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Mortality and morality: ageing and the ethics of care

LIZ LLOYD*

ABSTRACT

This paper focuses on the circumstances of death and dying in old age. It considers the ways in which social policies and social gerontology reflect the values of independence, autonomy and citizenship, and it considers the implication of these values for older people who are dependent on others for care and support at the end-of-life. It discusses the complexity of the relationship between ageing and dying, by exploring recent research from the fields of social gerontology and the sociology of death and dying. Arguing that a long-term perspective is required to understand fully the circumstances of older people's deaths, it analyses the third age/fourth age dichotomy as a conceptual model. The task of developing knowledge about the links between ageing and dying requires consideration of moral and ethical principles. The article examines the conceptual frameworks developed by feminists who argue for an ethics of care as a central analytic referent in social policy. The feminist ethics-of-care approach provides a powerful critique of the moral framework of independence and autonomy as characterised in contemporary policies and practices. Feminist ethicists argue that the inter-relatedness of human beings and the importance of the social context have been overlooked in the preoccupation with individual rights – as reflected more generally in policies and social life. It is argued in the paper that the need for care at the end-of-life highlights these shortcomings. The feminist ethics of care has considerable potential to illuminate our understanding of dependency and care, and to generate both new approaches to policy and practice in health and social care and theoretical perspectives in gerontology.

KEY WORDS – ethics of care, autonomy, independence, dependency, citizenship, third/fourth age dichotomy, social death, good death.

Introduction

It is said that death throws into the limelight the cultural values by which any society lives (Kearl 1989). The social status of people throughout life is reflected in the way their deaths are perceived and in the practices concerned with their dying. At the same time, social policies reflect prevalent

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social and cultural values. The policies and practices surrounding death in old age therefore illuminate broader cultural values, including those concerned with social status and inequalities. We do not have a language that represents adequately the nature of social justice and rights for those who are dependent on others for support and care. In contemporary British social and political life, these concepts are inextricably linked with independence, autonomy and citizenship. As a consequence, those who become dependent in later life suffer a loss of status and depend on the moral orientation of others for their wellbeing (Gilleard and Higgs 1998; Kendall 2001). This is particularly acute at the end-of-life in old age. With increasing proportions of people living to old age, death and dying are important issues for gerontology but they fit uneasily with the emancipatory models that have developed in the field. As Bauman (1992) has pointed out, the ultimate limit of dependency is on our mortal bodies. In the face of death, what is the point of emancipation?

This paper argues that a focus on the end-of-life in old age illuminates our understanding of some theoretical and political problems associated with concepts such as autonomy, independence, rights and citizenship. Conceptual frameworks developed in recent years by feminist ethicists are examined critically for their insights into dependency and care and to generate new models of welfare policy and practice. There has been increasing interest in the idea of an ethics of care in recent years. It is evident in various critiques of both the New Labour government's emphasis on work as a basis for citizenship rights and of the extent of individualism in social policy (see Barnes 1997; Bowden 1997; Daly and Lewis 2000; Sevenhuijsen 2000; Jenkins 2001; Williams 2001). In her critique of New Labour, Williams (2001: 468), for example, argued that 'an ethic of paid work has to be balanced by an ethics of care'.

This interest in the ethics of care has been paralleled by an increasing awareness of the need for a better understanding of the circumstances in which older people die. For example, a Health Equality Network seminar in April 2003 at the London School of Economics was entitled, 'Health care at the close-of-life: is this a cost the 21st century is prepared to meet?' Both *Age Concern England* and *Help the Aged*, the two most influential organisations representing the interests of older people, have recently produced policy position papers on death and dying. Debates have also developed among practitioners about the relevance of palliative care models to the care of dependent older people before their deaths. Perhaps most significantly, the Department of Health (2002) *National Service Framework for Older People* contains a reference to developing good practice in end-of-life care. These statements and debates inevitably raise questions about entitlement to resources and services and the assertion of individual rights.

No coherent set of policies pertains to death and dying *per se*, but policies in several other spheres, including health and social care, shape and influence the circumstances of dying. At whatever age we die it is likely that in the hours, days and weeks preceding our death we will use more health services than at any other stage of the life-course. Under contemporary demographic conditions, however, the 'cost' of dying has become inextricably linked with the costs of an ageing society. A focus on the end-of-life in old age therefore raises many issues related to older people's rights and entitlements to services, and to equity and non-ageist approaches to health and social care.

The paper first examines death and dying in old age, and identifies aspects of age-related inequalities and inequitable treatment. The discussion then moves to a consideration of the complex relationship between ageing and dying and why we need to take a long-term view of older people's access to support, both formal and informal. It considers also differences and inequalities between older people and the impact these have on their deaths. Next, policy responses are critically examined for their potential to address the issues raised. The perspectives of feminist ethicists are brought to bear on this critique. Finally, the article considers how older people might experience a 'good death' and how an ethics of care might influence this.

