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Christina Sinding
McMaster University

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Informal care—two-tiered care? The work of family members and friends in hospitals and cancer centres

CHRISTINA SINDING

McMaster University
Health Studies Programme & School of Social Work

In a qualitative study conducted in Ontario, Canada, family members and friends of ill people defined a normal territory in which care from health professionals could not be counted on to be timely, effective or empathic. Under these conditions relatives and friends took on considerable responsibility, both for providing care and for securing care from health professionals. Yet considerable variation was apparent in this study in the sense respondents had of their own capacities to provide and secure care. Findings from this study suggest that service tiers exist in the institutional care system, linked to the time, knowledge and resources of informal carers.

Key words: family care, social welfare reform, informal care, two-tiered care, end-of-life care

Introduction

Five analytically distinct dimensions of informal care—"the informality of informal care"—are elaborated by Graham (1991 p 508). Informal care is 1) provided for others 2) non-institutional 3) unpaid 4) provided through bonds of kinship and friendship 5) related to the care of individuals with a long-term need for help and support, individuals who might otherwise require institutional care.

The care that relatives and friends provide to people with advanced breast cancer maps onto the dimensions Graham identifies, with a few important caveats. First, Graham's framework

conflates the situation of a long-term need for help and support with the 'otherwise' requirement for institutional care. On average, people diagnosed with metastatic breast cancer live between two and three and a half years (Love, 1995), and many do not require care "beyond the normal reciprocities" (Twigg & Atkin, 1994, p. 8) for this entire time. Yet compared to other causes of death, metastatic cancer is associated with intense symptoms and restrictions (Seale, 1990). If they were not cared for at home, many people would be in hospital. In Canada, as in other industrialised countries, most people do die in hospital, and yet most dying takes place at home (Rhodes & Shaw, 1999). It is not necessarily the case, then, that an illness need be long term for the person with that illness to hover at the edges of institutional care.

Secondly, and more to the point of this paper, Graham's (1991, p. 508) analysis reflects the broad consensus of policy and research literature that:

Informal care is non-institutional care . . . However informal the atmosphere and however caring the relationships, care within hospitals or within residential homes is not defined as informal care. Instead, the term is restricted to care within the 'informal sector', differentiated from the state, market and voluntary sector by its base within the social relations of family and community.

In this framing of informal care, Graham collapses the location of care and its providers¹: care in institutions is equated with care from professionals. This conceptualisation obscures the ways care in institutions is, perhaps more and more, based within "the social relations of family and community"—the ways care in hospitals, for instance, is ensured, and often provided, by relatives and friends of ill people.

Over the last fifteen years Canadian governments, like other western welfare states, have been pressed to adopt programs of debt reduction (for discussion of the decline in the relative autonomy of the state accompanying globalization, see Coburn, 1999). As the single largest item in the provincial health care budget, hospitals have been a primary focus for both health reform and privatization: one in six hospitals across the province has shut down and almost 7500 beds have been closed (Armstrong & Armstrong, 1999; Bezanson & Noce, 1999). As well, and especially pertinent to this paper, 2,500 fewer nurses were employed in

1998 than in 1991 (Armstrong & Armstrong, 1999). A study released by the Caledon Institute of Social Policy (Bezanson & Noce, 1999) notes that continuity of care has been disrupted by hospital mergers and closures, with information about individual patients inadequately transferred. More generally, this study reports, both accessibility and universality of hospital care have decreased.

Tracking shifts in government policy, researchers have attended to the implications for the informal care sector of contractionist social welfare policies (see, for instance Graham, 1991; McKeever, 1996). They have also spoken to the considerable strain that individual relatives and friends experience while providing home-based care in a service context designed not to offer them genuine options or meaningful support, but rather to maintain them in their roles (Hooyman & Gonyea, 1995). Yet few researchers have examined informal care within institutions, considered how it too might be affected by welfare retrenchment, or examined its implications for equity in care.

