

Book Review

D’Cruz, P. (2004). *Family care in HIV/AIDS: Exploring lived experience*. Thousand Oaks, CA: Sage Publications. ISBN: 076193233X; \$48.95; 218 pp.

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Although health communication scholars have acknowledged the importance of talk about the subjective component of illness for more than 20 years (see, for example, Fisher & Todd, 1983; Hall, Epstein, DeCiantis, & McNeil, 1993; Stewart & Roter, 1989), the role of *communication* in explaining illness continues to be described (Whaley, 2000). The subjective component of illness includes a patient’s beliefs and emotions about illness and the ways that illness affects the performance of roles and responsibilities (Weston & Brown, 1989) and begins to inform the complexities of communication about illness. Health communication scholars continue to develop sophisticated research integrating theory and practice (e.g., Thompson, Dorsey, Miller, & Parrott, 2003), suggesting implications for the ways in which family relationships are defined by health and illness. In *Family Care in HIV/AIDS*, Premilla D’Cruz brings life voice to the subjective component of illness and illustrates how family systems are redefined through illness and caretaking.

Through provocative narratives, she depicts the voice of the lifeworld, providing language to articulate the meaning of the contextual and familial experience of illness and the private meanings of the caregiver role. D’Cruz brings the realities of the human experience of caring for HIV positive individuals to life and provides stories that challenge the reader to consider explanations for the layers of change in roles and relationships during the progression of the illness. The narratives in the text give meaning and intelligibility to the experience of being either a caregiver or care receiver, and they portray how women caregivers’ lives have been made invisible and their voices silenced.

Overview

D’Cruz divides the book into seven distinct chapters. The first three chapters focus on interdependence of the family system in HIV/AIDS care, and the last four chapters provide narrative accounts of caring for HIV positive family members at different stages of illness development. The first three chapters review the theoretical, conceptual, and empirical literature relevant to family care and AIDS. The last four chapters use narrative accounts of seropositive individuals and their caretakers to provide a language link to the subjective experience of the illness course. Overall, the volume brings life and voice to the ways that disease and caretaking affects identities, goals, and preconceptions.

In chapter 1, D’Cruz examines the ways in which family care goes beyond physical assistance and ordinary family activities to include direct care and activities that indirectly affect care. She identifies phases of care, describes care as a reflection and

acceptance of this new role within the family relationship, and notes the trajectory of the process of caregiving. In describing the organization of family care, she brings an interesting and nontraditional array of perspectives, including individual vs. collective accounts, gender theory and determinants, feminization of care, and alternatives to the primary caregiver role. In her review of caregiver outcomes, she provides evidence for both negative and positive outcomes for the caregiver (although her literature review and narratives in the second half of the book offer far more evidence for burdens on the caregiver than positive consequences). The overarching theme is one of family dynamics and the process of redefining the relationship, including shifts in interpersonal power, identity loss, and lack of reciprocity.

D'Cruz's second chapter provides a macro-level understanding of HIV and AIDS as a pandemic laden with social and cultural meaning and of the value in specifically addressing HIV/AIDS in family care. She develops interpersonal concepts such as uncertainty, stigma, and social support within the family context. The author explores the ways in which caregiving differs depending on the family role of the caregiver (women caregivers, parental caregivers, child caregivers, grandparent caregivers, gay and lesbian caregivers, volunteer caregivers). Next, D'Cruz reviews literature related to factors that have been shown to shape the family caregiving context, such as cost of care, gender of the seropositive individual, motivation for care, stigma of the illness, and fear and anxiety in care. Caregiver outcomes and skills (and the ways those outcomes and skills change during the course of the illness) are also explored in this chapter.

In chapter 3, the author emphasizes that she interprets the social phenomena of family care in HIV/AIDS from the points of view of those being studied. D'Cruz provides a clear argument for a qualitative, interpretive approach of the lived experiences of family caregivers. D'Cruz frames her study as a phenomenological description and reflection, focusing on meaning construction by families caring for someone with at least one opportunistic infection. Data included 17 participants from 16 families in India.

D'Cruz presents the fundamental meaning of the narratives in the last four chapters, with each chapter suggesting ways that the caretakers are highly enmeshed in their respective relationship with a seropositive individual. The caregiver's role in the relationship seems quickly to become that of the nurturer. Because the illness is ultimately fatal, the caretaker realizes the nurturing behaviors will not always be needed. Thus, complaints of lack of support seem unjustified, and even the emotional expressiveness of the caregiver is limited by the seropositive status.

Chapters 4 through 7 include the narratives from the interviews as they fit caregiving within the context of AIDS/HIV progression and into coping without the ill member. Chapter 4 highlights the stories of seven male care receivers and their perceived loss of autonomy following the seropositive diagnosis. Loss of independence, emotional strain, loss of goals, inability to reciprocate care, lack of control over disclosure of the diagnosis, stigma (and related isolation and rejection), and lack of access to medical care are particularly poignant for these male receivers. Important issues for those care receivers include relationship development, extended family complications, blame, and ability to repay their caregivers. Roles in the relationship seem so clearly defined that individuals are unable to communicate openly about the nature of the contradictions or about the nature of caretaking within the relationship. Without the ability to openly communicate about the contradictions, the caregivers seem to rely on nonspecific ways of making their desires known. Stories

illustrate the ways that negativity and lack of control are implied but not directly addressed. The subtle hostility that the caregivers feel for the seropositive individual may further validate a sense of worthlessness and stigma associated with HIV/AIDS.

