large "total institutions'. Residents must wake when they are told, eat when they are told, sleep when they are told. One nursing home medical director referred to the Three Plagues of nursing homes which must be attacked: boredom, loneliness and helplessness. (p. 116) There have been some nursing homes which have done this. Gawande discusses nursing homes which have changed the way in which they care for their patients to combat the Three Plagues. One nursing home allowed pets on the floors, canaries in the rooms, vegetable gardening outside. They also had the staff bring in their children. By

bringing life to the nursing home, the inhabitants had a more meaningful life themselves. There are also nursing homes where the elderly make their own schedule. They can eat when they want, sleep when they want, be alone or with others when they want. They are given some control over their own lives. In these nursing homes, the residents are livelier and express greater satisfaction than those in "normal" nursing homes.

In the section of the book on dying, Gawande also talks about people wanting to make their own choices and having control over their treatment options. Yet, it is very difficult to do so since many doctors have a difficult time discussing poor prognoses with their patients. They may tell the patient the diagnosis, but cannot discuss the patient's dying. Gawande points to a study which showed that sixty-three percent of the physicians of terminally ill patients overestimated the amount of time a patient would survive (p. 167). Many oncologists offer treatments which they do not believe will work. Physicians must overcome their reluctance to talk about dying in order to help the patient make decisions about care.

Historically, physicians were paternalistic. They made the decisions for their patients and often did not tell the patient about an incurable diagnosis. Today doctors believe they are doing their duty by just giving patients information and allowing them to make the decision on their own. Gawande points out from his own experience that this is just information dumping and is not helping the patient make a decision the patient is ultimately comfortable with. Instead, doctors need to participate in what is called shared decision making. Shared decision making is where the physician discusses the various treatment options and their risks and benefits; while the patient discusses his values and goals. Together they come to a treatment decision.

This is an important section because people must begin to have conversations with their loved ones and their physicians about what they would want if they were terminally ill. They must tell the physician what they expect to be told and how they will need to come to treatment decisions together.

Overall, whether a person is dying or elderly, there is a desire to maintain autonomy and control over their lives. There is a desire to have a life that continues to be meaningful. Gawande makes the case for this objective beautifully and tells us how we in society can make that

happen, although it will take a great deal of work.

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About the Reviewer: Natalie Hannon received her Ph. D. in sociology from Fordham University. She also earned a certificate in bioethics from Columbia University. Dr. Hannon was the Director of Training and Staff Development at a hospital in the Bronx, New York. Her professional career also included teaching courses on death and dying, and bioethics at Lehman College (CUNY) and facilitating discussion groups on bioethics for Albert Einstein College of Medicine. A life-long New Yorker, Dr. Hannon is the author of two books on death and dying.