"I know he controls cancer": The meanings of religion among Black Caribbean and White British patients with advanced cancer

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ABSTRACT

There is evidence that religion and spirituality affect psychosocial adjustment to cancer. However, little is known about the perceptions and meanings of religion and spirituality among Black and minority ethnic groups living with cancer in the UK. We conducted semi-structured interviews with 26 Black Caribbean and 19 White British patients living in South London boroughs with advanced cancer to explore how religion and spirituality influenced their self-reported cancer experience. Twenty-five Black Caribbean patients and 13/19 White British patients volunteered views on the place of religion or God in their life. Spirituality was rarely mentioned. Christianity was the only religion referred to. Strength of religious belief appeared to be more pronounced among Black Caribbean patients. Three main themes emerged from patients' accounts: the ways in which patients believed religion and belief in God helped them comprehend cancer; how they felt their faith and the emotional and practical support provided by church communities assisted them to live with the physical and psychological effects of their illness and its progression; and Black Caribbean patients identified the ways in which the experience of cancer promoted religious identity. We identified that patients from both ethnic groups appeared to derive benefit from their religious faith and belief in God. However, the manner in which these were understood and expressed in relation to their cancer was culturally shaped. We recommend that when health and social care professionals perform an assessment interview with patients from different cultural backgrounds to their own, opportunities are made for them to express information about their illness that may include religious and spiritual beliefs since these may alter perceptions of their illness and symptoms and thereby influence treatment decisions.

Introduction

National surveys consistently support the idea that religion and spirituality are central to many individuals (Ipsos MORI, 2003) and there is now evidence that the role of religion in the delivery of health care is becoming more important in an attempt to provide patient-centred care (Pargament & Saunders, 2007). In the UK, guidance on caring and supporting adults with cancer recommends that health and social care professionals ensure accurate and timely evaluation of religious and spiritual issues through regular assessment (National Institute for Clinical Excellence, 2004).

Distinguishing between religion, faith and spirituality

Conceptual confusion is common in relation to religion, faith and spirituality and there is little consensus about...
what these terms mean both in the USA and the UK literature. In this paper we understand religion as a system of faith and worship expressive of an underlying spirituality which is frequently interpreted in terms of particular rules, regulations and practices, as well as the belief in the content of the named religion. There is a clear acknowledgement of a power other than the self that some describe as God (Speck, 2003). Many definitions of faith have been suggested. A useful definition describes faith as an “assured confidence” that what is hoped for will actually happen (Puchalski, 2002). Spirituality is a relatively newer construct which has been subjected to increasing interest in relation to the experience of health (Weaver, Pargament, Flannelly, & Oppenheimer, 2006; Wulff, 1997). Spirituality is recognised as representing a search for existential meaning within a life experience, usually with reference to a power other than the self, not necessarily called ‘God’, that enables transcendence and hope (Speck, 2003). In the USA literature, spirituality has also been extended to include art and music (Puchalski & Romer, 2000). We acknowledge these definitions may not be understood in the same way by patient participants in this study.

Religion, spirituality and health

Research has indicated that religion and/or spirituality have positive effects on those experiencing chronic pain (Miller, 1989), among those with psoriasis receiving phototherapy (Kabat-Zinn et al., 1998), and those who have experienced cardiac failure (Harris et al., 1999). Religion has also been observed as conferring psychological benefits among geriatric patients (Koenig, George, & Titus, 2004), and providing guidance about prenatal decision-making for those where sickle cell disorders are common (Ahmed, Atkin, Hewison, & Green, 2006). Criticism of these findings and others are extensive. The central weaknesses include the failure to control for confounding variables such as socioeconomic status, behavioural differences, age, physical mobility and social support (Sloan, Bagiella, & Powell, 1999).

Most research examining the function of religious and spiritual coping in adjustment to cancer and its progression is from the USA, which limits the inferences for populations living elsewhere. Studies have shown how religion and spirituality enable patients to find meaning in their cancer and adjust to the symptoms associated with it (McCoubrie & Davies, 2006; O’Mahony, Goulet, & Kornblith, 2005) and reduce end-of-life despair (McClain, Rosenfeld, & Breitbart, 2006). Research has also observed the ways in which religious communities reduce psychological distress through the provision of instrumental and emotional support (Koopman et al., 2001). Whilst this growing body of research has made an important contribution to an understanding of the place of religion in relation to the experience of cancer there are methodological limitations involved in the conduct of these studies. For example, a recent systematic review of 17 studies that attempted to examine the influences of religion and/or spirituality in long-term adjustment to cancer showed that although religion and/or spirituality were beneficial, the authors stated that many studies suffered from serious methodological problems. These included the manner in which religious coping was conceptualised and measured, and that studies often failed to control for possible yet important confounding variables including stage of illness and perceived social support (Thuéné-Boyle, Stygalla, Keshtgar, & Newman, 2006).

Religion and/or spirituality have been shown to not always confer benefits. A cross-sectional study of 34 prostate cancer patients observed that when patients associated cancer causation with God’s anger, they experienced poor emotional and social functioning (Gall, 2004). Making use of phenomenological methods, Taylor et al. interviewed 30 participants with cancer from different religions about why, when, and how they prayed, and the outcomes they expected. The analysis showed many interviewed had hesitations about petitionary prayers for a cure. They also questioned the nature of God and ‘unanswered’ prayers. Several participants were concerned about how to pray in order to lead to favourable outcomes (Johnson Taylor, Hopkins Outlaw, Bernardo, & Roy, 2000).

Many studies have relied entirely on samples drawn from White populations. Little is therefore known about the meanings of religion and spirituality among ethnic minorities. Ethnicity relies on shared identities built on common cultures, histories, languages, religions and regional affiliations (Ahmad & Bradby, 2008). However, this traditional conceptualisation of ethnicity has been challenged because beliefs about the world are neither static nor an intrinsic property:

‘Ethnic identity may be for some little more than labels, with few behavioural implications and largely a residue of what is learned from parents or others. For others an ethnic label may include elaborate behavioural prescriptions or expectations, organise much of daily living and carry a powerful emotional charge.’ (Cornell & Hartmann, 1998, p. 198)

We also argue it is important to acknowledge that ethnic identities, like other collective identities, comprise highly variable and contingent properties that influence, but do not fully determine, the ways that people relate to each other and make sense of the world. This includes religion and spirituality. Culture, however, has been identified as assuming greater significance in peoples’ lives because it involves a conceptual scheme or a recipe for making sense of the world and of differences between individuals (Cornell & Hartmann, 1998). It is also acknowledged that the relative salience of different types of bonds, including a shared culture, varies across groups and over time, reflecting differences in histories, prevailing circumstances and the responses of the wider society. Identity and belonging are therefore always in the process of being created, reproduced or transformed. They are not cut in rock, nor are they secured by a lifelong guarantee but are negotiable and revocable (Baumann, 2004). Ethnic identities and therefore attitudes towards religion and spirituality may also be varied, a result of the on-going interaction between the circumstances of individuals and groups encounter, and the actions and conceptions of those group members.

Most studies that have explored the interface between ethnicity, culture and the meanings of religion, faith and spirituality among cancer patients are USA-based. These studies have shown that religion and belief in God appear to be more central among some ethnic groups than others.
For example, Potts interviewed 16 African American cancer survivors about the roles of religion during their illness experience. The most frequently identified themes were: healing was “God’s work”, prayer was important, “turning it over to the Lord” was a strategy for coping with their illness, and that cancer increased spiritual awareness (Potts, 1996). A qualitative study conducted by Juarez et al. of 17 Hispanic patients with advanced cancer also found that religious beliefs had an impact on the meanings they ascribed to their cancer-related pain and its management that included prayer and religious folk healers (Juarez, Ferrell, & Borneman, 1998).

Henderson conducted interviews with 43 African American women, living in southeastern USA who attended African American breast cancer support groups, to explore what helped them cope with their cancer diagnosis and treatment. She found that besides participation in their support groups, participants frequently referred to praying to God for help and comfort, and many believed this was more important to them than the help they received from family and friends (Henderson, Gore, Davis, & Condon, 2003).

Of the few comparative studies undertaken, Moadel et al. observed that among the 48 Hispanic, 62 Black American and 118 White patients investigated, Black American and Hispanic patients reported significantly more spiritual needs and were more likely to believe that religion was important in overcoming fears, finding hope, meaning, and peace of mind than White patients (Moadel et al., 1999). A study that explored coping strategies among African American and White women with breast cancer observed that both groups of patients tended to seek social support as a means of coping but differed in their sources of support, African American women reporting they relied more on God (Bourjolly & Hirschman, 2001). The authors, however, did not explore the contribution of church-based affiliations which may represent a source of important instrumental and emotional support.

