

# Making Sense of Care<sup>1</sup>

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## *Abstract*

*The paper is focused on relationship between family carers and those they support, and the meaning of care, that emerged from the narratives of caregivers. Starting with the stories of 12 family carers, based on narrative life history interviews, the author attempts to counter approaches which emphasise deficits and problems and which decontextualise caring relationships, both in the way in which care is researched, and in the way in which policies and practices provide and support care. In this paper, the feminist ethic of care is presented. This approach challenges the notion of care as a natural expression of women's capabilities, as well as the idea that it is only some people who need care, and recognises that we are all givers and receivers of care at some points in our lives. From this perspective, the meaning of care goes beyond one to one relationships between care providers and care receivers. Considering this significance of care, its implications for the quality of welfare are discussed.*

## *Keywords*

*Care – Feministic ethic of care – Family carers – Social justice – Narrative approach.*

## **Introduction**

The focus of this paper is relationships between family carers and those they support, and on the meaning of care that emerges from the narratives of lay care givers (Barnes, 2006). But one of my arguments is that care — as both a value and a practice, is necessary to an understanding of social justice in conditions of inequality, vulnerability and dependency and that the significance of care goes beyond one to one relationships between care providers and care receivers. In this paper I want to set out the outlines of this argument and consider its implications for the quality of welfare.

The issue of care has been addressed by researchers aiming to document what caring involves for lay carers and to make visible the impact this has on their lives, and raising issues for service delivery. It has also been addressed by social policy researchers

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<sup>1</sup> Due to its scientific value and the prestige of the author, this article has been selected directly by the editor-in-chief and associate editors, without being subjected to a single- or double-blind peer review procedure.

aiming to analyse the way in which the policies of different welfare states demonstrate assumptions about public and private responsibilities for care. Care has also been discussed by political philosophers concerned with the moral basis for social relations, as well as for political decision making. This approach is deliberately intended to counter the negative connotations often associated with care. In the context of social policy care is usually presented as a problem: for those giving and receiving care, as an expression of gendered social relations, as contributing to the oppression of disabled and older people, and for policy makers and service providers seeking to minimise the demands on the welfare state. Drawing on work on a feminist ethic of care I argue that including care is essential to the development of policies and practices capable of delivering social justice and this requires addressing care as a political as well as personal value.

Research on caring has focussed on the work involved in care, made visible the level of unpaid input being provided by family members and revealed the normative assumptions on which community care policy has been based. This has had a valuable impact in the development of support services for carers. But it has also arguably contributed to the development of a «them and us» position between carers and disabled people through positioning care receivers as «dependent burdens» on carers, and constructing carers as «tragic heroines» carrying the moral weight of society's obligations to its needy members. In part, I believe, this is because «care» and «caring relationships» have been viewed as distinct and separate from the relationships in which they are embedded and from which they draw their particular characteristics.

Much of the analysis of the reasons for the devaluing of care has concentrated on the gendered and racialised characteristics of care-giving. Caring is seen as «naturally» the province of women, in particular women of low social class or from «other» ethnic groups, and consequently of lower value than the work carried out in the public sphere and which is seen to directly contribute to the prosperity of society. But Tronto has suggested an additional reason for this devaluing of care:

... the disdain of «others» who do caring (women, slaves, servants) has been virulent in our culture. This dismissal is inextricably bound up with an attempt to deny the importance of care. Those who are powerful are unwilling to admit their dependence upon those who care for them. To treat care as shabby and unimportant helps to maintain the positions of the powerful vis-à-vis those who do care for them (Tronto, 1993, p. 174).

We can see something of this in the response of some within the disability movement to care. This is not to argue that disabled people occupy a powerful position in society, but to recognise the power of a discourse which makes a binary distinction between independence and autonomy and which is dismissive of those seen to occupy a position of dependence vis-à-vis others. In this context those who already experience themselves as marginalised as a result of social organisation premised on the assumption of able-bodiedness can be reluctant to acknowledge the necessity of interdependence when

asserting the importance of enabling increased autonomy. The rejection of care per se in favour of a rights based approach to support for disabled people has sometimes been couched in terms which are dismissive both of care as a social good and of those who provide it — both paid and unpaid. For example, Richard Wood, one time Director of the British Council of Disabled People, wrote:

Disabled people have never demanded or asked for care! We have sought independent living which means being able to achieve maximum independence and control over our lives. The concept of care seems to many disabled people a tool through which others are able to dominate and manage our lives (Wood, 1991, p. 199).