In this study, in the context of welfare retrenchment, family members and friends of ill people perceived that care from health professionals could not be counted on to be timely, effective or empathic. Under these conditions relatives and friends took on considerable responsibility, both for providing care and for securing care from health professionals. Yet considerable variation was apparent in this study in the sense respondents had of their own capacities to provide and secure care. Findings from this study suggest that service tiers exist in the institutional care system, linked to the time, knowledge and resources of informal carers.

Research purpose, sample and methods

The accounts presented here are drawn from a qualitative study with people who provided end-of-life care to a relative or friend who died of breast cancer. Carers were sought who had been involved in, or witnessed, interactions with formal service providers, who lived in south central Ontario, and who spoke English. In an effort to draw upon memories of specific interactions, the study identified people who cared for someone who had died within the past three years. Respondents were recruited with the assistance of oncology nurses, staff at hospices and Community Care Access Centres (CCACs, publicly funded

agencies that assess service eligibility and oversees its provision), and through informal social networks. Intermediaries were asked to use their judgement in order not to involve someone in the study who would be especially distressed by the interview.

The study aimed to achieve a sample with variability along the standard social categories of gender, age, socio-economic status, ethnicity and religious affiliation, as well as in the size of community in which the respondent lived. In the literature on informal care, kinship position is central both to the process of becoming a carer and to the care experience (Hooymann & Gonyea, 1995). The study also attempted, then, to ensure that a range of relationships between the carer and cared-for person would be reflected.

Eight women and five men participated in the study, among them seven spouses (five husbands, one lesbian partner, and one wife), two sisters, three friends, and one daughter. The age of the respondents ranged from 41 to 73, and of the person who died, from 46 to 77; more than half of the respondents were between 50 and 58. The income category \$40K–\$49K was selected by more respondents than any other category, while three respondents reported a total household income between \$20K and \$29K and two reported income in excess of \$100K. Most of the carers had post-secondary education; for two, secondary school was the highest education level completed. Three respondents lived in large urban centres, four in mid-sized communities (population between 100,000 and 499,000) and three each in small (30,000–99,000) and rural (population less than 30,000) communities. All were born in Canada and responded to a question about ethnicity with either 'white' or British heritage. The lack of variation by ethnicity represents a limitation on this study.

Two interviews were conducted with each of 12 study participants, and one carer responded by letter to a series of questions drawn from the interview guide. Initial interviews, which lasted between one and two-and-a-half hours, encouraged the respondent to 'tell the story' of caring for the person who had died. Prompt questions focused on times when respondents found themselves doing more for the other person; on shifts in the relationship between the carer and the ill person; and on moments of strain and reward or ease in caring. Second interviews (between a half-hour and one hour in duration) clarified respon-

dents' earlier comments and further explored their responses to and assessments of interactions with health professionals. In second interviews, in keeping with qualitative research principles for establishing or improving the credibility of research reports (Lincoln & Guba, 1985; Seale, 1999), respondents were also asked to comment on emerging conceptual models. The interviews were conducted in respondents' homes or in rooms in nearby cancer treatment centres or service agencies.

Accounts were analysed with reference to grounded theory methods (Charmaz, 1990; Strauss & Corbin, 1990). In a departure from grounded theory, however, this study aimed less to create a conceptually dense rendering at any particular 'level' in a transactional system (see Strauss & Corbin, 1990, p. 158–164), than to define pathways between social structures and individual actions, experiences and accounts. Data management was facilitated by the qualitative software package NVivo.

This study initially took as its central question, How do carers' perceptions of formal health services and their subjective experience of caring for someone who is dying, influence one another? The research was intended to illuminate ways that informal end-of-life care is shaped by and through the meanings carers draw from interactions with professionals. Yet as data analysis proceeded, it became clear that informal carers, while clearly affected by what health professionals said and did, also saw themselves affecting health professionals—affecting health professionals actions and perceptions, and ultimately affecting the care the ill person received. Initially focused on the question of how carers' experiences are shaped by interactions with health professionals, this paper takes up what emerged as the more salient theme: how, in a context of system constraint, relatives and friends perceive themselves to be shaping the level and nature of care an ill person receives, and the consequences of this for equity in care.

Results

In this study, respondents' commentary on conditions in the health system often took the form of assertions about the difficult working conditions faced by health professionals in hospitals

and cancer centres. In a typical comment, one respondent said, "they've got so much to do and there's so few of them" (V).

In this section I show how the common assertion that they are "busy" or "run off their feet"² tended to release health professionals from certain care duties. More centrally, I examine the myriad ways that the people who took part in this study assumed responsibility for the care tasks from which health professionals were released.

Providing care

In many instances, participants in this study took it upon themselves to provide hands-on care to relatives and friends in hospitals and cancer centres. In other instances, they described working in tandem with nurses to provide care for the ill person.

In her narrative about caring for her partner, L described arriving at the hospital at seven o'clock each morning to provide practical care: helping G on the commode, getting basins so she could brush her teeth and wash her face. L did not suggest that G would not have had these basic needs met, had she not been there; just that she would have had to wait. In this regard L describes watching as the other women in G's hospital room rang for a nurse, and then waited:

It just seemed like a long time . . . One woman sat on the edge of the bed and she'd just wait. She'd just sit waiting for someone to come and I really believe it's because they don't have the staff. . . . If they had to go to the bathroom—and these are cancer patients, these are people that maybe they can't hold it you know that sort of/ I mean G wouldn't have been able to wait.

L saw her decision to ensure that G did not wait partly in the category of "catering" to G's "whims," "mothering her to pieces." Yet L also judged nurses unable to respond to patients' needs in a timely way. Her caring work, then, was partly in aid of averting the real possibility of G's discomfort and distress.

Recalling the care he provided for his wife, another study participant, F, said:

There were a couple of times that I needed help, like if she really had a messy . . . whatever and the bed needed changing. But throughout

the night I, I was there, I got her up, I put her back down. And it helped them—understaffed and overworked and everything else.

Here F does not call upon the nurses to help his wife, nor to fulfil their professional roles, but rather to help him—to assist him when he is unable to complete care tasks alone. Nurses, “understaffed and overworked,” are released from responsibility for routine care; even in this hospital setting, F frames primary responsibility for his wife’s care as his own.

In a few instances participants in this study described working directly with health professionals to provide specific kinds of routine care. R, for example, would assist the nurses to turn her friend K in bed. Sometimes she moved to help simply because she was there, and not busy; in this way, her assistance was, as she says, “automatic.” Yet it was also clear to R that prompt nursing care for her friend was sometimes contingent on her own willingness and capacity to help:

I’d say, ‘it’s time for her to be turned, she needs to be turned.’ And they said, ‘well, we’re just in the middle of something, unless you want to help me, it’s going to be like 20 minutes,’ or whatever and I said, ‘OK, I’ll help you.’

Here, divisions of labour between formal and informal carers are explicitly negotiated, with R agreeing to stand in for a health professional. That relatives and friends of ill people perceived themselves to be working alongside—or even in place of—nurses, was evident in other passages of R’s talk:

I’d check out with [the nursing staff] because it got so that we didn’t stay through the night. And I’d just like you know, you’d stay till 11:30 or 12 and then you’d go. And I’d let them know I was going, that K was on her own.

The comings and goings of friends and relatives from an ill person’s bedside are constructed here, and in other respondents’ talk, as a shift change. Seale (1995) has pointed to the profound cultural and personal significance for relatives and friends of terminally ill people—indeed, the moral norm—of ‘accompaniment.’ Where the effects of health system constraint are visible to relatives and friends, accompaniment of someone who is dying increasingly seems to necessitate the adoption of nursing roles.

Writing in a Canadian context and particularly considering the area of long-term care, McKeever (1996, p. 200) notes that deficit reducing social policies over the past two decades have led to reallocations of work, with the work of family caregivers increasingly "appropriated from the domestic sphere and substituted for formerly paid nursing work." The accounts in this section show McKeever's analysis unfolding at a micro level, in institutional settings. In many instances, an awareness of conditions in the health system prompted relatives and friends to take up tasks that would otherwise be performed by hospital or cancer centre staff.

As I have described here, informal carers sometimes accommodate health system constraint by providing care themselves. Yet also very significant in this study were accounts of securing care from health professionals. It is to these accounts that I now turn.

Securing care

In their book, *Carers Perceived: Policy and Practice in Informal Care*, Twigg and Atkin (1994) discuss the range of ways that health professionals incorporate informal carers into their practice. This section takes up the question of how, in conditions of health system constraint, informal carers incorporate *themselves* into *health professionals'* practice in an effort to secure care. Respondents accounts of themselves, their actions and activities in this regard, can be organised into three general categories: progress chasing, becoming known, and trading services.

Progress chasing

'Progress chasing' was a term used by a study participant, M, to describe his relationship to the health professionals involved in his wife's care. As he put it, "progress chasing is, you know, we got this to do next, OK, well, is it happening?" For the purposes of this analysis, progress chasing includes the actions of monitoring and reporting on the ill person's condition, tracking care schedules, and, when necessary, intervening in the care provided by health professionals.

Participants in this study commonly described watching the ill person for signs of discomfort. Sometimes this monitoring was

described in quite offhand ways, presented simply as a function of being in the room. Others described a very active attention to physical changes. In some cases, the attention an informal carer devoted to understanding symptoms and care routines was explicitly connected to awareness of nurses' working conditions:

I have notes of every day . . . everything. How many pills she's taken, when did she have a bowel movement, colour of her skin, temperature, everything. Because they [nurses] can't. They got 110 patients. (M)

The monitoring informal carers provided meant that in many, many instances, they became involved in locating a health professional and drawing her or his attention to the ill person's discomfort. R, for instance, recalled noticing changes in her friend's breathing, and going to "track [the nurses] down." Respondents also commonly ensured that routine care was provided in a timely way, taking note of when the ill person's medications were to be given, for instance, or when she or he was to be turned in bed, and seeking a nurse if one did not appear. From respondents' perspectives, the monitoring and tracking they undertook secured health professional attention to the ill person's care needs, both routine and not. It also served to establish their credibility, and thus enable more substantive interventions in the care health professionals provided. D, at her friend's bedside for hours, found she could suggest that a breakthrough dose of pain medication was warranted "and 9 times out of 10 they [the nurses] said, 'yeah, I think that's what we should do.'"

The account M offered of his progress chasing on a hospital ward is set against his description of specialised palliative care. Distinctions between the two settings were perhaps most apparent as he spoke about a phone call he received from a palliative care nurse, telling him that his wife had little time left to live. The call was important to him for a variety of reasons, one of which was the statement it made about the nursing care his wife was receiving:

What it also said was, they were in touch with her at all times. Palliative is at all times. Acute is when you ring the buzzer. Well, I can't ring the buzzer, right. What if the caregiver isn't there? Well

that person may not have the right care at that moment in time, you know. Very different.

M did not, as he said, go “tearing my hair out going to the hospital” when he received this call. Partly this was because he believed his wife would die when she was ready to die. It was also, however, because he knew the nurses were “in touch with her at all times.” Alongside earlier accounts, M’s comments here make apparent the embeddedness, in broader health system conditions, of carers’ decisions and actions. With health professional care entirely reliable, relatives and friends can act out of a desire to be with ill people in hospitals and cancer centres, rather than out of the conviction that their absence allows for inadequate care. In this study, as I discuss elsewhere, the awareness that health care was unreliable³ created an imperative for relatives and friends to be present with the ill person (Sinding, 2003).

Becoming known

Almost without exception, participants in this study commented on the value of being or becoming known as an individual to health professionals. Sometimes a health professional’s knowledge of the patient or informal carer was simply cited as a factor in her or his supportive actions. In other instances, becoming known was described as a deliberate strategy to secure (better) care. Becoming known gained particular importance in relation to conditions in the health system: conditions of constraint, and conditions that tend to depersonalise patients.

In talking about the relationship she saw between her sister and the health professionals who treated her, C drew upon her own experience of receiving care for a serious chronic illness:

I would go dressed so that they’d notice me. And maybe she in her own way was doing that too . . . Because it’s like really really important that people, that people recognise you. Because I think that it, it just, I think it makes the whole thing/ it lightens the whole thing a bit . . . You know that it’s serious, and you know that you’ve got this terrible disease. But there’s something about nurses coming in with smiles on their faces . . . that I think that it just makes it not all so bad and so serious.

C made a point of saying that she did not perceive this kind of rapport between health professionals and patients as especially

common; her sister, she said, “obviously made an impact.” She also credited her sister’s husband for how the nurses and physicians acted:

He would take them stuff, and even afterwards, he’d pop in and see them you know, even after she was finished treatment . . . I think it was maybe a lot about him too, you know.

C perceived that the nurses, prompted and supported by the ill woman and her husband, created a kind of social situation, a valued sense of being among friends. The flip side of this analysis was also apparent to C. When her sister was moved to a ward, “I didn’t see the same sort of caring and stuff . . . But then they wouldn’t have known her in the same way either. She was just another one of those dying bodies up there.”

C’s comments here echo those of several other respondents, who set the value of being known against representations of hospitals and health care systems as factories, routinised and impersonal. R, for instance, commented on the kinds of perfunctory caring that she witnessed, occasioned, as she suggests, by nurses’ working conditions:

Sometimes they just, and I realise they’re busy and everything, but they almost do it by rote, or they do it, it doesn’t/ There’s just not that emotional investment, it’s just some body to turn. That’s what it is.

Both C and R described instances where ill people became ‘just bodies.’ In this study, being known emerged as a defence against conditions in health systems that render health professionals’ actions absent of personal engagement with the patient, and thus render patients ‘just bodies.’

Being known was also linked, in respondents’ accounts, to swift responses by health professionals to care concerns. F’s account of an oncologist saying the he would “like to start chemo immediately”—even prior to certain test results, F notes—was followed by a passage about the esteem in which the medical team had held his wife. M, recalling a time when an outbreak of a hospital virus halted patient transfers between sections of the hospital, notes that he made a deliberate point then of telling nurses on the palliative care ward that a family wedding was on

the horizon. M's wife was promptly transferred, and, as M said, "had we been silent, had it been just another patient going to transfer, we wouldn't have gotten there then." M saw his action of alerting the nursing staff to the upcoming wedding as elevating his wife from being "just another" patient, just "number 62 being transferred," as he said later. Above, 'just a body' receives care devoid of empathy; here, 'just a number' waits for care. Being known, it seems, acts against prevailing conditions in health systems to secure care that is both emotionally engaged, and swift.

Twigg and Atkin (1994), in their analysis of the relationship between informal and formal care providers, note that nurses tend to incorporate informal carers into their practice on the basis of *amplification*—training or transmitting knowledge such that the limited input of nurses can be enlarged and strengthened by the carer her or himself. In this study, we can see the ways that informal carers sought or achieved a kind of amplification of themselves, as they and the ill person became known to health professionals. Informal care conflates care 'about' with care 'for' (Graham, 1983); it is because we care about a relative or friend that we provide care for her or him. Respondents in this study, discussing how they and the ill person became known to health professionals, seemed to apply (or attempt to apply) a central tenet of informal care to the labour of health professionals: if health professionals knew the ill person and thus came to care *about* them, the theory seemed to go, their attentive, responsive and loving care *for* the ill person would also be secured.

Trading services

In several instances participants in the study spoke of 'helping' health professionals. As discussed earlier, assisting a nurse or physician was one of the ways that informal carers ensured that the ill person's care needs were met in a timely way. The move to help, however, also established a basis of reciprocity that was perceived to secure health professionals' labour and responsiveness.