There have been few equivalent European studies which may be the result of ethnic differences in the patterning of diseases. In the UK, minority ethnic populations have tended to be younger than the reference population so the incidence of cancer has, until recently, been lower (Jack, Linklater, Hofman, Fitzpatrick, & Møller, 2006). A comparative qualitative study conducted among 15 South Asian and 19 White British patients with advanced cancer reported that although some patients chose to attribute their illness to health-related behaviours, environmental and genetic factors, there were also a number of patients who held religious beliefs. These included “moral wrong doing” and a belief that cancer was “Allah’s will” (Chattoo, Ahmad, Haworth, & Lennard, 2002). Little is known about the ways in which religion and/or spirituality affect the experience of cancer in the Black Caribbean population who represent slightly under 1% of total UK population (Office of National Statistics, 2007). Many members of this community migrated to the UK in the late 1940s and early 1950s and settled in London, Birmingham and Manchester and have experienced persistent socio-economic disadvantage (Campbell & McLean, 2002). Health research among this ethnic group includes mental illness (Koffman, Fulop, Pashley, & Coleman, 1997) and diabetes and hypertension (Riste, Khan, & Cruickshank, 2001). This population is now experiencing demographic ageing where larger numbers are dying from advanced diseases that include cancer.

Although the 2001 Census reported that 74% of Black Caribbeans were Christian (White British: 76%) (Office of National Statistics, 2007), it is important to note there are wide differences in the traditions and ritual practices that govern their attitudes towards their religious faith and to God. However, the majority of Black Caribbeans are members of the Anglican, Methodist and Pentecostal churches where the church represents a strong source of community, as well as a focus for prayer (Koffman, 2001). Only one survey has examined the presence of religious faith among Black Caribbeans and White British people with advanced disease in the UK (Koffman & Higginson, 2002). This survey showed that a higher proportion of deceased Black Caribbean patients were reported to have ‘some/a strong’ religious faith compared to deceased White British patients. For those deceased patients with a religious faith, significantly more Black Caribbean patients were reported to have benefited from it during their illness. However, the survey was not able to explore in what ways religion and/or spirituality helped these patients. We, therefore, conducted a comparative qualitative study of Black Caribbeans and White British people living with advanced cancer to explore how religion and/or spirituality affected their illness experience. We chose to compare the two ethnic groups for the following reasons. First, just focusing on a single ethnic group can imply that they are ‘exotic’ (Bhopal, 1997) and by definition different compared to the majority population. Second, there is little published qualitative research of the accounts of religion and/or spirituality among White British patients with advanced cancer which would help understand areas of common ground between different groups.

Method

Participants

This study took place between December 2001 and April 2003 in three south London boroughs characterised by high levels of social deprivation and one of the highest concentrations (11.4%) of Black Caribbean people in the UK. Participants were recruited via three in-patient and community-based palliative care teams and from oncology out-patient and lung clinics. During the study a total of 1508 White British and 256 Black Caribbean patients were referred to the services. We attempted to recruit a diverse participant group with respect to age, cancer site and location of care within each ethnic group. Our inclusion criteria were Black Caribbean and White British people (ethnicity was self-verified) among patients with advanced cancer. At each meeting, new and current patients on the caseload were reviewed and discussed. New Black Caribbean or White British patients with metastatic disease were highlighted by health care professionals present. JK then discussed with the teams if they considered if these patients were aware of their clinical diagnosis and prognosis, and if they were capable of providing informed consent.
Interviews

Ethical approval was obtained from two local research ethics committees. The interviews were informal in style and loosely followed a topic guide that was guided by a review of the literature and then developed following discussions with a cancer patient advocacy service for the local Black Caribbean community. Interviews began with a general discussion about what participants felt about cancer and its causation and then progressed to explore symptoms that bothered or troubled them, particularly as their illness had progressed. Questions also explored how they managed to live with their illness. Prompts were used to elicit further information when required.

Following consent, participants were interviewed by JK. Twenty-nine interviews were carried out in patients’ homes which gave JK greater access to patients’ personal worlds ungoverned by the rules of hospital life. This included the participants’ time frame, their pace of living, as well as placing the interviews into context. For example, ornaments, pictures, books and iconic references to their deity, as well as photographs of relations and friends and photographs of the patient as they once were, all provided important sources of reference and valuable clues to patients’ identities. The remaining 16 interviews were conducted among participants treated and cared for in hospital either on an in-patient or out-patient basis. In some instances the researcher (JK) believed this would present challenges. For example, it was sometimes impossible to find a more private venue for the interview to take place, particularly for those patients located in large hospital wards. Often the only barrier that separated them from other patients and staff was the linen curtain. Given their physical frailty, moving them to a more private room, if it was available, would have been impractical. Despite this concern, participants in hospital settings frequently provided rich accounts of their cancer experience. The outpatient oncology clinics were, however, more amenable for conducting interviews where a ‘quiet room’ served as an environment to enter into conversation with JK with fewer possibilities of distraction. All interviews were tape recorded and lasted on average 40 min (range 20–60 min).