Tom Shakespeare (2000) offers an alternative discourse within which to understand this issue — that of help and helpfulness. He recognises the value of the feminist ethic of care as a counterbalance to the independent living model advocated by the disability movement. In his more recent work he recognises «*Giving and receiving care is a biological imperative for human beings*» (Shakespeare, 2006, p. 135) and he is critical of the independent living and direct payments options as the only way to solve the support needs of people in diverse circumstances.

## Biographies and Narratives

In the book *Caring and Social Justice* I tell the stories of 12 family carers based on narrative life history interviews. My primary purpose in these interviews was to understand what care giving meant to those I interviewed, and how they made sense of their experience of care-giving in the context of other aspects of their lives. I wanted to hear how carers spoke about care-giving, how they told their stories and to explore the relationship between «care» and «justice» in the way in which they spoke of care-giving.

Narratives have been used in a number of social and health care practice contexts as well as a means of conducting research. For example, Middleton and Hewitt (2000) describe life story work with people with profound learning difficulties who were moving from hospital to community based care. This work was prompted by a recognition that nursing care plans, in spite of a terminology which suggests both a trajectory and a purpose to the provision of support, quite specifically failed to ensure any sense of continuity, history or future. But as this example illustrates, much mainstream health and social care practice has little sense of the individual and shared histories of those who come to be users of services. Assessments are predominantly functional and focussed on the nature and intensity of individual deficits, rather than designed to explore how people are making sense of the situation in which they find themselves, what care means to them, and how this might be affected by who they have been, as well as who they are. Policies based on such an approach to determining need and risk emphasise the allocation of

individuals to categories in order to determine service eligibility. They focus on the care receiver and sometimes on the care giver, but rarely on the relationship between them. They have little to say about the achievement of social justice through care.

One of my objectives was to counter an approach which emphasises deficits and problems and which decontextualises caring relationships — both in the way in which care is researched, and the way in which policies and practices intended to provide and support care are developed. Another is to address the way in which care per se has become devalued as an emphasis on rights and empowerment has come to the fore. This is not intended to trivialise the demands that caring makes, nor to suggest that rights and empowerment are unimportant — indeed much of my own work has been concerned very directly with empowerment (see e.g. Barnes and Bowl, 2001). But I do want to suggest that opposing care and rights is unhelpful and that policies intended to achieve social justice need to embody both.

## An Ethic of Care Analysis

Carers' stories can be analysed individually to reflect on the nature of caring relationships in the context of individual and shared lives, but here I want to consider them from the perspective offered by a feminist ethic of care. I draw on the work of Joan Tronto (1993) and Selma Sevenhuijsen (1998) to do this. The ethic of care as developed by Tronto and Sevenhuijsen promotes care as a political value as well as one that concerns interdependencies between people in their private lives.

This perspective challenges the notion of care as a natural expression of women's capabilities, as well as the idea that it is only some people who need care. It argues the necessity of social policies based in an ethic of care as well as offering a framework within which ethical practice can be developed.

From this perspective, care includes both self-care and care for others; it does not oppose dependence and independence but recognises that we are all givers and receivers of care at some points in our lives. Care includes the perspectives both of care givers and care receivers, and recognises the existence of power and conflict within caring relationships. Care as a practice recognises the existence of messy moral dilemmas that can only be resolved through moral deliberation — what Sevenhuijsen (1998) has called «muddling through» in particular contexts, rather than the application of fixed guidelines and formal rules contained in many codes of practice. Such practices are constructed within relationships through processes of narrative that generate understandings of how the moral principles of care need to be applied within these particular contexts.

Tronto (1993) has identified four moral principles of care:

1. Attentiveness — without an awareness of and attentiveness to the needs of others it is not possible to act to meet those needs.

2. Responsibility — attentiveness without action cannot constitute a caring morality. Thus taking responsibility for action is the second element of an ethic of care, although an ethic of care does not presuppose a particular type of action, and the notion of responsibility needs to be understood flexibly.
3. Competence — a concern with the impact of care implies that one dimension of an ethic of care must be that caring work should be competently performed.
4. Responsiveness — because caring takes place in situations where there are greater or lesser degrees of vulnerability: «the moral concept of responsiveness requires that we remain alert to the possibilities of abuse that arise with vulnerability» (Tronto, 1993, p. 135).

For Tronto this means that we should consider the position of the care-receiver from their perspective.

These principles are located within an understanding of care as central to all our lives and which recognises that all of us are at some time care receivers. This perspective enables us to go beyond enumerating the tasks of care giving and offers a way of reflecting on care as a moral process as well as a multi faceted form of labour. In turn this provides a way of understanding the broader significance of care giving which also goes beyond an economic analysis of the amount lay carers save the state through the unpaid labour they perform.

