

CHAPTER 5

Ethical Issues in Family Care Today

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ABSTRACT

The abstract consideration of ethical questions in family and informal caregiving might rightly be criticized for ignoring the lived experience of people. This chapter seeks to avoid such oversight by reflecting on ethical issues in family care in a way that is based on careful social scientific inquiry into the well-being of caregivers. The chapter draws on our research and experience in working with family caregivers, both professionally and personally. We step back from a practical concern with policies to support the well-being of caregivers to consider ethical issues associated with their typically hidden role. The chapter begins by noting the growing reliance on family care today. It proceeds to outline the dynamic experience of moving into and out of the caregiver role, before discussing key ethical issues associated with family care. Many of these stem from the risk that caregivers can come to share in the reduced circumstances and vulnerability of those for whom they care. Critical ethical issues are related to the typically “unboundaried” responsibility of family caregivers for the well-being of the cared-for person, something that can be contrasted with the more boundaried and intermittent responsibility of formal caregivers. Additionally, all too often, family caregivers encounter situations where their responsibilities exceed their capacities, but where a choice to not provide care will result in harm to the

cared-for person. In discussing these issues, this chapter seeks to make the case for developing more responsive forms of support that promote positive benefits for both caregivers and care recipients.

INTRODUCTION

Abstract philosophical inquiry into ethical questions concerning family and informal care might rightly be criticized for ignoring the social experience of people, pointing to the wider issue of the disjuncture between philosophical scholarship and social science research. This chapter endeavors to bridge that gap by bringing conclusions based on careful social scientific inquiry. Our research has focused on questions associated with the well-being of caregivers with a view toward considering the need for better formal care policies. It draws on research and experience in working with family caregivers, both professionally and personally. In this chapter, however, we step back from that practical concern to consider the ethical issues associated with the growing dependency on family and informal caregivers. The chapter begins by noting the reliance on family care today. Our identification of ethical issues is framed within the context of our previous research, which has studied the caregiver experience as a rite of passage to capture the dynamic experience of moving into and out of the carer role. It proceeds to discuss specific ethical issues and how they might be responded to.

The paradigm shift in caring for people with multiple and complex needs, which over the past 50 years has driven the shift in care from the residential institution to the community and home, has resulted in new expectations of many family and informal caregivers, raising new ethical issues. Caring for an ill or disabled family member has become an expected part of family life (Lim & Zebrack, 2004). This is all the more so, given that families today deal with the consequences of the policy changes that have driven the shift from institutional care to community or home-based care. Families have become more, rather than less, involved in caring for members with impairments at different stages right across the life course, whether they live in the family home or outside of it. The significance of family and informal caregiving is all the more important, given the tendency for the greater longevity of people with chronic illnesses and disabilities, along with structural and numeric population aging. With more care being provided in the community as either support in the family home or supported living elsewhere, family and informal carers have become the “linchpin” of care (Nolan, Davies, & Grant, 2001, p. 91). This introduces family members into new normative stages and roles in the family life course, and these raise new ethical issues. Such challenges revolve around the demands of the care responsibilities

with other accepted life stage roles, tensions around the competing demands of paid employment and family work, and issues of carer “burden.”

It leads to practical questions about costs to families and to the wider society, how such care might be supported by formal care services, and the ideal arrangements of social service systems to complement family and informal caregivers (Arksey & Glendinning, 2007; Fine, 2007; Phillips, 2007). Key ethical issues, then, are related to questions about how family and informal care is integrated with formal care systems, including the vexed issue of financial and practical support for family and informal caregivers; the practical issue of organizational support for informal carers and developing sensitive needs assessment practices and training; and the need for greater recognition of the informal care sector and the development of shared understanding of the issues faced by family and informal caregivers by all stakeholders (Marin, Leichsenring, Rodrigues, & Huber, 2009, p. 5). These are, essentially, issues that stem from the tension in the relationship between informal and formal care. This is not a new observation. Twigg’s (1989) analysis observed that family and informal caregivers were marginalized in the care process when formal care workers were involved. She asserted that “carers are on . . . the ‘out-there’ against which agencies act.” Furthermore, care researchers have observed that not only do informal caregivers experience marginalization in relation to formal care workers, but all too often they are seen as a cheap resource that can be utilized to “reduce the long-term fiscal costs of care related to potentially avoidable institutionalization and worsening of disabilities” (Singer, Biegel, & Ethridge, 2009, p. 97). Nolan et al. (2001) point out that the most common goal in supporting informal caregivers is to maintain them in their role and thus contain caregiving costs. Such a view, he suggests, “is essentially exploitative and not supportable on moral, ethical or even pragmatic grounds” (Nolan et al., 2001, p. 92). Cummins (2001, p. 83) actually suggests that “the forces that encourage family care are minimally concerned with family welfare.” Both argue that formal care policies that conceive of family and informal care as a free resource with the potential to compensate for deficiencies in publicly funded care grossly misrepresent the contribution and significance of informal care (see also Marin et al., 2009, p. 14).