Analysis

The framework analysis method was used to inductively organise the data and identify emerging themes (Richie & Spencer, 1994). This matrix-based approach involved developing a thematic framework through the independent repeated reading of the interview transcripts. All data were indexed by JK and relevant sections of text were summarised within the framework, which facilitated exploration of relationships between themes within and across cases. To address issues of rigor and trustworthiness in the analysis a random selection of interview transcripts were also analysed by MM and IJH and then discussed with JK. Where coding differed areas were reconsidered until consensus was achieved. We also paid attention to deviant cases where emerging themes contradicted more common ideas. Participants’ ethnic identities are preceded by ‘BC’ (for Black Caribbean) and ‘WB’ (for White British). In an attempt to preserve anonymity names have been changed. We have made some use of numerical and verbal counting as this can help to clarify patterns emerging from the data while recognizing that the main emphasis is to identify meanings and conceptual categories.

Results

Characteristics of participants

Thirty Black Caribbean and 22 White British cancer patients were approached to participate in the study. Of these, four Black Caribbean and three White British patients declined participation. Reasons for this included not wanting to be disturbed or to discuss their cancer. Of the Black Caribbean participants who agreed to be interviewed nearly all (22/26) were older first generation migrants to the UK who arrived in 1950s and 1960s. There were a small number of second generation ‘younger’ participants under the age of 45 years. The jobs they held prior to retirement or illness were similar to their White British counterparts and included those who had worked as mechanics, cleaners, bricklayers, decorators, clerical staff or housewives. Participants were diagnosed with a range of cancers. The duration of disease was known for 31 participants. This ranged from 1 month for a breast cancer patient to 24 years for a patient with leukaemia. Table 1 presents the main characteristics of the participating participants.

A spectrum of belief

With the exception of one participant, all Black Caribbeans volunteered views on the meanings of religious faith and God within their life. This compared to 13 out of 19 White British participants. Two Black Caribbean, both of whom were relatively young (aged 35 and 43 years), and one older White British participant (aged 83 years) referred to the word ‘spiritual’, possibly suggesting this was not a term in common use to describe their beliefs. No participants referred to religions other than Christianity. Table 2 presents the four main groups in terms of participants’ attitudes to religious faith and belief in God.

<table>
<thead>
<tr>
<th>Table 1</th>
<th>Characteristics of participants</th>
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<tbody>
<tr>
<td>Gender</td>
<td>Black Caribbean (n = 26) White British (n = 19)</td>
</tr>
<tr>
<td>Male</td>
<td>17</td>
</tr>
<tr>
<td>Female</td>
<td>9</td>
</tr>
<tr>
<td>Median age (range)</td>
<td>68 yrs (35–82 yrs) 77 yrs (34–88 yrs)</td>
</tr>
<tr>
<td>Cancer site</td>
<td>Black Caribbean White British</td>
</tr>
<tr>
<td>Breast</td>
<td>2</td>
</tr>
<tr>
<td>GI</td>
<td>6</td>
</tr>
<tr>
<td>GU</td>
<td>11</td>
</tr>
<tr>
<td>Haematological</td>
<td>2</td>
</tr>
<tr>
<td>Lung</td>
<td>4</td>
</tr>
<tr>
<td>Site unknown</td>
<td>1</td>
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<tr>
<td>Duration of disease (n = 29)</td>
<td>3 months–10 years 1 month–24 years</td>
</tr>
<tr>
<td>Location of interview</td>
<td>Black Caribbean White British</td>
</tr>
<tr>
<td>Hospital</td>
<td>11</td>
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<td>Home</td>
<td>15</td>
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</tbody>
</table>
Views about religious faith and belief in God were central in defining participants' attitudes to life and relationships with others. Participants were ambivalent or more guarded about God's role. For a few Black Caribbeans and White British participants, the accounts from their interviews indicated they believed their cancer was due to God. Although this may have helped remove these participants from a personal responsibility over events, it did not represent a passive response to their illness. Instead, their views appeared to be embedded in a deliberate and trusting relationship with God who controlled their lives. For example, an older Caribbean man was convinced his cancer was just part of the wider picture of God being instrumental in both “creating” as well as “destroying” nature. He explained:

Franklyn: None of us put ourselves here. Only the man who made all things.
JK: God?
Franklyn: Exactly so! He is the inventor and the maker. (BC7, GU cancer, 72 years)

Petula, a Black Caribbean participant, shared a similar sentiment when she spoke of God “controlling” or “deciding” her life, particularly within the context of her cancer experience. She remarked: God means everything to me. He's my life, He's always been there in my happiest times, my happiest times. He's everything to me. He's there for me. He's brought me this far and I know he controls cancer, and whatever He decides I'll go along with it. (BC17, GI cancer, 57 years)

The use of biblical text to search for a meaning about cancer was particular to Black Caribbean participants. For example, Gwen recounted the servitude experienced by the Jewish people while they were slaves in ancient Egypt to help locate her cancer and its associated distress within her life. She explained: Once I cry out to God. “You were the same God who delivered the children out of Egypt when they were having a hard time, and you are the same yesterday, today and you aren’t changing” and I said, “I am suffering.” “Father, teach me to know your will. It’s not my will but your will.” (BC19, haematological cancer, 61 years)

Jack believed his cancer was also a direct manifestation of God’s plan for him and made use of words that implied he believed there was a glorification associated with his distress and suffering. Jack was adamant that he should not express any animosity about his situation, but instead accept his situation and all its consequences with joy. He explained:

Jack: Yes, you have to bear it, because you know that is the will of God because from Genesis, you know, from Genesis, from creation that this is his way.
JK: You think this is the will of God?
Jack: Yes. Well it’s all the suffering, the will of God. …and you just have to accept it with joy. (BC18, GU cancer, aged 82 years)

The need to delve into biblical text to comprehend the “Why me?” was not present for a Black Caribbean called Edna. When asked why she believed she had cancer, she believed that her illness was an example of God’s will, but its manifestation in her life was just one example of him working in a manner she did not need to understand. Instead, she accommodated the unknown with equanimity. She said: Well I don’t ask myself, you know, because it’s God’s work. It don’t make sense to say why me, because if it’s not me, it’s somebody else. God is working in (a) mysterious way. You just have faith. (BC25, haematological cancer, 80 years)

Having examined views of those for whom religion was central in their lives, other views will now be considered. Participants who were ambivalent or more guarded about the centrality of religious faith and God in their life included...
Becky, a White British participant, who shared her view on the predictability of a seemingly random event. The language she adopted, which may have had a covert divine orientation at its core, appeared to be driven by an external force she referred to as “fate”. She admitted that the journey though her illness was out of her control: Yeah, I believe in God, but I don’t know what’s happening with me at the moment. Yeah, I am Catholic, but I’m not the Catholic that goes to church every week or anything like that. I believe it’s just left in fate’s hands. (WB34, GI cancer, 34 years)

There were also a few White British participants who did not profess a religious faith yet who made sense of their cancer using a non-divinely inspired form to account for their experience. For example, Stanley applied the theory of probability to comprehend his situation: Everyone’s got to die. Isn’t it one in three who gets cancer? And I’ve got it. (WB45, lung cancer, 72 years)

Social and emotional support of religion

Rather greater numbers of Black Caribbean (11/25) than White British (4/13) participants discussed being involved in church-based communities that provided them with social, practical and emotional support. These sources of help were more common to those who were categorized as having a strong religious faith. Participants recounted how help was provided by both religious leaders and friends. Religious leaders were valued not only because they discussed religious or spiritual issues germane to participants, but also for the physical presence. Joseph, a Black Caribbean man, referred to how his church leader helped reduce his sense of loneliness since he had become housebound. This was in addition to fulfilling the important religious duty of providing communion for him. He said: Well it’s easier to cope, because you have someone around you, and they are a servant of God, come and say a word of prayer with you and give you communion. (BC10, GU cancer, 68 years)

Social support provided by friends made through participants’ church congregations or communities involved the delivery of practical and emotional support that took the form of talk about God, prayer and companionship. Milton, a Black Caribbean man, explained that his friends from his Jehovah’s Witness community made frequent visits to his hospital bedside where conversation often focused on the place of God within all their lives. But he added their physical company was equally valued; without it his life was empty: It encourages you, cos you talk about God, and then you got the company as well, you see. When I don’t have any company I feel terrible. (BC12, GU cancer, 69 years)

Participants sometimes considered that friends made through their churches were like second families. This was true for participants who did not always have access to their own immediate family during the crisis of their illness. For example, Sherwin, a Black Caribbean participant reported his congregation was central in providing him with help that included invitations for dinner or bringing hot food to his house. He said: They always want me to come down to have dinner with them. They phone up and find out if I’m feeling hungry and bring some food to eat and all that. (BC02, lung cancer, 67 years)

