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CARE-NEED AND CARE-RECEIVERS Views From the Margins

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Synopsis — Accounts of care from British academic feminist researchers have yet to include care-receiver experience at a theoretical and empirical level. This article examines some consequences for care-receivers and those with care-needs that arise from this omission. The question of why older people, and especially older women, with care-needs have been excluded from discourses of care is discussed. Drawing on empirical material from ethnographic research on care in later life, the article explores the ways in which care-receivers are silenced by their social position in the family and community. It is argued that care-receivers are not the homogeneous passive group that has been constructed in accounts of care and that the significance of generation for care relations has yet to be examined.

Both later life and care are issues of central concern to women in the industrialised world. In Britain there are currently 50% more women than men over the age of 65 in the population, and in all age groups over 65 "women are about twice as likely to report impaired mobility than men" (Arber & Ginn, 1991, p. 112). Moreover, women are more likely to face the prospect of becoming receivers of care from sources outside their own households including either coresidence with adult children or residential care in "a context which deprives them of their independence and self identity" (Arber & Ginn, 1991, p. 156), whereas the bulk of men's care is provided in the form of spouse care as a result of the present gender differential in life expectancy in Britain.

The feminist response to British community care social policies has produced conceptualisations of care based on an analysis of the gender division of labour where care is a product of women's unpaid labour and where care provision inhibits women's labour market activity (notably Janet Finch, 1984; Janet Finch & Dulcie Groves, 1980, 1983; Hilary Graham 1983, 1991; Clare Ungerson 1987, 1990). In

their influential article "Community care and the family: A case for equal opportunities," Janet Finch and Dulcie Groves (1980) argued that community care is fundamentally a gendered concept in that it rests on a double equation: "that in practice community care equals care by family, and in practice care by the family equals care by women" (p. 494). From what Finch herself described as a "starting point" for discussion has emerged a consensual two-category carer/cared-for account of care with a pervasive emphasis on women as carers (Finch & Groves, 1983; Lewis & Meredith, 1988; Nissel & Bonnerjea, 1982; Ungerson, 1987) that has only recently received critical examination: as over simplified and lacking contemporaneity (Baldwin & Twigg, 1991); as neglecting the issues of race and class (Graham, 1993); and, importantly for this discussion, as lacking disabled and older women's perspectives (Morris, 1993). This omission from discourses on care has implications for understandings of care in general and particularly for care in later life. Assumptions are made about those in need of care leading to an inadequate consideration of the significance of the unequal social conditions of care that, according to Joan Tronto, are fundamental to conceptualisations of care since: "by its nature care is concerned with

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conditions of vulnerability and inequality” (Tronto, 1993, p. 134).

In this article I draw on narrative material from my ethnographic study of care in later life to show that the care-receiver is not the over-determined passive consumer of care that sometimes has been constructed in accounts of care. I also argue that knowledge about care is culturally determined so that who has been sanctioned to speak on this topic, and, under what conditions, should alert us to the possibility that family-based models of care contribute directly to the silencing of the care-receiver voice and, accordingly, to issues of power and control in care relations. I begin by examining some general understandings which have emerged from feminist discussions of care, attempting to analyse the ways in which these conceptualisations have shaped perceptions about those in need of care. In the second part of this article I consider why the experiences of older women in need of care have been excluded from feminist conceptualisations of care. Finally I present case material from three women participants in order to draw attention to the social nature of care in the life of a situated care-receiver dependent on historical experience as a family and a cohort member of generation, class, gender, and ethnicity.

FOUR ELEMENTS OF CARE

A number of assumptions about the nature of care underlie feminist conceptualisations of care. In the following discussion I identify four aspects of the dominant model of care which, while embedded in discourses of care, remain underexamined. I argue that these understandings are oppressive for care-receivers and those with care-needs who, it is important to note, are not equivalent. The idea that care arises in direct response to need overlooks the negotiated reality of intergenerational care relations, and, similarly, the idea that need for care is a biologically intrinsic part of the ageing process (which underpins discussions about the ageing of populations) disregards the experience of individual “management” (di Gregario, 1986) of later life.

Care is good

Initial understandings of the nature of care highlighted a distinction between “caring for”

someone in affective terms and “caring about” someone in physical terms; the labour and the love involved in care giving (Graham, 1983). According to Jennifer Mason, writing more recently about this distinction, “caring about” is the “sense of being fond of or loving” someone, and “caring for” is the “sense of performing the labour of looking after them” (Mason, 1994, p. 3). Mason notes, however, that “the association with goodness and morality is problematic,” and she is alerted to the possibility that although care involves moral activity, care may not always be “done in a moral mode” and that any assumption that care practices are moral “pushes us toward the idea that they necessarily produce morally good care and good forms of responsibility for others” (Mason, 1994, p. 13).

