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The moral economy of selfhood and caring: negotiating boundaries of personal care as embodied moral practice

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Abstract This paper engages with the dichotomous notions of caring underpinning social policy and practice in Britain, that splits up the 'carer' and 'cared for' into autonomous, unitary subjects, by locating personal care as an embodied, moral practice within a theoretical framework of relational ontology. Drawing on empirical accounts and narratives related to personal care within the context of advanced cancer, we argue that personal care involves negotiation of boundaries between notions of relatedness and legitimate dependence on one hand, and independence and integrity of the embodied self on the other; and we analyse how these boundaries are informed by particular cultural or religious scripts on gender, relatedness, conjugality and filial obligations. The paper draws on data and analysis based on observations and in-depth interviews with White and South Asian participants between 19 and 89 years of age receiving treatment for cancer, and family members closely involved in their personal care. In using a comparative method for analysis and understanding caring as an embodied moral practice and site of subjectivity across cultural/religious groups, it is suggested that ethnicity is not necessarily the only useful analytical concept to explore the illness and caring experiences of research participants from minority ethnic backgrounds.

Keywords: caring, culture/ethnicity, inter-subjectivity, gender, moral identity

Introduction

The current academic and policy debate on caring in Britain reflects the pervasiveness of legalistic notions of individualism, autonomy and selfhood. Concomitantly, the politics of community care has superimposed a notion of professional care, premised on a dichotomy between the 'carer' and the 'cared for' onto family-based caring (see Twigg and Atkin 1994)[1]. Literature on caring highlights the conflicting interests of users/patients and carers (Grande *et al.* 1997); and constructs family-based caring in terms of burden, losses, disruptions and poor quality of life for carers (*e.g.* Schofield *et al.* 1997). Literature on cancer care, in particular, highlights potential conflict between perceptions of the person who is ill and the carer. It has, for example, been suggested that carers might overemphasise physical symptoms while underplaying psychological and spiritual distress faced by the person having cancer (Field *et al.* 1995); and carers might underplay their own needs while trying to represent the voice of the person needing care (Grande *et al.* 1997), despite legal recognition of their needs and concerns within the *Carers (Recognition and Services) Act* 1995.

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We are not contesting the contribution this literature has made to our understanding of the impact of caring on the lives of carers or the power dynamics underpinning caring relationships (see Parker 1993, Morris 1993). We argue, though, that a theoretical bias towards a dichotomous notion of caring underpinning the debate locates the voice of the 'patient' and the 'carer' in separate, unitary, autonomous individuals. Also, this literature privileges physical care and ignores the positive and emotional aspects of caring as being central to notions of identity premised on interdependence and reciprocity (see Wenger *et al.* 1996, Nolan *et al.* 1996), negotiated within complex biographical and cultural contexts (Chamberlayne and King 2000). Indeed, Fraser (1989) argues that mutual need and caring responsibilities cut across the lifecourse and are located within wider notions of relatedness and interdependence. These emerging debates attempt to mediate the long-standing tension between feminist writers defining care as exploitation of women's labour and some disability activists perceiving notions of care as disenfranchising and reinforcing perceptions of disabled individuals as passive and dependent (see Watson *et al.* 2004, Hughes *et al.* 2005).

This paper locates personal care as an embodied, moral practice within a theoretical framework of relational ontology, by focusing on the significance of moral boundaries in negotiating personal care, drawing on experiences and narratives related to cancer. Moral practice can be defined as, '. . . in part, a language of self-enactment; that is, a language in which a conduct can be recognised in terms of its "virtue" and an agent may recognise himself (herself) in terms of his (her) virtuousness' (Oakeshott 1975: 75, cited in Williams 1993: 103). Theoretically, we assume an embodied self that is inter-subjectively constituted (*cf.* Mead 1934), and engage with caring as a site of subjectivity and reconstitution of notions of a 'competent social agent' (*cf.* Giddens 1991) across cultural/religious groups, for both the family carer and person needing personal care.

Giddens (following Merleau-Ponty and Goffman) suggests that, 'Bodily discipline is integral to the competent social agent; it is transcultural rather than specifically connected with modernity. . . .' (1991: 57). Routine control of the (performative) body is central to maintenance of ontological security and biography of self-identity, a theme we have pursued elsewhere (Chattoo and Ahmad 2004). We have argued that it is equally important to analyse the wider reverberations of threats to bodily integrity in relation to disruptions caused to significant roles and relationships that seem to define notions of a socially competent agent. Further, Giddens's theory of self-identity within the context of modernity reveals an interesting tension between notions of inter-subjectivity and 'reflexive planning' premised on autonomy and control (*cf.* 'colonisation of the future') that is relevant to our broader discussion, as summarised below.

