

## From competence to vulnerability: Care, ethics, and elders from racialized minorities

YASMIN GUNARATNAM

University of Central Lancashire, Preston, UK

**ABSTRACT** *This article discusses the care of older people from groups most commonly referred to in the UK as being “minority ethnic”. It considers the significance and growing popularity of social policy initiatives aimed at cultural competence in care provided at the end of life. Drawing upon qualitative focus group interviews with 56 health and social care professionals involved in the delivery of palliative care in the UK, this paper examines how the end-of-life care of “minority ethnic” elders is talked about by professionals, highlighting the gaps that can exist between conceptual models and real-world practice. The role and relevance of cultural competence as an “abstract system” (Giddens, 1991) is examined critically and attention is drawn to the ethical potential of professional experiences of vulnerability and of not knowing what to do. It is contended that these components of care are marginalized in current approaches to cultural competence that can discourage engagement with socio-political realities and stifle emotional and moral thinking.*

**KEYWORDS:** death and dying; ethnicity; ethics; narrative; older people

### Introduction

The diasporic condition of the migrant shares with death and dying a symbolic location in late modernity, characterized as it is by increasing globalization, risk, and precariousness (Beck, 1992). Both represent a journey and movement into the unknown: both raise questions of embodiment, rights, and citizenship; and both can serve to disturb and question the social order, our sense of purpose and being, or what Giddens (1991) has referred to as “ontological security”. In the case of old age and death, it has been asserted that ageing, illness, and dying are experiences that are subject to processes of sequestration and collective denial (Aries, 1974, 1981; Baudrillard, 1993; Elias, 1985; Gorer, 1965).

Across Europe, first generation migrants are ageing (PRIAE Research Briefing, 2004) and death is a phenomenon of old age (Davies & Higginson, 2004). Yet, at a general level, the psycho-social, symbolic, and institutional plight of the dying migrant has been a marginal interest in the social sciences, and researchers have yet to interrogate with sufficient depth and complexity the ways in which

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Correspondence: Yasmin Gunaratnam, Senior Research Fellow, Department of Ethnicity and Health, University of Central Lancashire, Preston PR1 2HE, UK. Tel: 01772 892780.  
E-mail: YGunaratnam@uclan.ac.uk

end-of-life care for migrants and those from racialized minorities is conceptualized and felt, not only by patients and carers but also by professionals. As several authors have pointed out, care can be a versatile analytic lens in social policy, raising questions of “intimate citizenship” (Plummer, 2003) in the overlapping of the private and the public, and in highlighting the relationships between socio-cultural transformations and changing welfare relations (Fink, 2004; Lloyd, 2004; Williams, 2001).

In this paper, I seek to transpose socio-political concerns about international migrants and about the precariousness of embodied human life to the examination of the micro-interactions that constitute everyday, end-of-life care practices for elders from racialized minorities. I will do this by drawing upon focus group interviews with health and social care professionals involved in the delivery of palliative care in the UK. My focus is upon the narratives of the experience of professional care giving to dying elders and the policies and conceptual models that guide such care. As Lloyd (2004, p. 236) has observed: “The policies and practices surrounding death in old age...illuminate broader cultural values, including those concerned with social status and inequalities”.

A specific analytic concern in the paper lies with examining critically the growing promotion and popularity of models of cultural competence in social policy as a means to achieving greater equity in care. Concentrating specifically upon the central role of cultural knowledge in cultural competence models, I argue that contemporary policy and pedagogical approaches to the care of racialized minorities can undermine equity and erode responsibility for emotional and moral thinking through their attempts to simplify and control the threat of the unfamiliar. In this sense, I have seen cultural competence as possessing many of the characteristics of what the sociologist Anthony Giddens has called an “abstract system” (Giddens, 1991). For Giddens, abstract systems are a consequence of modernity’s drive for control amidst accelerated social and technological change and the increasing complexity of institutional frameworks. At their most basic, abstract systems, shored up by expert knowledge, serve to defend against threats to “ontological security”. They do this by promoting routinized practices that codify and regulate behaviour, thereby removing from social (and personal) life, events, and experiences that demand emotional and moral deliberation, a process that Giddens calls the “sequestration of experience”.

### **A note on terminology**

It is widely recognized that the terms used to describe ethnic identity are both flawed and contested (Aspinall, 2001; Brah, 1996). As I have argued elsewhere (Gunaratnam, 2003, 2006), there are specific conceptual and political problems with the term “minority ethnic”, which is the term that is dominant in current policy discourses in the UK. As Brah (1996) has pointed out, the use of the word “minority” has a history based in pathological representations of women, colonial subjects, and working classes, whilst its homogenizing tendencies can serve to discourage a critical analysis of power relations. For Brah, the simplistic numerical

minority/majority dichotomy and its repeated circulation has the effect of “naturalising rather challenging the power differential” (Brah, 1996, p. 187). In this paper, I use the terms “minority ethnic” (in scare quotation marks) and “racialized minorities” to draw attention to the active processes of social categorization and power that are involved in terminology.