Understandings of care as morally good arise in part because care has been discussed as the activity of the carer for the cared for as though the concept has a latent, preformed, and stable meaning which passes in a one-way flow from care giver to care-receiver; in the sense that Marcel Mauss indicated “that the gift object is bestowed with the attributes of the giver” (Broch-Due, 1993, p. 55). This interpretation overlooks how care is achieved as an ongoing and repetitive process of accumulated accomplishments in continual construction by all parties to care. The extent to which people transform practices into contexts of “care” does not entirely depend on the giver. “Responding” (Tronto, 1993) to the ministrations of the giver suggests that the receiver acknowledges the care activity. Where individuals appear not to respond, (for example, repeatedly asking the same question, or being incontinent immediately after leaving the toilet), there appears to be greater likelihood of abuse (Stevenson, 1993, p. 147) and a consequent inversion of taken-for-granted comprehensions of “care.”

Once care-receiver experience is included in the frame, therefore the dichotomy, labour and love transforms to more complex forms where the issue of control between care-receiver and care giver materialises as a critical constituent of care. Moreover, the distinction “caring about” and “caring for” emerges as equally significant for the receiver of care for whom the optimal care context is most likely to be the achievement of both elements — labour and love. Yet the care-receiver may not necessarily wish for support from the same source, even

though, as Gillian Dalley argues, the separation of these two principles runs counter to normative ideas about the nature of care:

Public discourse insists that there can be no separation between caring for and caring about. Those who care about are expected always to care for and vice versa. (1988, p. 11)

Recent British (Cotterill, 1992; West, Illsley, & Kelman, 1984) and Scandinavian (Waerness, 1990) research indicates that older people increasingly prefer public nonstigmatising care provision rather than family care. In expressing the wish for nonfamilial contexts of care, older people, either as care-receivers or future care-receivers, demonstrate cognitive awareness that the achievement of the goal — “caring for” — may jeopardise achievement of the primary goal — “caring about” — by placing undue strain on family relations (Phillipson, 1992).

Care-receivers are a passive and homogeneous group

There are a range of social, psychological, emotional, physical, economic, and political differences between children, younger disabled adults, disabled people who are also ageing (Zarb, 1993), and older people who experience the onset of physical and/or mental disabilities in later life. Yet care-receiver groups have not been analytically individuated in accounts of care. Older people in need of care differ from other groups of care-receivers in that:

1. Their disabled identity is acquired over time; therefore, **biography is of central importance to the experience of care in later life** (Bertaux, 1981; Cornwell & Gearing, 1989; di Gregario, 1986; Mills, 1959).
2. Unlike patients in other age groups who can be expected to “recover” a former position of health (Fox, 1993), care for older people is understood to be ongoing and necessary on a repetitive basis since they are unlikely to regain capacities and return to a nonsick adult role. Furthermore, unlike children, older people in need of care will not follow a previously charted path in developing capacities to perform everyday living activities, although people in this position often develop new skills based on a lifetime’s

resources in order to provide self-care. For younger adults the sick role provides an escape from normal duties; for the older care-receiver the onset of care provision heralds a change in status which represents a permanent exclusion from normal duties, which has particular significance for older women in the domestic sphere.

3. Confusion over the statutory responsibility for long-term health care of older people abounds so that, in Britain, there have been recent calls from the Labour party for a Royal Commission (Guardian, August 13, 1994). NHS cuts have led to a drastic reduction in geriatric beds and a progressive withdrawal of medical services from “natural” ageing processes which are deemed to be more appropriately experienced in private residential or family contexts.

The family cares

Although “the family is still the most important provider of care in old age” (Waerness, 1990, p. 117), this is not to say that all requirements for care are being provided by women within “the family.” Yet the now taken-for-granted double equation community = family = women is capable of such an interpretation. Thus, feminist descriptive accounts that women (in families) do care appears to correspond with prescriptive community care rhetoric that families (women) should care. Community care is based on a family model of care as the standard against which all forms of care are judged. If family care, at one polar end, symbolises the best form of care, then, by implication, residential care is symbolic of noncare or absence of care by family and society. Finch and Groves’ critique exposed the contradiction of community care and equality policies as it impacted on carers. The work of exposing the contradiction of community care based on family care for those in need of care still remains to be done.