Policies and practices at the end-of-life in old age

A focus on the end-of-life in old age highlights both horizontal and vertical stratification. Whilst older people are disadvantaged in death in comparison to those who die prematurely, there are also important differences between them. This section sets out the way in which age-related inequalities influence death and dying. Perceptions of death and dying in old age are radically different from those of deaths at younger ages, as manifest in services to support people who are dying (Clark and Seymour 1999). Howarth (1998) argued that older people's deaths are seen as 'natural', relatively straightforward and 'on schedule'. Consequently they are considered not to be in need of special care and support, in contrast to those facing a premature death who are more likely to receive specialist services. The association of death with ageing leads to assumptions that old people 'know how to die'. Field, Hockey and Small (1997: 6) argued that under contemporary conditions, in contrast to the low value placed on infant deaths in pre-industrial societies, 'it is now the deaths of the old which are undervalued'.

Policies on palliative and terminal care tend to focus on particular terminal conditions and older people are less likely than younger people

to be referred to specialist palliative care or hospice services (Addington-Hall, Fakhoury and McCarthy 1998; Grande, Addington-Hall and Todd 1998). The reasons are multifaceted and cannot be dismissed simply as an effect of ageist attitudes or institutions. The shape and duration of dying trajectories are always unpredictable, especially those without a recognisable starting point. Palliative care is more easily organised for people who have a terminal diagnosis. The complex health problems of many older people frequently give rise to correspondingly complex dying trajectories, which can often only be understood retrospectively. There is, however, increasing awareness of the lack of attention to older people's needs in palliative care and of the need to pay greater attention to diseases other than cancer (Addington-Hall, Fakhoury and McCarthy 1998). Future developments in palliative care provision may therefore benefit older people.

Over 70 per cent of deaths in Britain occur in hospitals or nursing homes, and older people are less likely than younger people to die at home (Grande, Addington-Hall and Todd 1998; Higginson, Astin and Dolan 1998). Seale (1998) pointed out that several forms of compulsory disengagement for older people still contribute to a form of social death. The narrow range of services available to frail older people in their own homes contributes to this social death (Melzer *et al.* 1999). For example, Hockey (1990: 36) argued that the space where we live has come to be regarded as 'inappropriate as a space for dying'. A form of separation continues within residential care-homes. Hockey (1986) showed how 'fit' residents attempted to separate themselves from those who were perceived to be 'frail', and that staff also clearly distinguished the two groups. At the same time, there is evidence of age-related rationing, as in renal replacement therapies (New and Mays 1997), and in death-hastening in the form of 'not for resuscitation' injunctions which have not been discussed with the patient (Howse 1998; Age Concern England 1999; Davey 2001). Such practices form the context of older people's perceptions of their place in the world and their rights to a share of resources that enable them to exercise control over decisions about their treatment.

Suicide rates are higher amongst older people than any other age group, and are probably under-estimated, with the availability of prescribed drugs making 'indirect' suicide possible (Brogden 2001). Yet the recent England and Wales Department of Health (DoH) 'Suicide Prevention Strategy' focuses particularly on rising rates amongst younger men, which are seen as a 'waste' and an indication of dysfunction (DoH 2002). In fact, the *National Service Framework for Mental Health* refers to the problem of rising rates of suicide amongst people aged under 75 years but

not at all to the rates at older ages. In the *National Service Framework for Older People*, suicide prevention is referred to in the mental health strategy but not highlighted as a major problem. The conclusion can safely be drawn that policy makers perceive suicide in older age as far less of a social problem than suicide among younger people.

Lawton (2000: 174) observed that modern 'western' understandings of death have developed 'in tandem with an ideology of individualism'. She maintained that it is the process of dying rather than death itself that provokes the greatest fear and anxiety, not only amongst older people but also in wider social and cultural senses. The status of those who are dying is liminal, placing them in an ambiguous position as members of society. Lawton argued that the protracted period of deterioration and decline, frequently experienced under secular and individualistic conditions in contemporary western societies, constitutes an extended period of liminality. This is a particularly acute problem for older people, who are regarded as having already had a 'good innings' and whose claim on the support of others is therefore regarded as limited (Sweeting and Gilbooly 1997; Seale 1998; Froggatt 2001).

Lawton's observations on the ambiguous position of dying people need to be examined in relation to Howarth's (1998) view that older people's deaths are generally perceived as relatively straightforward. Howarth provides convincing empirical evidence that this perception is mistaken and argues that the idea that death in old age is straightforward may be a construction of younger adults. Lawton's description of the dying person's social position as liminal, or ambiguous, applies to all age groups. She argued that, 'one must look to broader cultural factors to understand why the experience of a prolonged period of deterioration and decline prior to death is seen and experienced in self-debasing ways' (Lawton 2000: 173).