### **The project and interviews**

The development project from which the interviews are drawn was based in the voluntary sector and had two main aims: to increase awareness of palliative care amongst older people from racialized minorities, and to raise awareness amongst health and social care professionals about the experiences and palliative care needs of these groups of service users. The project was guided by a project advisory group that included palliative care professionals, patients and carers, community group representatives, and academic researchers. In response to the lack of existing research on ethnicity, older people, and palliative care, the project undertook qualitative exploratory interviews with older people and carers from racialized minorities ( $n=33$ ) and health and social care professionals ( $n=56$ ) to elicit their accounts and views of the relationships between ethnicity, old age, life-limiting illness, and care. In addition to generating information on service needs and experiences, the project used the findings from the interviews to develop information for older people and carers on palliative care and to contribute to the development of training and education initiatives for professionals. All of the interviews were audio-recorded (except for one spontaneous and elder initiated telephone interview with a carer) and transcribed verbatim.

The interviews with professionals took the form of focus group style interviews, which involve participants engaging collectively with a topic selected by the researcher (Krueger, 1988). The decision to use focus groups was taken with regard to both efficiency and because group interactions are relatively naturalistic and offer social contexts of meaning-making (Wilkinson, 1999). The latter point was important because the project was concerned with examining the everyday social processes that can be involved in caring for elders from racialized minorities. Eleven group interviews were conducted by the author with 56 health and social care professionals in hospital, hospice, and community-based teams in five multi-cultural, urban areas in England (London, Berkshire, Hertfordshire, Nottingham, and Leicester). In general, the interviews took place at the workplace of participants and lasted 50–90 minutes.

Recruitment of professionals was achieved using contacts from the project advisory group and snowball sampling. Effort was made to ensure that different sectors of palliative care provision (i.e., hospice, hospital, and community) and different professional disciplines were included in the sample. The main professional groups interviewed were nurses ( $n=30$ ) and social workers ( $n=16$ ). Other professionals included doctors ( $n=2$ ), cultural link/liaison workers ( $n=2$ ), an occupational therapist, a day centre manager, a hospice

volunteer manager, and a social work trainee ( $n=4$ ). The majority of those interviewed were white British ( $n=42$ ) and female ( $n=51$ ). See Figure 1.

The interviews were semi-structured, with open-ended questions aimed at generating narrative accounts relating to four main areas: the care of older people and carers from racialized minorities, experiences and perceptions of the needs of these service users, areas of difficulty and challenge in providing culturally responsive care, and care that was seen as being responsive to ethnic/cultural difference. As the interviews progressed, additional areas were explored as new issues and themes were identified. The interview transcripts were numbered sequentially according to chronology. Analysing the interviews involved reading each transcript several times to establish familiarity with the whole interview and the identification of descriptive codes to represent the main themes. This form of coding, whilst highly valuable in enabling comparisons between interviews, can result in the fragmentation of narratives (Hollway & Jefferson, 2000). In order to compensate for such fragmentation, analysis also included attention to the content of whole narratives or “narrative units” (Kidd & Parshall, 2000). Specific attention was also given to identifying commonalities and differences between different sites of care and between professional disciplines.

### Cultural competence and abstract systems

Despite the popularity of cultural competency approaches in social policy arena across the international spectrum (American Institute for Research, 2002; Bhui *et al.*, 2007) and their increasing inclusion in training curricula in medicine, nursing, and social work, their practical use and application have been variously

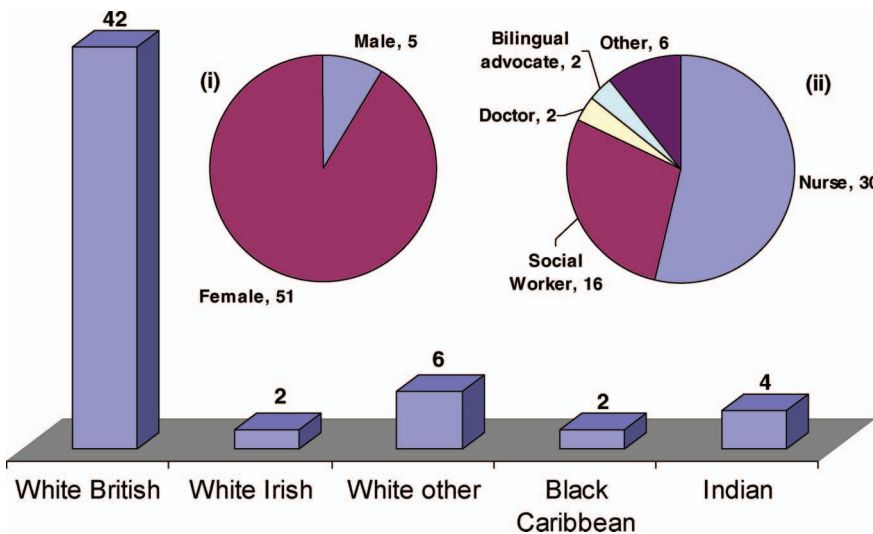


Figure 1. Main figure shows ethnicity of focus group participants. Inset (i) shows gender, inset (ii) profession. The number of individuals in each category is indicated.

