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The Maintenance Of Life: Preventing Social Death Through Euthanasia Talk And End-of-Life Care - Lessons From The Netherlands



Synopsis

The landscape of death and dying has changed. Today, death most often does not happen in an instant, it is more typically a long process of life mixed in with decline and social losses that eventually and sometimes many years after an initial onset of terminal or serious illness culminates in some combination of social and biological death. British sociologist Clive Seale (1998) suggests that changes in death and dying have been accompanied by changing tactics for maintaining social life. He suggests two strategies that have developed in response to modern death including the development of a kind of therapeutic discourse which is used to transform social losses that occur at the end of life into something meaningful and euthanasia practices where patients choose to alter the exact time of their death to have death of the body more closely coincide with death of the social being. *The Maintenance of Life* is about what has developed in one present-day society to address social death and modern dying. It is based on a 15-month qualitative study of home death in the Netherlands with general practitioners, end-of-life patients and their family members. The book develops from two study findings: (1) that euthanasia in practice is predominantly a discussion, which only rarely culminates in a euthanasia death; and (2) that euthanasia talk in many ways serves a palliative function, staving off social death by providing participants with a venue for processing meaning, giving voice to suffering, and reaffirming social bonds and self-identity at the end of Dutch life. Through the mainstream practice of euthanasia talk, space has been created within healthcare which helps people live longer as active participants engaged in Dutch social networks at the end of life. Using direct observation and in-depth interviews with patients, families and physicians, this book looks critically at Dutch euthanasia policy and broader end-of-life practices from a cultural perspective and in comparison with U.S. end-of-life practices and policies. It concludes with a discussion of what lessons the U.S. may take from the Dutch experience maintaining life at the end of life. This book is a part of the *Ethnographic Studies in Medical Anthropology* series.

Book Information

Paperback: 320 pages

Publisher: Carolina Academic Press; 1 edition (August 15, 2009)

Language: English

ISBN-10: 1594605181

ISBN-13: 978-1594605185

Product Dimensions: 1 x 5.5 x 8.5 inches

Shipping Weight: 15.2 ounces (View shipping rates and policies)

Average Customer Review: 5.0 out of 5 stars 6 customer reviews

Best Sellers Rank: #775,276 in Books (See Top 100 in Books) #79 in Books > Textbooks > Medicine & Health Sciences > Medicine > Clinical > Hospice & Palliative Care #155 in Books > Medical Books > Medicine > Hospice Care #1306 in Books > Textbooks > Humanities > Philosophy > Ethics

Customer Reviews

Rumors about end-of-life in the US health care reform debate of 2009 loomed large, enflaming talk about "death panels" that would "pull the plug on grandma." Anyone who seeks to be informed about alternatives to the current US system (or non-system) for end-of-life care should read Frances Norwood's book, *The Maintenance of Life: Preventing Social Death through Euthanasia Talk and End-of-Life Care--Lessons from the Netherlands...* Norwood's book is important, well-written, and will give you much to think about I hope more cultural anthropologists take up the challenge to study the end of life, social death, and non-medical therapies. --Barbara Miller, Associate Dean for Faculty Affairs and Professor of Anthropology & International Affairs at George Washington University, Washington DC. Everyone who thinks about end-of-life issues should read *The Maintenance of Life*. It is a beautifully written book on an important topic. Anthropologist Frances Norwood spent 15 months in the Netherlands, learning first-hand how the dying, their families, and their physicians confronted this difficult subject. She tells this powerful and touching story with both a close eye for personal detail and a researcher's care. After the depressing debate in the U.S. over 'death panels,' it is especially important to hear what Norwood has to say: While the Netherlands has allowed euthanasia for decades, few there use it. Instead, the simple fact that those with terminal disease have an opportunity to express their wishes makes them less likely to end their lives. It is a powerful lesson for us all. --Howard Gleckman, researcher with Urban Institute and author of *Caring for Our Parents: Inspiring Stories of Families Seeking New Solutions to America's Most Urgent Health Crisis...* [a] well-written, sensitive, and timely study of euthanasia and assisted suicide in the Netherlands...Summing Up: Recommended. All levels/libraries. --Choice Magazine

Frances Norwood is director of research at Inclusion Research Institute, Washington, DC.

This book is the result of a serious ethnographic study of euthanasia in the Netherlands where it has been legalized more than 25 years ago. "Euthanasia talk" consist in an ongoing discussion between

terminally ill patients having requested euthanasia, their family and their family doctor: the result being that no more than 10% of these patients get actually involved in doing it. The socio-cultural context of end-of-life situations is convincingly described. This book brings new and thoughtful insights into a debate which is too often based and biased by irrational reactions. It demonstrates how death can become a positive and quieting moment when it is the result of a common effort. A must for those concerned by the problem of long-term duration of incurable disease where biological death is increasingly postponed, whereas social death due to the succession of physical (and at times mental) losses and deteriorations precedes biological death.