The limitations of older people's claims for support result from a combination of social and individual factors. For example, older people contemplating suicide virtually never seek support from health services or other support, despite high levels of depression (Age Concern England 1999). Brogden (2001: 48) states the facts bluntly: 'Older adults' [attempts at] suicide have greater lethality, greater intentionality, less desire for attention or rescue, and motives not amenable to easy resolution'. Individual perceptions of self-worth and quality of life cannot be separated from the social context. Yet, in community care for older people, the overwhelming emphasis on physical needs has created a serious lack of attention to their social needs. It is sadly ironic that the pills given to older people to extend their lives are the means by which some choose to bring them to an end.

Differences among older people

An important question to consider is the extent to which differences between people are cancelled out in the final stages of life. As the saying goes, 'there are no pockets in a shroud'. However, the well-documented impact of socio-economic differences on the experience of ageing remains to the end, and death is evidently not 'the great leveller'. In fact, as Field, Hockey and Small (1997: 1) argued, 'worldly inequalities are in no way levelled at the time of death but persist, permeating every aspect of death and dying'. Socio-economic inequalities highlight the difference between the concept of *dependence*, the inability to look after one's self, and that of *autonomy*, the capacity for self-direction and choice (Arber and Evandrou 1993). Choice and control over support and care are a great deal easier for those who are able to purchase services; and the privatisation of care services reinforces socio-economic inequalities in access to care (Deeming and Keen 2002). For the wealthy, being cared for in old age may be experienced as a logical extension of their privileged position throughout life, while for the relatively poor, choice and control are highly constrained. For example, the cost of care at home, particularly at night, confounds many attempts to enable frail and sick people to remain at home. In England currently, the cost of care for one night is approximately £120 – which puts regular 24-hour care well beyond the reach of most people (Johnson 2003). The relatively long dying trajectories of many older people means that they may be obliged to leave their homes because they cannot afford services that are categorised as non-nursing or social care, whilst the more complex nursing care that they may require when nearer death is free.

Minority ethnic older people have particular difficulties in accessing care and support services and rely heavily on specialist voluntary agencies (Henwood 2001). Ethnic differences raise particular issues about the appropriateness of services at the end-of-life, including, for example, the ways in which religious and cultural needs are recognised and addressed in nursing homes and hospitals. It is also necessary to consider the value to minority groups of the westernised perceptions of independence that underpin all health and social care policies but which reflect particular cultural values.

Gender differences are also important at the end-of-life. For example, older men take their lives at four to six times the rate of older women, with social isolation being widely regarded as the crucial differentiating factor (Brogden 2001). Differences are also evident in the provision of care, with women providing the bulk of front-line, personal care to people who are dying (Field, Hockey and Small 1997). There are therefore compelling

reasons to develop a better knowledge of the complexities of the end-of-life in old age and to understand the nature of age-related injustices and inequities. Developing an understanding of the relationship between old age and death is a complex task, necessitating consideration of individual capacities and social relationships as well as broader social and political contexts.

The relationship between ageing and dying: the need for a long-term view

A long-term perspective on the circumstances in which older people die is necessary. As pointed out earlier, there may be no definable moment when a person can be said to be dying from rather than living with a disease. It is therefore necessary to examine how older people's relationship to health and social care services in the long-term influences the circumstances of their deaths. It is important to observe that the underlying values expressed in palliative care bear a striking resemblance to the principles of care in the community. These include person-centred, non-institutionalised, holistic approaches to care, openness in professional-client relationships, respect and regard for the dignity of the patient/service user, and choice and control over treatment and care options. It might therefore be argued that care in the community for older people could easily extend to palliative care without any reference to whether a person is dying or not.

The reality of community care practice, however, suggests that these underlying values have become seriously eroded (Glendinning 1998; Henwood 2001). Johnson (2002) argues that the privatisation of long-term care has led to injustices and a loss of rights for older people and that targeting has led to a preoccupation with physical needs and a neglect of social needs. The location of care is an important aspect of the slight application of good practice principles. The wish to remain in one's own home to the end-of-life is widespread and has been incorporated into policies on health and social care for older people (Heywood, Oldman and Means 2002). The White Paper, *Modernising Social Services* (Department of Health 1998), reiterated the aims of the 1990 community care reforms in specifying the national objective, 'To enable adults assessed as needing social care support to live as safe, full and as normal a life as possible, in their own homes whenever feasible' (1998: 111). There are, of course important questions to be asked about the nature of a 'normal' life, given the lack of attention to social needs, but even more important questions about the objective are the interpretation of feasibility, who

assesses the limits of feasibility, and in what way should they act on that recognition?

Preventive and rehabilitative strategies are compromised when older people become more dependent, particularly if they live alone or have no available family support (Lloyd 2000). Changing the care routine and moving the older person away from their own home into a residential care or nursing home should not be understood simply as a change in type and extent of need. Determining when the limits of feasibility have been reached is about the rational management of resources and perceptions of the 'proper place' to be at the end-of-life (Hockey 1990). Strenuous efforts made by older people, their families and by voluntary organisations can extend the time that older people stay in their own home, but support for families and funding for the voluntary sector is patchy and uncertain.

The *National Service Framework (NSF) for Older People* has a reference to end-of-life care in a one-page boxed text. This calls for older people and their carers to be given choice about treatment and care options, including the choice to die at home if that is what they wish. It appears to have been strongly influenced by the palliative care approach, calling for 'dignity' in end-of-life care and referring to spiritual and psychological care, the use of complementary therapies, and bereavement support for families, friends and carers (Department of Health 2001: 26). The issue has therefore reached the policy agenda – apparently as a result of pressure from older people (Harding 2003). It is, however, difficult to see how the wish to remain at home until death could be granted in the current climate, since the cost of maintaining older people in their own homes when they become highly dependent would far outstrip the resources available to service providers.

This is not to imply that practitioners in residential care and nursing homes are unaware of the importance of good care at the end-of-life (Froggatt 2001; Davies and Seymour 2002). On the contrary, they are increasingly likely to receive training from hospice staff in palliative care methods. The point is that policies that continue to emphasise the importance of supporting older people in their own homes – even to the point of death – fail to engage with the possibilities for more holistic forms of care that are available in other settings. Indeed, cases in which older people die alone in their own homes generate considerable disquiet and discomfort among those living around them, particularly if they are discovered some time after death (Howse 1998; Seale 1998). The need to be accompanied at the time of death is very strong, and a need for company may override some people's desire to remain at home independently. Residential care-homes can provide a welcome alternative to a lonely death (Lloyd 2000).

The third age/fourth age dichotomy

Even a superficial study of policies demonstrates that policy-makers and practitioners struggle with age bands and attempt to impose a kind of chronological order on the vagaries of old age. For example, overt suggestions have been made about limiting older people's rights to healthcare after the age of 75 years (Callahan 1994), the same age at which the government's suicide prevention strategy shifts the focus from mental health to old age. The *NSF for Older People* proposes that three groups of older people with indeterminate age boundaries need different types and combinations of services:

1. *Entering old age*: those that enjoy good health, who could be as young as fifty or have attained the official retirement ages.
2. *Transitional phase*: those between healthy active life and frailty, which could be at any age but occurs commonly in the seventh or eighth decade.
3. *Frail older people*: with frailty often being experienced only in late old age (Department of Health 2001: 3).

The task of 'rooting out' age discrimination is all the more difficult if there is a parallel aim to promote a better awareness of age-related needs. The desirability and appropriateness of age-specific medicine continues to be a subject for fierce debate (Roberts, Robinson and Seymour 2002). Thus, it becomes difficult to establish whose rights we are talking about and in what circumstances. An important question is how willing older people are to take up the cause of improving conditions of death and dying in old age? In general, campaigns against ageist practices frequently dissociate older people in general from death and dying, to give priority to positive images of ageing. Gilieard and Higgs (2000: 99) maintained that the third age/fourth age dichotomy characterises a fourth age of 'dependence, decrepitude and death', which is necessary to enable the third age of independence, economic, social and physical wellbeing and positive enjoyment to emerge. As they point out, 'the "frail elderly" remain as the "other"—a problem always framed in the third person, for and by every voting adult' (2000: 199). There is therefore a question about whether campaigns for the rights of dependent older people can thrive.

At the individual level, older people are acutely aware of the risks inherent in being seen to have become 'decrepit'. This was powerfully demonstrated in Minichiello, Browne and Kendig (2000). Their older respondents reported that carers would 'keep watch' over them to check for signs of decline in their appearance and behaviour. Consequently the older people often went to great lengths to avoid giving the impression that

they were giving up, the effort they put into 'keeping going' being perceived as equally important as their actual state of health and ability to function. These experiences had serious effects on older people's concept of self, their views of their own competence and of their safety in the community. Minichiello, Browne and Kendig's findings imply that in contemporary western societies, increased dependency is inextricably linked with the loss of autonomy.

Autonomy is frequently cited as a precondition of a good death, as demonstrated in recent policy position papers on death and dying developed by organisations representing the interests of older people. *Age Concern England* presents 12 principles that constitute a 'good death'. These include: to be able to control what is happening, knowledge and awareness of one's dying condition, choice and control over treatment and who else is present at the death, dignity and privacy, access to information, spiritual and emotional support, hospice care, the ability to issue advance directives, time to say goodbye and control over aspects of timing, including the ability not to have life prolonged (Age Concern England 2002). A policy statement on the 'End-of-life' developed by *Help the Aged* (2002) similarly emphasises individual autonomy as an essential element of a good death. The organisation is currently campaigning for more clarification of the situation of people who lack capacity to consent to treatment, and in what circumstances and how the power to consent is passed to someone nominated by the older person. Presently in Scotland a nominee has the ability to make decisions on the patient's behalf, but this is not the case in England and Wales. The positions of both *Age Concern England* and *Help the Aged* are clearly in line with prevalent conceptualisations of individual autonomy, choice and control, and are an attempt to construct the rights of those who are dying within this framework. There are, however, many problems with this standpoint.

First, there are inherent tensions between the ideals of autonomy and the physical and social constraints that are generally placed on the dying person (Lawton 2000). How can any of us exercise 'control over what is happening' at the time of death? Is this not stretching a desire for autonomy beyond the limits of possibility? Opposition to euthanasia by *Help the Aged* and other organisations can be seen as a logical outcome of fears about the vulnerable position of older people, despite the potential of euthanasia to increase people's control over the process of dying. Second, we must question how older people at the end-of-life are enabled to assert their rights in relation to death when their rights in old age have been diminished. Third, what happens to those who have not appointed proxies or made living wills? Should rights at the time of death depend on previous actions and decisions? The problem is that there are limits to choice

and control, which will vary according to individual people's capacities and the opportunities available to them during the process of dying.

The loss of social and citizenship status experienced by older people at the end-of-life highlights the inadequacies of social policies that aim to promote equity and social justice (Higgs 1998). These may be explained as a deficit in implementation, inadequate resources, or a lack of individual commitment. The problem, however, goes deeper because we still need to consider the liminal position of those who are dying in old age. The next section considers the ways in which perspectives from feminist ethicists shed light on this particular problem.

Morality, ethics and the political agenda

Critiques of social policy frequently show that the aspirations of policies are not reflected in the everyday experiences of service users. For example, the *NSF for Older People* states, 'In recent decades an overdue and new found respect for older people has emerged and the attitude that wrote people off as "elderly" has given way to one that demands that older people are seen as having individual needs' (Department of Health 2001: 2). It is, therefore, not so much a problem of getting issues on the agenda but of achieving desired outcomes. The finger of blame for failure to meet expected standards is pointed increasingly at politicians and managers at the local level, who are inundated with guidance, targets and financial sanctions from central government. A recent King's Fund survey, for example, noted that whilst senior managers in health and social care welcomed the emphasis in the *NSF for Older People* on tackling age-related discrimination, they resented the unrealistic time frame for putting the principles into practice (Roberts, Robinson and Seymour 2002).

The reality of policies is that they often do not promote social justice but end up reinforcing already existing inequalities and injustices. It is a ubiquitous problem that may be explained as a fault in the policy process – an implementation gap, which is the result of inadequate resources or a lack of political will or both. However, according to feminist ethicists such as Tronto (1993), Weir (1995) and Sevenhuijsen (1998), the problem lies at a deeper level, to a large extent in the way that concepts such as equality, justice and autonomy are conceptualised. Understanding this as a conceptual problem implies that to understand its ramifications, one must look beyond the lack of resources or political will. The argument is that because moral theories concerning the equal worth of all human beings are conceptualised as separate from and superior to cultural and political life, the question of how these theories are to be applied in people's

everyday lives is not engaged. As Bowden (1997) has argued, moral philosophy has traditionally distanced itself from the practical world and claimed impartiality for its theorising. Feminist ethicists reject this stance and assert that moral philosophy has to pay attention to the psychological, social and political dimensions of life.

Through this conceptual dichotomy, argued Tronto (1993), morality is confined to matters such as human relationships and awareness of 'proper' behaviour, whilst the practice of politics is confined to matters of security, public order and the allocation of resources. Consequently, we end up either in a 'politics first' position, in which the moral order has to bow to the supremacy of the political agenda (a Machiavellian situation), or in a 'morality first' position, in which moral principles are established and then pressed on the political world to accept. In reality, despite being conceptualised separately they are deeply intertwined.

In addition, failure to address the question of how ideals such as social justice can be made a reality places an enormous burden of responsibility on people and gives rise to feelings of hatred for 'the other'. This is particularly difficult in terms of a generalised sense of responsibility for other human beings. Tronto points to Arendt's (1973: 236) *The Origins of Totalitarianism*, which argued that racism and totalitarianism are the very realistic, if destructive, ways of escaping this predicament of common responsibility. Ageist practices in health and social care for dependent older people can be understood in a similar way. When equal rights of access to healthcare are asserted with no reference to the resource-base of healthcare provision, the conditions are in place for discourses to develop that are antagonistic to older people (as on bed-blocking). As one manifestation, a colleague who was recently a hospital in-patient recounts that the frustrations of nursing staff about the lack of facilities in the community, which delayed the discharge of older patients, readily transformed into aggressive talk about *and sometimes to* the older people themselves.