On one hand, Giddens (drawing on Wittgenstein) suggests that inter-subjectivity (*i.e.* being part of a linguistic community) is the basis of subjectivity (1991: 51). On the other, he treats autonomy as being mutually exclusive with notions of inter-dependence and reciprocity. This is brought to sharp relief in the dualism he poses between an 'externally referential' system of norms and morals characterising pre-modern society, and modernity being characterised by a set of 'internally referential' values chosen by the individual. Hence, 'pure relationship' – a sign of high modernity – is characterised by trust that, 'by definition', cannot be based on criteria of kinship, social duty or traditional obligation (1991: 6; also see Sevenhuijsen 2000: 27, on how obligations and responsibility are located within the domain of law in *The Third Way Politics*). Even though parent-child relationship appears as an exception, premised on obligations, it must eventually follow the same principle of trust. Reciprocity here is opposed to the notion of dependence, whilst reflexivity, '. . . should produce . . . insightful self-knowledge and help reduce dependence in close relationships' (1991: 93).

Mackenzie and Stoljar (2000: 3–31), drawing on feminist critiques of an association of autonomy with a self-sufficient, self-realising, integrated individual, explore a relational framework within which autonomy and inter-subjectivity are not mutually exclusive. They use the concept of 'relational autonomy' to analyse the implications of inter-subjective and social aspects of selfhood and identity for moral (and political) agency. It is suggested that 'autonomy competency' (*cf.* Meyers 1989), *i.e.* capacity for choice, reflexivity and self-direction, is both achieved (rather than ascribed) and/or potentially impaired within the context of social relationships, practices and institutions that constrain the options available to an individual.

We draw on these feminist critiques that outline a framework of care based on relational ontology premised on moral agency of individuals (also see Gilligan 1987, Tronto 1993) and caring is perceived as an 'ongoing process of moral orientation' (Sevenhuijsen 2000). This is not to deny that caring relationships might also reflect dimensions of power and conflict of perceptions and interests. We therefore suggest that the meaning of caring as an embodied moral practice needs to be understood within the biographical context of negotiation of moral choices informed (rather than determined) by various cultural scripts available to individuals (*cf.* Seale 1998: 31).

Methods and analysis

The arguments presented here are based on qualitative data collected as part of a larger study focusing on the meaning of cancer and caring among South Asian (of Indian, Pakistani and Bangladeshi origins) and White-English (hereafter White) participants receiving palliative care for cancer, and their family carers, living in three cities in North and Central England during 1999–2001. The study involved observations and in-depth interviews with participants who had cancer, their family carers and professionals. We recruited 56 (28 men and 28 women) participants between 19 and 89 years of age, well enough to talk to us. We were able to interview 54 of these (18 White and 36 South Asian), and 41 family carers, of whom 15 were interviewed separately and 26 with the person who was ill.

The sample was selected purposively to represent diversity related to age, family support, religious and socio-economic background within each ethnic group. The 36 participants of South Asian origin included 15 Muslims, 12 Hindus, seven Sikhs and two Catholics. One elderly couple lived in an Asian residential home, while three women lived on their own, one with no family support. The 18 White participants included three Roman Catholics, one 'non-believer' and others who designated themselves broadly as followers of the Church of England. Two men (one of whom had never married) and one woman lived on their own, while one couple lived with their son, separated from his wife.

The participants were recruited through professionals involved in their care and interviewed in their preferred language. Most of the interviews took place at home, three at a hospice, one in hospital and one at an Asian residential home. SC conducted most of the interviews with some help from part-time researchers, and was able to follow up two families from the time of initial contact with a palliative care team to the death of the participant. The interviewers used a broad topic guide covering *the meaning of illness* and *caring*, and *negotiating care with professionals*, lasting on an average for an hour and a quarter. Interviewing two or more participants within a family, especially when sitting-in together, posed 'risky moments' in negotiating issues about diagnosis and prognosis within the boundaries set by each.

All the interviews were transcribed verbatim or (those conducted in Hindi, Punjabi or Urdu) translated and transcribed, demanding constant appraisal of translators' bilingual skills and checks against original tape-recordings where necessary. The dataset was analysed using thematic analysis, comparing similarities and differences within and between ethnic groups. In addition, detailed case-studies, based on narrative reconstitution of events and experiences, were written for 27 participants and their family carer/s using a biographical or life-story approach (Chamberlayne and King 2000), making careful decisions about how these voices are represented within the text (see Alvesson and Skoldberg 2004: 5-6). This complementary approach mediates between the individual, cultural as well as structural levels of analyses of illness and caring (*cf.* Williams 1993), providing a comparative framework that cuts across ethnic boundaries.

The data extracts used in this paper have been selected specifically from case studies, following various levels of retranscriptions, analysis and alternate interpretations. Whilst these extracts provide a minimal set that best represents the themes and tensions outlined above, the 'selection and reduction' itself had a dialogical relationship with the theoretical framework informing the analyses (Reissman 2002: 249, 253). This process involves 'systematic, and contestable, exclusions', given our premise that representations of social relationships are partial (*i.e. committed and incomplete*), as suggested by Clifford (1986: 6-7).

The terms 'South Asian' and 'White' are being used here as commonly denoting ethnicity. Without going into a debate on the semantics of the term, ethnicity as a process of multiple identifications by self and the other, rather than a category with fixed attributes, is not the focus of our discussion here. Whilst ethnicity remained an important marker of difference and discrimination in the narratives of some South Asian participants, it was not a useful concept to explore the themes underpinning this paper. This exclusion signals our move away from the essentialising binary of majority: minority cultures, reiterating a basic premise that culture is not, '. . . an object to be described, neither is it a unified corpus of symbols and meanings that can be definitively interpreted. Culture is contested, temporal and emergent' (Clifford 1986: 19).

It is interesting to note, for example, that often participants of Indian and Pakistani origin appropriated the notion of 'Asians take care of their own' as a statement of exclusion (difference) and moral superiority. However, such notions of moral and cultural distinction did not address stories of neglect within or similar patterns of 'caring for one's own' as a virtue cutting across ethnic and religious groups. Similarly, whilst White participants seldom professed corresponding notions of a 'White culture', this did not mean that their caring practices were free of shared cultural underpinnings of gender, age, conjugality and filial responsibility. Hence, we treat such descriptions as data rather than analytical distinctions (see Baumann 1995: 721).

We therefore refrain from outlining the cultural scripts implicated in caring as a site of moral practice and subjectivity, whilst acknowledging the significance of relevant cultural or religious values within the context of a particular narrative. These come to life as the following sections (using pseudonyms) analyse the meaning and negotiation of moral boundaries focusing on gender, relatedness and notions of legitimate help; caring as an embodied moral practice within a framework of relational autonomy; and fulfilment of obligations and caring with a *telos*.

The meaning and negotiation of moral boundaries

Lawton (2000: 165) has argued that when a family member or friend becomes a patient's carer, the relationship between the two often ceases to be of 'pure type', since many carers

have little or no choice over whether they take responsibility for providing the patients with 'hands-on care'. This notion, rather inadvertently, locates the role of the carer as arising at a point in time. We argue that people exercise choice not only in fulfilling or, conversely, in not recognising, a responsibility to care but also in how moral boundaries are drawn around what constitutes care and who can be involved in providing such care. As suggested earlier, we assume that caring arises within an existing set of kin and non-kin relationships, and previous cycles of 'material and moral inheritance', to borrow the insightful phrase from Finch and Mason (1993). The centrality of reciprocity to the notion of caring was well summarised by John Ross, who was in his eighties and suffering from prostate cancer:

> I mean, I hear of people who have to wipe their old man's bum everyday and or *vice versa*. It happens, and as far as I'm concerned, it's payment back for 40 or 50 years of other things that she (wife) has done for me or I have done for her. . . .

Whilst this paper focuses on personal or intimate care, it is difficult to maintain a clear distinction between what constitutes personal care or 'caring for' and other aspects of 'caring about' (*i.e.* emotional, practical and financial support) in narratives on caring, often highlighting the non-dyadic nature of caring relationships. This comes out clearly in how Nahida Khan perceived the importance of fulfilling her responsibilities towards her father who was seriously ill. In making a distinction between the notion of filial responsibility or obligation and *caring from the heart*, she draws our attention to how not only the fulfilment of obligations but *the way* we fulfil them can be a signifier of moral identity.

Nahida was in her thirties and lived with her husband and two children round the corner from her parents' house. She felt responsible not only towards her father who was suffering from prostate cancer that had spread to his spine, but also her mother who had severe arthritis and was finding it emotionally difficult to reconcile to the situation. (Her sisters lived and worked away from home.) She was helping her parents with cleaning, cooking, banking and shopping and, as described by another carer, 'living as a family in two separate houses'. They had a home care package to assist her father get washed and changed. Anticipating a difficult period towards the end of his life, the palliative care nurse had suggested the option of 'end-of-life care' being provided at the local hospice. Nahida said:

> . . . you know, we want him home. And it is okay, I get a little bit tired but you know, it has not been horrendous, really. It has been something that *I have wanted to do from my heart.* Not really as a *duty* . . . because my father has always been there for me. . . . And we actually needed a deposit to move into this house . . . , and he didn't even ask, he just gave us the money. . . . He never asked for it back or anything, you know. So he has always, financially whatever, been there for us and I just know that I have to be there for him. I wouldn't want him to be anywhere else. There is no way he is going back into . . . (the hospice). (our emphasis)

For Nahida, sending her father to the hospice for end-of-life care, as distinct from short-term stay for symptom control, was an abrogation of her responsibilities towards her father as well as her mother in supporting her to care for him at home[2]. This was despite her apprehensions that he might be 'like a vegetable' towards the end and need 24-hour personal care. Nahida's comments bring to light the centrality of notions of delayed reciprocity and maintenance of moral identity through fulfilment of filial responsibilities as part of the lifecourse of a family. It is important to mention that her ethic of caring was not located

within an 'Asian-Pakistani' culture. She lived in a predominantly White, middle-class suburb and distanced herself from her relatives, largely due to a family feud and partly as a marker of social mobility. Her emotional proximity to her parents was reflected in the move to live closer to them so as to be able to support them in their old age, a common practice defined as 'reflexive relationism' by Mason (2004). Equally importantly, her notion of caring was located within the specific context of her father's illness being terminal – that defines caring as a practice bounded in time as distinct from caring practices related to chronic and disabling conditions in general – a point to which we return in the following section.

Negotiating gender, relatedness and notions of legitimate help

Even though friends and neighbours were an important resource of practical and emotional support, they were rarely involved in physical care (see Payne and Ellis-Hill 2001: 6). Personal or intimate care, given that a majority of participants in our sample were married, was largely perceived as belonging to the domain of the conjugal relationship, supporting Qureshi and Walker's hierarchy of caring responsibilities (1989: 126). This was reflected in John's comment on the reciprocal nature of caring between spouses, and reiterated in the boundaries defined by his wife, Anne, related to the kind of help that she was able to accept from friends or professionals. Although friends offered help, there were obvious issues related to gender and social boundaries of care, as is clear from Anne's following comment:

> One of the difficulties with having people in for John has been because of, you know, there he is, he's a man, *wants to keep as much dignity as he can*. And I have had quite a few offers of help from friends, lady friends . . . but I don't feel able to put them to the difficult (task), and I don't feel able to put John through the difficulties. I think they are between husband and wife. Isn't it? (her emphasis)

Anne defined her responsibilities towards her husband's care in terms of being 'natural', whilst recognising the restrictions imposed on her own life by the routine of care. She remarked, 'Well, it feels quite *natural really* because, you see, I am used to looking after the family. When they are ill, who else do they turn to?'

Anne's remarks about caring being central to female identity cut across differences of ethnicity and class. It is interesting that her notion of caring as a 'natural' function of women's life seems to reconstitute the dominant male imaginary that, according to Hughes *et al.* (2005: 262), sequestrates care within the domestic domain of love and nurturance reserved for the 'feminine other'; and is further institutionalised through state policies providing better professional support to male than female carers (Twigg and Atkin 1994). However, the role of male carers, especially in relation to spouses and children, might well be under-represented due to this wider, cultural construction of care being 'women's work' (see, for example, Fisher 1994). We therefore need to represent men's experience of undertaking main responsibility for personal care, and to see whether they negotiate boundaries related to caring any differently. The following summary is provided to illustrate this point.

Prabhat Chauhan and his wife Savita, a couple of working-class background, lived with their 18-year-old daughter and 13-year-old son[3]. Savita's breast cancer was inoperable by the time it was diagnosed a year earlier when she was 37 years old. Following a course of radiotherapy, she was left with an oozing wound that complicated the routine of personal care and issues related to maintenance of social identity and stigma (see Chattoo and

Ahmad 2004). Her 'smelly' wound and the fear of being sick in public symbolised a 'leaky body' that challenges the social boundaries of an embodied self (*cf.* Lawton 2000). Withdrawal from every day social life was her way of managing potential embarrassment, whilst Prabhat was keen on maintaining a semblance of normalcy in their everyday life. He took time off work to be her 'full-time carer'. It is important to remember that his experience of caring is located within the specific context of end-of-life care that, as suggested earlier, defines caring as an activity bounded in time – pre-empting a form of narrative closure imposed by a sense of imminent loss and bereavement.