There were several White British respondents who did not want to discuss the centrality of religion in their lives, but reported they benefited with help from other group-based affiliations that in some ways were similar in nature and outcome to religious congregations. For example, Reginald discussed his friendships made through the Freemasons who afforded him help, relieving social isolation. He remarked: I’m a Freemason. And that’s where a lot of my friendships come from. It’s not a religion. It’s for men who enjoy being men. It’s very much an extended family. And they’re all on the phone to me. It’s just an extended family, a big family. (WB29, haematological malignancy, 77 years)

For a few participants, the presence of a religious faith and belief in God produced a state of mind that assisted them emotionally to live with their cancer and its progression. Participants who discussed this meaning referred to the companionship and friendship that was associated with a palpable feeling of God’s presence in their lives. However, two Black Caribbean participants were not convinced they could adequately explain the nature of their relationship with God or the feelings they experienced when they prayed. For example, Grace stated that whilst she admitted it was impossible to physically see God there was never a time when she felt alone during her illness. It was under these conditions that she was assured of her safety and well-being in a manner that no doctor or other health care professional was able to impart to her. She remarked: ... I don’t think you can describe it like you could describe something that you can see. It is just a sort of like well-being. Spiritually you’re not on your own, if you know what I mean. It’s, erm, a, comforting thing that no one else can see. I mean you can go to a doctor or you can go to, erm, a dentist and they can extract the tooth ... but it is something much deeper than that. I can’t explain it. All I know is that I’m not on my own. (BC14, GI cancer, 35 years)

Other Black Caribbean participants felt less hesitant about their ability to share their strong belief that God was personally watching over them, although the focus of this attention and the manner they used to describe this differed. John contextualised God’s intervention within his illness experience by recounting the many occasions during his life when he had experienced evidence of God’s help, particularly since he had come to live in England. He believed the almost parental-like care he had benefited from was totally unqualified and his needs during his illness had been no exception. According to him this unbridled love from God had continued during his current crises. He explained:

JK: Do you pray at all?
John: Mm.
JK: And has that helped you since you’ve been ill?
John: It helped all my life through. All my life through, because I mean living in, living in England it is not easy. Every day you need God. (BC8, lung cancer, 59 years)

Seeking emotional support through religion was not just limited to those categorized as having a strong religious belief. When Sally, a White British woman, was asked what provided her with happiness as her illness had progressed, she indicated her interest in religion was routed more in pragmatism than the divine. It offered her a distraction
and replacement for a spouse whose enduring characteristics were not endearing: ‘I suppose just my religion, because I haven’t had my husband. He’s been a right old moaner all his life, you know.’ (WB31, breast cancer, 88 years)

Seven Black Caribbean participants and one White British participant chose to focus on the healing powers and relief of distressing cancer-related symptoms associated with their religious faith and prayer with God. ‘Healing’ represented two inter-related categories that always referred to physical dimension. The first meaning related to a cure from cancer, and the second to the alleviation of symptom-related distress. With the exception of the White British participant, both these themes were held by Black Caribbean participants. In the first example, Jack shared his surreal, divinely inspired dream of a personal ‘angel’ who cared for him. His prophetic dream convinced him of his recovery from cancer and helped provide a meaningful and accessible path through his illness experience. He explained:

> I dreamt that I went to heaven and when I was going up I saw my recovery. … and about a week after the doctor came and said that in the next two weeks I will be able to go home. (laughs) So it was a miracle. (BC18, GU cancer, 82 years)

The White British participant who alluded to the ‘healing’ capacity of her faith was Margaret, who throughout her interview displayed more ambivalence towards her religious belief. She qualified her motivation to pray not for herself, but to protect her family she believed would be lost without her: ‘I was brought up Catholic. I’ve lost a lot of the faith along the way. And I don’t go to church anymore. But I do pray morning and evening. I don’t pray for myself. I pray for my family. I say, “Just give me a few more years, please” Just to, basically, see that Alison’s alright and to see the kiddies grow.’ (WB33, breast cancer, 63 years)

Strength resulting from a strong belief in God represented the physical and almost tangible capacity to deal with the relentless impact of cancer and its symptoms. Only Black Caribbean participants shared their perspective. Although the source of their strength appeared to vary, all made use of a very expressive language to convey their views. When asked what helped Audley, he replied that his belief in God was so strong that he was convinced he was capable of overcoming any obstacle, cancer being just one example. He explained: ‘It’s that strong. If I can walk through glass, it won’t cut me. Faith can move mountains.’ (BC11, lung cancer, 70 years)