Consideration of public/private divisions (Ungerson, 1990) is understood to be central, although problematic, to analysis of the division of labour in care relations, where “many of the tasks to be performed straddle the domestic and public domains and involve ideologies associated with both” (Stacey, 1988, p. 10). A critical examination of the social organisation of space, however, has been missing; the

concepts of “community,” “home,” “household,” “family,” and “co-residence” remain underexplored. Without empirical studies of care-receiver experience across different household and institutional arrangements, many questions associated with social space have yet to be critically examined. For example, *how the presence of care might constitute a sense of home and family? How and why household and kin relationships transform into particular forms of care (Finch, 1989)? What is the importance of “home” for people in later life in need of care (Sixsmith, 1986)? What constraints and opportunities are offered to those involved in care relations across a variety of social domains? What is the meaning of community for older people of gender, generation, class, ethnicity, and disability? And, most crucially, how are older people to be reincorporated in family structures where, as Graham Crow and Graham Allen tellingly suggest, a questionable quality of life awaits them?*

Dependent elderly people fit only awkwardly into the routines of ‘normal’ family life. In a quite literal sense there is little room for dependent elderly people in the modern domestic ideal, despite their undoubtedly large presence in the reality of their carers lives. Like lodgers in the past, the absence of elderly dependants from the domestic ideal has less to do with their numbers than with their perceived undesirability, not least the threat they pose to domestic privacy. (Crow & Allen, 1989, p. 29)

Clare Ungerson (1987) has shown how parent/child roles may have to be reversed in order for forms of intimate care to be practised. While it is clearer that adult females who take on parent care have a mothering model synonymous with nurturing available to them, it is less clear whether elderly parents, particularly elderly mothers, are able to respond in a child mode and, if they do, at what cost this is achieved.

Daughters care

The kind of case which seems to underlie and is implied by Finch’s analysis is care by daughters for mothers (Harris, 1985, p. 117). More-over, evidence from Hazel Qureshi and Alan Walker’s (1989) research shows that daughters, followed by daughters-in-law, head

a hierarchy of normatively preferred carers. I suggest, therefore, that we can usefully conceive of the feminist orthodox care discussion as being about, at a symbolic level, the interests of two groups represented by mothers and daughters, older and younger women. The former will have had limited opportunities in the labour market, and the latter, it is claimed, will have, or stand to have, their prospects of access to wage labour constrained by the “burden” of care for a generation of mothers in need (Finch & Groves, 1980).

Older mothers and adult daughters in relationships involving care are female kin of generation in relationship. However, there has not been enough consideration of the influence of *generation in relation to older parent/adult-child care relations in general and, in particular to mother/adult-daughter care relations (Mens-Verhulst, Schreurs, & Woertman, 1993). Analysis of mother-daughter relationships have concentrated on mother-child relationships, where ideas of individuation, separation, and moral development have been central (Chodorow, 1978; Gilligan, 1982). These ideas have yet to be considered in relation to how present and future generations of female kin care-receivers and care givers will experience care based on attitudes to, and experience of, mothering and domestic life. The present generation of older women in need of care have been enculturated in the domestic, conjugal, nuclear family, where they have experienced a rigid gender division of labour. The present carer generation — those women born in the 1940s and 1950s — however, have had different opportunities, although still constrained, for a life outside the home and the development of gender subjectivities. Writing about the transformation of gender subjectivities and identities across generations from a psychological perspective, Harriet Bjerrum Nielsen and Monica Rudberg argue that this generation (which they refer to as “our” generation) have had an ambiguous socialisation process:*

Unconsciously mother transferred her gendered subjectivity to us, while she told us about a more modernised version of gender identity . . . thus, one can say that we, the daughters, “inherit” both our mothers “updated” gender identity and her “old-fashioned” gendered subjectivity. (1993, p. 51)

Such analysis has important implications for future intergenerational care relations.

Care as burden

A dominant theme in care literature is carer stress. Here the images are of carers taking up and carrying the "burden" of care on behalf of society and of care-receivers as no more than aggregate bundles of needs. Clearly, many carers experience high levels of stress (Challis, Chesterman, Darton, & Traske, 1993) and experience care giving as a burden, but this finding does not mean that care-receivers do not also experience stress in understanding themselves as the cause of strain for a "significant other" (May, 1992). Anthony Warnes argues for careful thought in response to the burden of care approach since:

The focus on care giver burden by definition gives a primary position to the provider of care. The burden is shifting from a descriptive term for the interactive relationship of a stronger with a weaker person, to a designation of who does what for, not with the weaker party. Projects of "gerontological imagination" would strive more to understand the experience of becoming sick and of receiving care. (1993, p. 326)

The empirical data which follows later demonstrates how those in need of and receiving care experience their needs as burdensome. The narrative material also suggests that analytic emphasis on the forms of social relationships that contribute to the production of individuals as social burden through loss of autonomy (Doyal, 1993) might be more productive than ahistorical discussions of carer stress.