Greater reliance on family and informal care has been occurring within the context of changing family structures, higher labor force participation by middle-aged women, and the emergence of “sandwich” generation caregivers. The taken-for-granted nature of informal and family care—it is “what one does” as an expression of family and neighborly affection, responsibility, and duty—tends to hide the fact that, typically, caregivers are female and the caregiving role is typically seen as an extension of the domestic work role

(Waring, 1990). The fact is, many adult children who care for a parent, particularly daughters, are also recognized as facing “sandwich generation” issues—caring for individuals at both older and younger life stages. Changing work practices mean more women in their middle years are in employment, and balancing care work and employment is increasingly a challenge. Employment consequences for adult children caregivers include loss of income and difficulties in returning to the workforce if time is taken out for caring (Bourke, 2009; Cook, 2007; Raschick & Ingersoll-Dayton, 2004; Stoller, 1983). So while family and informal care today have come to play a critical role in social care systems, it presents significant risks for individual caregivers in terms of the consequences of carer stress and burden and significant social, economic, and personal costs.

WHEN FAMILY CAREGIVING BECOMES EXTRAORDINARY

The care relationship begins with the care recipient and caregiver, but it generally extends to encompass a much wider constellation of actors. Consequently, caregiving places the individual in a context in relation to others as well as the care recipient. This involves at least three separate layers:

1. The care recipient, and his or her level of need, life expectations, and reactions to the need for care
2. The social and family network including formal carers where present, and their expectations, level of involvement, and recognition of the contributions made by the primary caregiver
3. The social care system, the availability of services, and conditions attached to support, and recognition and support of both informal and formal caregivers

Despite growth in formal care services over the past 40 years, family and informal care remains the preferred option for people with chronic illness and disability, particularly those with significant disability (Marin et al., 2009, p. 14). It is family members who almost always provide hands-on care, while emotional support and assistance with instrumental activities are also often undertaken by neighbors and friends and less socially close connections such as club or church contacts. Care provided by family and community connections reflects the goodwill, commitment, and capacity of social networks, and these are not necessarily long-standing ties as Peek and Lin (1999) and van Tilburg (1998) suggest. Such commitment can become designated as “caregiving,” a set of actions that differ from the usual normative social relationships in everyday life (Walker, Pratt, &

Eddy, 1995), when family and informal caregivers are asked to increase instrumental or social and emotional support for an individual who is dependent “for any activity essential for daily living” (van Groenou & van Tilburg, 1997; Walker et al., 1995, p. 403). These include instrumental activities of daily living (such as cleaning, laundry, and meal preparation) or activities of daily living (such as bathing or walking). It is the level of need that is important in determining whether care becomes nonnormative and extraordinary, rather than the actions and emotions of the caregiver. In situations where the extent of the need is such that caregivers cannot walk away from an expression of dependency, caregivers cannot be said to have choice. Moreover, it is the level of need that determines the frequency and amount of care that is given, and, more importantly, the meaning of that care.

Informal care is preferred because it is seen as an ordinary expression of love, help, and support within families and among neighbors. Caregiving is, as Hilary Graham (1983) defined, a “labour of love,” comprising two indispensable elements: the physical work of caring and the emotional work. Kittay (2002, pp. 259–260) adds that it is “a labor, attitude and a virtue.” Differentiating between the labor involved in care and the kinds of attitude with which it is carried out captures what is required for “good” care.

As labor, it is the work of maintaining ourselves and others when we are in a condition of need. It is most noticed in its absence, most needed when it can be least reciprocated. As an attitude, caring denotes a positive, affective bond and investment in another’s well-being. The labor can be done without the appropriate attitude. Yet without the attitude of care, the open responsiveness to another that is so essential to understanding what another requires is not possible. That is, the labor unaccompanied by the attitude of care cannot be good care. (Kittay, 2002, p. 259)

Family and informal care becomes extraordinary, given that it goes beyond normal or usual care within the family life course (Biegel, Sales, & Shulz, 1991). Caring for a family member with a chronic illness or disability presents distinctive challenges. This type of caregiving is a significant extension of what families normally do, it is extraordinary to the extent that it constrains the caregiving family member from leading a normal life. Informal caregiving is, therefore, both ordinary and extraordinary. It implies an ongoing need and an ongoing commitment by the caregiver beyond the usual family care situation. It can be seen as an extension of family or neighborly duty, one that has important consequences for care recipients and caregivers.

ETHICAL ISSUES AT DIFFERENT STAGES OF THE CAREGIVING CAREER

Ethical issues in caregiving are evident during the dynamic process of moving into a caregiving role. The dynamic nature of caregiving has been captured by researchers who emphasize transitions (Bury, 1982; Hirst, 2005; Janlov, Halberg, & Petersson, 2006; Nolan et al., 2001; Olaison & Cedersund, 2006; Williams, 2000). Individuals move into and out of caregiving at different stages of the life course, and just as the person in need of care will be influenced by his or her life course stage, so too will the needs and experience of the family and informal caregiver be affected.

Process-oriented methods for examining caregiving experiences focus on key stages in the caregiving cycle, particularly the transition points in terms of initial points of change and disruption, periods of liminality and doubt, and reconnections. Such an approach has illuminated the dynamic experience of upheaval and change associated with the adoption and relinquishment of informal caregiver roles. The different care situations, the nature of the need or disability, and its trajectory, all influence how the care role is accepted, how the activity of caring changes over time, and the way in which caring will come to an end, or as Wilson (1989) says, how the role is taken on, worked through, and ended. In the words of Janlov et al. (2006, p. 334), these transitions are “marked by a starting point of change, through a period of instability, discontinuity, confusion and distress to a new beginning or period of stability.”

Subdividing the transition into three stages—separation from a current role and identity; liminality, the uncertainty brought by change; and a third stage of “reconnection,” the re-entering of the social world in a new life stage—allows for a detailed examination of the process of change and issues that arise.

The model illuminates the experience of *becoming* a carer and captures both the individual and social aspects of transition. The framework allows attention to be given to the stage of liminality, an “in-between” stage characterized by an unsettledness. The third involves reincorporation and reconnection with the wider society, with a new set of rules, roles, and responsibilities, raising the question of “reconnections” and some of the key issues with achieving “reconnection.” Other theorists who have applied this concept to secular situations include Teather (1999); Hugman (1999); Hallman (1999); Hockey and James (1993); Twigg (2000); Frank (2002); Hale, Barrett, and Gauld (2010); and Barrett, Hale, and Butler (2014).

Separation: The Beginning of Transition

Family and informal caring is a moral or ethical response to the need of a family member, friend, or neighbor. However, with the provision of care in the home

and community now being an aspect of the public service sphere (Fine, 2007), there are other means of meeting that need. So when someone's increasing need moves him or her across a threshold, then, an exchange with health and allied care professionals is initiated. Although the implications of the process of assessment are underacknowledged, this is a significant moment in the lives of both the person in need and the family or informal caregiver (Hale et al., 2010; Janlov et al., 2006; Olaison & Cedersund, 2006; Richards, 2000). For informal caregivers, it is associated with the movement into a new social role and identity, that of caregiver.

The process involves an ordinary family caring situation being transformed into a type of patient-caregiver relation (Efrainsson, Høglund, & Sandman, 2001, p. 813). Bury's (1982) term *biographical disruption* seems to us to capture the nature of the experience. Becoming an informal caregiver is a dynamic experience. It can occur as a "drift" or a "sharply punctuated event," with subtle changes of relationships, group memberships, and social participation, and equally subtle changes in the attitudes of others. What makes this change significant as an experience of separation is the way in which it involves a challenge to the normatively defined role of spouse, parent, child, or neighbor.

The defining experiences are an initial realization of responsibility for care, a personal decision to take it on, and meeting with formal care services or assessors in the development of care plans, where the carer is officially recognized as a part of the arrangements for care. Cameron and Gignac (2008) observe that such experiences comprise that point in time where the primary responsibility of the family member or friend as that of caregiver is clearly recognized and expanded to such an extent that caregiving begins to define the identity and life choices. Ducharme et al. (2011), in their study of care for a family member with dementia, capture the significance of this when they refer to the way the inclusion of a spouse, parent, child, or neighbor in "diagnostic disclosures" mark entry into the caregiver role. Keady and Nolan (2003, pp. 25–26) refer to this as "the confirming stage," this being

a period of transition to the caregiver role during which time caregivers are inevitably faced with new responsibilities. They must learn to cope with the losses and the changes in the relative's behavior that characterize the [need for care] and to plan for future care needs. (Ducharme et al., 2011, p. 485)

Typically, it is needs assessments or diagnoses that provide the basis for the formal recognition of needs and brings the caregiver into contact with the formal care system. The situation and capacity of caregivers is usually assessed at this

time as well. Care plans, for example, formally take account of what the primary caregiver can do and what support she or he is able to call on.

Interactions with formal service personnel expose carers to dominant discourses of care, framing their role in the caregiving process in relation to the norms that inform the formal sector, with the effect that the caregiver learns the accepted philosophy and rationale for the provision of formal support services, such as respite care or other forms of funded support. This interaction is characterized by the power of the assessor to determine eligibility for assistance. In these exchanges, the informal caregiver has a relative lack of power. Assessors are the gatekeepers of access to formal support and the information required to get that support (Olaison & Cedersund, 2006). Care plans that incorporate an assessment of what it is the family member can do are thus developed, and these assessments and plans both reflect and reinforce socially defined expectations of caregiving and might be thought of as providing a social script for carrying out informal caregiving. The caregiver becomes aware of the particular needs categories recognized by the formal sector and begins to see her or his situation as falling within these. The cared-for person's needs are a defining element, influencing how the caregiver is positioned in relationship with the formal sector, for example, taking full responsibility as in the case of children or assuming increasing responsibilities in the case of older people. Situations vary depending on the disability, the level of need, and the degree of autonomy and control that can be exercised by the care recipient.

Liminality

The rites of passage framework suggests that separation experiences are followed by a period of liminality. Liminality indicates discontinuity, a threshold between what has been and the future, a state of betwixt and between and, as such metaphors suggest, the emotions here are of anxiety, bewilderment, confusion, and fear. Our analysis of the reported experiences of people who become informal carers leads us to conclude that they too experience liminality following the assumption of the caregiver role. In fact, many caregiver experiences could well be described as liminal (see Pereira & Botelho, 2011). Family carers can also be said to be in a liminal position in that they are neither professional caregivers nor passive family members. Their situation is often one of responsibility without authority. Stoltz, Willman, and Udén (2006) observe that family caregivers do "worry a great deal about the future" and there is "much despair." Wilson (1989) referred to the type of experience we describe as "living on the brink." For individuals who are becoming caregivers, their ambivalent status in medical environments is linked with the little recognition they receive from health professionals for their interest in and knowledge of what is needed. They are expected to

assume more responsibility for making decisions or in persuading the cared-for person about decisions, but at the same time they report that they are excluded from decisions that affect the person they care for, or decisions are made without consideration of the implications for them as caregivers.

The experience of liminality, as Olaison and Cedersund (2006) suggest, is not only one of confusion, anxiety, and of searching for a way through bewildering new systems but also of learning to negotiate within these systems. There is an important stage of learning the game. This is, however, a game where the assessors are in charge, controlling the engagement with the recipient and, when included, the caregiver. The subsequent allocation of care responsibilities affects caregiver capacity to control the organization of daily lives, influences choices about housing and household organization, and constrains the capacity for social participation as an individual, couple, or family.

Reconnection

Many informal caregivers become disconnected as a consequence of taking on the caregiving role, and many remain in that state through their experience of caregiving. Liminality is seen in the rites of passage framework as a temporary phase in the transition process. It is followed by a phase of reconnection to the broader community with a newly recognized and valued social standing that is characterized by its own set of “rules, roles and obligations” (Hockey & James, 1993). Searching for meaning is a part of the liminal experience. Finding meaning and making sense of the care situation in terms of one’s life story implies reconnection. While becoming an informal caregiver presents many difficulties and stresses, the capacity to make a “larger sense” of the situation, as Pearlin, Mullan, Semple, and Skaff (1990) observe, has been found to be an important factor in coping. The way caregivers see their situation and ascribe meaning to it is linked with their ability to cope. Meaning in this sense, as Rubinstein (1989) defines it, is “the often affectively laden array of significations and associations individuals attribute to the events they experience” (p. 119). Giuliano, Mitchell, Clark, Harlow, and Rosenbloom (1990, p. 2) define meaning in this context as “positive beliefs one holds about one’s self and one’s caregiving experience such that some benefits or gainful outcomes are construed from it.”

Reconnections, however, are not assured, and much of the research into caregiving experiences suggests informal caregivers live in states of liminality. That is, many caregivers, despite aspiring to express their moral duty to help a spouse, parent, child, friend, or neighbor in a way that meets their needs, have experiences of continuing liminality. The aspiration to provide help to a family member, and the actual provision of such help, is not sufficient to move the carer beyond the liminal state. From our observations, for example, many find

themselves expected to carry the responsibility for the well-being of the person in need of care, while having little authority to make key decisions about that care. This is particularly the case of adult children caring for once-independent older people. Those who live in the same house as the person they care for are faced, often, with their home becoming a space for the delivery of care. Private spaces become public, and home takes on new meanings, which are defined by the disability or need for care. The need to be present as caregivers ties them to their homes or places of care and limits their mobility. Caregivers thus find themselves losing control over the organization of their daily lives, how they use their time being defined by the needs of the care situation. This has a profound influence on their ability to maintain social connectedness, and social networks are thus modified, usually in the direction of becoming narrower. Many informal caregivers become disconnected as a consequence of taking on the caregiving role, and many remain in that state through their experience of caregiving.

Addressing disconnection and facilitating reconnection in a new and socially valued role is, therefore, critical. But what does it mean to say that a caregiver has become reconnected? Reconnection means the informal caregiver is not alone with the responsibility for the life and well-being of the person he or she cares for but is connected through lines of support that allow the expression of the basic human inclination to care for a family member or neighbor. Reconnection, thus, implies a social context—connection with others. Stoltz et al. (2006) have captured this sense of connection when they describe the experience of “togetherness with others” and “togetherness with oneself.” Stoltz et al. (2006) have studied the experience of caregivers of older people at home with a view to understanding the meaning of support. Their findings are most helpful in making sense of the meaning of reconnection at this stage of life. They examined what support for family caregivers, in the form of day care services, respite care, telephone support, online support, and group sessions, meant to those receiving that support. Their analyses pointed to the importance of a sense of togetherness with others in the care tasks as a key to managing and coping. While they acknowledged that there was a large amount of evidence indicating that the “effectiveness of interventions for family carers is not convincingly strong,” (Stoltz et al., 2006, p. 595) with much research focusing on the negative outcomes of caregiver burden and stress, they were concerned with understanding better what characterized positive outcomes.

The idea of being connected can be taken to imply not being alone in the caregiver role and being able to share the responsibility for decision making or the practical tasks of caring. It is this sharing of the role that provides caregivers an assurance in, as Stoltz et al. (2006, p. 595) state, the “resourcefulness of others.” Being connected to support provides caregivers an assurance that others, be

they health professionals, care workers, or wider family and friends, will ensure things work out well and that they will be “helped to help their loved one” (p. 595). It is having their needs recognized that provides reassurance, and this can be contrasted with the feelings of abandonment, of having care situations dismissed or unacknowledged, which occurs when support is not forthcoming.

Alongside a strong sense of assurance in the resourcefulness of others, Stoltz et al. (2006, p. 595), along with Scorgie and Sobsey (2000), identified confidence in the “resourcefulness within oneself,” a sense of calm and confidence in knowing how to respond in caregiving situations and in where to turn for rightful help. Caregivers who felt this assurance of their own resourcefulness were said to be connected with themselves, their own strength or ability to cope, and their capacity to ensure their own needs were met within the caregiving situation.

Connectedness in caregiving, therefore, can be understood as meaning “togetherness with others” and a sense of “togetherness with oneself.” When caregivers experience a sense of togetherness with others, they describe “feeling encircled by action potential . . . [a] sensing of a network that would step in, should they need it, . . . [this being] a great asset to them in the reassurance of honouring the promise that many had made to care for their relative at home” (Stoltz et al., 2006, p. 600). A strong sense of trust that someone else “could step in and take over caring, should the need arise” provided reassurance that family caregivers would be assisted in coping with the practical and felt demands of caregiving. It was a sense of shared responsibility and knowledge that someone else could step in if required that provided this assurance, and of not being “the sole accountable bearer of the wellbeing of their relative or for making decisions pertaining to the health of the person cared for” (Stoltz et al., 2006, p. 601).

The notion of “togetherness with oneself” refers to the increasing clinical competence of the caregiver, acquired through the trial and error of caregiving. That competence leads to a transition to a stage where family caregivers are able to have a sense of equality with the formal caregivers and allied health professions they work with. They get a degree of control within the process—and learn how to get the help that they need.

While these experiences imply reconnection, a lack of connection implies ongoing liminality—being alone with the responsibility, feeling overwhelmed by that responsibility and, as a consequence, feeling unsure and apprehensive. The feeling of having nowhere to turn, no one to turn to, is captured in the comments of one of their respondents:

Because this was unbelievably tough, this was probably the toughest time when nobody listens, they listen to you and say certainly, right, sure we will

do that, and then nothing happens. I think that is really bad because you should keep your promises. . . . You called: “No it’s not our pigeon”; “No, it’s not us”; “No, we have to have a referral from the physician” . . . so that it was, mmm, yeah five, six places before we got hold of someone who could help. (Stoltz et al., 2006, p. 601)

Having presented the family and informal caregiving experience as a dynamic process that presents many threats to the well-being of caregivers, the chapter now moves to address specific ethical issues that emerge within that process.

ETHICAL ISSUES IN FAMILY CAREGIVING TODAY

Many of the critical ethical issues in informal caregiving stem from the fact that caregivers can come to share in the reduced circumstances of the person with complex needs. Carers’ needs tend to be unacknowledged, but both the person in need of care and the family caregiver are vulnerable to poor and negative outcomes. Unrecognized caregiver needs lead to shared vulnerability of care recipients, carers, and the wider family. The caregiver actually comes to share the dependency of the person cared for, during the lifetime of the cared-for person and afterward. In fact, the greater the need of the cared-for person, the greater the risk to the caregiver (Kittay, 2002). In effect, the complex need can become the circumstance for reducing the resources (we might characterize these as social capital) of the family group. The manner in which this can push a family to the edge of endurance has often been kept as a private matter. Affluent as well as poor families can find themselves overwhelmed with the responsibilities of care. It is easy to ignore the extraordinary stresses faced by families when they lack sufficient resources, financial, social, physical, or emotional. How these are negotiated has important implications for the well-being of the caregiver, the cared-for person, as well as wider family members.

The Absence of Boundaries for the Potential Response of Family Caregivers

Since informal care is given to single individuals who are connected in some way with the carer, this relationship is troubled from the outset by the fact that there are no boundaries for the potential response (Levinas, 1989). Formal care, by contrast, is constrained from the outset by organizational pressures in the direction of efficiency. Formal care is provided by a range of individuals, with a greater or lesser degree of training and skills from paid carers to health professionals. The degree of formality in the relationship varies considerably, depending on the

bureaucratic context. It is, in Ignatieff's (1984) terms, society's response to the "needs of strangers." While informal care has a lower level of social recognition than paid or professional care, it typically requires a higher level of focus and responsibility across multiple domains. The degree of responsibility carried by informal carers tends to be constant and without borders, whereas professionals have a more bounded responsibility. It is not possible for informal carers to avoid responsibility in the same way as formal caregivers. Their relationship is sustained over time in the sense that it is "continuing," whereas the typical response of the health professional is occasional. The differences in the temporal and spatial parameters of formal and informal care are compared in the following table. Table 5.1 also identifies the implications of each form of care for the degree of responsibility that lies with the caregiver and the implications for the relationship between the caregiver and the cared-for person.

The degree of formality, depicted in the left-hand column, has implications for the time spent caring, the place for the delivery of care, and the responsibility of care. Informal caregiving tends to be continuous and sustained, it is associated with a lack of mobility for both the cared-for person and the caregiver, and the responsibility for that care is constant. Formal paid care is much more episodic, formal caregivers move into and out of the caring space much more readily, they are not tied to the space for the delivery of care in the same way as informal caregivers, and the responsibility for care is intermittent. Care and oversight by professionals is, by comparison, irregular with defined temporal boundaries, occasional, and mobile and has, in general, much more clearly defined boundaries.

TABLE 5.1
The Relationship Between Care and the Degree of Formality and Informality of the Relationship

	Time	Place	Responsibility	Relationship	
Degree of Formality	Informal	Sustained	Constrained	Constant	Thick
		↓	↓	↓	↓
	Formal paid carer	Episodic	Permeable	Intermittent	Less thick
	↓	↓	↓	↓	
Formal professional care	Occasional	Mobile	Bounded	Thin	

The quality of the relationships is obviously different and Margalit (2002) used the comparison of thick and thin to capture this distinction:

Thick relations are grounded in attributes such as parent, friend, lover. . . . Thick relations are anchored in a shared past or moored in shared memory. Thin relations, on the other hand, are backed by the attribute of being human. Thin relations rely also on some aspects of being human, such as being a woman or being sick. Thick relations are in general our relations to the near and dear. Thin relations are in general our relations to the stranger and the remote. (p. 197)

Depicting the care relationship in this way emphasizes the particular challenges associated with the role of family and informal care. It is a constant responsibility that is sustained over time and one that places real constraints on the caregiver.

Need for Informed Choice

Being forced to take on responsibilities that exceed capacity, however, leads to situations of unsustainable carer burden. Being an active agent indicates the possibilities of choice, and choices include to not care, to care, to have help, to be in the workforce outside the home, and to recognize care at home in terms of work, rather than solely in terms of family duty, love, and affection. All too often, carers entering the care relationship feel that there are few or no choices. Featherstone (1980) described this when she likened the moment of choosing to care with the situation of saving someone from drowning. It would be hard to call this a choice, where inaction will result in harm, and action, conversely, has such a peculiarly urgent quality. For many it is a kind of Hobson's choice.

The issue of choice touches on the interconnectedness of the choices that are made by both the carer and the cared-for person. But there is a need to recognize the importance of informed choices in care, the need for adequate support and preparation, ongoing responsive support, and the provision of information, knowledge, and skills. Nolan et al. (2001, pp. 92–93) talk of many carers who “feel ill-prepared for their role, lacking essential information and basic caring skills” and describes Askham's call for carer support as interventions that assist carers to “take up (or not take up) the caring role; continue in the caring role; give up the caring role.”