problematic. There is little, if any, agreement about how cultural competence should be defined, what methods should be used to teach it, or how practice should be assessed and evaluated (Bhui *et al.*, 2007; Gerrish *et al.*, 1996). A systematic review of research on cultural competence in education and service delivery observed that:

There is considerable confusion about what constitutes cultural competence. For example, it may be narrowly interpreted to mean better knowledge of the cultural beliefs and practices of a specific cultural group, with little attention to how culture modifies illness perceptions, illness behaviour, and acceptability of specific interventions... Despite a growing body of health and educational policies that prioritize cultural competency in health care provision, there is surprisingly little agreement on the meaning of cultural competence training or knowledge about its effectiveness (Bhui *et al.*, 2007).

Despite such conceptual confusion, core components of cultural competency models have been identified as cultural sensitivity, cultural knowledge, and cultural skills (Kim-Godwin *et al.*, 2001), each of which attempt to address the affective, cognitive, and behavioural dimensions of practice (Gerrish *et al.*, 1996). Cultural sensitivity has been viewed in the context of partnership working between professionals and patients, involving trust, empathy, and respect for different cultures (Papadopoulos *et al.*, 1998). Cultural knowledge refers to knowledge and understanding of different cultural worldviews and practices, while the development of cultural skills implies some degree of synthesis of cultural sensitivity and knowledge within existing professional roles, functions, and skills (Kim-Godwin *et al.*, 2001).

In relation to palliative care, emerging discussions about cultural competence (Firth, 2001; Randhawa *et al.*, 2003) have been given added impetus by wider policy developments aimed at achieving greater access and equity. These developments have recognized the need for palliative care to respond equitably to demographic changes in the population and to ensure appropriate care for all those with life-limiting conditions, irrespective of care setting (House of Commons Health Committee Palliative Care, 2004; National Council for Palliative Care, 2005). The National Institute for Health and Clinical Excellence (NICE) in guidance on *Improving supportive and palliative care for adults with cancer* (NICE, 2004) made recommendations for the delivery of cancer palliative care in England and Wales. The guidance recommended “cultural awareness training” for health and social care practitioners (NICE, 2004, p. 60). This recommendation was broadly similar to that made by the House of Commons Health Committee on Palliative Care (2004) that affirmed: “(t)he need to ensure that all services are culturally sensitive should form an important dimension of the training of both generalist and specialist palliative care staff” (paragraph 78).

At first sight, the lack of conceptual clarity and the diversity of approaches to the provision of culturally responsive care can appear at odds with my reading of cultural competence as functioning in the same way as an “abstract system” (Giddens, 1991). It is important to recognize that Giddens’ conceptualization of

abstract systems does not necessitate internal coherence nor does it exclude differentiation. Rather, for Giddens the generation of abstract systems is characterized by their ability to develop “an internally referential system of knowledge and power” (Giddens, 1991, p. 144) that “may be internally contradictory and riven with chronic confrontation” (p. 150). However, in the last instance, Giddens sees such conflicts as being contained and determined by the internal system and not by external demands.

There are two main points from Giddens’ complex theorizing that are especially pertinent to my contention that cultural competence functions as an abstract system. First, abstract systems are concerned with controlling knowledge and everyday routines. Second, they are concerned with protecting “ontological security” by excluding fundamental moral and existential questions from the everyday that are raised by nature, criminality, sexuality, and sickness and death. As Smith (2002, p. 44) has observed: “Abstract systems encourage trust and promise security by underpinning daily routines, promoting expert knowledge and managing risk. Not only is morality extrinsic to these endeavours but morally unsettling questions must be hidden from view”.

It is my contention that as an anachronistic and abstracting system, cultural competence in the end-of-life care of elders from racialized minorities can function as a “protective cocoon” (Giddens, 1991, p. 182). It can shield professionals from threats to ontological security by obscuring the complex and profound emotional and moral questions that can be raised by dislocated ageing, frailty, and the death of a stranger. My argument is made more complex by recognition of the simultaneous challenging and undoing of the abstract systems of cultural competence in the micro-interactions of contemporary care. For Giddens, abstract systems are a hangover from modernity and their failure to keep up with the pace and the complexity of technological and social change can lead to a “return of the repressed” with unsettling moral and existential questions being pushed back into the centre of contemporary social life. Although Giddens has been criticized for failing to recognize the ways in which ethical codes and law can serve to deflect moral questions (Smith, 2002), the narratives presented in the following discussion demonstrate how some of the emotional and moral questions raised in encounters marked by sickness, death, and difference cannot be so easily reconfigured or standardized into a legalistic or rights discourse and not only provoke moral deliberation but also leave their mark upon practitioners. By this I mean that such encounters are remembered and can continue to trouble professionals.

### **Cultural knowledge and care at the end of life**

There has been a particular emphasis upon cultural knowledge as a means of achieving cultural competence in palliative care education and training, where a number of resources and training initiatives have been developed in order to provide professionals with information about different cultural and religious groups and death related beliefs, practices, and rituals (Green, 1993; McNamera



*et al.*, 1997; Neuberger, 2004). However, the relationships between cultural knowledge and culturally responsive care are far from straightforward (Gunaratnam, 1997; Jones, 2004).

In the focus groups, there were tensions and contradictions in the ways cultural knowledge was seen as playing a role in the care of “minority ethnic” elders. In interpreting these tensions, attention should also be given to methodology and to normative expectations. A significant problem with interviews is that participants can respond in ways that show themselves in a favourable light, particularly with regard to “sensitive topics” (Lee, 1993) such as ethnic/cultural difference, resulting in accounts of how participants think things should be, rather than how they are (Bourdieu, 1977). Bruner (1990) has used the term “canonical narrative” to describe those accounts that express normative expectations.

Given the promotion of cultural knowledge as a key component of cultural competence, it is perhaps not surprising that some of the professionals interviewed were enthusiastic about the value and role of cultural knowledge in the care of elders from racialized minorities:

I think we do need more information about cultures so that we can relate to people even more than we’re doing at the moment, so we are really trying (Nurse, Focus group 7).

While such attitudes can be read in the context of canonical narratives relating to the desired attributes of culturally competent professionals, canonical narratives can also take more differentiated forms (Frosh *et al.*, 2002). Thus, at times, extremes of the attributes articulated within canonical narratives, such as the literal interpretation and application of cultural knowledge, can be opposed by some practitioners and in this way comes to symbolize the very cultural insensitivity they wish to avoid. So, although some professionals showed awareness of the desirability of cultural knowledge, they also talked critically about the form, source, and constraints of such knowledge:

... we take the time to think about not making assumptions about families...and it’s very much tapping into what they want. You get the textbook stuff, but actually everybody’s interpretation is their own, particularly when it comes to religion and culture (Nurse, Focus group 1).

I think we need to guard against “I’ve read the Ladybird book of religion and therefore I know what Muslims want”...everyone lives out their faith differently anyway, so in some ways it was better not to read the book at all and say “How do you want this done for you?” (Social worker, Focus group 3).

I think most of us choose to step out of our cultural context. I do...I deviate wildly and if I was in a country or I didn’t speak the language and somebody from my culture came along and said...“this is how we do things in our culture” that may be very, very different to how I would have chosen in that situation and I think we need to assume that other people in cultures with which

I'm not familiar may choose to do the same thing... I don't want to work in a way that doesn't allow them to make that choice (Doctor, Focus group 5).

I mean you have to be careful that you don't put everything down to culture because the situations are incredibly complex... I would actually ask the patient... because I would prefer to get their version of it, because you may think you know what that culture or that religion generally do, but I still think it's an individual thing (Nurse, Focus group 11).

The references to “books” in the first two extracts show how the speakers are aware of wider expectations and approaches to the education of professionals in cultural knowledge. At the same time, in all four accounts the abstract nature of cultural knowledge is regarded as unreliable when faced with the increasing individuality of lived experiences of ethnicity, culture and faith. In the second speaker's account this unreliability is emphasised and parodied irreverently through the reference to “Ladybird books” (books for young children, using a reduced vocabulary and presenting stereotyped versions of English family life).

As Giddens (1991) has argued, when abstract systems can no longer keep up with the contingencies of the social world and when they cannot maintain control over the risks they seek to manage, doubt and uncertainty about the truth claims of abstract systems can proliferate leading to existential angst and “the return of the repressed”. However, in between such a movement from submission to the authority of abstract systems and radical scepticism and doubt, there are mediations or what Giddens refers to as “compromise packages”. In the context of palliative care, I see such “compromise packages” as including commitment to certain forms of routine practice in addition to “the vesting of trust in a series of abstract systems” (Giddens, 1991, p. 196). Of relevance is Giddens' further contention that, when under pressure, compromise packages can break down, resulting in individuals taking refuge in the prescriptions offered by abstract systems, whilst at the other extreme individuals can be immobilized and overwhelmed by doubt and uncertainty.

These extremes of experience were recognizable in the focus group accounts and are important because of their detrimental impact upon relations of care for certain older people from racialized minorities. Such accounts largely concerned first generation migrants who did not speak English and should be read against the broader context and aspirations of holistic care in which communication and patient involvement in the planning of care and in decision making are central (NICE, 2004). It is important to note that even in situations where interpreters are provided, it was significant that professionals can still experience language differences as having a negative and constraining impact upon their care:

But I must say when I get a referral, I do, my heart sort of sinks, when I think “Oh I need to use an interpreter” because I always find that it can get in the way... It makes meeting with the family far more rigid and formal than perhaps I would normally want to work... (Social Worker, Focus group 3).