Ethics, according to Sevenhuijsen (1998: 37), is the 'systematic and critical reflection on human action in the light of good and bad, right and wrong'. Right and wrong are identified in the moral agenda, morality being 'the totality of rules, codes, values and norms which are used to justify behaviour by labelling it right or wrong' (1998: 36). For Sevenhuijsen, it is important that ethics is not confined to academic theory but is a social *practice*, that is a socially-based and organised activity underpinned by formal or informal institutions or both. A strength of this definition is that it allows for many different kinds of moral considerations and value judgements to be considered, including those about resource distribution.

From the perspective of feminist ethicists, the moral and ethical (social justice) agenda is problematic because it is conceptualised in highly individualistic terms that ignore the social basis of human life and the interdependency of human beings (Higgs 1998; Williams 2001). The individual tax-paying employed worker can be seen to be in a losing situation if taxes are raised to pay for healthcare for which he or she currently has a low demand. Similarly, Jenkins (2001) points out that the promotion of individualism in community care has the effect of opposing the concept of community and that this dilemma cannot be resolved through recourse to individualistic, Kantian philosophy.

The feminist ethics of care can therefore be understood as an attempt to develop a new moral epistemology, which breaks with the rules of liberal political philosophy and offers a new conceptualisation of equity, justice and autonomy (Sevenhuijsen 1998). It takes into account the needs and rights of those too young or too old to be the active 'independent' adult citizen, as well as the needs and rights of those who provide the care. Thus the needs of older people at the end-of-life should be considered, not only in relation to their individual rights and claims but also in relation to their connectedness to others and the ethics of practices concerned with their care and wellbeing. The feminist ethics of care poses a major challenge to the politics of identity. Sevenhuijsen acknowledges, however, that identity politics often ends up as a 'politics of indignation', as groups assert their rights to a share of goods on the basis of their difference from others. This leaves those who are dying in old age in a particularly invidious position – at the bottom of the pile in terms of the liminality of their position and their extremely low social status. This is a familiar problem in the politics of community care.

A well-rehearsed argument in community care is that the idea of 'care' reflects and perpetuates inequalities in power and prevents disabled people from obtaining the civil and political rights enjoyed by the non-disabled population. The importance of this perspective is that it highlights a problem in the way we understand not only care but also rights. Social justice and rights – the moral agenda – are conceptualised differently from care. In answer to the question, 'Can there be a relationship between the ethics of care and justice?', Sevenhuijsen (1998: 39) posed a prior question, 'Why do these two have an uneasy relationship?'

From the standpoint of feminist ethicists, care is a central concern of all human beings. This includes the need not only *for* care but also *to* care: these exist in different ways in infancy, childhood and throughout adult life. They argue that the inter-relatedness of human beings and the importance of the social context has been overlooked in the preoccupation with individual rights that is reflected in policies and in social life more

generally. Tronto (1993) also argued that the centrality and power of care necessitate its confinement and devaluation within contemporary political life. Our need for care challenges the characterisation of the human as an autonomous, independent being, which makes it necessary to banish it from public life. From this perspective it is easy to understand the conditions described above of social death in old age.

It is important to stress that whilst values of care have often been associated with women's interests, they should not be understood as identical to 'women's values'. As Sevenhuijsen pointed out, whilst an ethic of care has its origins in feminist theory, it does not need a feminist 'tag'. Over many years feminists have argued that practices of care are devalued through their confinement to the private domain (Land 2002). Sevenhuijsen (2000) argued that there should be no presumption of a natural feminine orientation to care for others, but that on the contrary an ethics of care should take into account that there are inherent conflicts within caring relationships and situations. What is needed is for care to be brought into the political arena so that the interpretation of needs of everyone concerned in caring relationships can be better understood. As long as care is kept on the periphery of public life, those involved in caring relationships will be perceived as 'other' and their rights as citizens will be attenuated.

Sevenhuijsen (1998) and others have been careful to distance themselves from communitarianism. Whilst aspects of their position are shared with strands of communitarian thought, there are also important differences. The feminist ethics of care emphasises a constructivist and interpretive approach to understanding care, which avoids the problem of functionalism and the tendency to homogeneity inherent in communitarian thought. This is an important point in relation to dying in old age. In order to develop good support and care, it is essential to take into account the differences between older people and to overcome the standardisation that has become prevalent in health and social care.

Applying the feminist ethicists' analysis to end-of-life care

Tronto (1993) conceptualised care as a process with five stages: attentiveness, responsibility, competence, responsiveness and integrity. This model can be applied constructively to an examination of social policies (see Williams 2001) and is particularly useful in the context of end-of-life care.