Prabhat's narrative on caring was structured by a notion of conjugal responsibility in relation to personal care – crosscutting the divide between kin (blood ties) and affines (relations through marriage) – that informed negotiation of boundaries with professional carers. He believed that his wife felt physically and emotionally closest to him when it came to personal care. She would accept help from her mother and children but certainly not her mother-in-law (who was visiting from India) or sister-in-law who lived locally. Whilst the family was part of a larger Gujarati-Hindu community, she would be ashamed to seek help from 'others' (distant relatives and friends). Savita's side of the family lived in Canada and even her mother, who visited and helped when her illness was first diagnosed, was discouraged from visiting again.

The reasons why Prabhat did not want his mother, mother-in-law and close relatives (or professionals) to help with Savita's personal care or routine were complex. First, personal care (including housework) involved moral boundaries around notions of self-reliance as a family on one hand and personal dignity and shame (for Savita) on the other. In fact, the community palliative care nurse looking after his wife was quite anxious that he was 'taking on too much' since he had refused professional help though the District Nurse visited regularly to dress her wound and help her with a bath. Secondly, and more importantly, he needed to contain the discussion related to his wife's illness, since she was still struggling to come to terms with the knowledge of her impending death. Whilst he appreciated that relatives and friends visited or rang out of concern, the tight routine of 24-hour caring left little space for attending to visitors and phone calls.

At one level, Prabhat seemed like a carer whose life was completely 'trapped in the private sphere' by the routine of caring, with little sleep at night, time for a bath or social life (see Twigg and Atkin 1994, Chamberlayne and King 2000 for broader discussion on 'coping' strategies). In fact, he acknowledged that he was as much 'a prisoner in his own house' as was his wife. On another level, it seemed that his engulfment was concomitant of his wife's terminal condition, clashing with his efforts at 'keeping her going'. Prabhat would not consider alternate arrangements for his wife's nursing care. He believed that respite care was for 'the elderly and infirm' – an idea that undermined his role as a younger, caring husband. The couple had been offered hospice care till the end – an option that was not acceptable to them since Savita wanted to spend whatever time she had at home, with her children. Despite the narrative closure forged by the prognosis and his decision to take care of her at home, Savita went back to the hospice for pain and symptom control and died there.

Prabhat's effort at maintaining the caring routine with minimal assistance from extended family or professionals reflects a notion of 'coping' as physical endurance and moral resilience – identified as a virtue of women's identity but a threat to a male carer's masculinity (Katbamna *et al.* 2000). However, given that identities are gendered, and assuming that an ethic of care must address difference, we find it unhelpful to suggest that Prabhat was 'feminised' through the practice of caring (*cf.* Hughes *et al.* 2005: 262). We suggest that the male voice in a caring relationship needs to be represented on its own, without subsuming it within the hegemony of an alternate, feminist imaginary.

We do not wish to gloss over the significant differences in how dominant norms related to conjugality and filial responsibilities are structured within South Asian and White communities, both in terms of a notion of 'legitimate dependence' on adult children (*cf.* Vatuk 1990) and the differing role of sons and daughters (see Finch and Mason 1993). It is not possible, however, to engage with the subtle interplay of the dominant and demotic norms in practice, given our focus.

Hence, choices and boundaries related to notions of legitimate help with personal care implicate gendered sensitivities as part of the larger biographical and socio-cultural context within which meaning of caring and relatedness are nested. At the same time, choices related to caring with regard to self and significant others might be articulated differently by men and women during different phases of their lifecourse. For example, women's narratives on real or potential situations of caring related to self, in particular, suggested that they did not wish their children to be tied-in with personal care, reflecting a 'gendered sensitivity' to the notion of dependence (*cf.* Finch and Mason 1993: 49) and previous experience of caring for a relative that frames the meaning of caring. Anne, who otherwise believed in 'taking care of one's own' rather than relying on professional help, wanted her sons to 'feel free' of any potential responsibility towards her personal care. She had painful memories of caring for her mother who had died of Alzheimer's disease. Similarly, Nahida, who would not contemplate sending her father to a hospice for terminal care, would much rather go into a nursing home than see her children struggle with her care.

Contrary to Finch and Mason's suggestion (1993), men who haven't had personal experience of caring might still find accepting help with personal care equally difficult, reflecting fundamental tensions in caring as an embodied (rather than only gendered) practice, as explained in the following section.

Caring as an embodied, moral practice within a framework of relational autonomy

We shall now look at the implications of caring as an embodied practice by focusing on the notion of bodily integrity as being central to the notion of a competent self[4] and how it hinges on one's ability to sustain identities through important roles and relationships. As suggested by Donchin (2000: 239–40), 'Interconnections continue to shape us and define us throughout our lifetime. . . . The threat of serious illness or trauma both endangers these connections and thwarts autonomous pursuits'.

