Looking Back to the Future

In the September 2007 issue of the Journal of Psychosocial Nursing and Mental Health Services (JPN), Editor Shirley A. Smoyak wrote a provocative editorial about the need to carefully examine evidence about therapies to ensure that we are not unwittingly doing harm to those we aim to protect and help heal. Smoyak cited Scott Lilienfeld (2007) in his admonition to pay attention to emerging data that warn us of harmful “therapeutic” practices that may cause more harm than good. It is an admonition for the present and the future as we look to events of the past.

I recently read a fascinating and inspiring book that explores issues of who owns our bodies, the dark history of experimentation on African Americans individuals, the birth of bioethics, and the use and misuse of medical authority. The Immortal Life of Henrietta Lacks (Skloot, 2010) documents how cervical cancer cells from a poor African American tobacco farmer, Henrietta Lacks, were taken without her knowledge to serve as the basis for countless medical experiments and scientific breakthroughs. The cells, known as HeLa cells, are still alive today, more than 60 years after Lacks’ death. They were the first to grow in culture and have grown to be one of the most important tools in medicine. HeLa cells have helped bring about amazing scientific breakthroughs: the polio vaccine; new understandings of cancer, viruses, Parkinson’s disease, and AIDS; and important advances with in vitro fertilization, cloning, and gene mapping. Yet, neither Lacks nor her family knew of her “donation” of her cells to make these breakthroughs possible. The book beautifully describes the clashes between scientific discovery and human consequences and the incredible sense of entitlement that science has assumed, without informed consent, to achieve a “higher good.” The book demonstrates, often frighteningly, how easily science can do wrong, especially to those who are most vulnerable.

Reading about the life of Henrietta Lacks has caused me to appreciate the important influence that Institutional Review Boards and principles of informed consent have had in the past few decades for scientists and health care professionals in their efforts to do no harm. Thank goodness we now have more insight into the need to respect the autonomy and decision-making capacity of all individuals in our care. But my research with individuals with Alzheimer’s disease has also made me think further about vulnerable people in our society who may be denied these rights. Factors of poverty, age, race, and physical and mental disabilities can often obscure the need to protect autonomy and decision-making capabilities. These vulnerable individuals can be found in “thin places”—a concept described in Celtic traditions as an in-between place in which the marginalized and excluded may be unseen and unheard (Sorrell, 2006). Individuals such as Henrietta Lacks and her family lived in such a thin place in which her cells made important scientific discoveries.
possible, but until recently, there was no one to listen to her story. Adults with early dementia are often isolated in thin places that obscure their ability to make appropriate decisions related to their health care (Sorrell, 2006). And as previously noted in JPN's Aging Matters column, individuals with advanced dementia also exist in thin places when feeding tubes are inserted without evidence of their effectiveness (Sorrell, 2010).

Coles (1989) has reminded us that “the people who come to see us bring us their stories…. They hope they tell them well enough so that we understand the truth of their lives” (p. 7). To avoid doing harm to those in our care, we need to establish listening practices so we are able to hear the stories of the past and of the present, of those who can easily become marginalized and invisible in our society. In this way, we can come to understand the stories of vulnerable individuals in our care and the embedded values, goals, joys, and disappointments that are a part of their experience in occupying thin places in our society. In addition, we need to guard against what Bekemeier and Butterfield (2005) called the “think small” position that focuses on individual patients rather than the system that has compromised them. Stories of individuals and science need to be connected to create changes within the health care system that help us understand how to protect the vulnerable in our care from harm.

REFERENCES

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