The limitations of communicating across language and experiential differences can have specific repercussions for professionals and older people across different sites and forms of care. In the next two examples, I focus upon nursing care and the retreat to cultural knowledge in the face of the pressures of end-of-life care in the home. I then turn my attention to the negative consequences of professional immobilization in the provision of psycho-social care in the institutional setting of a hospice.

The following extract is from the account of a nurse in a community-based palliative care team. In the extract, the nurse tells the story of an older Hindu patient whom she was caring for at home. For some Hindus, lying on the floor, as a way of being closer to the earth, is a part of death ritual (Firth, 1997), a practice that this nurse was initially unaware of. The nurse prefaced her account by stating that holistic care can be better achieved by patients who are “open and honest with us about their culture”. She went on to describe how:

... when she [the patient] was very poorly, the nursing profession wanted to get her into a bed, but she insisted on sleeping on the sofa and the background to that actually was that the sofa was very much nearer the floor than her bed would have been, which is where she needed to be, but none of us knew that and that caused horrendous frustrations and difficulty. If we knew that from the beginning, we could work with her.

Interviewer: How did you find out about that?

I think it was the district nurses that established that in the end. But who told them or how they got it out of the family, I don't know, it was probably the granddaughter who's actually involved in the care as well and who was very Westernized, so she might have, I don't know (Focus group 10).

This extract can be interpreted in numerous ways. It can be seen as a part of a canonical narrative that reiterates the importance of cultural knowledge for professionals and it can be seen as exemplifying some of the very real and practical barriers to care that professionals can experience when they are working across language and cultural difference. In my interpretation, the narrative also provides some insight into the corrosive emotional dynamics that can surround cultural knowledge and intercultural care (Gunaratnam & Lewis, 2001), by showing how the obstruction and/or subversion of the ideals and routines of holistic care through cultural difference can lead to frustration and resentment amongst professionals. In this case, what is obstructed for the nurse is the partnership and “working with” aspects of holistic care. The subversion of holistic care through cultural difference takes two forms in this account: it takes place through the positioning of the patient as the keeper of cultural knowledge, and through the oppositional positioning of the “cultural” and the “individual”.

Within the account, the older Hindu patient in her amplified otherness as non-English speaking and not “Westernized” is the object of the nurse's frustrations about the consequences of a perceived lack of cultural knowledge and information. This frustration is then played out in the expectations and responsibility that the nurse attributes to the patient: patients should be “open

and honest about” their culture/religion in order to receive holistic care. The account further suggests that certain forms of cultural difference cannot be “worked with”, i.e., those where cultural information is not readily and unambiguously accessible to professionals. There is also the simultaneous division and privileging of what is “cultural” over that which could be individual. The implication within the account is that once behaviours are understood as being cultural/religious they can be more readily accommodated by professionals. As Porter (1996, p. 69) has noted in a different context, such accounts are valuable at an analytic level because it is difficult to construe them as “disingenuous attempts” to portray professional practice in intercultural care as more benign than it actually is.

A different but related dimension of these relationships can be seen in the next account of experiences of washing an Indian patient from a community-based nurse:

... we started off having to bath him every time we went in, which was three times a week to start off with... his wife couldn't speak any English at all, he seemed to speak very little and it was difficult trying to get him to understand what we wanted to do... he always fought against us trying to give him a shower... We weren't aware of how we were supposed to address it. Nobody ever taught us how a gentleman likes to be bathed, whether they like to stay robed or whatever. I felt awkward because we used to just take him into the bathroom and sort of try and undress him, but he fought us all the time and it was a very bad experience and in the end we actually stopped showering him and just went in to do his dressings... We should have, I suppose, in retrospect, we should have got someone to translate and lay down the rules to discuss what we wanted to achieve... but he didn't seem to ever want to know. He seemed to fight us all the time, which I found quite difficult... It was sad, you know, we had no link. It could have been a nice experience for all of us, but it wasn't. It was like “oh you can go in today. I went in three times last week. You go today” (Focus group 7).

This account has many different dimensions. For the sake of brevity, what I wish to draw attention to here is how the blame for a lack of cultural knowledge and its negative consequences in caring relationships can be both more fragmented and more ambivalent in paternalistic models of care in which professionals see themselves as being able to “lay down the rules”. In this narrative, although the patient is implicated in the causes of the bad experience (“he didn't seem to ever want to know”), a deficit in training and in the nurses' failure to use an interpreter are also invoked. In this more traditional framework of professional–patient relationships, the decentring of the patient's agency in care relationships allows both a greater emotional ambivalence to be expressed (“It was sad... we had no link”) and recentres professional and institutional responsibilities.