The notion of relational autonomy is brought to sharp relief in how people experience and talk about their own loss of mobility. Hence, whilst threatening the integrity of the embodied self, certain aspects of loss of mobility might focus on the other – the carer – rather than the self[5]. This was succinctly brought to light by Hafiz Khan, Nahida's father, a 61-year-old retired engineer. Hafiz defined his loss of mobility due to the spread of cancer to his spine as the most difficult aspect of his illness. He perceived it as a form of imprisonment for his wife and three daughters, as is clear from the following excerpt:

SC: What has been the most difficult aspect of your illness?

H Khan: Losing my independence . . . I can't cope myself. I have to be dependent on my wife or children. I find I have given them a life imprisonment, this is my thinking. I know they don't think (so), but I think I have given them life imprisonment because *they have to suffer* in the same way (with me). Although they do their best . . . that is what I cannot come to terms with. This is the only stressful thing for me.

SC: We were talking about losing your independence (but) you seem more worried about what it means to them rather than to yourself?

Hafiz broke down in response to this probe and explained that whilst his family had been the greatest source of strength for him, he found it difficult to watch his wife go through such an emotional trauma. The whole family had been affected emotionally and physically by his illness, especially Nahida (introduced earlier), with whom he shared a special bond. He knew that his wife and daughter cared out of love but was still worried that he might become 'a burden on the family' – not a fear of neglect but of physical dependence that contradicted his roles and obligations as a supportive husband and protective father.

We found that accepting help with personal care from family often had serious reverberations for notions of personal dignity as well as gendered identity of a person needing care. It is hardly surprising that some of the participants felt upset over questions regarding personal care and who they thought was 'ideally responsible for taking care of them'. For example, Ken Smith, who was in his fifties and reasonably well at the time of the interview, insisted that he did not need anybody 'taking care' of him. However, his wife, Shirley, suggested, on the contrary, that he had recently been poorly during chemotherapy when he lay in bed all day, and needed help with bathing and changing. Ken's resistance to the notion of being 'cared for' is understandable since he did not wish to dwell on the discontinuities posed by his illness and likely prognosis (as reiterated by his wife) – a common process of 'bracketing off' unsafe information rather than denial (*cf.* Schou and Hewison 1999).

There is, however, another context within which resistance to the idea of being 'cared for' might reflect a denial of emotional legitimacy to the carer's role. The following example of a disjunctive narrative, where a couple (interviewed separately) are presenting conflicting accounts, suggests the implications of such perceived denial. The point is not about whose narrative better represents 'reality', rather, what these disjunctures tell us about their relationship.

Andrew Smith, a 72-year-old devout Roman Catholic, seemed reconciled to having advanced oesophageal cancer for which he was receiving palliative treatment. His wife, Mary, suffered from severe arthritis and had recently started using a wheelchair. The couple had four sons and a daughter, of whom two sons lived locally. Only the youngest son, Mark, himself disabled, who lived close by, was involved in their daily routine of cooking, cleaning and shopping. (Mark was interviewed on Mary's suggestion though his voice, corroborating hers, is not represented here since that seemed unfair to Andrew who was not present)

Andrew said that he was quite independent and went for hospital appointments on his own since (he thought) Mary felt that she was in his way. Mary acknowledged that she felt terrible that he had to push her wheelchair around, when she ought to be taking care of him since he was terminally ill. Whilst Andrew talked quite openly about his own death, drawing strength from his faith and work within the church community, Mary said that she wasn't sure whether he had accepted his prognosis, given his attempts at being 'independent', 'carrying on' as being fine and still playing golf despite being told by the doctor that he was 'looking at months'. Hence, both seemed to be interpreting Andrew's independence differently, whist being thoughtful of each other's need for personal care. However, there was an undercurrent of resentment in Andrew's narrative when asked, 'who ought to' take care of him:

> . . . who should be looking after me? Well, sometimes I feel a bit sorry for myself that nobody cares about me and I am . . . looking after other people, when I should be looked after.

Andrew's remark betrayed a tension in his relationship with Mary that he did not voice openly. He seemed to suggest that Mary's disability precluded her from fulfilling her caring responsibilities. However, she felt that Andrew deliberately wanted to exclude her from his illness – reflecting long-standing tension in their relationship marked by disagreements and flashes of temper (on his part)[6]. One night she had heard him cough and tried to comfort him and offered to make him a cup of tea. He refused and said that he would go down himself to make some tea. Mary felt especially hurt that Andrew would not eat anything she cooked, though he ate whatever Mark (their son) cooked for him. Whilst it was clear that Andrew was unable to eat most of the foods due to his illness and oesophageal surgery, his 'refusal' or inability to eat was construed as symbolising his rejection of her love and care (also see Seale 1998: 149–71). As she put it, 'I am not angry that he has cancer (*i.e.* is dying) but because he won't let me do anything for him. . . .'

