Jennifer A. Parks

No place like home? Feminist ethics and home health care

BLOOMINGTON: INDIANA UNIVERSITY PRESS, 2003

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ISBN: 0253341922

Jennifer Parks has written an important book about the ethics of home health care. While she was in graduate school, Parks supported herself by working as a home health aide, and her book is passionately informed by her experiences. Much of the book is well argued, sensible, and wise.

In the United States today, the "old old"—those over 85—are the fastest growing segment of the population. Medicare estimates that about 7 million disabled or elderly Americans need long term care. Over 70% receive that care in their own homes. <1> Home care is essential to enabling many of these and other clients to stay at home and to maintain the quality of life they desire. The ability to live—and die—at home is much prized by many, as Parks clearly recognizes (6, 11). Yet most home care workers, women and minorities, are underpaid and exploited, if indeed they are paid at all. In the face of such an unjust system, Jennifer Parks has written an important book about the ethics of home health care. While she was in graduate school, Parks supported herself by working as a home health aide, and her book is passionately informed by her experiences. Much of the book is well argued, sensible, and wise.

Despite these praiseworthy features, Parks's argument also manifests a certain lack of focus that makes it less compelling than it otherwise might have been. Her sweeping indictment of the contemporary system of American health care brushes aside very real problems about what justice requires—and does not require—with respect to home health care. Parks might well attribute my concern to a failure to appreciate the depth of her critique of home health care as it exists today. Indeed, relying on Marxism and feminism, she proposes a whole-scale revamping of the contemporary home care system in the United States. Nonetheless, very real problems remain about the boundaries of home health care, the nature of relationships between care workers and clients, and the problem of setting limits to the care that should be subsidized socially. Had she gone beyond the critique to address these problems, the book would have been far stronger.

Literally, "home health care" is health care performed in the person's home. Parks's own services as a home health aide ranged far more widely, from providing companionship to doing laundry to administering skilled medical care for which she was not appropriately trained. Her definition of "home health" responds to the breadth of her experiences: "Home care services run such a wide gamut that they cover all aspects of clients' lives: physical, emotional, nutritional, social, and economic" (36). This definition is reminiscent of the World Health Organization's definition of "health" as a "state of complete physical, mental and social well-being and not merely the absence of disease or infirmity."<2> Parks is critical of Medicare and Medicaid for imposing limits on services to control costs (16). To be sure, Medicare coverage is limited to skilled nursing care, assistance with personal care activities such as bathing and dressing, physical and occupational therapy, speech language pathology, medical social services to assess

social and emotional factors related to illness, medical supplies and medical equipment—and then only for eligible patients. <3> Medicare specifically excludes meal preparation and homemaker services from coverage. In some states, Medicaid covers even fewer services; and Medicaid eligibility itself is need-based and requires near-complete spend-down of resources. Parks is surely correct that in order to stay in their homes people may need a broad range of services, from help with meals to housekeeping—and even to services she does not mention, such as help with home repair, snow removal, or lawn maintenance. But this is just the problem. For which of these services are obligations socially shared? How are lines to be drawn theoretically? Drawing the line at health care and health-related services is at least drawing a line, even if one in need of further argument.

Parks embeds her critique of the justice of home health care in a critique of the American health care system. Drawing from Marxist accounts of alienation, she believes that health care generally and home care particularly should not be provided on a for-profit basis (123). To capitalism, she attributes the ills of cost control and managed care (121). Indeed, she sees profit-seeking, managed care, and cost cutting as of a piece: "the corporate, market-driven managed care model of care provision" (33). This identification is simplistic, however. A for-profit system need not manage care in the sense of "managed care" in contemporary U.S. health care. And a managed care system need not be for profit. Parks is certainly right that those seeking profits will want to cut costs. But health care systems generally, whether or not they are for profit, face issues of cost control. Home care services are no exception. In general, more home care is better than less, especially if home care is defined as broadly as Parks would have it. The companionship and services of a home health aide—at least, one doing the job well—are welcomed by those who are frail and alone. The discomfort and risks of many medical interventions do not function as deterrents to home care. Parks is critical of Medicare's imposition of the requirement that the client must show benefit in order to continue to qualify for home health services; she regards this requirement as an unjustified example of cost cutting (14).<4> Yet without some theoretical way to set limits, it is hard to know where a commitment to home care services might end. Parks says at the outset that she regards Sen's capabilities approach as the preferable theoretical paradigm to set home health care needs (16). In the book's final chapter, she returns as promised to the capabilities approach, to emphasize the importance of translating goods into flourishing—that is, of translating resources into what people can actually do with them (134). She also underlines the need to attend to the capabilities of both cared-for and care-givers (135). At no point, however, does she take up the question of what capabilities should be the core demands for home health care.

From the point of view of justice, Parks believes that home health care is a collective obligation. On this basis, she argues that care provided by unpaid family members or friends represents a social subsidy (51). In relying on free or underpaid care, the state is avoiding resource expenditures that it would otherwise be obligated to make. I am generally sympathetic to the claim that responsibility for dependency care should be socially shared. She rightly attacks the Medicaid spend down provisions that impoverish families in need of long term care while leaving others to pass extensive resources intergenerationally (18). This said, I would have liked to have seen Parks's argument for the view that home health care is a collective obligation, if only because that argument might have provided an outline of answers to troubling questions of

https://doi.org/10.1017/S2753906700000759 Published online by Cambridge University Press

justice. How much is it reasonable to expect people to provide ahead for their own home health care? What should we expect from families?

Parks is at her best when she considers the difficulties posed by cost control for home care workers. Drawing on feminist theory, she argues that care should be "care about" the whole person rather than merely "care for" the bodies of those who are clients (40-41). Underpaid, overworked, and inhumanely treated, care workers all too frequently are alienated in the sense that they are deprived of the genuinely human satisfactions that could attend what they do (121). All care workers (110) should receive decent pay and benefits in order to enable them to achieve their capabilities (130). Structures of care work should be democratized to allow care workers increased control over their circumstances of labor (128). Parks defends unionization and other similar strategies for care workers over consumer-driven strategies as a better way to achieve the coalitions needed to improve the circumstances of home care work (126).

Within this context of injustice, home health care workers face many ethical dilemmas as they go about the daily tasks of providing care. The context of injustice surely exacerbates some of these dilemmas, but many remain. Parks's book contains only one chapter devoted principally to the daily ethical dilemmas faced by home care workers and those they serve. This is to be regretted, as she has much to say about these problems. The theoretical paradigm she draws from feminism is relational autonomy. People must be viewed as whole beings, with past present and future (83), embedded in relationships (85). It is a mistake to focus on autonomy as independence and choice alone, as it has been too often viewed in bioethics. Parks believes that the difficult ethical choices in home health care require balancing and contextualizing. All of these points seem exactly right.

Consider, for example, the problem of the risky client, an issue that is especially well developed in Parks's discussion. A client's desire to remain at home may put others at risk, if burners are left on or garbage collects. Any analysis of this issue must see the individual client's choices as embedded in her relational context. Parks's treatment of gift giving is similarly nuanced. She argues persuasively that a flat prohibition of all gifts, even a carefully selected tribute of little or no economic value, denies respect for agency and reciprocity (95). She also recognizes that expensive gifts are inappropriate, and that gifts when their giver is cognitively impaired may not be a recognition of true agency (97).

Throughout the book, Parks raises appropriate concerns about the role of racism in home care. Racism too frequently contributes to the devaluation of home care work. One of the best discussions in the book concerns the problem of racist clients. Should clients, who may be cognitively impaired and suspicious of difference, be permitted to reject caregivers of color? To permit clients to vent racist attitudes against caregivers is morally intolerable and clients clearly have obligations of decency (100), yet the negative dynamic of a racist client can hurt caregivers deeply (99). Parks's suggestion is that caregivers should play a role in determining the extent to which racist attitudes on the part of clients should be tolerated.

On the other hand, it is disappointing that Parks devotes only a single chapter to the ethical issues faced by caregivers in working with clients. She leaves largely unexplored issues such as whether caregivers should take risks in attending to clients, lie (38) or provide unauthorized

services to help clients remain in their homes (42-43), or maintain confidentiality about abuse or other matters such as the refusal of medical treatment or the possibility of suicide.

Finally, even in the discussion of the caregiver-client relationship, Parks would benefit by theoretical attention to limits. Parks attributes the alienation of the care worker to the difficulties of preserving "caring about" in a cost-based system (40-41). The care worker, concerned about time and the need to move on, cannot engage in genuine caring about (121). Home care is set up to require caring but to block the genuine expression of care (121). But the problem of boundaries in home care is not just the problem of limits set by costs. There are deeper issues of limits that the strategy of blaming capitalism obscures. What are the appropriate boundaries between care provider and client? Should the care provider be regarded as "fictive kin," as Parks suggests (44)? To be sure, home care is underfunded and home care workers are exploited. But there is a deep paradox in home care that reaches beyond the problems of cost: home care workers, *qua* workers, are not family or friends. How to conceptualize these different roles, even for family members when they undertake home care, remains enormously difficult, both personally and theoretically.

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https://doi.org/10.1017/S2753906700000759 Published online by Cambridge University Press