DRAWING CARE BOUNDARIES

It has been academic feminists who have had most to say on care, and this generation of women have been, until now, most likely to find themselves in the carer rather than the "in need" position. Jennifer Morris (1993) describes how disabled and older women have been constructed in these accounts as "them" in relation to the "us" of feminist writers and researchers. The central omission for Morris is the failure of the feminist researchers concerned "to identify with the subjective experience of 'such people'"

(Morris, 1993, p. 212). This important point raises the question why feminist commentators have been seemingly indifferent to the situation of those in need of care. Rejecting the "burden of care" and aligning with the world of paid employment can be understood, in psychological terminology, as an expression of individuation and separation. Building on Helen Evers' (1981) analysis of elderly female patient-nurse relationships where the patient is perceived as "an image of the nurse's future self," Shulamit Reinharz argues:

that the very development of feminist consciousness among some women stems from a rejection of the world of their mothers, a 'limited world' which may consist of voluntarism, housework, living for one's husband and children, and sacrificing one's education and career. (Reinharz, 1986, p. 507)

Similarly, I suggest that the rejection of those with care-needs in social discourse of care reflects Peter Laslett's definition of ageism as "a hatred of self — of what you will become" (Laslett, 1989, p. 97). The ambivalent response to the position of the care-receiver or the person in need of care thus distances the authors from the "objects" of care and reflects an inequality of power between women who have access to media of communication and those who do not:

On the most general level, to require care is to have a need; when we conceive of ourselves as autonomous, independent adults, it is very difficult to recognise that we are also needy. Part of the reason that we prefer to ignore routine forms of care as care is to preserve the image of ourselves as not-needy. Because neediness is conceived as a threat to autonomy, those who have more needs than us appear to be less autonomous, and hence less powerful and less capable. The result is that one way in which we socially construct those who need care is to think of them as pitiful because they require help. (Tronto, 1993, p. 120).

As writers on the social construction of disability (Lonsdale, 1990; Oliver, 1990) have shown, needs are socially constructed. William Leiss argues that human needs "are shaped in

historically specific forms which are the outcome of differential class interests and power relationships" (Leiss, 1978, p. 59). The orthodox dualistic model of care thus expresses cultural definitions of needs. The creation of the "them" and "us" boundary expresses a reluctance to cross age and health boundaries. Mary Douglas (1994) has identified how humans construct boundaries in response to anxiety and confusion, and how boundary maintenance and the crossing of boundaries are a continual source of anxiety. Older people in need of some forms of care are in a transitional phase across independence/dependence, life/death boundaries. A marginal position provokes anxiety in others who would define them clearly into either one category or the other. Thus maintaining control through "sustaining an ideological split between the carer and the cared-for" (Fox, 1993, p. 71). care-receivers and people in need of care are left on the margins of a society in which personal autonomy and independence is valued and interdependence is not recognised.

RESEARCHING CARE-NEED AND CARE-RECEIVING IN LATER LIFE

The omission of care-receiver experience in accounts of care is reflected by a general lack of sociological interest in old age. The sociological neglect of older people has only recently been recognised (Fennell, Phillipson, & Evers, 1988; Kohli, 1988), identified as resulting from sociology's traditional "malestream" concerns with production in the formal economy. Graham Fennell et al. suggest, moreover, there is a lack of sociological research which brings researchers into face to face contact with elderly people because of a general reluctance to "knock on that door and confront the stranger within" (1988, p. 58). Any tendency toward avoidance of exposure to the sensitivities surrounding the position of older people in need of care is mutually reinforced by the social "invisibility" of older people in general (Hazan, 1994) and by the restricted mobility of individuals with care-needs. Fennell et al. go on to note that even though the numbers of elderly people in institutions have seldom exceeded 5% in recorded history, most research on old age has predominantly focused on elderly people in special settings "predominantly or exclusively intended for the use of elderly people" (1988, p. 138). Since the expressed aim of

community care is a reduction in residential living, it is paradoxical that the most developed understandings of need in later life are associated with institutional settings. Knowledge of care in the domestic setting is limited because these relations lie at the heart of the "contemporary domestic ideal" (Crow & Allen, 1989) and are strongly associated with privacy and intimacy. It is interesting to note that most empirical studies of care (Qureshi & Walker, 1989, being an exception) have started from the perspective of the carer. In most cases they have made their point of entry into research settings via those who have identified themselves as carers through carer groups (e.g., Lewis & Meredith 1988; Ungerson, 1987). As members of such groups carers have a strong sense of the nature of care and their own involvement in care practices. They may, therefore, have an equally strong sense of control over the issue of research participation and access since, as Tronto suggests:

Care-givers come to see themselves as more capable of assessing the needs of care-receivers than are the care-receivers themselves . . . Such a proprietary sense of being in charge is even more likely to occur among those who have assumed responsibility for some problem . . . thus care-receivers are often infantilized. (1993, p. 170)

Moreover, it is not only care-givers who come to see themselves as more capable. Care-receivers frequently respond to this "proprietary" sense of being in charge by accepting an "infantilized" identity. Thus, there are physical, emotional, and cultural barriers between people in need of care and the researcher. It is small wonder that care-receiver perspectives have been examined in "hypothetical" modes (Cotterill, 1992; Finch & Mason, 1993) or by "structured" interviews (Qureshi & Walker, 1989).

So in developing a method to explore the dynamics of care-needs and care-receiving that starts from the person with care-needs, it is necessary to enter a research field where potential participants will have some autonomy with regard to research participation. For my own research, after many, mainly unsuccessful, attempts to contact individuals through health professionals I eventually volunteered as a helper in a local Age Concern¹ day-centre in order to carry out observational ethnographic

research on the nature of care in a semipublic setting. As a result of researching within this setting over a period of 2 years, I have been able to build long-term relationships with club members, most of whom have participated in biographically based interviews. Current ethnographies of old age clubs are in the realist ethnographic tradition with analytic emphasis on an explanation of the club as a discrete social world (Hazan, 1980; Jerrome, 1989), whereas empirical research on care has prioritised the interview as a research tool with which to examine the nature of care with little recognition of the influence of the past as it bears on present care relations. However, just as club life is part of wider community processes, there is more to care than talk. Older people, and especially older working class women in need of care, are at a number of social disadvantages. To develop a more rounded account of their position involves gathering data from different sources using different methods to emphasise different cultural forms (Skeggs, 1994). Tracking individuals through their daily and weekly round enables a deeper understanding of the nature of care-receiving in different settings within the community to emerge.

Profile of participants

Women over 75 are most likely to be widowed, living alone, have a low income, and no access to an occupational pension (Arber & Ginn, 1991; Groves, 1992; Peggs, 1994). Generally they have a high level of disability and concomitantly need a high level of support. Similarly, the majority of my participants are working-class widows who live alone. All are White women; most are mothers and grandmothers, and some are great-grandmothers. In assigning a working-class position to my participants I am taking into account a variety of definitions of class based on both an "objective" analysis of their position to the labour and domestic economies (Gittins, 1985) and a "subjective" approach to their own understanding of their class position where shared values and life-style inform a class awareness (Bourke, 1994). The women's different experiences in these economies will constrain their present access to economic and domestic/familial and cultural resources. Writing on women and poverty, Caroline Glendinning and Jane Millar assert that:

Access to all resources in our society has been and is gendered, with the consequences that women found and find themselves enmeshed in a web of different dependencies. (Glendinning & Millar, 1992, p. 30)

The women in my study were mostly born in the first two decades of this century. Their dependency on male relatives throughout their lives has been arguably greater than will be the case for future generations of women, who, when faced with the question of social support, will have experienced both greater activity in the labour market and higher levels of state provision across their life course.

The following data are drawn from audio-recorded interviews with three women participants. I have selected this material in order to illustrate three distinct locations of care and to show how social changes at an individual, familial, and institutional level contribute to care as it is experienced in the lives of older people. A lack of care-receiver voice (Ardenner, 1993; Berger Gluck & Patai, 1991) is pivotal in this discussion, and, for this reason I have attempted to (re)present this material in a manner which allows the three women's voices to emerge as distinct from one another. For many of the participants in my research the interview provided a rare arena for self-reflection. It consequently raised painful feelings, as they articulated their present and past positions against normative ideas about caring families, good daughters, happy and hard lives, independence and autonomy, all within a framework of ideals of womanhood and the domestic. However, in listening to these narratives, we hear three older women struggling with often conflictual ideas about the ideal, the ordinary, continuity, change, fairness, and self-worth in relationship.

Lilly. Lilly is an 84-year-old woman who has been widowed for 12 years. She and her husband, a fisherman, channelled their financial and emotional resources into buying a house at the end of the second world war. As a consequence, her home has been of major significance to her as a symbol of hard work and achievement. She had two daughters, but the eldest daughter died in her 30s, leaving Lilly grief-stricken. She has lived with her surviving younger daughter, son-in-law, and two granddaughters for 6 years since she suffered a stroke and collapsed in her home: