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Threat to valued elements of life: the experience of dementia across three ethnic groups

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Abstract

Purpose: There is a fundamental knowledge gap regarding the experience of dementia within minority ethnic groups in the UK and elsewhere. The present study examined the subjective reality of living with dementia from the perspective of people with dementia within the three largest ethnic groups in the UK.

Design and Methods: This was a qualitative study in which in-depth individual interviews were conducted with 11 black Caribbean, 9 south Asian and 10 white British older people with dementia. The lack of information in this area prompted the use of a grounded theory approach.

Results: The main theme to emerge from the interviews with the people with dementia was, "threat to valued elements of life". Participants engaged in a process of appraisal in which they assessed the degree to which their condition and support needs interfered with valued elements of life. The analysis revealed that each element of this process was culturally informed.

Implications: There is potential for modifying beliefs to reduce the perceived threat of dementia and for family and professional carers to promote the roles, relationships and activities that each person with dementia values. The findings outlined in this paper can inform the development of a culturally sensitive approach.

Introduction

The UK population is ageing and the number of people with dementia is projected to double over the next 30 years (Knapp et al., 2007). This increase is expected to be greater in minority ethnic groups, as first-generation black Caribbean and south Asian migrants enter the age groups with the highest incidence of dementia. This will have a profound impact on the lives of older people and their families within minority ethnic communities, yet there remains a fundamental knowledge gap regarding how dementia is understood, experienced and managed among black and minority ethnic groups in the UK and elsewhere (Milne & Chryssanthopoulou, 2005).   Research has suggested low levels of service use among minority populations, but there is limited evidence on which to base the development and provision of culturally appropriate care (Mackenzie, Bartlett, & Downs, 2006).   Where evidence does exist, it relies solely on the perspective of the caregiver, whose priorities and concerns may be different from those of the person with dementia (Lyons, Zarit, Sayer, & Whitlach, 2002).

The discourse surrounding dementia has changed considerably over the last 20 years with the focus of the medical model on dementia as a disease entity gradually giving way to an awareness of the individuality of the person with dementia (Innes, 2002). Through the concept of "personhood", Kitwood (1997) identified aspects of self that are not bound to the preservation of memory, including feelings, emotions and reactions that can be sustained in relationships with others. Thus, it is no longer assumed that dementia leads to "the inexorable dissolution of the self" (Cohen & Eisendorfer, 1986). This has highlighted the need to understand individual preferences, interests, values, relationships and achievements (Woods, 2001), which is reflected in the growth of research exploring the subjective experience of the person with dementia (Steeman, Dierckx de Casterle, Godderis, & Grypdonck, 2006).

Qualitative studies have revealed that people with dementia are able to express feelings and concerns with clarity and that a level of insight can exist, even in the later stages of the disease (Clare, Rowlands, Bruce, Surr, & Downs, 2008). It is evident that people with dementia are confronted with many losses that can engender feelings of incompetence and worthlessness (Harris & Sterin, 1999) and undermine individual's sense of control, autonomy and independence (MacQuarrie, 2005). People with dementia have also expressed fear regarding anticipated losses and of becoming a burden in the future (Pearce, Clare, & Pistrang, 2002). Harris (1999) identified three core values that comprise the sense of self of people in the early stages of dementia: the need to be meaningfully productive, the need to be independent, and the need for comfort and security. Subsequently, Steeman (2007) suggested that individuals were concerned less with cognitive decline than with remaining someone of value.

However, this is an emergent field and questions remain regarding how people with dementia appraise their situation and conceptualise their lives. The existing knowledge base is predominantly underpinned by research with white, well-educated, married professionals in the early stages of dementia (Hulko, 2009). Most striking is the stark absence of research with people with dementia from minority ethnic groups. A review of the international literature and meta synthesis of qualitative studies identified 50 articles (de Boer et al., 2007) and 28 qualitative studies (Steeman et al., 2006) respectively that examined the perspective of the person with dementia, yet none reported experiences within minority ethnic populations. Kitwood (1997) conceptualized dementia as a socially embedded phenomenon in which the person's neurological impairment interacts with the surrounding social environment. Accordingly, it is important to consider the experience of dementia within its cultural context (Downs, 2000). Downs (2000) emphasized that cultural meanings of changed cognitive abilities are likely to

influence the subjective experience of dementia and the manifestation and response to the condition.

Research with caregivers has confirmed that cultural norms and beliefs influence the meaning attached to dementia symptoms (Dilworth-Anderson, Williams, & Gibson, 2002). South Asian caregivers in the UK have been found to attribute symptoms of dementia to normal ageing or "an act of God" while others have attached stigma and shame to the condition (Patel, Mizra, Lindblad, Amastrup, & Samoli, 1998) In the US, African Americans have been found to attribute cognitive deficits to excessive worrying or "thinking too much" (Gaines, 1989). A large portion of the caregiver research that occurred in the 1990's also identified ethnic and cultural variations in the caregiving experience. Much of this literature suggested that African American caregivers experience lower levels of burden and higher levels of rewards than white American caregivers (Dilworth-Anderson et al., 2002). Explanations include possible cultural differences in appraisal of stressfulness, coping strategies, support networks and attitudes towards providing care (Aranda & Knight, 1997; Lawrence, Murray, Samsi, & Banerjee, 2008). The profound impact of culture and ethnicity on caregiving underlines the imperative of addressing the cultural context of the person with dementia's experience. We therefore report data on the attitudes, experiences and beliefs of people with dementia within the three largest ethnic groups in the United Kingdom.

Methods

The lack of information in this area prompted the use of the grounded theory approach (Glaser, 1978), which provides a way of studying the world from the participants' perspective. Grounded theory is primarily inductive and themes are derived from the data, rather than from existing theory. Grounded theory methods, including the simultaneous collection and analysis of data, theoretical sampling,

theoretical memos, constant comparison technique and negative case analysis, were used here to investigate the main concerns of black Caribbean, south Asian and white British people with dementia. As will be discussed, these methods helped to ensure the credibility and authenticity of the final theory. The local Research Ethics Committee approved the study.

Data Collection

The study recruited from a wide range of sources to explore a diversity of experiences. This included Community Mental Health Teams for Older Adults (i.e. multidisciplinary health and social care teams that provide specialist assessment, care ant treatment to older adults within the community with complex mental health needs), memory clinics, day-centers for people with dementia, and community mental health programs for minority ethnic elders across four south London boroughs. Purposive sampling was used to recruit participants with a range of characteristics including different levels of dementia, different living arrangements and different levels of support. Mental health professionals and "community leaders" (prominent members of black and minority ethnic communities that were involved with mental health projects) assisted in identifying, and on occasion, recruiting suitable participants; alternatively older adults were sent an invitation letter, followed by a phone call from a member of the research team. All participants either had a formal diagnosis of dementia or were attending a dementia specific day-centre or group. The research team was mindful that members of minority ethnic groups (or indeed the white British majority) might not frame their experience of dementia within the Western medical model.   Therefore, the expression "memory problems" was used in place of "dementia", as this did not require individuals to be aware of a formal diagnosis or to identify with a potentially stigmatizing and / or culturally inappropriate concept.

Data collection and analysis proceeded simultaneously and participants with a range of characteristics and experiences were sought to test out and refine the emergent theory (Glaser, 1978).   For example, we actively recruited people with dementia who lacked family support to examine whether this increased the threat that the condition posed. Data collection continued until theoretical saturation was reached, that is, until the devised categories had been fully explored and new data was easily accommodated within them (Glaser, 1978).

In-depth Interviews

In-depth interviews provided structure, which helped orientate the older adults, but also allowed the researcher to adjust the pace and complexity of the interview to each participant. Open-ended questions were generated from a review of the literature and in consultation with experts in dementia and cross-cultural psychiatry. The interview guide was amended iteratively and aimed to follow the participants' own concerns. Initial topics included: the experience, impact and understanding of the condition and participant's priorities and fears. Questions loosely fell into three clusters. The first related to a vignette, which depicted a man (Mr G) with moderate dementia (see Figure 1): this method, used previously by the authors (Lawrence et al., 2006), provided a culturally unbiased situation to which everyone could respond. The story of Mr G was constructed from vignettes previously used in a cross-cultural study of concepts of dementia (Patel and Prince, 2001) and was tested for cultural appropriateness with colleagues from diverse ethnic backgrounds.   Secondly, participants were asked questions regarding their own condition and thirdly, generic questions were posed in relation to "dementia" and "Alzheimer's disease". Individuals' responses to the vignette / word "dementia" provided additional layers of insight into how they conceptualized their own situation. Interviews were conducted in the participants' preferred language, in their homes or at day-centers if preferred and lasted around one hour. Interviews were recorded and transcribed verbatim. In

instances where the person with dementia was judged to lack capacity to consent, we established that the individual was happy to take part in the research and sought the assent of their main caregiver.

Data Analysis

The interview transcripts were repeatedly read to enable the researcher (VL) to become immersed in the data. Through a process of "open coding", data was then broken up into incidents, to be closely examined and compared for differences and similarities. In the early stages of analysis, descriptive codes were applied to the incidents in the data, often using the participants' own words e.g. "nuisance", "annoyance". Using the "constant comparison" method, new data was compared to existing data, and patterns of similar data were grouped together to form higher level conceptual categories e.g. "acceptability of support". In grounded theory the generation of theory occurs around a core category, which must be central, recur frequently in the data and have explanatory power (Glaser, 1978). The core category to emerge from the interviews with the people with dementia was "threat to valued elements of life". Once identified, data collection and analysis was restricted to those variables that related to the core category. The transparency of the research process was increased through theoretical memos, which documented thoughts, interpretations and questions about the data, the ongoing development of categories and their relationships, and the emergence of the core category (Glaser, 1978). Identifying and exploring divergent cases, i.e. participants with seemingly contradictory experiences, helped to capture the full complexity of the data and added depth and density to the emerging theory e.g. two south Asian participants displayed higher levels of distress than the other south Asian participants. A closer examination revealed that they were alone in their awareness of the progressive nature of their condition and lack of confidence in family support, thus highlighting the importance of these beliefs. Multiple coding occurred with researchers with different

disciplinary backgrounds at two separate time points and, on each occasion, instances of disagreement were discussed until a consensus was reached. This process helped to highlight alternative interpretations and, alongside interview notes and project meetings, raise awareness of personal values and preconceptions (Barbour, 2001). Finally, mental health professionals and community leaders from ethnic specific community mental heath projects were invited to attend a feedback meeting where they were asked to consider whether the emerging themes reflected the experiences of participants in a believable / meaningful way. The inclusion of quotations in the text helps to demonstrate that themes are grounded in the data. These are labeled by the participant's ethnicity (Black Caribbean, or BC; south Asian or SA; white British, or WB) and identification number.

Figure 1

Results

Thirty people with dementia were interviewed: 11 were black Caribbean (3 male, 8 female), 9 south Asian (5 male, 4 female) and 10 white British (5 male, 5 female). Ethnicity was self-designated using British census categories. Scores on the Mini-Mental State Examination (MMSE) (Folstein, Folstein, & McHugh, 1975), one of the most widely used screening instruments for dementia, and key socio-demographic characteristics are presented in Table 1. All participants were living in the community, either independently or with relatives. The black Caribbean and south Asian participants were predominantly from Jamaica and India respectively, reflecting the ethnic composition of this age group within Greater London. MMSE scores ranged from 1-29 (Mean 17; SD 8.2). On the basis of the MMSE scores, roughly equal proportions of the sample could be categorized as having severe

dementia (MMSE<11), moderate dementia (MMSE 20-11) and mild dementia (MMSE>20) (Perneczky et al., 2006).

Table 1

Threat to valued elements of life

All participants suffered from symptoms of dementia and experienced changes in cognition, mood and behavior.   However, the experience of dementia evoked different levels of distress in different individuals that cannot be accounted for by variation in symptoms alone. The process through which distress developed was largely consistent across the sample. This paper posits that the threat posed by the experience of dementia depended upon the individual's "understanding of the condition" and "attitudes surrounding support needs" and the perceived interference with "valued elements of life". The analysis revealed that each element of this process was culturally informed. This model is illustrated in Figure 2. While care must be taken not to neglect the individual differences that exist across the sample, cultural commonalities and differences were evident across the ethnic groups and these are summarized in Table 2 for ease of comparison.

Figure 2

1. Understanding of the Condition

Much of the discourse surrounding participants' own experience, the vignette and the word "dementia" related to their understanding of the condition. The belief that the condition was serious, progressive and / or stigmatized increased the threat posed to valued elements of life.

Is the condition serious?

Every participant, at some point, explained his or her memory difficulties in the context of getting older. A proportion of these individuals asserted that memory problems did not warrant concern. However, a closer examination of the data reveals a more complex picture. Participants were asked whether they considered Mr G's condition to be serious. White British participants mostly viewed Mr G's situation as worrying, variously citing his apparent dependency, his evident confusion and the perceived irreversibility of his condition. There was a propensity among the black Caribbean older adults to judge the severity of Mr G's condition according to whether he had a relative or friend who could act as safeguard against his poor memory. It was felt that he would be vulnerable if he did not have this support. Notably, one third of the south Asian participants spontaneously identified themselves with Mr G. The vignette depicted a man in the moderate stages of dementia, yet these participants construed his condition, like their own, as benign and normal for his age.

"He is 75 years old, he has a few memory problems. It isn't anything that serious. So he goes out and forgets a bit, even I do." (SA7)

The majority of black Caribbean and white British sample were unequivocal in identifying dementia as a serious condition. Participants were not asked questions about dementia in direct reference to themselves, yet half of the black Caribbean sample expressed concern that they may suffer from this condition, while the majority of white British participants either volunteered their diagnosis of dementia or asserted that dementia had no relevance to their lives. Conversely, the majority of the south Asian participants appeared not to recognize the words "dementia" or "Alzheimer's

disease" and seemed unaware that they might apply to their own situation. The exception was one south Asian man who had recently been informed that his condition was Alzheimer's disease. He recounted what this was like in the context of his peers who continued to conceptualize his condition simply as "memory loss".

"You tell them that my memory has gone, that's a symbol for it, but it's not just my memory that's gone, it's the comprehension that's gone…when I'm giving an argument I don't know what point I should give next you see, and that's not my memory, that's a different personality and people don't realize that's the more major reason. If I start stammering they wouldn't imagine, can't imagine that it is due to Alzheimer's disease or dementia because they are not aware of that condition of Alzheimer's." (SA9)

Is the condition progressive?

There was a propensity among black Caribbean and white British participants to identify with Mr G's milder symptoms, but to quickly demarcate where the similarities ended. On occasion, this implied a level of awareness that their condition might progress to that stage.

"Well this is partly what I've got but I'm nowhere near as bad as this, nowhere near it. I mean this poor devil, he's, well yeah I do understand what it's about, but I'm nowhere near." (WB3)

A number of black Caribbean participants exhibited anxiety about the apparent worsening of their memory. These individuals, all of whom lived alone and were managing with limited informal support, had observed recent changes in their memory and were alert to any further fluctuations. One south Asian man and a small

number of white British participants that were aware of their diagnosis spoke about their fear of developing specific physical and behavioral symptoms. Other white British and black Caribbean participants held diffuse concerns that their condition might deteriorate. South Asian participants rarely recognised the progressive nature of their condition.

Is there stigma attached to the condition?

A common worry within the black Caribbean sample was that their difficulties might be due to impaired functioning of the brain. There appeared to be a large amount of stigma attached to this notion. This dual sensitivity to deteriorating memory and "getting off your brain" evoked considerable fear for the future.

"It makes me feel how far am I going, what is the worst that can happen, you know it make me feel inadequate…sometimes I think oh Lord what is going on, am I getting off my brain or what?". (BC10)

Towards the end of the interview participants were asked to describe what the words "dementia" and "Alzheimer's disease" meant to them. Many of the black Caribbean participants used stigmatizing language such as "mental", "madness", and "crazy". Although the majority purported not to view dementia in this way themselves, fear of how they would be perceived within society remained.

"I think some know and some don't know, you know? Some people think well this person is mad, they don't know, they don't know what the cause of it would be." *(BC6)*

While the white British individuals who denied having dementia rarely adopted words such as "madness", they did describe dementia in equally pejorative terms. To a large extent these comments seemed to reflect a fear of being labeled as "stupid" or "dim-witted".

"Dementia is losing memory."
"Interviewer: I was going to ask you what kind of person does it make you think of?"
"Well not me. Well absent-minded idiot I suppose, I don't know, that's not very nice is it?" (WB9)

These participants used similar language to describe Mr G, from whom they also distanced themselves. In contrast, south Asian participants tended to conceptualize Mr G's condition and their own memory problems as normal, while "dementia" was viewed as a disturbing, yet ultimately abstract construct that held little relevance to their own lives.

2. Attitudes surrounding support needs

Participants across the ethnic groups and at different stages of dementia demonstrated awareness, either implied or explicit, of their own need for support. The belief that family support was unavailable, unacceptable and that alternative support was necessary yet undesirable compounded the threat that memory problems posed.

Availability of support

Variation existed in the extent to which support was perceived to be readily attainable. South Asian participants provided distinctive accounts: they were more

likely to describe receiving help from more than one family member and almost the entire sample displayed confidence in the presence of this support. Only one south Asian woman expressed doubts about its permanence. She was grateful for the help that her son was providing, but was hesitant about "taking advantage" of his kindness over a protracted period of time.

"It's fine if I live with my family but if I have to live myself alone that will be a problem with me. I spoke with my son who is very cooperative and said they take me out with them, they are always there for me and they are taking care of me very well so I am hoping that I will be staying with my kids, but this just worries me, what will happen in the future". (SA4)

Conversely, many white British and black Caribbean older people stated that their children's circumstances placed constraints on the support they were able to offer. Black Caribbean women commonly cited the distance from children who had settled abroad. Others understood that work and family pressures prevented their children from doing more. Where participants lived with their partners, support from the spouse seemed largely to be assumed across the sample.

Acceptability of support

While there was a tendency among black Caribbean participants to suggest that Mr G should rely on care professionals for practical assistance, half of the south Asian sample stated that Mr G should lean on his family for support. Therefore, these participants appeared to consider it appropriate for family members to provide the intensive support that Mr G required.

"He can get help from his wife and if he's got children he can get help from his children…don't bother the neighbours or anything, maybe they are not at home, gone away, so they won't help him. So it is a good thing to ask for help from his family". (SA5)

To a large extent, the individual's assessment of his or her imposition on a family member (current and anticipated) versus his or her own contribution to the relationship determined the acceptability of receiving family support. Although south Asian participants valued family support, many did not consider its provision remarkable and the majority did not feel that it exceeded their own contribution to the relationship. One south Asian and one black Caribbean participant explicitly identified their children as reciprocating the support that they had received during their upbringing. Other south Asian participants drew attention to the success of their children, as if signaling that they had fulfilled their parental obligations and it was this that their children were now reciprocating. In contrast, over half the white British participants depicted themselves as burdening their relative and expressed concern that their behaviour was irritating or upsetting their spouse. One white British man was assured of support, but stated "I would rather be dead than drive somebody least of all my own wife to that sort of situation". Many of the married British participants appeared distressed that their role in their marriage had changed. They were uncertain about how to contribute to their relationship and appeared keen to assist their partner in whatever way they could.

Alternatives to informal support

Thus, many participants understood that they needed support, but did not consider family members as a possible or suitable source of help. As a consequence, care homes assumed increasing personal relevance to some participants' lives. Around

half the black Caribbean and white British participants had contemplated this prospect. Black Caribbean older adults frequently implied the undesirability of this eventuality, not least because it was seen to circumscribe independence. The word "dementia" triggered associations with care homes, which propagated the fear attached to the condition.

"Oh Lord I hope I don't have it [Alzheimer's disease]…because when you have it, it is terrible. I knew somebody who had it and then they put her in a home and that made her worse". (BC6)

White British participants were more positive about care homes, frequently identifying value in enabling people with dementia to avoid depending on loved-ones in the later stages of the illness. The majority of south Asian participants explained that residential care was not something they considered. Participants throughout the sample accessed a wide range of community services, but did not anticipate that these would adequately compensate for a lack of informal support or enable them to avoid residential care.

3. Individual's valued roles, relationships, activities

Valued elements of participants' lives largely defined the interview narratives and were apparent in individuals' concerns, coping strategies, priorities, descriptions of self, and approach to life. The level of threat varied from individual to individual, as participants appraised how their condition and support needs might interfere with their valued roles, relationships and activities.

Independence

A large proportion of black Caribbean participants, all of whom were single or widowed, defined themselves as self-sufficient and were distressed by the threat that their condition posed to their independent lives.

"Because before I used to do everything for myself, go out, go to help people and do different things you know, around. I did everything for myself. But now I can't do anything, I always forgetting you see". (BC6)

White British older adults similarly underscored the importance of being independent of others, although to a lesser extent than black Caribbean participants. The significance attached to self-reliance was also reflected in individuals' assessments of their current circumstances. Identifying retained abilities appeared to ease anxieties and presented as a common coping strategy. Black Caribbean and white British participants were most likely to positively evaluate their situation through emphasizing their continued ability to manage practical tasks such as cooking and shopping.

'Good brain'

A small number of south Asian participants identified themselves as educated men, and implied that it was this characteristic that led others to hold them in high esteem. A retired teacher described how deteriorating abilities eroded his sense of self.

"I can't talk well, I can't figure out the sums you see, taking 8 from 12 is difficult for me, changing, getting the change if I go to the shops, I don't go now. So it has affected my life very badly. I avoid going to people, especially former friends, unless I go to places where everyone has Alzheimer's". (SA9)

Black Caribbean participants tended to view the importance of having a 'good brain' in an entirely different context. As previously suggested, a "good brain" was often used to indicate a brain that was functioning properly, which in turn was euphemistic for not being "mad". Within the white British group a "good brain" was generally associated with intelligence, and the concerns and coping strategies of a number of individuals reflected the value that they placed on this. One white British woman vacillated between vigorously rejecting the notion that there was anything seriously wrong with her mind, to displaying concern that her poor memory might generate annoyance or criticism.

"Michael [husband] has got a very good brain, very good memory but absent-minded Barbara [participant] is probably an irritation". (WB9)

Predominant concerns within the white British group were how impaired cognition might influence close relationships with relatives or affect the way that they were perceived within the wider social group.

Happy family

A number of south Asian participants placed emphasis on the value of family and many exhibited an expectation of family support. Participants often projected an image of a cohesive and happy family, and the attentiveness of children and spouses seemed to represent one aspect of this.

"Everybody in my family help me. My son, my son's wife and his sons and daughters, 8 sons he has. I have three daughters, they are all married here in England, in this country, all living in London. Yeah. They are all very happy in their homes. We are all a very happy family, they come visit me lots of times". (SA8)

Remaining within the family was essential, both practically and emotionally, and afforded peace of mind. South Asian participants were also most likely to demonstrate concern for their children's achievements and well-being, and to be comforted by their success.

Helping others

Black Caribbean participants frequently stressed the value of helping others. Comments suggested a religious component, as individuals explained that helping others was part of being a good Christian or a good Sikh. South Asian participants portrayed helping others as a means to garner respect, which was reinforced by the ensuing deference of others.

"People usually come to ask me for help. They ask me to write something for them or read for them, and I am happy to do it… If someone needs to go to the doctor, I go with them. All these years, I have always loved helping others". (SA1)

Other valued roles

There was a wide range of valued roles, relationships and activities that were integral to participants' self-identity. One white British man was distressed that he was unable to attend to practical tasks around the house, such as putting up pictures. One woman valued looking her best and continued to take pride in her appearance. The commonality across the disparate roles, relationships and activities was that they were integral to participants' self-identity, which may or may not be undermined by the experience of dementia. Culture and ethnicity have been afforded prominence in this discussion as it accounted for the greatest variation, yet considerable individual

differences existed.