Hence, a lack of emotional legitimacy for the caring role led to a notion of a failed self for Mary, despite her own disability and legitimate excuse for not being able to take care of Andrew. Whilst she attended church regularly, she suggested that her relationship to God was different (less regimented) from Andrew's, and did not state explicitly whether her sense of failed responsibility had a particular religious connotation. It is of theoretical interest to note that within certain cultural scripts, caring appears to have a *telos* – a moral purpose or objective (see Blackburn 1996: 374) legitimised by religion – reified and appropriated to reaffirm a virtuous self, as discussed below.

Fulfilment of obligations and caring with a telos

Ikhlaq Din, an 80-year-old Muslim man of Pakistani origin had, until his illness, led an 'independent life' in sheltered accommodation reflecting a wider notion of 'intimacy at distance' (*cf.* Finch 1989) in relation to his three sons and their families living within a radius of 15 miles[7]. He was diagnosed with cancer of the prostrate that had spread to his spine, leading to a difficult hospitalisation and an eventual move into the middle son's house, suitable for his needs.

Ikhlaq Din was upset about being 'totally crippled' by his illness – he couldn't walk without help and was dependent on his son and daughter-in-law for personal care, especially prayers and his religious routine that were central to his notion of a competent self:

> (Now) I am totally dependent, you know. I don't like (it) this way at all. I have to get washed completely five times (a day) for my prayers, (as) in Islam. That is the main difficulty. (Later on) My son gets up early in the morning at that 4 am, which is my prayer time, in the middle of the night. He has to get me washed. It is *gratifying to him*, but more troublesome to him as well as to me, you know. (our emphasis)

The excerpt points to the spiritual significance of personal care in Ikhlaq Din's daily routine, and the role of the son in maintaining that routine within a reified ethic of 'legitimate dependence' of ageing parents on adult sons (*cf.* Vatuk 1990). At the same time, the process of negotiating decisions related to his personal care towards the end of life reveal a complex interplay of social, religious, personal and interpersonal factors brought to the surface by a crisis event, rather than a simple appropriation of a dominant script of caring for one's elderly parents.

The daughter-in-law, Hamida, asserted that she and her husband were happy that her father-in-law had moved in with them rather than the older or younger brother-in-law, both of whom had 'legitimate excuses' for not fulfilling their filial obligations. The older son and his wife (Hamida's sister) ran a family business, leaving nobody at home during the day to

take care of father. The youngest son was unemployed at the time, hence it would be unfair to expect him to undertake any additional responsibility, (though Hamida believed that her father-in-law would have preferred moving in with the youngest, his favourite, implying differences within the extended family). The decision to move in with them involved pragmatic issues of 'economic stability', a downstairs room and toilet and the fact that Hamida was at home, even though she had three young children to look after. The move had a special moral significance since caring for one's infirm and elderly parents, especially towards the end of their lives, is a *farz* (obligation sanctioned) within Islam, fulfilment of which entails *swab* (religious merit). At the same time, her commitment to care for her father-in-law (also her paternal uncle) 'as my own parents' was linked to a significant loss – both her parents had died a few years earlier, at a time when she had not been able to go back to Pakistan to be with them.

Ikhlaq Din was incontinent and confined to his bed during the last few weeks of his life, needing 24-hour care and morphine for pain relief. The family had declined offer of terminal care at a local hospice where he had been treated for a brief period earlier in the illness. It is important to mention that Hamida was, in fact, involved in intimate care that would normally be perceived as inappropriate and a breach of gendered boundaries of caring within Islam in general, and their relationship in particular. The exceptional circumstances of end-of-life care allowed for certain transgressions, negotiated carefully within the notion of *farz* (obligation/duty):

Hamida: . . . even when I used to change his bed I would never see him, you know, fully naked . . . it might have happened (accidentally) once when he needed to change his (urine) bottle, when he was very ill. So I was always careful about that and sometimes he used to say, . . . 'no don't do that'. Because, you see, it is a question of the relationship and both of us felt that . . . I felt that it's my duty, and he was relying on us.

SC: Did you explore the possibility of having a male nurse to help with these matters?

Hamida: Well we never really pursued it because at night my husband, his son, used to look after him, and during the day I used to look after him, and the nurses used to come in three to four times a day. But you see, it's not so critical that a man has to look after a man or a woman a woman, you know, especially when they are in that condition.

SC: Do you think it would be different if, say, it was not a life and death situation?