Chapter 5 examines caregivers' narratives, highlighting their attempts to provide optimal care and extend the life of the HIV-infected family member amid limited assistance of the health care system or resources and lack of social support. Again, a primary theme was the impact of illness development on the caregivers' role within the relationship. Narratives illustrate how the relationship with the HIV-infected family member changed due to illness and how other relationships become strained due to stigma, secrecy, disproportionate resources used for care, and inconsistency in the health care system. Caregivers described how they forgo their own needs and resist asking others for help, not expecting any sort of reciprocity.

Chapter 6 shares the stories of seropositive women who had been caregivers for their seropositive husbands. Although they were also infected and their seropositive status was because of their husbands, they tended not to expect reciprocity. These women attempt to preserve their families by extending the life of their husbands and maintaining their own health in order to care for the kids. They described putting aside their own feelings and goals, reassuring their husbands instead of sharing their anger with them, and, otherwise, generally doing as much as they could do for their husbands. Their stories illustrate the isolation of caregiving and lack of social support.

Chapter 7 provides D'Cruz interpretation of the narratives and implications for the context of family care as depicted in her interviews. She places particular emphasis on the dynamics of family care, especially the struggle to prolong the life of the loved one. The predominant theme is providing social support, especially emotional support, to caregivers. It is not until this final chapter that D'Cruz highlights the importance of interpreting the narratives within the ways Indian culture and tradition define women. In particular, she acknowledges the ways in which a woman's identity is defined in terms of relationships with others (wife, mother, daughter-in-law, etc.) and the roles in terms of labor of caring, and she calls for empowerment through such things as changing paternalistic institutions and ending women's economic dependence on men.

Together, the narratives illustrate how individual identities and roles within the family are transformed through illness. The role of the caretaker is to provide social support in order to contribute to physical and mental well-being and reinforces their feelings of intimacy, care, and love. Through this caretaking behavior and over the course of illness, however, the caretaker's role as nurturer becomes the primary role. The narratives demonstrate how caretaking behaviors and even displays of the caregiver's emotions are controlled and limited by the seropositive status.

Critique

A strength of the book is the way that the narratives challenge traditional constructions of health and integrate layers of family communication with interpersonal issues in health communication. D'Cruz illustrates how the social construction of health intersects with social expectations for family and close relationships. A related limitation, however, is the lack of breadth in her interpretations of the narratives. She provides thick, rich description of the meaning of caregiving, but the unique

intersections between health communication and family communication are not directly addressed. By interpreting the narratives within Sprey's (1990) description of family systems theory, for example, the author could have highlighted the ways that family embodies qualities of wholeness and interdependence, hierarchy, change and adaptability, and interchange with the environment. The environment and the relationship are shaped by the seropositive status, and illness becomes the primary means for interpreting and defining family roles.

The narratives offer a tangible means for the reader to hear the voice of the caregiver and of the subjective component of illness. In their chapter, Sharf and Vanderford (2003) suggest that illness narratives are implicitly appealing and comprehensible because they make use of familiar elements with which we have learned to shape our perception of the world. Illness narratives in this book are engaging because D'Cruz uses a process and style to bring life voice to perhaps otherwise unheard voices and their underlying values of self-risk and persistence in care. Through the familiar elements of roles in the family, she exposes the reader to important aspects of illness, including fear, concern, stigma, accommodation, discrimination, social support, and loss.

References

- Fisher, S. & Todd, A. D. (Eds.) (1983). *The social organization of doctor-patient communication*. Washington, DC: Center for Applied Linguistics.
- Hall, J. A., Epstein, A. M., DeCiantis, M. L., & McNeil, B. J. (1993). Physicians' liking for their patients: More evidence for the role of affect in medical care. *Health Psychology, 12*, 140-146.
- Sharf, B. F. & Vanderford, M. L. (2003). Illness narratives and the social construction of health. In T. L. Thompson, A. M. Dorsey, K. I. Miller, & R. Parrott (Eds.), *Handbook of health communication* (pp. 9-34). Mahwah, NJ: Lawrence Erlbaum.
- Sprey, J. (1990). *Fashioning family theory: New approaches*. Newbury Park, CA: Sage.
- Stewart, M. & Roter, D. (Eds.). (1989). *Communicating with medical patients*. Newbury Park, CA: Sage.
- Thompson, T. L., Dorsey, A. M., Miller, K. I., & Parrott, R. (Eds.). (2003). *Handbook of health communication*. Mahwah, NJ: Lawrence Erlbaum Associates.
- Weston, W. W. & Brown, J. B. (1989). The importance of patients' beliefs. In M. Stewart & D. Roter (Eds.), *Communicating with medical patients* (pp. 77-85). Newbury Park, CA: Sage.
- Whaley, B. B. (Ed.). (2000). *Explaining illness: Research, theory, and practice*. Mahwah, NJ: Lawrence Erlbaum Associates.