

Emily Abel. *Living in Death's Shadow: Family Experiences of Terminal Care and Irreplaceable Loss.* Baltimore: Johns Hopkins University Press, 2016. 184 pp. \$39.95, cloth, ISBN 978-1-4214-2184-1.

Reviewed by Pamela L. Dale

Published on H-Disability (August, 2017)

Commissioned by Iain C. Hutchison (University of Glasgow)

I received my review copy of this book on Saturday, July 10, two days after the UK general election. I did a preliminary read through over that weekend while following the election coverage on television and in the newspapers. As experts sought to explain what was, for many, a surprise result, discussions ranged over a number of themes that are also addressed by Emily Abel's important and timely study. While several policy areas, and different sections of the electorate, were considered, few commentators missed the opportunity to underline the anxiety that a specific Conservative Party manifesto commitment to reform adult social care had caused older voters. There was concern that the suggested changes indicated that, in the future, central government (dealing with major economic, political, social, and demographic shifts) would be less willing and able to meet all the needs of a growing number of vulnerable individuals, including those living with a terminal illness, leaving them ever more dependent on their own resources. This was a bleak conclusion for those already weary of austerity measures and concerned about protection of key public services. Clearly, many people either experiencing or contemplating end of life issues were frightened.

Dying has become a very sensitive political issue, and people in twenty-first century Britain as

well as America seem increasingly keen to share their personal experiences of serious and terminal illnesses. Yet despite the plethora of literature created by, and for, professionals working in the field; an endless stream of new advice books aimed at the general population, patients, and their carers; and a rapidly expanding genre of memoirs seeking to capture personal journeys, relatively little attention has been paid to what Abel terms "family experiences of terminal care and irreplaceable loss" in either contemporary or historical settings. Her book not only starts to fill this difficult gap in the historiography, but compellingly changes the time frame that researchers need to consider—from the actual deathbed to the months, years, and even decades that individuals and their families might live through following a diagnosis of terminal illness.

By drawing on published memoirs and other accounts written by carers, Abel develops a strong sense of a journey that is both highly personal to the individual and yet applicable to many people's experiences. Narratives often start with the first awareness of health problems and the earliest encounters with the medical profession, and continue through the process of having tests and receiving a formal diagnosis and prognosis while patients and their family/friends both learn and desperately seek more information about the disease

and its treatment. At this stage, many lay people with only the sketchiest knowledge of modern medicine recount finding themselves invited to choose from what they clearly find a bewildering array of therapeutic options with highly uncertain outcomes. Particular problems appear to surround the question of participation in clinical trials and concerns about not being able to maximize both the quality and quantity of life available to patients. Much guilt and anguish inevitably attach to these decisions, and trust in the medical profession is clearly tested by the problematic way in which information might be communicated.

These issues are of course familiar from other strands of the historiography that capture the illness experience from a clinical, professional, or patient perspective, but important new insights are gleaned from Abel's unusual focus on family and friends acting (with varying degrees of willingness) as carers. As a reader, I felt the most significant of these was the relentless emphasis on the emotional dimensions to the whole experience and the stress of coping with dying that is imposed on individuals and families who simultaneously wanted to support each other through the ordeal and conceal from loved ones the depth of their personal distress so as not to add to the suffering of others. It is the raw human emotion that makes the personal testimony of the carers so hard to read and there is occasionally a strong temptation to escape by skipping to the more detached and academic commentary that Abel effectively uses to frame and organize the narratives. This instinctive distancing helps the lay reader understand the otherwise inexplicable attitudes of clinicians who have presumably chosen to work with the sick and dying, but reportedly struggle to meaningfully engage with patients and their families. While staff are trained to recognize the emotional dimension to the illness experience, the accounts that Abel draws on suggest that too many doctors still seek to protect themselves by limiting opportunities for communication (prefer-

ring to make brief remarks in inappropriately public settings) and keeping the focus on clinical rather than personal issues. This clearly adds to the distress of families, but even "caring" professionals who make themselves available to offer support at key moments such as diagnosis, changing prognosis, and even the deathbed, can still disappoint patients and carers because they cannot possibly sustain the effort over the whole course of a lengthy illness and its aftermath.

Abel's book effectively captures the way the promise of modern medicine sustains hope for many sufferers and their loved ones, but also reveals how its limitations create space for other sorts of remedies and the search for alternative forms of solace and support. In the chapter titled "When Medicine Fails," Abel follows Anne Harrington's exploration of people's reactions to both the inability of mainstream medicine to always deliver cures and, perhaps more universally, "validate fully the complexity of one's suffering."^[1] While Harrington underlined the religious roots of mind-body practices, Abel pays equal attention to the role of faith and organized religion in the lives of the terminally ill and their carers. I think some of these themes, especially faith in modern medicine, could have been expanded to take account of the fact that a surprising number of health professionals mention that their decision to follow their chosen career path was influenced by witnessing the serious/terminal illness of loved ones and a deep-rooted desire to help/save others. An important part of training and practice must then necessarily involve somehow coping with the inevitable number of deaths witnessed and acceptance of the fact that pain and suffering cannot always be relieved. This perhaps makes the experiences of doctors and nurses caring for terminally ill relatives particularly poignant.^[2]

The limitations of the mixed economy of care is another major theme that is really illuminated by Abel's focus on carers and their experiences. There are endless policy documents that talk

about how services should theoretically work, but the reality is often a confusing patchwork of provision through which the general public struggles to navigate its way. While Abel is quick to acknowledge that most of the families whose experiences find their way into print are the more affluent and articulate, their very obvious difficulties are clearly a too-common experience and hint at a much wider problem. Even arrangements that seemed to work well while a person's condition remained relatively stable could soon be destroyed by an emerging crisis. In these circumstances it was the family carers who disproportionately had to provide as well as organize care, including performing quite complex nursing procedures with very little training or supervision/support. None of the existing policy-led or service-evaluation critiques of the current state of provision, and the difficult interface between high-tech medicine and the traumatic human experiences of those caring for the dying capture the sheer anguish of the heart-rending testimony assembled by Abel. In this case the personal really is the political.

In dealing with a subject as personal as dying, the reader inevitably casts their mind over deaths among their own family and friends. My grandfather, who died in 1999, certainly received a lot of support from a variety of health professionals when first diagnosed with terminal cancer, and over the next year accessed a number of services that proved very helpful; it was in the last few days of his life when he was very seriously ill at home that the inadequate, even threadbare, nature of what was available became apparent. It is a very long night between the brief evening and morning calls from the cancer nurse. Painful memories of that time resonate strongly with the insights offered by Abel, particularly the undesirable necessity for untrained lay carers to have to exercise clinical judgment within a developing crisis situation while doing their best to honor a stated preference for a non-institutional death. Many relevant issues and extremely painful per-

sonal, professional, moral, and legal dilemmas are carefully unpicked by Abel, although a UK reader may well benefit from reading this study in parallel with other works that place the past, present, and future of the National Health Service at the heart of their analysis. I certainly gained from having recently read Jennifer Worth's book that covers not dissimilar ground to Abel from the perspective of reflection on her nursing career.[3] For example, both Abel and Worth explore the influence of key thinkers like Dr. Elisabeth Kübler-Ross and Dame Cicely Saunders in their respective countries.[4] Hospice care is also a shared theme, but here the UK reader needs to be very alert to significant organizational differences as Abel's devastating critique of for-profit care of the dying should not be confused with UK hospice provision, which has a very different ethos despite serious financial pressures and some concerns about why certain groups of patients are underrepresented among its clients. The risk of undermining, even perverting, the original goals of hospice care is an interesting if worrying message to take from Abel's study. This finding plays into an emerging debate in the UK about the need to embrace, accept, tolerate, or reject US-style healthcare provision and for-profit healthcare. At present, an apparent lack of understanding about what "choices" might exist in the United States is serving to support a number of complicated misunderstandings, with those for and against different policies drawing on much the same data.[5]