Collectively the carers' stories suggest a number of characteristics which reflect conclusions consistent with an understanding of care in this way:

1. They support previous conclusions about the emotional, physical and organisational labour involved in care-giving, the significance of anticipatory and (re) constructive care and the frustrations carers often experience in their relationships with statutory agencies. But talk about the tasks of care-giving were often in response to questions from me, rather than what carers chose to talk about in starting their stories. Carers spoke of caring in terms of moral principles and dilemmas as well as burdensome tasks. The process of care giving often involves moral dilemma that are faced in the context of difficult and messy day to day situations.
2. It was clear that caring is often not a one off activity, and people are often involved in a variety of caring relationships throughout their lives. People often take for granted that care giving is something that they will do in different circumstances.
3. The identities of care giver and care receiver are not necessarily distinct. This is the case empirically in that people are frequently both care givers and care receivers during the course of their lives. But, in different ways carers recognised the importance of receiving care, of caring for themselves, as well as of giving care.

4. Stories of caring are interwoven with stories of other aspects of people's lives — the experience of care giving is itself interwoven with developing and sustaining other relationships, interests and employment, and of dealing with other challenges life may present.
5. Whilst care giving may challenge or even fracture previous relationships, such relationships cannot be separated from relationships of care and carers often look for continuities between their experiences as carers and other parts of the lives.
6. The intimate and personal knowledge which characterises caring relationships was often connected with aspects of care giving which were concerned very directly with ensuring that the rights of care recipients were respected. Fighting for proper treatment for the person they cared for and for themselves was part of the process of care giving and in many cases it is hard to separate whose «rights» are at stake. Experience of fighting such battles in their personal lives can often result in carers taking those battles onto a wider stage and campaigning both for carers' rights and the rights of disabled and older people to receive appropriate support.

## Conclusion

The latest approach to social care in the UK that is intended to improve the quality of welfare is the introduction of personalised budgets. In this system service users are allocated a budget based on an assessment of their needs and they then plan how they will use this money to purchase the support necessary to deliver their personal plan — which also has to specify how it meets government objectives. Alan Johnson has proclaimed that this represents «A major transformation of power from the State to the Citizen. This has the potential to be one of the most radical Public Service reforms for a century. 21st Century social justice with an active and empowering state, rather than one which is paternalistic and controlling.»

Central to the self-directed care model is the process of planning. Individuals are helped to assess their needs by professionals. They are then given an indicative budget and draw up a «self-directed support plan», with help as necessary from professionals and others in their personal networks. Once approval is given the money is released for the individual to spend on the services identified.

This process suggests a very particular way of thinking about both the individuals in need of support, and the nature of the relationships they have with friends, family members and other «significant others». It implies a high level of self-knowledge and reflexivity; substantial predictability in relation to needs and the circumstances in which they may be met, and a willingness to take on the responsibility for constantly reviewing whether the support and help being given is enabling the achievement of objectives.

Support becomes instrumental and the individual is incentivised to find ways of making their money go further, as well as being required to share responsibility for the risk that services will not, in fact, deliver what was anticipated. There are circumstances in which these conditions apply. For disabled people with relatively stable conditions, for whom the primary need is to ensure appropriate personal support that can enable them to get to work on time and take part in cultural or leisure activities, and who are in personal relationships where it is reasonably unproblematic to agree the role of paid carers in relation to the support offered by partners or family members, then this model makes sense.

But the stories carers tell demonstrate that often it is not like this. People's lives are often messy and unpredictable, and the biggest challenges to be faced are concerned with personal emotional responses to illness, impairment or injustice, and the interpersonal impacts of this. These circumstances often raise moral as well as practical dilemmas that can only be resolved through highly specific negotiations.

A model of service delivery that focuses only on the personal dimension, that works with a concept of care as a commodity that can be planned for, bought and controlled is inadequate in the face of the messy moral dilemmas, and the need to be able to construct and re-construct lives and relationships in the context of pain, hurt and unpredictability. The skills and qualities required for this are not those of the brokers and support agencies necessary to help service users negotiate terms and conditions and manage a pay roll for their care staff. Rather they are the relational skills, the capacity to engender trust and confidence that the best social workers, nurses, occupational therapists, day centre and home care workers can demonstrate, and which service users in a wide range of contexts say they value. Such skills are nurtured through dialogic practices based on ethic of care principles that can deliver support through negotiation with service users and those close to them.

Such an approach is necessary to ensure justice in conditions of vulnerability in relation to both individual care givers and care receivers. As Kittay (1999) has argued we need principles of justice that are capable of accommodating the «dependency» of severely disabled people and the «dependency work» of those who care for them. Such principles form a vital aspect of welfare quality — at both policy and practice level.

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