Power relations and processes of inclusion, exclusion, and racism in care can be stark, as well as subtle and complex (Gunaratnam, 2001b). In understanding how such processes might work in the end-of-life care of minoritized elders, I would suggest that they can operate in the uneven application and subversion of holistic

care and through differing constructions of cultural competence. What is more, such unevenness is not always detectable or measurable in the practice and evaluation of cultural competence and can take place in those care situations where professionals can feel most under pressure and where elders lack autonomy, in the form of the capacity to make choices (Arber & Evandrou, 1993). In other words, it is not simply that certain “minority ethnic” elders are subject to direct and intentional forms of exclusion and marginalization from care by professionals, it is also that some of the most vulnerable and most “different” elders do not benefit from a full spectrum of holistic care and/or its optimal forms and this can happen without conscious intent and with full regard for cultural competence.

In the emotion-rich/time-scarce environment of palliative care, it has been possible to open up to scrutiny some of the specific ways in which the emphasis upon cultural knowledge can result in some elders from racialized minorities receiving uneven and emotionally ambivalent care at the end of their lives. By pointing to these relationships, I do not wish to suggest that cultural knowledge is unimportant in the care of racialized others (see McNamera *et al.*, 1997), particularly in palliative care where death and dying can sometimes intensify the significance of cultural beliefs and rituals (Ekblad *et al.*, 2000). Rather, I have been concerned to show how the primacy given to cultural knowledge in the care of elders from racialized minorities can sidetrack attentiveness to personalized care and regard for patient autonomy and choice. Having examined how the promotion of cultural knowledge within cultural competence approaches can constrain care in direct and obtuse ways, the next section moves on to examine the emotional and moral potential of the antithesis to professional competence: vulnerability.

### **Vulnerability, not doing anything, and morality**

Expressions of vulnerability and uncertainty in the care of elders from racialized minorities arose in narratives of professional passivity in the focus groups. Accounts of vulnerability, as not knowing what to do or say, stand in sharp contrast to the securities of practice promised by the abstract systems of cultural competence. What is more, having cultural knowledge and/or being of the same ethnicity as a patient/carer does not appear to protect professionals from feelings of vulnerability that can be inherent to an ethics of care and connection with others (Gunaratnam, 2003). Such connections cannot be pre-known (Bauman, 1993), rather they are characterized by surprise and an opening up of questions of responsibility through what is not known and what cannot be done. In complicating Giddens’ suggestion, that when under pressure individuals who do not invest in abstract systems as a defence against threats to ontological security can be immobilized and engulfed by doubt, I will argue that such immobilization may sometimes enable a morally charged form of care that is capable of responding to the emotional pain of social exclusion.

It is not uncommon for people who are dying to re-examine and disclose past traumas as a part of a conscious or unconscious search for meaning and a

preparation for death (Stanwoth, 2003). For those who are migrants or who are from racialized minorities, serious illness and dying can provoke reflections upon experiences of migration and settlement, racism and social exclusion, raising questions of identification and belonging (Gunaratnam, 2001a). One nurse described how such reflections can emerge:

If you say tell me about your early life, tell me about your family, tell me about what's important to you, often we'll get stories then about people's difficult start when they first arrived in this country, what they thought and how they were rejected, how they were perceived (Nurse, Focus group 4).

The impact that such experiences can have upon professionals is elucidated in the following extract, taken from an account by an Indian-Hindu nurse in which she describes her care of an older Indian-Hindu patient, who had migrated to the UK from India. The patient had been a qualified teacher in India, but had not been able to get a teaching job in the UK and had worked as a bus driver and in factories until his retirement:

I think it had an impact on how he dealt with his condition, because unfortunately his diagnosis had been quite delayed. For a year he'd been going backwards and forwards to the GP, telling him all the classic symptoms of what he'd got . . . he still had this idea and he said, "I know I'm educated and I know I'm completely in the wrong box. I think they haven't treated me properly because I am who I am, because saying I was only good enough for bus driving, not for teaching and for the same reason they didn't think I was important enough to be diagnosed early enough to be treated in the right way". And I found that very hard. That was really difficult, that was hard for me to take. I mean what can you say? . . . What can I actually say to him that's actually going to make a difference to him and I found that really difficult (Focus group 6).

In this narrative, it is possible to grasp something of the redundancy of cultural knowledge and shared ethnicity in the face of emotional pain and "traumatic memory" (Gheith, 2007). Rather than the foregrounding of ethno-religious commonalities or empathy between patient and nurse, the narrative conveys attentiveness to a broader range of dynamics. These dynamics include simultaneous feelings of professional responsibility and inadequacy, a questioning of care as an active doing and "fixing" (Waddell, 1989), and a singularity of the patient's experience that is demanding of some level of response that the nurse feels unable (perhaps, incompetent) to provide ("what can I actually say to him that is actually going to make a difference to him?").