One Black Caribbean participant spoke openly about her hope that prayer would in some way contribute to relieving breathlessness that impacted on her ability to negotiate the stairs in her house or perform previously taken-for-granted activities of daily living. Although June stated that she had personally been praying to God, her utter desperation to be free of her unabated distress led to her make the following plea to JK: ‘I want you to help me breathe! Pray for me! To help me – especially for the short breath. I don’t mind the pain, but the shortness of breath!’ (BC1, GI cancer, 68 years)

**A better life**

‘A better life’ refers to the third category to emerge from the qualitative interviews and relates to a very small number of Black Caribbeans who displayed a deep belief in God. These participants discussed the ways in which their cancer experience and its progression were embraced rather than viewed as a source of burden that they would rather do without. In this sense the experience of living with and dying from cancer were worthy of spiritual investment and would permit them entry to a more fulfilling and richer existence than their mortal presence on earth. Jack spoke of his expectation of joy at arriving at his final destination. He explained: ‘Probably my future life will be better than this, so I have that great hope, because I’m a Christian and I know that God will care for us all, you know, and we’re promised a better life and I’m looking for that. A far better life than this one.’ (BC18, GU cancer, 82 years)

**Discussion**

This is the first qualitative study to explore and compare the meanings of religious faith and belief in God among Black Caribbean and White British participants with advanced cancer in the UK. The findings from this qualitative study should be viewed within the context of the following methodological considerations.

First, we are aware that the sampling frame of potential participants available far exceeds the total number of participants recruited. The main challenge of conducting research in palliative care includes the complex and frequent multiple physical, psychological, existential and spiritual problems faced by patients that exclude many individuals from participation. There are also practical difficulties associated with recruitment that include ‘gate-keeping’ by professionals. We do not believe that this occurred and consider we were successful in recruiting representative samples of participants from both ethnic groups living in south London.

Second, the method of data collection may affect responses, particularly in sensitive areas. Here ‘racialised differences’ between the research participant and the interviewer can potentially affect the ‘genuineness’ and ‘accuracy’ of what research participants are prepared to report (Gunaratnam, 2003). This concern is above and beyond obvious differences such as shared language. There are suggestions that matching the interviewer and participant on characteristics such as ethnicity, gender, age, or experiences in relation to the research topic may help to build rapport (Grewal & Ritchie, 2006) which can lead to improved validity of data. The interviewer (JK) is White British and not Christian. Despite this concern we were successful in undertaking interviews across both ethnic groups and elicited meaningful accounts of participants’ cancer experiences, a result also achieved by others who recently conducted cross-ethnic interviews in the UK (Graham, Grewal, Lewis, & NatCen, 2007). Moreover, achieving true ethnic matching is difficult since it addresses only one possible marker of identity and is further complicated by suggestions that we are all subject to ‘social hybridity’ (Song & Parker, 1995), a composite of many influences. We also believe that in the process of matching, participants may assume the researcher possesses a body of taken-for-granted knowledge about their ways of life and as a consequence may not volunteer important aspects of their experience relevant to the study. Third, the cross-sectional design of the study...
did not allow for exploration of the changing meanings of religious faith and belief in God with time and how these may relate to how participants’ understand and live with their advanced disease. It has been suggested that prospective longitudinal recruitment is possible if a good initial relationship between interviewer and participant is developed (Steinhauser et al., 2006) although previous research has shown that this is often difficult because progressive disease leads to significant participant attrition (Murray & Sheikh, 2006).

The evidence from the qualitative interviews shows that, with the exception of one participant, all Black Caribbeans referred to religion or belief in God. This compared to 13 out of 19 White British cancer participants. All who stated they had a faith referred to Christianity as being their religion. However, the strength of belief varied among participants interviewed and included those with very strong convictions to those who were more ambivalent about its place in their lives, but stronger beliefs were a more frequent feature of Black Caribbean participants. Very few participants from either ethnic group referred to ‘spirituality’, possibly indicating this is a newer and more contemporary construct compared to religion (Weaver et al., 2006) and therefore not a term used by the older sample of participants we recruited.

Comprehending the place of cancer

Meaning has been defined as the nature of the perceived relationships between the individual and his/her world that is developed within the context of specific events (Fife, 1994). Evidence from previous studies has shown that religious belief has an important role in helping individuals understand the cause of cancer and can help them sustain a sense of justice (Strang & Strang, 2001). Our study suggests that among those participants who volunteered information on the centrality of religious faith and a belief in God in their lives, both offered a structure to help locate a positive place for cancer in their lives and supports Victor Frankl’s belief that the presence of meaning can help one to survive even the worst conditions (Frankl, 1992). This theme was more prominent among Black Caribbean participants, a number of whom memorized Bible verses and scriptures to help in this process. Although this approach may be perceived as representing a denial of events or avoidance of personal responsibility for their illness, we suggest the purpose of religious faith was not about passivity, but a deliberate attempt to understand cancer and its effects in their lives.

Living with cancer and its progression

Descriptive studies of cancer participants have shown that religion and a belief in God include a secular as well as a spiritual component that provide individuals with comfort and support during crises. These have been shown to produce a positive state of mind distinct from those without a faith (Albaugh, 2003; White & Verhoef, 2006). We observed that participants in this study, who volunteered that their faith and belief in God were central in their lives, discussed the ways in which they derived practical and emotional help from their community, in addition to a personal connectedness to God. This helped them manage the on-going impact of cancer and its associated symptoms and distress. The meaning and importance participants attached to the practical and emotional social support provided by their church-based communities or congregations was more frequently voiced among Black Caribbean than White British participants, a finding reflected in both USA (Williams & Dilworth-Anderson, 2002) and UK studies (Moriarty & Butt, 2004).

Morgan et al.’s research amongst women with breast cancer and their partners described a situation where participants believed that God walked with them wherever they went throughout their cancer journey (Morgan et al., 2005). Our study shows that at a personal level, participants with stronger rather than more ambivalent or negative views towards religion or God believed that even in the absence of family or close friends they did not feel isolated. Indeed a few participants spoke of the physical presence of God in their lives that protected them.

The importance of perceived spiritual support in relation to ‘healing’ and ‘strength’ was evident in the interviews. A number of Black Caribbeans spoke of a belief that God would grant them a life extension or even recovery from cancer. In others, whilst the expectation of a cure may not have been present, requests for the alleviation of symptoms were still central to their lives, particularly when they were distressing, or affected their ability to lead normal lives. Research has shown that people who perceive God as a supportive, guiding force in their lives tend to experience less psychological stress. For example, Maton’s study of college students observed a stress-buffering effect of perceived spiritual support on levels of depression in high stress situations (Maton, 1989). Research among African Americans with cancer has also shown that belief in the power of God can be pivotal in how successfully participants accommodate the physical and psychological vicissitudes of their illness and its treatment (Ashling-Giwa & Ganz, 1997).

Cancer and connection with God

Our study identified a very small number of Black Caribbean participants as believing their cancer experience was linked to their ultimate meaning, a transition from an existence on earth to the company of God in heaven. Cancer, its associated distress and the strong possibility of death were not viewed as a burden that they would rather do without, but actively greeted with enthusiasm. This experience helped magnify their religiosity. Previous research has similarly shown that the experience of cancer can lead to increased interest in religion and spirituality. In a study of end-of-life issues among 108 gynecological cancer patients, 76% indicated that religion had a prominent place in their lives, 49% said that they had become more religious since having cancer, and none reported a decline in religiosity since diagnosis (Roberts & Brown, 1997). Two qualitative studies conducted in North America among African Americans have observed that accepting cancer and the glorification of suffering are worthy of spiritual investment (Bolling, 1995; Henderson et al., 2003).

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Conclusions and implications

Cancer is a life-changing encounter influenced by many factors including religion, which is culturally shaped. It is not enough to know how to care for patients with advanced cancer and their symptoms; health and social care professionals also need to care for them sensitively and holistically. The results show that within any ethnic group there will be diversity of beliefs which caution against stereotyping. In 1964, Dame Cicely Saunders proposed the concept of ‘total pain’ which incorporated physical, psychological, social, emotional, and spiritual elements (Saunders, 1964). This approach viewed the illness experience as a key to unlocking other issues and as something requiring multiple interventions for its resolution. ‘Total pain’ was tied to the use of narrative and biography, emphasizing the importance of listening to the patient’s story with an authentic curiosity to understand their distress. We therefore recommend that health and social care professionals are aware of how religion and spiritual belief can affect understanding cancer and other diseases and the interpretation of symptoms. When performing an assessment interview with patients from different cultural backgrounds to their own, health and social care professionals should ask questions that go beyond a detailed description of symptoms, instead facilitating opportunities for patients to express information about their illness that may include religious and spiritual beliefs and how these may alter their perception of the illness and symptoms, and thereby influence care and treatment decisions.

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