Discussion

The person with dementia and cognitive appraisal

To our knowledge, this is the first study to simultaneously explore the perspectives of black Caribbean, south Asian and white British people with dementia. Three important conclusions can be drawn from the data. Firstly, participants were at different stages of dementia, yet all depicted discernable roles, relationships and activities that they valued. This challenges the assumption that dementia leads to "the inexorable loss of self" (Cohen & Eisendorfer, 1986) and supports evidence that a sense of self exists even in the advanced stages of dementia (Cohen-Mansfield, Parpura-Gill, & Golander, 2006). Secondly, the data indicate that people with dementia appraised their condition and their support needs according to perceived interference with valued elements of life. The emphasis placed on cognitive appraisal is consistent with the adaptation-coping model (Droes, 1997), which states that personal, illness related, material and social factors influence the significance that individuals ascribe to the losses they are experiencing. Droes gives the example of a former bookkeeper, arguing that someone who had previously derived status from this profession would be profoundly distressed by the realisation that they could no longer make simple calculations (Droes, 1997). This "signification process" is considered fundamental to the emotional response that dementia evokes. The person with dementia's need to maintain core values, including meaningful productivity, autonomy, comfort and security, has been identified as tantamount to survival (Harris & Sterin, 1999). The present study takes this further by revealing that the person with dementia's "understanding of their condition" and "attitudes surrounding support needs" inform the perceived "threat to valued elements of life".

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Few studies have explored how individuals conceptualise dementia related changes and their implications. A recent exception applied the self-regulation model (SRM) of adjustment to illness (Leventhal, Nerenz, & Steele, 1984) to dementia to explore the representations that people with dementia hold about their condition (Clare, Goater, & Woods, 2006). The SRM suggests that individuals develop cognitive models to help them make sense of their illness. Five key dimensions of illness representations have been outlined in the literature: beliefs surrounding the cause, consequence, identity, course, control / cure of the illness. Clare et al. (2006) successfully elicited each of these dimensions in people with dementia and while the present research did not seek to test the applicability of the SRM in this population, these themes were evident in the participants' conception of their condition as serious, progressive and stigmatised. Leventhal (1984) proposed that illness cognitions subsequently inform coping behaviour, mood and adaptation. Similarly, we propose that conceptualising dementia related changes as serious, progressive and stigmatised increases the perceived threat of the condition. Clare and colleagues (2006) focussed their study upon the original 5 dimensions of illness representations outlined in the SRM, yet pointed out that future work might reveal other dimensions of importance. For example, Harman and Clare (2006) devised an interview schedule based upon the SRM, but aimed for data collection to be guided by what was important to the participants. Two overarching themes emerged that deviated from the original 5 dimensions ("It will get worse" and "I want to be me"). In the present study, participants were highly mindful of a need for support and evaluated if and how this need would be met. While this could be categorised within the "consequences" domain of the SRM, the present study affords it greater prominence arguing that the perception of current and anticipated support needs exist alongside conceptualisations of dementia in determining the perceived threat of the condition.

The third conclusion that can be drawn from the data is that each element of this process was culturally informed. The data revealed that black Caribbean, south Asian and white British people with dementia were likely to hold different fears, as they tended to conceptualize their condition and support needs in distinctive ways. These findings are summarized in Table 2. This has implications for the information, advice and reassurance that they require. Informal and formal caregivers are in a position, firstly, to reduce the threat to valued elements of life, through addressing beliefs surrounding the condition and support needs, and secondly, to promote valued roles, relationships and activities. We will now elaborate on these two points.

Reducing threat to valued elements of life

The data presented here corroborate the importance, as identified in the first ever National Dementia Strategy for England (Department of Health, 2009), of raising public and professional awareness of dementia. A large proportion of black Caribbean participants displayed a fear of being viewed as "crazy" or "mad" that is consistent with African American communities (Hinton, Franz, Yeo, & Levkoff, 2005). White Americans have been shown to be more knowledgeable about Alzheimer's disease than ethnic minority populations (Ayalon & Arean, 2004), but we found that this co-existed with stigmatising language, such as "stupidity" and "dim-wittedness". This underlines the necessity of addressing the stigma associated with the condition and suggests that public education campaigns may benefit from a culturally tailored approach. The findings also support the role of memory services, which offer assessment, diagnostic and treatment services while avoiding much of the stigma attached to psychiatric services. Preliminary research suggests that memory services are more acceptable than traditional psychiatric services to members of minority ethnic groups (Banerjee et al., 2007).

In many ways, the propensity of the south Asian participants to conceptualize their condition as a normal part of ageing helped them cope with their condition. Previous research has identified the capacity of such explanations to deflect or diffuse stigma (Hinton, 2005) and educational campaigns aimed solely at modifying these beliefs may constitute an oversimplified response. Again, memory services and a skilled individualized approach may provide a solution, as there is potential for eliciting the patients' and the family's cultural understanding of dementia in this context. Practitioners would then be able to enter a negotiation towards a shared model, particularly with regards to expectations and therapeutic goals (Kleinman, 2006). Accurately identifying dementia as serious and progressive evoked considerable fear for the future among black Caribbean and white British participants and the data are unequivocal that individuals require support in managing these anxieties. Woods and Pratt (2005) note the value of preparation for diagnosis and the fundamental importance of breaking the diagnosis well to the person with dementia and their family.

A high proportion of black Caribbean older people in the UK live alone (Office for National Statistics, 2003) and many black Caribbean participants conceptualized care homes as an undesirable, yet unavoidable part of their future. Entering into a dialogue about their options may dissipate some of these fears and assist them in finding a satisfactory solution. This highlights the value of Advance Care Planning and of enabling people with dementia to articulate concerns and preferences for the future. The majority of south Asian older adults displayed a striking confidence in the continuing presence of family support, which mirrors reports of the perceived irrelevance of care homes among the south Asian community (Bowes & Wilkinson, 2003). However, a distinctive level of distress was evident in the few south Asian participants who lacked confidence in family support. If this is a developing trend the

experience of dementia is likely to evoke increasing levels of fear among south Asian older people with dementia.

Promoting valued elements of life

The data support the argument that culturally determined concepts of self are fundamental to the experience of dementia (Hashmi, 2009). Retaining an active and agile mind assumed the greatest importance among white British participants, regardless of education level. The value that they attached to intellect and autonomy is compatible with what Post (1995) terms the "hypercognitive culture" of Western society, which prioritizes cognitive abilities over other domains. As such, the status of individuals with cognitive impairments is reduced. Within the south Asian sample, several men felt that their memory problems threatened their position with the community. However, the majority of south Asian participants valued being part of a wider family and did not feel that dementia undermined this. Instead, emphasis was on the collective identity, with the family central to the conceptualization of "self". Parallels can be drawn with Gaines (1989) who hypothesized that less importance may be attached to cognitive decline in African American communities as higher value is placed on emotional interactions and roles within the family. The emphasis that black Caribbean participants placed on autonomy is consistent with descriptive accounts in this population (Goulbourne, 1999). Unfortunately, these circumstances exacerbated the threat that the condition posed.

This paper has presented cultural trends, but in doing so the overriding aim has been to highlight the significance of core values in mediating the subjective experience of dementia. Core values are unique to each individual and caregivers need to be aware of the roles, relationships and activities that each person with dementia

values. If a person's interests and valued roles are understood, then it should be possible to adjust the psychosocial environment to affirm the sense of self (Harris & Sterin, 1999). Individualized interventions with people with dementia that target salient role identities have been shown to have a positive impact on the emotional and psychological well being of individuals in day centers and nursing homes (Cohen-Mansfield et al., 2006).   This rests upon the proposition that constructive interaction requires that caregivers recognize, respect and provide opportunity for the individual's self-expression (Kitwood, 1997).

Table 2

Strengths and weaknesses

This study purposefully recruited people at different stages of dementia, as there has been a propensity to focus on people in the early stages of the disease (Steeman et al., 2006). It is arguable that the perceived threat posed by dementia diminished as participants' insight into their condition and support needs decreased, yet the process through which distress developed presented as consistent across the sample. The diversity of recruitment strategies is considered a strength of this study and enabled a variety of experiences to be explored. Yet the heterogeneity of the sample also made it difficult to fully examine how characteristics such as gender, socio-economic status and age might influence the individual's experience. Given the lack of research with people with dementia within minority ethnic groups we consider this an essential first step in building the knowledge base in this area.

Table 1

Key characteristics of participants

	Black Caribbean (n=11)	South Asian (n=9)	White British (n=10)
Place of Birth, *n*			
Jamaica	10	0	0
Trinidad	1	0	0
India	0	8	0
Kenya	0	1	0
England	0	0	10
Gender, *n*			
Male	3	5	5
Female	8	4	5
Age			
Mean	76	77	82
Range	67-87	65-87	72-96
Marital status, *n*			
Single	1	0	0
Married	3	7	7
Divorced	2	0	0
Widowed	5	2	3
Living situation, *n*			
Alone	4	0	1
With spouse	1	4	7
With family	4	4	1
In sheltered	2	1	1

accommodation			
MMSE			
Mean (SD)	18 (8.9)	17 (9.2)	17 (7.5)
Range	1-27	7-29	8-28
MMSE<11	2	3	3
MMSE 11-20	3	2	4
MMSE >20	6	4	3

Table 2

Cultural commonalities and differences in participants' "understanding of the condition", "attitudes surrounding support needs" and "valued roles, relationships, activities" and their implications for policy and practice

	Black Caribbean	White British	South Asian
1. Understanding of the condition	▪ Condition identified as serious and progressive ▪ Stigma expressed as "madness" and "craziness"	▪ Condition identified as serious and progressive ▪ Use of pejorative terms such as "stupid" or "dim-witted"	▪ Rarely aware of progressive nature of condition ▪ Often conceptualized as benign and normal for age

Implications	▪ Importance of breaking the diagnosis well
	  ⁻ Support in managing difficult beliefs
	▪ Challenge stigmatizing beliefs
	  ⁻ Public education campaigns
	  ⁻ "Memory services" rather than psychiatric services
			▪ Increased role for "memory services"
			  ⁻ Forum for negotiating shared understanding of dementia

2. Attitudes surrounding support needs	▪ Family support considered unavailable or unacceptable ▪ Care homes considered likely, yet undesirable alternative	▪ Concern about becoming a burden to spouse. Limited support available from children ▪ Care homes preferable to burdening family members	▪ Confidence and pride in the presence of family support ▪ Care homes considered irrelevant to situation
Implications	▪ Provide opportunity to discuss fears for the future ▪ Explore options with person with dementia and family		▪ Sensitivity to diminishing expectations of support

