

Elder Care in Crisis: How the Social Safety Net Fails Families

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Book Title: Elder Care in Crisis: How the Social Safety Net Fails Families

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Public attention drawn to the COVID-19 pandemic crisis illustrated how desperately insufficient our medical system is for providing care for chronically ill elders. Emily Abel, a professor emerita in the Department of Health Policy and Medicine at UCLA, has written extensively on the history of women as caregivers for the sick, injured, and elderly. In her newest book, she brings to this topic not only the perspective of a historian but also a superb grasp of the public health consequences of social norms and specific policy decisions in the modern US health care ecosystem.

Dr Abel begins with a discussion of the limitations of the concepts of caregiver stress and burden, as described in the recent medical literature. Although caregiver stress can be measured, each caregiving situation is different, so generally applicable remedies are nonexistent. She follows with a discussion of the poverty of the medical model as applied to dementia and the difficulty of applying the personhood model to people whose personalities are changing as a result of the disease. Readers who enjoy social history will appreciate the third chapter, in which she uses letters and diaries of 19-century women to demonstrate the heavy burden of caregiving they carried and to show that the modern crisis in caregiving is nothing new. She shows how, in addition to their taxing everyday household labor, women nursed family members or neighbors who were ill or injured. Those caring for people with the common contagious illnesses of that period (eg, measles, cholera, tuberculosis) often became ill or even died themselves.

Chapter 4 describes the more recent emphasis on programs that encourage (and, to a limited extent, support) family-based caregiving as, basically, a cost-cutting measure to keep people out of expensive hospital and nursing home beds. The conflict in needs and interests between family and paid caregivers is illustrated using memoirs and other narratives by caregivers. Next, Dr Abel uses posts on the Alzheimer Association's support group¹ (the modern equivalent of online letters and diaries) to describe in agonizing detail the challenges faced by caregivers in current times. Posts on the spouse and partners forum illustrate the extreme difficulty of caregiving by people who are elderly and often chronically ill themselves. The severe limitations of assisted living, adult day care, short-term respite, and long-term care are discussed from the point of view of the caregivers.

The book concludes with an all too brief review of recent policy initiatives to provide increased funding and broaden eligibility for home and community-based services. Readers interested in health policy likely would have appreciated a more complete discussion of the policy options in play, the political forces at work, and the likelihood (however slim) of getting anything across the finish line in the next Congress.

Plenty has been written about the burden of caregiving for families of persons with chronic illness in general and dementia in particular. Dr Abel herself did a PubMed² search revealing 2,981 articles with keywords "Caregiver," "Dementia," and "Burden" from 1983 to 2019. Her book is unusual in focusing on the spouse caregiver but not alone in that regard. Her discussion of the history of caregiving adds a perspective that I think is helpful to the

policy discussion.

Those interested in advocacy will find the current material as well as the historical background helpful but might wish for more discussion of specific policy. For a student of the history of medicine and health, the book has value, but her earlier work, *Hearts of Wisdom*³, might be more relevant. What I liked best about the book was that it helped put my own experiences—giving care to my parents and supporting caregivers of my patients—into perspective. Dr Abel’s detailed understanding of the burdens of both paid and family caregivers and her strong empathy for both make this a worthwhile read.

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