



Clark, D. (2021) Emily K. Abel, Prelude to Hospice: Florence Wald, Dying People and Their Families. *Social History of Medicine*, 34(4), pp. 1385-1386. [Book Review]

(doi: [10.1093/shm/hkaa074](https://doi.org/10.1093/shm/hkaa074))

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Deposited on: 8 October 2020

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Emily K. Abel

Prelude to Hospice: Florence Wald, Dying People and their Families.

New Brunswick, Camden, and Newark, New Jersey, and London: Rutgers University Press, 2018

ISBN-13: 978-0813593920

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Emily Abel is a respected historian of family caregiving, of hospice and palliative care and of the wider fields of medicine concerned with 'incurable', older and dying people. Unlike the broad sweep of much of her previous work on these topics, this short book takes a deep dive into the archives of a single research project that was undertaken in the late 1960s to inform the development of what became a foundational hospice programme in the United States.

The book is unusual in giving detailed insights into approaches to terminal care in the USA in a decade when new ideas about this subject were being developed by Cicely Saunders, Elizabeth Kübler Ross, and their associates on both sides of the Atlantic. The study, and Abel's analysis of it, show how activists of the time were building a case for a new and more compassionate orientation to care at the end of life, eager to demonstrate not only the wrongs of the day, but also their proposals for righting them.

The book's central character is Florence Wald, sometime Dean of Nursing at Yale and by the time the book's narrative begins, a close admirer of the work of Saunders and the newly opened St Christopher's Hospice in London. A complex and challenging figure, Wald worked with a group of like-minded spirits to form 'Hospice Inc.' which became operational in 1974 and was later known as the Connecticut Hospice.

Abel's opening chapter sets the scene in a now familiar account of the development of hospice ideas and practices in the 1960s, but also contains the telling observation: 'We shall see that one of the many ways Wald followed Saunders's example was by romanticizing deaths that occurred under hospice care' (p.15). The converse also applied – the success of hospice could be highlighted by its corollary in the mainstream health system. Activists and advocates were therefore keen to emphasise the widespread problems of unrelieved pain, unacknowledged suffering, and especially in the USA, a form of medicine that was intrusive, death denying and the producer of iatrogenic distress. Wald and her group saw their cause as a form of protest movement and drew further inspiration for their efforts at vigils for peace and civil rights gatherings in the black ghettos of New Haven.

The 'study' therefore had some powerful biases from the outset. Its goal in effect was to make an advocacy case for hospice and to do so by revealing the inadequacies of current care. Her primary collaborator was the oncologist and breast cancer surgeon, Ira S. Goldenberg, with whom she worked closely, clashed frequently and from whom she recruited patients to the study. The research orientation was for Wald to become a participant observer of selected patients and their families, following them up over extended periods.

Abel gives us a handful of very detailed accounts of what emerged from this approach. These provide a vivid insight into prevailing medical norms – such as the reluctance to cease treatment, to

be open with patients and families about the prognosis, and the ways in which clinical research needs could over-ride the best interests of patients.

Equally troublesome however is Wald's involvement with these cases. We see her building herself into the narrative, over-involved with the families, blurring and over-extending professional boundaries. 'Now you have gone too far' said Goldenberg to Wald on one occasion when she suggested taking care personally of the daughters of a patient, whose death was imminent.

The study had no formal or peer-reviewed published outcome, but it was woven into Wald's subsequent writings and the many talks she gave to promote ideas about hospice. Her work was riddled with ethical limitations and transgressions. It is surprising therefore that Abel herself is silent on her own use of the archival material from which her book is drawn. We are introduced by name to Wald's collaborators, we learn in detail about the lives of patients and families with no clue about the extent to which the details have been anonymised, and it is unclear on what conditions access to the archive was granted.

Despite such concerns, Abel delivers a fascinating account here of early elements in what became the modern hospice movement. She also highlights the contradictions in the goals of some of its main protagonists, concluding that Wald's study: 'demonstrates that some of the original hospice ideals were unattainable and describes a model of compassionate care that can be easily betrayed' (p116). Abel therefore contributes another important element to the emergent historiography of hospice and palliative care.