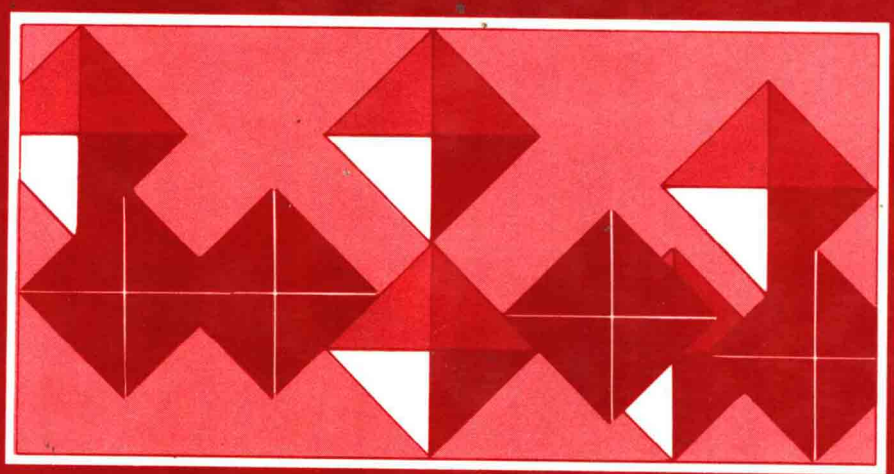
THE HOME CARE EXPERIENCE

Ethnography and Policy

Edited by
Jaber F. Gubrium
Andrea Sankar



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Introduction

JABER F. GUBRIUM
ANDREA SANKAR

The deinstitutionalization of medicine is underway. It is being accomplished by reimbursement systems that encourage the early discharge of patients, often with high levels of acuity, and by advancements in home-based technology and pharmacology that have enabled acutely ill patients to be cared for at home. A growth in the number of chronic care patients who must be cared for in the home parallels the introduction of acute care into the home. The aging of the population, especially the increase of those over 85, has been accompanied by growth in the number of those suffering from the combined effects of age and chronic disability. The majority of these people, even those suffering from severe mental and physical disabilities, are cared for at home. This combination of factors is converging on the household and family to produce the predominant setting for health care delivery.

The home care experience is only dimly understood. Policymakers, insurers, health care planners, and professional home care providers appear to conceptualize the home as a kind of black hole into which a range of medical services and conditions can be transferred. Little is known about *how* care is delivered in the household or *how* the family copes with the increased level of responsibility. Few in fact have even posed the question of whether the family should be expected to cope with the life-and-death responsibility often associated with this level of caregiving.

Indeed, the simple task of defining what is caring—how it is variously understood by those concerned—seems to be furthest from the minds of most researchers. Concepts have been defined, variables selected, hypotheses formulated, measures and scales constructed, samples selected, inquiries conducted, and data analyzed—all as if the basic meanings and concepts of the home care experience were known. Few, if any, have bothered to ask whether care, caring, and caregiving have different meanings to those directly or indirectly involved in home care. None seem to have wondered whether caring and caregiving are the same or contrasting orders of experience. Rarely, if ever, has anyone even raised the question of whether there might be different versions of the home's goings-on as a sickroom, which would imply that measurement would necessarily produce multiple, possibly contradictory, "figures."

Existing Research

Existing research on the family in home care has involved large, statistical studies (Soldo & Manton, 1985; Stone, Cafferata, & Sang, 1987) or multivariate analyses of what Gubrium and Lynott (1987) call the "care equation," namely hypothesized covariations between such caregiving attitudes as perceived burden, felt stress, and the institutionalization decision (Gwyther & George, 1986; Zarit, Orr, & Zarit, 1984; Zarit, Reever, & Bach-Peterson, 1980; Poulshock & Deimling, 1984; Morycz, 1985). There is little work on the actual dynamics and processes of home care or what we call the "home care experience." The few studies that have been undertaken have explored how the household's interpersonal relations figure in the behavior of children (Henry, 1985; Bermann, 1986; Kantor & Lehr, 1977), alcoholics (Steinglass, 1979), and mentally-impaired adults (Laing & Esterson, 1964; Anderson & Bagarozzi, 1983; Bagarozzi & Anderson, 1982; Reiss, Gonzalez, & Kramer, 1986; Leff & Vaughn, 1985). These studies were focused on elucidating possible pathological processes, not on understanding the complex response of a family to the task of caring for a member who is acutely or chronically ill. Further, these studies were primarily focused on the interaction of young children, adolescents, and their caregiving parents. In contrast, much of current home care involves

relationships between elderly parents, spouses, and older adult children in which the problem of redefining the family of origin or priority involves different developmental issues. Studies are needed to evaluate how families at various points of development react to the increase in the scope, intensity, and competing loyalties of caring.