Hamida: Yes, it would be, for example if he had only been disabled or whatever – then he would himself feel embarrassed.

Thus, the religious script of *farz*, defining filial responsibility, allowed modification of gender relations within the particular context of end-of-life care. Legitimacy for 'the right thing to do' was provided by the notion of *swab* (religious merit) in taking care of one's terminally ill parent – locating the narrative on caring within a higher moral (religious) order. The religious script of *farz* and *swab* established their moral credibility within the extended family and the Pakistani *biraderi* (used in its broader sense of 'community'), whilst their children had an opportunity to experience the ideal notion of 'taking care of your own'.

It is important to remember that the family had not followed this particular script in the past, just as the three brothers responded to the same situation differently depending on their situations. This appropriation of the textual notion of caring as *swab* with a *telos* or

a moral purpose seems to be in contrast to the notion of 'caring from my heart' in Nahida's narrative; reflecting different moral orientations to self- and kinship obligations within the same cultural-religious group. This reiterates two points. First, '. . . agents are both psychically internally differentiated and socially differentiated from others' (Mackenzie and Stoljar 2000: 21). Secondly, looking at moral responsibility within a relational framework suggests that notions of a competent self depend on legitimate membership of a moral community since shared norms shape the moral assessment of an agent's actions and the account thereof provided to others (*i.e.* self-worth), as suggested by Benson (2000: 81–3).

Concluding comments

As suggested in the Introduction, the notion of caring within British social policy is premised on a dichotomy between the 'person needing care' and the 'carer'. Within this dualistic construction of caring, the voices of the person needing care and carer are located in separate, unitary, autonomous individuals, often locked in a conflict of interests. This notion of an autonomous and unitary self, a legacy of enlightenment, is reinforced in liberal social theory where the individual is perceived to face endless, fluid choices based on 'lifestyle' rather than a moral framework derived from norms or values associated with family, religion or tradition (Giddens 1991), and caring may be perceived as an infringement of autonomy (*cf.* Giddens 1998, for review see Sevenhuijsen 2000).

As an alternative to this dichotomous notion of caring, we located the meaning of caring as part of a moral orientation of an embodied self within a framework of 'relational autonomy', in accord with our ontological premise that 'autonomy competency' is both achieved and/or potentially impaired within the context of structural constraints of social relationships and institutions. Rather than implying that self and significant other(s) are seamless, we suggested that, for both the carer and the person needing care, self is constantly reconstituted as a balance between notions of interdependence or legitimate dependence on the one hand and independence on the other. We tried to show how bodily integrity played a central role in negotiation of moral boundaries involved in caring as an embodied moral practice; and how these boundaries were informed by particular cultural or religious scripts on gender, relatedness, conjugality and filial obligations irrespective of the ethnic background of individuals. To conceptualise caring as an 'infringement of autonomy', therefore, seems to undermine its meaning and centrality in the negotiation of moral economy of self and identity.

Finally, our use of the comparative method for understanding caring as a site of subjectivity across ethnic groups reiterates that ethnicity is not necessarily the only useful analytical concept to explore the illness and caring experiences of research participants from minority ethnic backgrounds. The marginal though subaltern field of ethnicity within mainstream sociology of health and illness has made a significant contribution towards our understanding of difference, discrimination and inequalities in health and access to services within Britain. We need to strive towards a more inclusive sociology of health and illness by developing methods and concepts that incorporate diversity – whilst avoiding the dangers of reifying difference and research participants from minority ethnic backgrounds as subjects of a marginalised field.

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Notes

1 Heaton (1999) has suggested that the term 'carer' did not appear as part of the debate until the 1970s.
2 This distinction was salient for other participants, across divisions of ethnicity, and invokes notions of good death that lie beyond the scope of this paper.
3 It was not possible to interview Savita, given her deteriorating condition and Prabhat's concern about upsetting her, though he had previously agreed to a joint interview that had to be cancelled.
4 Lawton (2000: 175) suggests that bodily incapacity can lead to a 'deconstitution of self' and social death in cases of advanced cancer. However, her data relate predominantly to an ageing self in a hospice setting, pre-empting her analysis of loss of relationships as arising from biographical circumstances rather than bodily capacity per se.
5 Narratives on pain are another good example of how relatedness is constituted. Some of the participants talked about how distressing their physical pain was for their spouse or elderly parent, and why they would not ever wish to change places with their carer.
6 Mary's narrative portrayed him as an 'unsocial' person, tracing his personality to a harsh childhood in an impoverished 'Irish ghetto', marking a class distinction within the family.
7 This account is based on two interview sessions with Ikhlaq Din and his daughter-in-law, and a further interview with the daughter-in-law following his death.

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