Rather than glossing over or avoiding discussion of these instances of practice as inaction and ineptitude, such stories animated participants as they puzzled over dilemmas and uncertainties in care, particularly those relationships between activity and passivity in professional practice. For instance, one participant who described intercultural practice with patients/carers as an active "trying to get into their world", also described connection in more passive terms, but where understanding as a response to difference was possible:

I think it's partly, I think a lot of the process is listening and showing that you're there for them . . . I think even if you were someone that was telling me stories of racism, I'm not sure that they would totally expect you to have to do anything with that, but for you to actually connect with them at that moment and understand the importance of what they're telling you (Nurse, Focus group 11).

Drawing upon the work of the philosopher Levinas (1978), passivity in encounters with others can be seen as involving moral relationships precisely because the encounter does not recuperate or flatten alterity by claims to know and understand it. In a reversal of the rationalist logic of cultural competence, a vital feature of an ethics of connection for Levinas is that it is not dependent upon understanding, critical judgement or shared experience as the foundation for ethical responsibility or moral thinking. Responsibility and obligation to others in this sense is not so much a choice, but involves an unpremeditated receptivity and responsiveness. Although it is recognized that Levinas's work should not be interpreted literally in relation to everyday conduct and is best seen as hyperbole (Barnett, 2005), Levinas's engagement with passivity as an ethical event has relevance to the forms of professional practice discussed here. This relevance can be heard in the following account by a focus group participant of mourning rituals that involved Muslim women "bashing their heads against the walls" in a hospital. Despite the nurse's description of active professional intervention to try to minimize injury to the women, her role as a nurse is depicted as superfluous:

... it was a situation I hadn't come across before. I found it difficult to understand as well, when they are causing physical pain to themselves... we were just alongside them really, trying to put pillows in the way, but they didn't injure themselves too much. I suppose that was our need to do that and then it all stopped after about 40 minutes and that was it... But we were left a bit shaken. Whether we could have managed it any differently, I don't know... I think you very much wanted them to do what they had to do because it was important to them, but you didn't really understand it from your own culture... (Focus group 1).

Attempts to manage the cross cultural encounter in this narrative give way to forms of professional passivity in emotional and sensual exposure to, and accompaniment of, others ("we were just alongside them really") in which professionals can be left "shaken" and without full understanding. What I see as characterizing the morality of the encounters described by some professionals is both the disruption of routine professional practice and the personal and singular impact of the other that is neither easily understood nor calibrated. The significance of the encounter and the responsibility it demands are thus left open rather than being managed, closed, or completed through understanding or categorization.

For Levinas, passivity involves something more than simply being the opposite or absence of activity. As the capacity to be moved, touched, or affected by the predicament of others, it is a condition of future activity, a possible opening to new ways of doing things and of being with/for others (see also Gibson, 2001). In other words, passivity, in the context of the accounts discussed here, is productive and full of potential. Its potential lies in the ways it can bring professional selves/

assumptions/practices into question, without which it might be said there would be no desire or impetus for new forms of practice or indeed “competence”, even though such desires can never be fully captured nor satisfied by competency models or by social policy.

There is a need to be cautious about idealizing professional vulnerability in palliative care however. There were other examples from the focus groups which contest the value that I have given to professional vulnerability and uncertainty. They also enable understanding of how different disciplinary philosophies and knowledge can facilitate and/or suppress moral thinking. For instance, within the focus groups, it was social workers, in the main, who talked about the implications of structural inequalities and histories of racism for their work with “minority ethnic” elders, reflecting discourses of anti-oppressive practice (Dominelli, 2002; Gil, 1998) that are unique to the social work tradition. In a multi-disciplinary focus group, a social worker talked about how her inability to get welfare benefits and re-housing for a family (they were recent migrants and not entitled to state benefits and housing) as leading to her retreat from the family “because of our embarrassment and feelings of not being able to do anything”. Her social work colleague remarked, “Yes . . . there’s something about being representative of a, sort of what can feel like a very racist system and how we react as workers around that” (Focus group 3).

In a focus group with hospice social workers, a social worker introduced a story about her work with an Afghanistani patient by stating, “I feel my knowledge is not as good as it could be”. In her account, the patient was said to have disclosed “terrible things” that had happened to his family in Afghanistan. Using metaphor, he had talked about himself as a lion who was responsible for protecting his family, at the same time he had felt guilty about surviving and coming to the UK as an asylum seeker. Talking about his experiences had been distressing, and the social worker was later confronted by the patient’s son who was reported as saying: “You don’t understand our culture. You mustn’t talk about these things . . . you brought up things which should never be brought up”.