We were assigned this one for a class. It is very well written, and really makes me wish we could have a serious, calm, and rational national dialogue about it in this country.

Rumors about end-of-life policies in the US health care reform debate of 2009 loomed large, enflaming talk about "death panels" that would "pull the plug on grandma." Anyone who seeks to be informed about alternatives to the current US system (or non-system) for end-of-life care should read Frances Norwood's book, *The Maintenance of Life: Preventing Social Death through Euthanasia Talk and End-of-Life Care--Lessons from the Netherlands*. In *The Maintenance of Life*, Norwood provides poignant narratives of home visits, including those that resulted in the voluntary death of the patient. She laces the narratives together with a convincing analysis of how "euthanasia talk" is a critical component of end-of-life care in The Netherlands. What is euthanasia talk? According to Norwood, it is a "discourse," or culturally shaped way of discussing one's preferred death. Euthanasia itself, while an option in The Netherlands, is rarely resorted to. But euthanasia talk is widespread and has five steps. It begins with an initial request by a patient with the huisarts. Of Dr. Norwood's 25 participants who were facing the end of life, 14 had made the initial verbal request. No doctor, however, would grant the request immediately. It must be repeated over time, and family members must be involved in the discussion and agree to the choice. All of this makes for an orchestrated pause in the discussions. The second step requires a written statement. A third step involves setting a date for a second opinion. In the fourth step, the patient repeats the request for a euthanasia date and their reason. The fifth step is a euthanasia death. All along the way, euthanasia discourse is happening. Euthanasia policy in The Netherlands, far from pulling the plug on grandma, gives grandma some sense of agency as she faces death, according to Norwood. It helps reduce, to some degree, the pain of "social death" in which a dying person is no longer considered by family members and others to be the whole person they were before

becoming terminally ill. Euthanasia discourse thus serves as a kind of therapeutic narrative which helps to retain a person's social self, identity, and sense of orderliness. Orderliness and control are, according to Norwood, key features of Dutch culture. At the end of her book, Norwood offers insights for US health end-of-life policies. She advises that policies and practices that work in The Netherlands are not easily transferrable to the United States for many reasons, both structural and cultural. The US does not have universal health care and a tradition of home-visiting physicians. The emphasis in the US on individualism means that patients, families, and physicians do not typically work together as a collective. The medicalization of death in the US does not allow sufficient attention to non-medical and cost-effective options that can improve the end of life: home care, nursing and personal care, respite for family members, and coordinated case management. Norwood's book is important, well-written, and will give you much to think about. I hope more cultural anthropologists take up the challenge to study the end of life, social death, and non-medical therapies. Barbara Miller, Associate Dean for Faculty Affairs and Professor of Anthropology & International Affairs at George Washington University, Washington DC. A slightly more detailed review appears on the blog, [...]

This book represents what must have been an enormous amount of research. The author has clearly wrestled an enormous amount of first-hand observation, academic legacy - this from several fields of study - into a clear description and cogent analysis of one of the thorniest intersections of modern medicine and human social organization. Norwood is a dedicated researcher, extending her focus across disciplines, learning the Dutch language to assure accuracy and understanding, citing the theoretical underpinnings of her analysis of the material. It is difficult to imagine how all of this got organized so that it manages to fit between two covers. The book is informative, thought-provoking and exceedingly well documented. One only wishes that a thoughtful copyeditor and proofreader could have given the author the gift of clearing the manuscript of the minor grammatical issues that remain (tense disagreements, word forms, etc.). In addition, while the academic community requires precise documentation at each point in the development of an argument, a lay reader such as myself could do a bit of winnowing to reduce the duplication in arguments across the work. Disclosure - I am a friend of a friend of the author and know her just well enough to say hello to in the street.

Everyone who thinks about end-of-life issues should read "The Maintenance of Life." It is a beautifully written book on an important topic. Anthropologist Frances Norwood spent 15 months in

the Netherlands, learning first-hand how the dying, their families, and their physicians confronted this difficult subject. She tells this powerful and touching story with both a close eye for personal detail and a researcher's care. After the depressing debate in the U.S. over "death panels," it is especially important to hear what Norwood has to say: While the Netherlands has allowed euthanasia for decades, few there use it. Instead, the simple fact that those with terminal disease have an opportunity to express their wishes makes them less likely to end their lives. It is a powerful lesson for us all.

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