Support at the initial stage of the care process, therefore, is critical. Family caregivers at the initial stage of the caregiving process are often

at a loss of what to do . . . feel confused about which services are available and from which institutions or agencies. . . . Not knowing what to do and

feeling abandoned or alone with caregiving could be labelled as feeling unsupported, for although the family carers are in need of support, they are also expected, sometimes by others but also by themselves, to support the person they care for. (Stoltz et al., 2006, p. 603)

The sense of responsibility to meet the needs of the cared-for person alone can be overpowering. Within this context, the experience of engaging with health and care professionals is critical. The quality of service at the point of engagement is a critical factor in determining the extent to which caregivers have choice in their situation.

Decisional Autonomy and Independence in the Care Relationship

Within family and informal care exchanges, family caregivers are often expected to, and often do, take on greater decision responsibility leading to tensions around supporting the decisional autonomy and independence of the cared-for person. Within the context of the care relationship, family carers often play a role in persuading the cared-for person, for example, to accept decisions relating to his or her health care. This may involve persuading care recipients to have an assessment, to visit the doctor, to change or review medication, to go into hospital, to have an operation, or to accept formal help. Moreover, family carers are often expected by formal care workers to take responsibility for such decisions.

This points to changes that occur in the relationship between the family caregiver and cared-for person through the care process. For example, becoming a caregiver involves carrying out personal care tasks that can lead to challenges to the norms of spousal or parent–child relationships, such as showering or toileting. As one partner becomes dependent on the other for care, the structure of the relationship changes. Taking responsibility for physical safety and hygiene of another is a key part of this changing dynamic. In one sense, the relationship is a continuation of family care norms, yet, in another, it exceeds these norms and redefines the boundaries and content of the relationship. For example, the role change can involve an adult child becoming a parental caregiver carrying out the intimate work of toileting, showering, and “cleaning up” a parent’s body. The change is often experienced as a tussle for authority. These may relate to the management of medication, the performance of domestic work, the preparation of meals, personal care, and house maintenance. Each of these can be a point of some resistance and opposition from the cared-for person. Caregivers cannot, however, be said to have authority over the cared-for person—this goes against the norms of reciprocity and compassion that are often the motivation for the caring role.

Power Dynamics in the Care Relationship

Questions over authority and control in the care relationship, however, have been a key concern of the disability movement (Kroger, 2009). Disability researchers have voiced the criticism that the historical practice of care has reinforced narratives and perceptions of care recipients as dependent, nonautonomous citizens. This has led to some harsh commentary from the most articulate disability researchers: "Care . . . has come to mean not caring about someone but caring for in the sense of taking responsibility for. People who are said to need caring for are assumed to be unable to exert choice and control" (Morris, 1997, p. 54).

The criticism draws attention to the way caregiving presents a fundamental threat to the ability of the cared-for person to be self-directing. It indicates the existence of conflicting interests between the carer and the cared-for person. Furthermore, leading spokespeople from within the disability movement have stressed that informal family care is the worst possible scenario since "enforced dependency on a relative or partner is the most exploitative of all forms of so-called care delivered in our society today for it exploits both the carer and the person receiving care" (Morris, 1997, p. 56). These arguments have informed strategies for individualized funding that challenge assumptions of dependency and promote greater choice and control.

The apparent polarity, however, does not appear to be so great when it is remembered that both the disability movement and the carer movement (through its feminist links) have a strong commitment to emancipatory aims (Watson, McKie, Hughes, Hopkins, & Gregory, 2004, p. 341). Williams (2001, p. 483) has suggested that there should be new dialogue between informal carers, formal carers, and those who receive care and support. The individualized funding movement, which seemed originally to exacerbate the divisions between caregiving and disability, has increasingly begun to articulate common aims. Caregivers require some form of recognition for the vulnerability that they share with their disabled family members; people with disability increasingly want to include family care among the range of possible options that are available to them. However, neither party wants to feel that this relationship is marked by the kind of exploitation described by Morris (1997) earlier.

Real choice, however, should include family and informal care:

Some people will wish to have their support needs met through personal relationship, which means there will still be family members and friends involved in providing care. However, this must be something that both parties feel they have choice over and, where choices conflict, that they have some scope for negotiation. (Parker & Clarke, 2002, p. 357)

The development of a range of alternative concepts, such as “help” (Shakespeare, 2000), “support” (Finkelstein, 1998) or “assistance” emphasizes the contractual element of the relationship that began to arise around questions of individualized or personalized funding. In practice, these terms have been used as people with disability have moved into the market for employing personal assistants, rather than in relation to informal care. As this relationship has become more commonplace, there has been a tendency on the part of disability writers to return to the language of care (Morris, 2001; Shakespeare, 2006). At the root of these struggles is a tension about what is considered “good” care; Disability activists, working within a justice paradigm, emphasize rights, independence, choice, and control. Care scholars highlight the underlying collective interests between caregivers and those for whom they care (Kroger, 2009, p. 406).