In her emotional account of the case, the social worker described feeling “so bad . . . that I then didn’t go back to see his father and very quickly after that, his father actually deteriorated”. She concluded the narrative by saying:

I mean that always sticks in my mind, because it’s something that I don’t feel that I did well, after reflecting on what I did and what perhaps I should have done, but I found that quite scary, because they’re traumatic situations that are very different to what I’ve experienced. I didn’t feel that possibly I was qualified to deal with it . . . I think we have all been trained . . . to ask questions [but] . . . there’s still the sense that we are white and British and that . . . can take away our voice . . . because . . . we’re holding guilt that we have abused people in the past. I mean racism (Focus group 2).

This account is rich in its reference to the varied dynamics that constitute it: geopolitics, emotional pain, difference, gendered and intergenerational relations, disciplinary concerns, and historical legacies of racism. However, in the context of the preceding discussion about the value of professional immobilization and



vulnerability, the account illuminates two interrelated issues. First, it provides insight into the profound challenges of end-of-life care for migrants, whose lives are all too often characterized by multifarious forms of violation and abuse. Second, it shows how without recourse to the protection offered by abstract systems such as cultural competence, professional vulnerability and moral thinking can lead to professional withdrawal and distancing, with detrimental consequence for both patients and professionals. A fundamental question here concerns the capacity of disciplinary and policy discourses to support and enable professionals to recognize the difference between an emotional standing-by in apparently non-active care (Waddell, 1989) and the abandonment of retreat in the face of unbearable internal and external realities (see Cohen, 2001).

## **Conclusion**

In theorizing cultural competence as an anachronistic abstract system (Giddens, 1991) that promises to manage the threatening nature of the interrelations between death and difference, this paper has questioned the promotion of cultural competence as a social policy response to the care needs of “minority ethnic” elders at the end of life. Although cultural knowledge may sometimes facilitate culturally responsive care (McNamara *et al.*, 1997), there is a danger that it can be given primacy over personalized care. In such cases, those who are seen as being the custodians of cultural knowledge can become the objects of anger and resentment when such knowledge is not readily accessible to professionals and/or is seen as obstructing routines of care.

By drawing upon professional narratives of vulnerability and incapacitation, I have hoped to demonstrate how a lack of knowledge and non-action in psycho-social care might form the basis for moral thinking and a receptivity to the emotional pain of social exclusion. These arguments raise a series of more technical questions about the end-of-life care of older people from racialized minorities. How might the need for competence and confidence in clinical care be taught alongside psycho-social approaches that recognize the ethics and the productivity of vulnerability and not knowing what to do? How are such combinations of care experienced by professionals and elders and carers and across different sectors of care? What relationship does cultural knowledge have to the quality and experience of care for elders and carers? How might personal identity, clinical experience, and training differentiate the capability of some practitioners to be affected by and be receptive to the moral responsibilities of their encounters with others?

It is of course important to highlight the limitations of generalizing from the accounts discussed in this paper. Although the professionals in the sample came from a range of settings, they were all involved in the delivery of palliative care, which should be borne in mind in interpreting the relevance of their accounts to the end-of-life care experiences of older people in different contexts. For example, there are significant differences between professional practice in the curative ethos and “medical heartland” (Twigg, 1997, p. 213) of acute services and in palliative care (see also Page & Komaromy, 2005). In acute care, the emphasis upon active,

sometimes aggressive, treatment and “cure” can mean that death is experienced as a “failure” by professionals. The ethos of palliative care, in contrast, where the focus is upon affirming “dying as a normal, rather than a biomedical process” (Pennell & Corner, 2001, p. 518), can be regarded as more passive. Such passivity may be further amplified in the care of older people, whose deaths can often be regarded as “natural” (Howarth, 1998; Owen, 2005). It is possible therefore that working with older people with palliative care needs, where “cure” is not the aim of care, emphasises feelings of professional passivity and/or enables them to be more readily articulated in circumstances where the clinical focus on palliation rather than active cure recognizes and affirms professional passivity. A wider consideration concerns the extent to which the experiences described here are characterized by racialization and migration. For example, are there any commonalities of experiences of ageing and difference that also inflect the palliative care provided to white, British elders?

If we are to take seriously the legal and moral imperatives to “root out” (Department of Health, 2001) not only age discrimination but also all forms of inequality and oppression that debase older people, then there is a need for a more sophisticated approach to the challenges of providing holistic care to elders from “minority ethnic” groups. In problematizing the emphasis given to cultural knowledge in cultural competence models and in insisting that professional experiences of vulnerability and incomprehension can be significant and valuable features of care at the end of life for those from racialized minorities, it is hoped that this paper may contribute towards a shift in current debates and approaches to care across difference. A central part of such a shift would include attention to how social policy and educational and training initiatives might engage practitioners with the socio-political and emotional complexities of the lives and deaths of elders from racialized minorities.

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### Biographical Note

Yasmin Gunaratnam's research has been concerned with questions of race and gender equality in health and social care. Her previous research has included an ethnographic study of the production of race and ethnicity in a hospice. She has a particular interest in qualitative research methods and is author of *Researching "race" and ethnicity: methods, knowledge and power* (2003).

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