Yet the prospects for work in this area seem equally problematic. In a recent editorial in *The Gerontologist,* Zarit (1989), a pioneer in studying the social psychology of home care for the elderly, questioned the usefulness of continued research on caregiving. He pointed out that numerous studies had affirmed that caregiving is a stressful undertaking and that the sources of this stress are multidimensional and the relationships involved are complex. Zarit noted the move beyond bivariate studies to sophisticated explanatory models, but he doubted the feasibility of large-scale testing for these models. From these observations, Zarit went on to discount the utility of self-report data, which he criticized as inaccurate, in the reporting of the magnitude of events (p. 147).

Frustrated by the complexity of the problem, Zarit advises researchers to "control" those complicating factors and move toward more precise measurement. In contrast, this volume is expressly devoted to the appreciation and documentation of that complexity. By its very nature, caregiving is complex, involving concepts of self; familial and gender roles; cultural and social values and expectations; the symbolic spatial dynamics of the home context; economic and political factors which promote or inhibit the ability of the caregiver to care; relationships with professional caregiving institutions; and perhaps most significant, the meaning of the experience for the caregiver, the person cared for, the family, and significant outsiders. Clearly, it is not possible to incorporate all these factors into an analysis. To fully comprehend the dynamics of the care experience, however, an appreciation of their salience and interactive quality must be present.

Caregiving may defy meaningful measurement, (that is, informative and conceptually accurate measurement). If meaningful measurement is possible, however, then it will only be after far more basic research on the phenomenon has been conducted. Zarit is correct in highlighting the complexity of the problem; but the solution is to delve into that complexity so as to *understand* it, not control for it.

The Emerging Ethnography

A small but growing number of researchers on both sides of the Atlantic has chosen to examine the home as a dynamic context of caregiving. They have oriented to several analytic understandings. First, because of the "native informality" of the household, relatively unstructured methods are being used to examine interpersonal relations and circumstances. Some have conducted participant observation in the home (Henry, 1965; Sankar, 1986, 1987, 1988), while others have utilized open-ended interviews with family members (see LaRossa & Wolf, 1985; Rubinstein, 1987). Still others have focused on the household/institution nexus for its diverse interpretations of domestic order and familial responsibility (Gubrium, 1987, 1988). Much of what goes on in the home as a caregiving setting does not allow access through standard testing and measurement procedures. The latter would tend to spoil what might be said to be the household's most natural characteristic, namely the family "at home" (Skolnick, 1983). Thus ethnographic methods and analytic techniques appear to be the most effective means of constructing an accurate and insightful understanding of the home care experience.

Second, because the home has not been extensively studied in general, and certainly little understood as a care setting in particular, those currently engaged in research have permitted themselves to *explore* its social organization. It is important to keep in mind that, when little is known, there must be provision for open investigation lest the unknown be shallowly conceived or prematurely standardized into a research entity. There is much speculation and popular opinion about the household and home care. What is lacking is "basic" research—that is, research into the basic concepts and understandings of caregiving.

Third, since there are few, if any, guidelines for conducting social research on home care, methodological standards have not been selected that are appropriate to home care's social characteristics. As a step in this direction, the existing ethnographic research has plied new ground in as reasonable a fashion as possible, developing procedural insights and rules as it moved along. This is characteristic of any new orientation to a field of study. The assumption is that we are only beginning to have the means to evaluate the quality of related research and the basis for comparison.

Fourth, because little basic research exists, home care policy should be developed and initiated with considerable reservation. If policy considerations move too far ahead of what is solidly known, the search for basic knowledge will be hampered by unrealistic definitions, views, and expectations. Policy initiatives run the risk of inappropriate targeting, inadequate implementation, and unrealistic goals.

Taken together, these understandings suggest the broad outlines of an emerging, ethnographic research agenda. It is important that studies of the home care experience be flexible enough to explore, be open to the natural characteristics of the home as a setting, and aim for the kinds of analyses befitting the native dynamics of the household and the institutions to which it is linked. Findings from this type of research can provide the basic information required for effective policy development and implementation.

Plan of the Book

As a point of departure for developing a pertinent analytic discourse and public debate on the nature of home care, researchers in the United States and the United Kingdom whose work is guided by the preceding understandings were asked to contribute to a collection of original papers on related issues and policy. We believe the resulting collection—*The Home Care Experience: Ethnography and Policy*—provides a useful context within which to address the area's important questions and critically assess its existing answers. Needless to say, the collection is relevant to the classroom too, especially in such disciplines as nursing, family practice, social work, and the medical social sciences, which are rapidly moving in the direction of training an informed generation of home care practitioners and professionals.