Although Abel's work is unashamedly centered on people's experiences of caring for dying loved ones in the United States, the personal testimonies she draws on are so powerful that they speak to a much wider audience. Indeed, by capturing the most intimate, personal, and necessarily unique experiences of individuals living through what nowadays can be the long process of caring for the dying, the study develops findings with almost universal application. The dust jacket description for the book suggest that it seeks to focus on "three significant developments

that transformed the experiences of those dying and their intimates,” but while Abel provides a really thoughtful and detailed account of people’s perceptions of the benefits and drawbacks of participating in drug trials, the rise of high-tech medicine, and the financial and organizational constraints imposed by Medicare and Medicaid, the reader who chooses to focus exclusively on these issues will miss many of the more interesting and subtle points raised throughout the text. This may be a particular concern for UK readers whose familiarity with the National Health Service often acts as a critical filter when examining healthcare systems elsewhere. To maximize the impact of the study it seems important to appreciate, rather than be distracted by, the very different systems, procedures, and policy environments so thoroughly dissected by Abel.

It is perhaps for this reason that the more I read the book, the more I gained from the experience. At first glance, the structure and content of the study can appear rather alien and even off-putting. My first concern was the intended audience. The book is beautifully presented, well organized, engagingly written; extensively referenced, and, for an academic study, reasonably priced. It should have wide appeal, but I fear the subject matter will deter potential readers. I have previously researched history of nursing topics, and am currently working with Jan Walmsley on a project exploring deaths in long-stay institutions for people with learning disabilities, so am familiar with the issues in Abel’s study, but I found some of the discussions deeply distressing. But this is perhaps the point. While Abel reveals in uncompromising detail the problematic nature of dying, and even explodes the myth of a good death, her work does point the way toward improving the situation for family carers by acknowledging their pain and offering emotional as well as practical support.

While I would be reluctant to recommend the book to lay people currently involved in caring

for the dying, it should be studied carefully by policymakers and care providers and used as a resource by those who train staff in the health and social care sectors. Abel’s work is not only intended to improve the interface between the lay and the professional; she also makes a number of really interesting points about current and future workforce issues. There has been a blurring of lines and responsibilities between paid and unpaid carers as families take on ever more caring, and an army of low-paid, and sometimes inadequately trained, carers serve to support their endeavors. Questions about the exploitation of labor, as well as desired staff numbers and skill mixes, need to be addressed by policymakers and service providers in different countries. Yet Abel’s relentless focus on the physical and emotional demands placed on all carers (not just those caring for someone they love deeply) also speaks to a much older debate about issues surrounding nurse recruitment and retention and the problem of burnout in the caring professions. I suspect that it will be historians of nursing who will make the deepest engagement with the themes highlighted by Abel, although frequently it was Joanna Bourke’s groundbreaking study of “fear” that resonated when reading about the multilayered difficulties of carers forced to confront, not just mortality, but any number of societal taboos.[6] I hope and expect that Abel’s book will be appreciated by historians of the recent past and those concerned with the changing nature of family life as well as evolving patterns of caring. Abel’s book also represents something of a challenge to medical historians by questioning the assumption that “patient autonomy has steadily increased and that its expansion always represents progress” (p. 1).

A major concern for me was, however, the selection and presentation of the case studies. The difficulty with dying is its universality. If Abel had recounted her own family experiences of caring for the dying, spoken to her friends and co-workers, or interviewed random strangers, I think very similar themes and issues would ultimately have

emerged from the study. This raises the question, why use previously published sources at all and, while I think the answer lies in the way this testimony allows appropriate detachment and encourages objective analysis, it also inevitably creates some problems of selection and bias. Abel acknowledges that it is the privileged who find it easiest to tell their stories in this way, making their experiences interesting yet hardly representative. In some ways this helps; since the narrators are largely (though by no means completely) free of immediate financial hardship, their words concentrate on the emotional issues that are of most interest to Abel. The problem is that the memoirs cannot tell us everything and many were written with a deliberate purpose in mind that, however worthy, does tend to compromise the writer's objectivity. Abel is more than capable of unpacking what the narratives tell us through their silences as well as through their disclosures, but the reader needs to exercise her/his own judgement as well. I found Abel's commentary on the AIDs epidemic particularly interesting, but I have some concerns that this is because I had previously read and reread Paul Monette's haunting book that is a major source for Abel.[7] Other authors will have their own stories that are no less important, despite not being critically acclaimed, best-selling writers.