In a passage quoted above, F describes staying with his wife during the nights at the hospital, and providing care for her: "And it helped them, understaffed and overworked and everything else." F went on to link the nurses' appreciation for his help

to subsequent positive interactions with them. Trying to sort through documentation about his wife's medication after she was transferred between hospitals, he phoned one of the nurses whom he had 'helped.' He described his pleasure that she remembered his first name, and commented on how she dealt with his request: "it was almost like having personal service or whatever, but she immediately went and got what we needed." The informal carers' assistance to nurses, then, especially important in relation to their difficult working conditions, was also seen to facilitate future responsiveness to care needs. Similarly, for D, assisting with hands-on care was a very concrete way in which she worked to ensure her friend's needs were met. This assistance was also, however, perceived as helpful to the nurses, something they appreciated, and thus as a kind of inducement to their services:

The nurse would come in and say, 'oh, good, you're here.' I think they were more prepared to give her some extra time, maybe in the middle of the night if nobody was there, because they knew that during the day I'd be there (D).

Variation in carers' capacities to secure care

Considerable variation existed in this study in the sense respondents had of their own capacity to affect health professionals and secure care. In a few instances study respondents perceived a link between their capacity to affect health professionals, and their (or the ill person's) social location. L, for instance, noted that she always made a point of telling health professionals that she and her partner had been together for twenty years. L foregrounded the established nature of their relationships—foregrounded, that is, the ways their relationship conformed to dominant family values—in an effort to ensure that health professionals "would not slight me in any way." That their relationship had lasted twenty years was, as L says, "my only ace in the hole," her only source of confidence and security against professionals' assumptions about gay and lesbian relationships. She could reveal this 'ace' and health professionals would be more likely, she felt, to defer, to take her as family and thus confirm her capacity to affect G's care. In her own narrative, B perceived that young people with cancer may be especially likely to move health professionals to action, and especially likely to garner health system resources.

When an oncologist discouraged B's mother from pursuing further treatment, B attributed his reluctance to a belief that "there's no point in treating for a 10 per cent chance when you're 73."

The link between social location and an individuals' perceived capacity to affect health professionals in positive ways is perhaps most evident in the contrast between M's and S's accounts. When M first used the term 'progress chasing' to describe his interactions with nurses, I told him that it was a new term for me. He explained:

I used to do this with suppliers, I'd say, well, I know my suppliers are not going to call me with a quotation. They're just not going to do it. Well, how am I going to get it? I got to ring them. I expect to ring them. I expect to do half their job.

M's expectation, in relation to nurses, that he would 'do half their job' translated, from his standpoint, into a thorough and effective program of positively affecting health professionals and securing care. His narrative clearly reflects a comfort and familiarity with managing resources, and people. "My job," he said, "was to get the very best I can out of the greatest people they've got here [at the cancer centre] . . . and the worst."

In marked contrast to the confidence and ease M expressed in securing health professional care, S describes feeling "horribly clumsy" about caring for her sister. Approaching nurses was not easy: "I always felt like you're bothering them," she said. "You'd approach that nursing station cautiously." Talking about her sister's bedsores, S takes considerable responsibility; as she said, "I just want to know what we should be doing for her." Her position here is parallel to M's: it is her job to 'do half their job.' And yet, as she says, she did not have sufficient knowledge or training to do this well, and her sister suffered for it.

Yet quite aside from the particular competencies each brought to the role of informal carer was the contrast in M and S's life situations. Progress chasing, by its nature, requires a familiarity with the day-to-day unfolding of a situation, its possibilities and their likely outcomes and remedies. Such familiarity is only gained in this context when informal carers are able to be at ill people's bedsides over time. M, a successful independent businessperson, was able to relinquish all formal work responsibilities to care for

his wife. S, raising two children on her own and facing work deadlines that her supervisor would not shift, was in quite a different position in relation to her sister's care. M is an entrepreneur, accustomed to making things happen, well versed in strategies that rally people around his own goals. In his interactions with health professionals he relied upon knowledge, deeply embedded in culture and class, about how to secure the best effort of people working in circumstances that impede them from offering it. He was also, however, in a position to bring his knowledge and skills to bear on his wife's situation. Obviously, as well, the capacity to offer "a big donation" to a hospital, as T did, is rare, and clearly a reflection of class position; so too, are the social and professional ties with senior hospital administrators that another respondent, H, drew upon to secure care for his wife.

Even among people who deeply desire to care for a relative or friend in the best possible way, then, clear differences are apparent in the extent to which they are able to do so—differences that appear, in this study, to be patterned by class and gender, though of course a larger study would be required to fully explore this association. In this regard it is also worth noting that several respondents, reflecting on their own situations, wondered aloud how people who do not speak English or who are recent immigrants to Canada manage when a relative or friend is hospitalised. In the context of their overall narratives, it seemed that these comments did not only reflect a concern about the communication at a literal level between health professionals, patients and carers, or about how information regarding available services is transmitted and received. Rather, comments along these lines may well reflect respondents' implicit understanding of the levels of culture and class-linked skill and knowledge they exercised in the process of securing care for their ill relative or friend.

Conclusion

Certainly it is in their responsibility for care tasks in the home that relatives and friends of disabled, elderly and ill people most clearly experience the effects of—and, indeed, find themselves accommodating—welfare retrenchment. In the study presented here, yet more of the accommodations individual citizens under-

take in relation to contractionist social welfare policies become apparent.

In recent Canadian research, increasing patient-to-nurse ratios have been associated with nurses' implicit rationing of care (Bourgeault et al, 2002). The study presented in this paper draws our attention to the ways informal carers also participate in the allocation and the rationing of nursing care resources. In hospitals and cancer centres the strain of inadequate staff resources on nurses and physicians is apparent to informal carers. Care by health professionals is commonly assessed, then, as unreliable: it may be timely, proactive and empathic, or it may not; adequate care may well be provided by professionals, but it cannot be assumed. In this context, ill people and their relatives and friends undertake responsibilities of considerable range and substance. In some instances, relatives and friends provided care themselves, or assisted nurses; more commonly, and in an impressive range of ways—by progress chasing, becoming known, and trading their services—they acted as bridges between the ill person's care needs and care from professionals.

The importance in this study of informal carers' roles in ensuring health care for ill relatives and friends begs the question, of course, of what happens when ill people do not have relatives and friends with them in hospital. As Graham (1991) points out, the giving of care in the informal sector reflects the obligations of carers rather than the statutory rights of dependants. The informal sector is "unable to establish *rights* to support; it is only the public sector that can implement and secure rights" (Walker, 1987, p. 380). People with limited or fractured social networks are denied access to informal care.

In the context of the current study, to be denied access to informal care is not only to be denied access to the labour and support of relatives and friends: it is also to have access to the attention and empathy of health professionals compromised. In Canada, universality and accessibility are key principles of health care. Yet insofar as the findings of this study speak to general processes, the level and timing of health care in Canada, and the extent to which it is 'caring' in an affective sense, are increasingly contingent on informal carers and on ill people themselves. Formal care is, thus, unequally distributed amongst the population—accruing more

readily to people with informal carers, and unequally distributed by the capacities and resources of informal carers themselves. Despite continuing declarations on the part of public officials that two-tier health care will not be tolerated in Canada, findings from this study suggest that service tiers exist in the institutional care system, linked to the time, knowledge and resources of informal carers.

Notes

1. Graham herself, of course, has called for feminist analyses of caring that draw conceptual distinctions between the location and social relations of care. Reflecting on work by Carby (1982), Graham (1991a) considers the case of domestic service—the work often done by Black women for and in White families—to claim that feminist research, fusing location and the social relations of care, has obscured forms of home-based care not anchored in kinship and marriage. Here, I make a parallel claim: that fusing location with the social relations of care has obscured forms of *institution-based* care that *are* anchored in kinship, marriage and friendship.
2. Interestingly, while physicians and nurses were both described as “busy” in this study, the phrases “run off their feet” or “not having enough hands” were attached exclusively to nurses. The demands on nurses are such that, at least metaphorically, they are pushed beyond the limits of their physical bodies.
3. I trust it is clear that in using the term ‘unreliable’ I do not intend to connote moral judgement in relation to health professionals, but rather simply to assert that respondents in this study did not perceive that they could count on health professionals to provide prompt, high-quality, empathic health care. This does not mean, of course, that such care was never received; very often, it was. And yet, consistent in the accounts presented here, was the sense that it could not be assumed.

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