Attentiveness means noticing what is going on and realising that there is a need, although under contemporary conditions one must prevent attentiveness becoming over-intrusive or a form of surveillance. It is however the

lack of awareness of older people's needs at the end-of-life that is currently the problem. Perceiving a need for care does not necessarily mean that we will proceed to the second stage of *responsibility*. Whether or not we do depends on several factors, including the extent to which an individual feels that responsibility rests with them. For example, it may be because of the nature of the relationship – care within marriage is a good example – or because of a sense of personal indebtedness. The third stage is *competence*, concerning not just individual ability to respond effectively but ensuring that the necessary resources are available to do so. The fourth stage is *responsiveness*. An ethic of care requires that we start from the standpoint of the one needing care. The fifth dimension is the *integrity of care*, which requires that all of the above four stages be taken into account.

Tronto's approach is useful in understanding how care for older people at the end-of-life should be developed. First, the issue of attentiveness is crucially important. Given the circumstances described above, it is easy to see how older people's deaths have become hidden from everyday life and from public scrutiny. Raised awareness is therefore necessary. However, raised awareness does not necessarily mean that there will be an increased interest in improving conditions. Those in favour of rationing resources by age include health system planners and policy makers who are only too well aware of discriminatory practices against older people. Whilst inequitable treatment in health and social care may give rise to demands, these need to be seen in a wider context. According to Tronto (1993: 136), this is not a simple process but involves conflict, and to resolve this will require a 'deep and thoughtful knowledge of the situation and of all the actors' situations, needs and competencies'.

We therefore need to tackle the issue of what level of resources should be made available to provide a high standard of care. Would the general public be willing to pay for older people to remain at home until they die? Or would there be an expectation that they should go into nursing homes in order to economise and give younger-age people priority in accessing resources for health and social care? There is also the issue of competence. The nurses who react so negatively against 'bed blockers' reflect a deep dissatisfaction with their inability to do a good job. Resources are an essential element of competence. Competence is also an issue for informal care. Care for people at the end-of-life is a very demanding activity in which the knowledge and skills of professional health-care staff need to be provided to support families and other informal carers.

Tronto's concept of responsiveness raises an important point for health and social care practitioners. The concept of empathy – a basic tenet of good professional practice – is the ability to put oneself in the position of the person needing care. However, the interpretation of need is still through

the mind of the professional. The ethics of care approach is about understanding the person's own perception of their situation. As Barnes (1997) has pointed out, this is a real challenge to professionals whose approach to practice would require a fundamental shift. She also argued that such an understanding cannot emerge from a one-off assessment but would require a more long-term approach that allows a dialogue between all parties involved in arriving at a decision about what is needed and how to meet the need. Human agency is central to the ethics of care. Sevenhuijsen (1998) argues that perceptions of need are not determined by objective necessity but by the language used to describe care and the psychological and emotional dispositions of those involved. This is abundantly clear in community care practices, with managerialist definitions and re-definitions of need and eligibility criteria that shape the whole picture of care. It is also clear in the frequently expressed concerns of older people who dread becoming a burden on others (Biggs 1998).

Tronto (1993) argued that an ethics of care provokes moral dilemmas because the level of need for care cannot be predicted and because of the variety of people's lived experiences. An important question to be addressed is *which needs must be met?* This is essentially a political issue and, as discussed above, part of the privilege enjoyed by the powerful is their ability to define needs in a way that suits them and which obscures their own dependence on others. From the perspective of social work practice, Conn and McVicker (2000) argued that the dominance of procedural and resource considerations often prevents clients' own perceptions of their needs from being articulated (see also Aronson 2002). Bauld *et al.* (2000) argued that whilst resources are targeted more effectively at those in greatest need, this has been at the cost of meeting the needs of other older people and their carers. The other fundamental question posed by Tronto is 'how do we evaluate the proper level of care?' This question directs attention not only to the needs of those requiring care but also of those providing it, and it breaks down the divide between informal carers and service users still evident in policies and practices. Ross (2003: 190), for example, has argued that 'the role of the carer, whilst increasingly recognised in law is not well understood in the legal framework for the support and protection of users', and pointed out that, 'we have care delivered privately in a private domain to [a] presumptively autonomous adult by [another] presumptively autonomous adult, but implemented in the name of the state and regulated according to public law descriptors' (2003: 191).

As Tronto has argued, a political order that understands rights only in terms of autonomy misses out on a great deal of human experience. Again, a focus on the end-of-life in old age poignantly highlights this issue.

The concept of a good death demonstrates the importance of our inter-relatedness and essentially social nature. In order to be considered good, a death should satisfy broader cultural norms, social expectations, the needs of those who are close to the dying person, as well as the needs of the person who is dying. Privileging individual rights over social needs might lead us to the conclusion that suicide is a good death, since it is entirely within the control of the individual, yet it is regarded as the antithesis of a good death. Quite apart from the distress caused to bereaved family and friends, it offends social norms and expectations. At the same time, a seemingly straightforward demand for equality of access to the whole range of available healthcare, with no reference to chronological age, ignores the problems associated with prolonging the dying process in old age and the maintenance of dignity at the end-of-life. There is therefore a need for more sophisticated analysis and greater openness in debating the issues.