My hope is that readers will use the extensive references provided by Abel to delve further into the publications she draws on to such good effect, and then perhaps imaginatively seek additional and alternative sources. I certainly think that biographies, autobiographies, and printed diaries can all offer insights into people's experiences of living with dying even when they are not structured to foreground caring issues.[8] While such publications, like the memoirs by kin utilized by Abel, also prioritize the experience of notable individuals and elite families, they can perhaps capture a prehistory that Abel ignores by stressing the importance of the era of high-tech medicine in her book. A complete history of dying seems im-

possible; but the experiences of, for example, early and mid-twentieth-century tuberculosis sufferers could easily be brought within the parameters of the study as there were not only a significant number of painful and protracted deaths, but so many of the same themes reappear: frequent lay and professional concerns expressed about experimental treatments, the pros and cons of care in different institutional settings, and issues linked to both stigma and false hopes.

One of the problems with the kin carer memoirs chosen by Abel is that there are relatively few of them, just 105 published in the United States since 1965. This means a little has to go a long way and I found Abel's assertions of significant changes over her chosen time frame quite hard to reconcile with what appeared to be more similarities than differences over a time line that was kept very much in the background. Also, while different types of illnesses and distinct patient groups are usually treated separately in the literature, there is an odd juxtapositioning here. It is only the terminal nature of the illnesses that seems to link fatal childhood cancers with Alzheimer's disease, and while Abel makes all the necessary connections with her descriptions of the shared caring experiences, this sense of cohesion is sometimes undermined by separate chapter sections for different diseases. Yet, for all the illnesses covered, many important areas are relatively neglected. Almost all the case studies start from the point when a person previously in good health becomes seriously and then terminally ill. For some groups of disabled people, their whole lives are lived in the shadow of life-limiting illness and the similarities and differences of this experience need to be explored in more detail.

The families studied by Abel also seem to lead quite compartmentalized lives; friends and co-workers get a mention, but usually only briefly and problematically. There are some groups of terminally ill people who are either in, or make themselves part of, particular communities that

draw on distinct occupational identities for support. Arthur McIvor and Ronnie Johnston have used innovative oral history techniques to explore fatal industrial diseases in a Scottish context. Workers from heavily unionized workplaces, such as coal mines and shipyards, often turned to co-workers and union officials for financial and legal support, but in the later stages of their illnesses these men were often entirely confined to their homes. While many men reportedly felt this social isolation badly and found their masculinity threatened by physical weakness and financial dependency, some wives explained that this new shared existence provided them with a period of unexpectedly warm companionship after previously unsatisfactory, even abusive, marriages shaped by the husband's physical absence at work and involvement in the associated male leisure culture.[9] Caring clearly held multiple meanings and could even offer unexpected benefits, and these themes are addressed sensitively and imaginatively throughout Abel's study, although there is perhaps scope to contrast the different experiences of long-term carers of sufferers of serious physical or mental illnesses that are not inevitably fatal.

One area that I really think is worthy of further consideration is the question of what happens afterwards. For the carer, the experience of caring both ends and does not end with the actual death. Funerals and other acts of memorialization can bring healing, but too often only serve to exacerbate existing family tensions, especially between those who wanted a larger or smaller role in the caring process than circumstances allowed. Abel captures some of this, but the difficult questions keep coming as the people most closely affected by the death attempt not so much to resume, but rebuild their normal lives over lengthy periods. Some carers spectacularly fail to make the necessary transitions, and marital breakdown, family disintegration, drink and drug abuse, and serious mental illness can all follow both the pain of caring and the grief of loss. Others find solace

in campaigning (the caring experience often being complicated by pursuing/supporting right to life and right to die causes, or other litigation aimed at exposing medical malpractice or malfeasance by nursing homes, etc.) or fundraising to support research into diseases that have claimed loved ones. But their lives are not the same and these aftermath activities also need consideration within the envelope of carers' experiences. Sadly, for many the experience of caring for one person is closely followed by the need to either do it all again (for example, an adult child facing terminal illness of surviving parent) or personally receive care.