Relationship With the Formal Care Sector: A Need for Greater Recognition

A central theme in research on informal caregiving addresses the extent to which formal care arrangements facilitate or frustrate the abilities of families to provide care to family members. The way we appreciate the significance of informal care is evident in the way it is seen as being linked in with the formal care sector. This is evident in the way informal care is conceptualized within the caregiving process. The role has been characterized for formal care workers as that of an “informant,” a “therapy assistant,” a “coclient,” a “collaborator,” and a “director” (Nolan et al., 2001, p. 94; see also Twigg, 1989). Each of these perspectives positions informal caregiving in relation to formal care, with the former tending to see it as a marginalized activity and the latter as central to the care process.

In becoming informal caregivers, individuals build up detailed knowledge about the cared-for person. Caregivers learn the skills of caring by doing—by the hands-on care, emotional and behavioral care, and coping with, for example, the difficulties of dementia. Some health professionals are meticulous in asking for caregiver input, acknowledging their expertise and knowledge. Recognizing caregivers as experts, however, can present a profound challenge to professionals and the formal care sector who are less able to recognize caregiver knowledge, and, in fact, may give very little time to become involved with the family care situation.

Practical Responses to Ethical Issues

Becoming a caregiver is increasingly an inevitable part of the life cycle and a likely life transition for family members. Positive outcomes are often disregarded in the caregiving literature (Jorgensen, Parsons, Jacobs, & Arksey, 2010), given

the focus on highlighting the vulnerabilities of family caregivers. There is, however, an association between family caregiving and both high stress and high satisfaction (Walker et al., 1995, p. 404). Both can coexist. Caregiving can lead to lives that are rigidly scheduled, with less flexibility and a loss of privacy, but it can also lead to emotional satisfaction (Scorgie & Sobsey, 2000). Studies that identify positive outcomes for caregivers suggest it can be an enjoyable and a positive transformational experience. It can improve the quality of the relationship and, within the context of that relationship, can be an important form of social and emotional support to both the care recipient and the caregiver.

Reconnected caregivers are supported in their caring through, for example, opportunities for respite care, and they may be linked with formal support systems. Social recognition of the needs of carers implies being included in discussions with the cared-for person and professionals. Reconnection implies a social context that encourages positive meanings of the caregiver role and the support to sustain that. Reconnection is finding one's feet as a caregiver and being recognized and valued in that role. It means not being alone but being reintegrated into the wider community, sharing the burden of care, feeling assured in the resourcefulness of oneself as a caregiver, as well as feeling assured in the resourcefulness of others, be they formal care services or other members of a social network.

With much attention in policy and practice concentrated on ensuring that carers continue in the role, and less interest in why and how they take it up or how they move on afterward, informal caregiving continues to be poorly appreciated within formal health and social services, and, as a consequence, these have been less than responsive to the needs of informal carers. Formal care services, however, are the primary means for support of reconnected caregiving. They can complement the day-to-day, round-the-clock care of family caregivers by providing episodic support and more specialized care to the older person when required. Day care services, respite care, education, telephone support, online support, and group sessions for caregivers have potential to supplement and enhance informal care. Seen as something that complements rather than supplants informal care challenges views that suggest formal care services somehow weaken the incentives for family members to care for their own. Such views are influential among policy-makers who look for arguments to cut the costs of formal care, but they are not empirically supported and serve only to weaken the capacity and sustainability of family and informal caregiving. The resources of the formal care sector, in terms of information, expertise, and funding need to be seen as complementary to the resources of informal caregivers.

In contrast with the view that an active formal care sector weakens the incentives and inventiveness of the informal "community" sector, we assert that

smart policy informed by a grounded knowledge of the needs of carers, particularly at key moments in the caring cycle, enhances the capacity of both sectors to provide quality care for those in need. If informal carers are to be supported effectively and if such care is to be sustained, there is a need for a greater awareness by formal care workers and health and social care professionals of the experiences of carers and the issues they face. The purpose of such awareness is, of course, to support the environments of home and community, so that carers are empowered and able to perform the practical and emotional work of caring in such a way as to facilitate quality care that respects and supports the dignity of the cared-for person. Support for caregiving families ought to be aimed at not only reducing stress and ameliorating distress but also promoting potential positive benefits to the caregiver and care receiver (Singer et al., 2009, p. 98). Such supports should be considered as a matter of justice, suggests Kittay (1999, p. 132), and carers should be treated “as if their work mattered (because it does) and as if they mattered (because they do).”

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