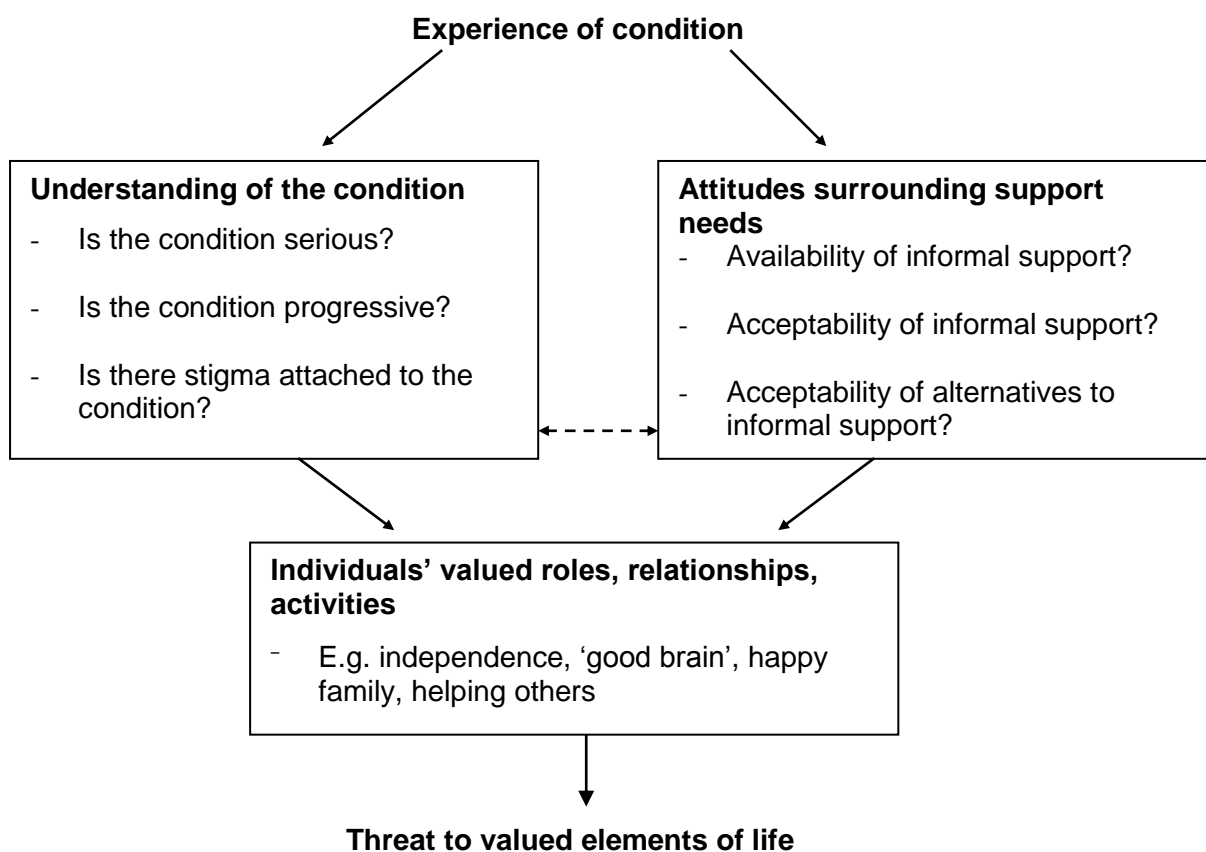| 3. Valued roles, relationships, activities	▪ Emphasized the value of independence, social interaction and a "functioning" brain	▪ High value on having a "good brain" and being an equal contributor to their marital relationship	▪ Valued being part of a wider family and often took pride in position in the community
Implications	▪ Sensitivity to cultural variation in roles, relationships and activities ▪ Recognize, respect and provide opportunity for individual's self-expression ▪ Offer services that reinforce rather than challenge valued elements of life ⁻ E.g. emphasis on services as a way of retaining independence and choice		

Fig 1. Vignette used in the interview

> Mr G is 75 years old. He has become very forgetful. He confuses people's
> names, even his own family, and often seems unable to remember things from
> one moment to the next. Yesterday when he went to the market to buy food, he
> came back with nothing, having forgotten what he went out for. He repeats
> himself in conversation. Sometimes, when he goes out, he gets lost and has to
> be brought back by neighbours.

Fig 2. Mediators of the relationship between experience of condition and level of fear

Experience of condition

Understanding of the condition

- Is the condition serious?

- Is the condition progressive?

- Is there stigma attached to the condition?

Attitudes surrounding support needs

- Availability of informal support?

- Acceptability of informal support?

- Acceptability of alternatives to informal support?

Individuals' valued roles, relationships, activities

- E.g. independence, 'good brain', happy family, helping others

Threat to valued elements of life

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