Abel usefully supplies information about the gender of the memoir writers and describes their relationship to the person being cared for. This works to a point, but prioritizing the experience of the writer, who may or may not be the main carer, risks losing the perspectives of other carers and other kin. One of the themes that Abel really effectively develops is that caring and being cared for are highly testing experiences, and the pre-illness relationship may be the key to understanding the success or otherwise of any caring arrangements (with illness duration and/or disturbing symptoms also emerging as key variables). Yet this is only part of the story. Many cancer narratives, in particular, have drawn attention to generational issues and the way carers are stereotyped by statutory and voluntary sector providers. Thus it is often assumed that the child patient has a parent carer, while the main carer for an adult will be another adult of the same generation (usually a spouse/partner), and the elderly person can rely on their adult children; but all of these arrangements struggle to cope with the realities of modern life, and I think Abel could have made more of the practical and emotional difficulties created by being an atypical carer. For example, my brother-in-law became the main carer of his frail, elderly grandparents who both died of cancer when he was aged about thirty. While hospital staff had been comfortable with him acting

as a supporter for Gran when she was supposedly caring for Grandad (who predeceased her), when it came to her end-of-life care there seemed more embarrassment about his involvement and this served to restrict his communications with both Gran and her medical team, which only added to everyone's distress.

Ultimately, I think it is one of the strengths of Abel's work that the reader is left rather unsatisfied in the sense of desperately wanting to see more, and different, stories included within her important study. This book is not an easy read, but its aims and achievements make it an impressive contribution to the history of caring.

Notes

[1]. Anne Harrington, *The Cure Within: A History of Mind-Body Medicine* (New York: W. W. Norton, 2008), 18

[2]. Edith Cotterill, *Nurse on Call: The True Story of a 1950s District Nurse* (London: Ebury Press, 2010), 289-316.

[3]. Jennifer Worth, *In the Midst of Life* (London: Orion Books, 2010).

[4]. Worth, *In the Midst of Life*, 51-67, 62-67; Abel, *Living in Death's Shadow*, 4, 13, 14, 63-66, 70, 117-124, 131-132, 137; Elisabeth Kübler Ross, *On Death and Dying: What the Dying Have to Teach Doctors, Nurses, Clergy and their Own Families* (London: Routledge, 2009 [1969]). Worth notes that Saunders wrote six seminal articles on the care of the dying in the *Nursing Times* in the late 1950s and early 1960s and Abel explains how Saunders's work was adopted and developed in the United States by leading nurses such as Florence Schorske Wald.

[5]. Medicine Balls, "Assisted Dying," *Private Eye*, April 21-May 4, 2017, 15; and related correspondence from Bill Sang and Fay Marshall under the title "Death Sentences," *Private Eye*, May 5-18, 2017, 19; and Dr. R. Clearkin under the title "Dead Reckoning," *Private Eye*, May 19-June 1, 2017, 20.

[6]. Joanna Bourke, *Fear: A Cultural History* (London: Virago Press, 2005).

[7]. Paul Monette, *Borrowed Time: An AIDS Memoir* (New York: Avon Books, 1988).

[8]. In a particularly loving tribute as well as thoughtful study, Mary Soames identifies caring and the problems of caring as key themes in her parents' lives. Winston and Clementine Churchill had to cope with the loss of parents, siblings, children, and any number of close friends and relations before the great drama of Winston Churchill's final illnesses. Mary Soames, *Clementine Churchill* (London: Cassell, 1979).

[9]. Personal communications with Arthur McIvor and Ronnie Johnston at a series of conferences and seminars held at the University of Exeter, 2001-09.

If there is additional discussion of this review, you may access it through the network, at
<https://networks.h-net.org/h-disability>

Citation: Pamela L. Dale. Review of Abel, Emily. *Living in Death's Shadow: Family Experiences of Terminal Care and Irreplaceable Loss*. H-Disability, H-Net Reviews. August, 2017.

URL: <https://www.h-net.org/reviews/showrev.php?id=49855>



This work is licensed under a Creative Commons Attribution-Noncommercial-No Derivative Works 3.0 United States License.