Critiques of the 'ethics of care' approach

Many find the argument for an ethics of care problematic, for 'care' is a difficult word with many negative connotations. From a disability rights perspective, Shakespeare (2000) called for it to be replaced with the word 'help', which has connotations of friendship rather than dependency. Silvers (1995) argued that an ethics of care fails to take account of the ways in which dependency and vulnerability are constructed and disabled people marginalised. It turns vulnerability into a virtue, but Silvers's position can be challenged on two counts.

First, regarding dependency as part of the normal human experience neither elevates nor debases it. In contemporary western societies, independence has become the ideal quality of the adult human being and the *sine qua non* of public policies. The effect of this is to generate a sense of obligation to struggle to achieve as near as possible the ideal – as highlighted in Minichiello, Browne and Kendig's (2000) research. Second, Silvers fails to address adequately the problem of how struggles against marginalisation and oppression are constituted in the prevailing constructions of independence and citizenship. The concept of 'active ageing', so prevalent in contemporary policy discourse, stresses the importance of older people being able to function in ways that best approximate to the ideal of the independent autonomous adult – and for as long as possible. In contrast, a focus on the whole lifecourse enables us to see more clearly our essentially social nature and the ways in which vulnerability and dependency are experienced by all human beings at different times.

Others argue that whilst an ethics of care is relevant to the private domain it has no power in the public domain, in which relationships of care are already highly controlled. Several analyses have demonstrated, however, that relationships of care in the public domain are more complex than they superficially appear (Daly 2002). Hoschild's (1983) work on emotional labour is a good example, and another is the concept of 'complex mundanity' developed by Baldock and Ely (1996), which they apply to seemingly mundane and straightforward activities such as home care which are actually highly complex, and experienced as such by the person receiving care. Thus, caring for a sick and frail older person requires the kind of responsiveness called for in Tronto's model of care.

Bowden (1997) pointed to the potential contradiction of regarding care as a universal concept whilst at the same time emphasising the variety of forms of care in real life. Sevenhuijsen adopted a 'care is everywhere' stance, which raises the danger of care being seen as so pervasive that the concept becomes meaningless. This does not mean, however, that the feminist ethicist critique should be entirely dismissed. Bowden's effective defence used empirical examples from motherhood, nursing and citizenship. The idea of an ethics of care requires continuity of analysis and refinement. In the context of death and dying in old age the argument mounted by feminist ethicists is too important to ignore, since it addresses many of the concerns that have been raised over recent years by gerontologists. Like Daly and Lewis (2000) and Sevenhuijsen (2000), Williams (2001: 470-1) has stressed that care has the capacity to be a central analytic referent in social policy: a point at which social and cultural transformations meet with the changing relations of welfare. A focus on care is relevant, therefore, not only to inter-personal relations but also to broad welfare trends. The ethics-of-care approach directs us to fundamental questions about social organisation and challenges the ways in which these have been answered.

Conclusions

This paper has argued that the emphasis in contemporary social and political life on autonomy and independence has led to a highly impoverished view of how wellbeing can be promoted even through the dying process (Kellehear 1999; Lloyd 2000). There is a need to expand our vision of what a good death would be, going beyond the assertion of rights and control. Whilst death might be regarded as a supremely individual experience, evidence suggests that we have a deep need to be accompanied at the end-of-life. In a letter to the *British Medical Journal*, Grogono (2000)

referred to the idea of an *amicus mortis* – a friend at death. Dying should be understood therefore as a time when our social nature is evident and when an ethics of care is highly appropriate. Understanding older people's experiences of the end-of-life requires considerable skills in listening and interpreting what is said. Moreover, it is important to recognise that needs change over time as do people's understandings of and ability to articulate them. We need a much more sophisticated level of understanding of how older people negotiate their way through changing circumstances at the end-of-life. The separation of a period of life surrounding death and calling for the introduction of palliative care at a defined stage simply does not take into account fluctuating levels of need and dependency. The principle in the *NSF for Older People* of enabling people to die at home if that is what they wish will not be realised if they are unable to remain at home through a prior chronic illness.

Care for older people who are at the end-of-life might appear to be the most difficult context in which to imagine a good quality of life. A perspective on the end-of-life brings our own mortality into sharp focus and disturbs our senses of purpose and order in life. The concept of a 'good death', however, is both broad and practical and enables us to understand that this is not simply a matter of how 'they' die but how deaths can be made as good as possible under today's cultural and social conditions. What is understood as 'good' in death is a moral issue but also the outcome of cultural and social interactions, political deliberations and resource distribution. The feminist ethic of care provides powerful insights into the social and political issues that confront older people at the end-of-life and sheds light on the inadequacies of the relevant policies and practices. A social policy based on the centrality of care to social life in general would be an important corrective to the current depiction of older, dependent people as a separate group whose rights as individual citizens must be subjected to the political imperative of maintaining limits on expenditure.

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