Defining What 'Care' Means: A Book Review of *The Soul of Care: The Moral Education of a Husband and a Doctor*

By Bruce Greenfield, PT, MA (Bioethics), PhD

While I was working on my PhD in higher education and educational sociology, my professor in philosophy, in the spirit of Socrates, often challenged us to define taken-for-granted words or phrases. He referred to those words and phrases as "bumper stickers": they sound good, but what do they mean? Clearly, the message he was conveying was how words and phrases can be ambiguous and often require scrutiny to crystalize their meanings. I was reminded of this when I began reading Arthur Kleinman's new book, The Soul of Care: The Moral Education of a Husband and a Doctor.

What 'Care' Actually Means

A noted psychiatrist and anthropologist with several books to his credit, Kleinman is not shy in tackling issues of caring for those in extremis amidst suffering and healing. In this book, he challenges healthcare professionals to look beyond a patient's medical condition to the human experience of illness—as the lived experience of being sick. He argues to rethink what it means to 'care' for someone—to move beyond a narrow definition of caring as technical excellence to caring based on a continuous healing relationship, where care is customized according to patient needs and values. Thus, care is patient-centered where patient values, goals, needs, expectations, and fears are invited into the decision-making process.

Kleinman thinks of care as an existential and phenomenological state that deeply commits one human being to enter the life world of another—the world as immediately or directly experienced in the subjectivity of everyday life of one who is suffering. Kleinman argues that when we acknowledge the phenomenology of care as a state of being, we can embrace the human element of suffering in response to disease and injury.

Published online 17 DECEMBER 2021 at jhrehab.org

The Journey of Caring

Kleinman takes us on his journey of learning to care for others, first as a budding psychiatrist with a fine eye for uncovering the biographical disruption that accompanies those with mental illnesses, and second, by his extraordinary commitment to caring for his wife as she plunges deeper into the fog of dementia. While readers admire his tenacity of caring for his wife, he also illustrates how caring imposes risks on the one who cares. His message is that to care selflessly for another is not only an act of kindness and compassion, but of courage.

The book is a testament to perseverance. Kleinman experiences what the American writer and philosopher Susan Sontag refers to as "the night side of life...the kingdom of the sick." (Susan Sontag, *Illness as Metaphor*, 1978). In that sense, Kleinman's account is daring us to invite suffering and the illness of others into our lives.

At once a display of the unrelenting nature of a neurodegenerative disease and a love story deeply felt and described, *The Soul of Care* does not hold back. Kleinman eschews any romantic notion of caring as a noble endeavor; like the Biblical Job, he is a righteous

man enduring the hardships of caring while struggling to remain faithful to his wife's diminishing quality of life. For Kleinman, caring is a moral enterprise.

Recompense

Yet for all the disasters, failures, burdens, and frustrations of caregiving, there is recompense. For, according to Kleinman, learning to care results in a reciprocal benefit to the one who cares—a chance to learn to care for oneself. He learns that to give is to get back. Kleinman is not clear precisely what caregivers get back, but he is satisfied that it remains a mystery, as nourishment to the soul. Caring may help us create a new moral and emotional form of self, an existential sense of what we mean to ourselves and others.

Ultimately, Kleinman gives some slack to the reader engaged in caring. We are not saints, and at times we cannot provide the level of care we know we want to give. But the question is, as human beings, can we at least care some of the time and gracefully accept the pain of others? Reading this book may help you find that out for yourself.

About the Author



Bruce H. Greenfield, PT, MA (Bioethics), PhD is a Professor in the Division of Physical Therapy and the School of Medicine and Senior Fellow in the Center for Ethics at Emory University. Dr. Greenfield is a well-known physical therapy educator and qualitative researcher. He serves on the APTA Ethics and Judicial Committee, and on the editorial boards of the Journal of Physical Therapy Education and the Journal of Orthopedic and Sports Physical Therapy. At Emory, Dr. Greenfield is a member of the Emory University Hospital Ethics Committee. For many years, Dr. Greenfield was an orthopedic clinical specialist and edited two textbooks on the rehabilitation of the knee and shoulder published by F.A. Davis. His current areas of research are exploring the use of narrative and reflection in clinical practice and exploring ethical reasoning and ethical issues in clinical practice. His interest in *the Journal of Humanities in Rehabilitation* stems from his passion to incorporate the use of narrative in his teaching and to increase awareness of the need for the humanities in the study of ethics in the PT profession.

Website Link (Official Bio): <u>https://www.emorydpt.org/bruce-howard-greenfield-ph-d/</u>