The chapters herein fall into three parts. The first part, "The Home as Sickroom," deals with the culture and social organization of the household as a care setting. Focal are its adaptations, ritual borders, cultural variations, crisis resolutions, interpersonal histories, and dynamics of affection. Steven Albert's chapter, "The Dependent Elderly, Home Health Care, and Strategies of Household Adaptation," introduces us to the home as sickroom by showing how members variously adapt to caregiving demands and parental impairment. Albert

argues that adaptation strategies often evolve to prevent the radical reorganization of the household, to maintain traditional allocations of space and time. Robert Rubinstein's chapter, "Culture and Disorder in the Home Care Experience: The Home as Sickroom," focuses on a clash of expectations: the tensions between household order and developmental strivings on the one hand and the disorders of sickness and chronic convalescence on the other. The chapter presents ways families differentially resolve the clash. The chapter by Juliet Corbin and Anselm Strauss, entitled "Making Arrangements: The Key to Home Care," features the surprisingly adept management strategies of the household to show how informal arrangements can make the household both a sickroom and home rivaling the ostensible efficiency of formal care settings. The fourth chapter, "The Defiance of Hope: Dementia Sufferers and Their Carers in a London Borough," by Joel Savishinsky, shows how variable the sickroom is that home caregivers offer, associated with different experiences in obtaining household help for themselves and a demented member of the family.

Part Two, "Patterns of Caregiving," reveals the diversity of caregiving relationships. Highlighted are the various "others" who enter into the care experience, ranging from family members and distant kin to neighbors, friends, and ostensible strangers. Judith Barker and Linda Mitteness's chapter, "Invisible Caregivers in the Spotlight: Non-Kin Caregivers of Frail Older Adults," zeros in on a category of caregiver commonly labeled "other" in many studies. The authors inform us that what is otherwise virtually dismissed in reports of research findings reveals a complex and significant configuration of assistance in home care. In contrast, the next chapter, "Support Systems for the Familyless Elderly: Care Without Commitment," by Lucy Rose Fisher, Leah Rogne, and Nancy Eustis, cautions us that while "others" (namely, non-kin caregivers) may offer assistance, they are not as formally compelled by the normative commitments of filial responsibility, which raises the issue of the long term in home caregiving. Clare Wenger's chapter, "Personal Care: Variation in Network Type, Style, and Capacity," reveals the diverse networks that set the background for home care, informing us that the type of network is as important as the number of social ties for the provision of personal care. Using a life-course perspective, Myrna Silverman and Elizabeth Huelsman's chapter, "The Dynamics of Long-Term Familial Caregiving," interprets case histories to show how experiences and behaviors prior to the current caregiving

situation differentially pattern the meaning of caregiving. Chapter 9, "Daughters Caring for Elderly Mothers," by Emily Abel, describes how the dynamics of affection mix with interpersonal history among very significant others, creeping into the daily routines of home care to convey caregiving's manifold feelings and oscillating intergenerational meanings.

Part Three, "Service Provision: Definitions and Decision-Making," takes us outside the household proper and its front-line domestic workers to examine broader contexts that serve to define home care. While the focus is the same—the home care experience—we find that the meaning of home care roles, actions, and events are bound up with diverse organizational, professional, and public policy interests and agendas. James Holstein's chapter, "Describing Home Care: Discourse and Image in Involuntary Commitment Proceedings," instructs us about the place of language and professional image in the interpretations of household events and domestic order. In a useful caution against too naturalistic an ethnography, Holstein argues that being in the home is no guarantee that one succeeds in "accurately" defining the organization of caregiving. The next chapter, "Transformations of Home: The Formal and Informal Process of Home Care Planning," by Ann Dill, extends the argument to show how perspective produces facts otherwise considered to be undeniable features of domestic life. Taken together, the Holstein and Dill chapters indicate how definitional and decision-making issues intertwine, regardless of the age of care receivers and caregivers. Finally, in a chapter entitled "Policing the Family? Health Visiting and the Public Surveillance of Private Behavior," Robert Dingwall and Kathleen Robinson raise important public policy questions concerning the borders of household care and its privacies on the one hand and, on the other, the increasing demand for surveillance by a welfare state bent on quality assurance in the care of its citizenry. While centered on the surveillance of home care for the young, the chapter is broadly suggestive of looming issues in home care for all ages.

Although research in home care is virtually exploding, we hope this collection will persuade practitioners, researchers, and policymakers to pause to consider guiding assumptions and taken-for-granted concepts before moving ahead. As the onus of care is increasingly placed on families, significant others, and the home, they deserve to be understood in their own terms, against the complex and varied backgrounds that both influence and articulate the caregiving effort.

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