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“We’re talking about black men here, there’s a difference”

Cultural differences in socialised knowledge of prostate cancer risk: a qualitative research study

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ABSTRACT

Purpose: To detail social knowledge of prostate cancer risk amongst cultural groups. Prostate cancer is the most common cancer in men, and black men are at the highest risk. Despite this, black men are the least likely to be diagnosed early with prostate cancer. It is important to understand why this is so that these men can receive early access to effective treatment and support.

Methods: A constructivist grounded theory methodology was used. Data were collected between December 2015 and October 2017; seventeen men were interviewed, and eighteen men took part in focus groups.

Results: There were differences in the way the men constructed their understanding of risks for prostate cancer. The social construction of prostate cancer risk knowledge was mediated by the way the men were socialised to understand and accept this risk. The Somali and African Caribbean men placed social importance on the healthy body, whereas the white working class men seemed to find social value through the unwell body. This research proposes the theory that social constructions of knowledge mediate the way men perceive and accept their risk for prostate cancer.

Conclusion: Understanding socialised knowledge of risk may mediate the acceptance of specific prostate cancer risks. This knowledge may help health providers and third sector organisations produce targeted health-related information. Health practitioners may also benefit from understanding how socially constructed ideas of the body could influence the way men respond to conversations about prostate cancer so that tailored and culturally appropriate support can be offered.

Key words: Prostate Cancer, cancer nursing, black men, Somali men, African-Caribbean men, white men, social risk perception, deprivation, ethnicity, constructivist, grounded theory.

INTRODUCTION

Background

Prostate cancer is the most common cancer diagnosed in men, and men of African and African Caribbean origin (black men) have the highest risk of all men (Siegel et al. 2018). The lifetime risk for prostate cancer in white men is estimated to be 13.2-15.0%, whilst for black men the risk is 23.5-37.2% (Cancer Research UK 2018). The reasons for this higher risk in black men remains unknown, and despite advances in our understandings of risk for prostate cancer, black men are less likely to be diagnosed early and have a lower survival rate when compared to white men (McAllister 2019).

Research focused on the risks for prostate cancer has uncovered a genetic predisposition for mutations in BRCA1 and BRCA 2 genes, associated with an aggressive prostate cancer accounting for approximately 2% of all prostate cancers (Lecarpentier et al. 2017). Although currently only relevant to a small percentage of men, overall recent advances in prostate cancer treatment are now opening possibilities of targeted treatment for men with these gene mutations, with the outcome of extended progression free survival for men with metastatic hormone refractory prostate cancer (Hussain et al. 2020). However, genetic mutations specific to black men have not been identified and researchers comment that this may be because of historical migration of African populations as

slaves, which has resulted in dispersed genetic differences and therefore lessening the possibility of isolating a specific genetic risk (Lachance et al. 2018).

Alongside genetic risks for cancer, deprivation is also seen as major contributor to cancer diagnosis and cancer mortality (Surbone and Halpren 2016; Salas et al. 2019). Lifestyle risk factors, such as poor nutrition and inactivity, are often associated with poorer health outcomes (Eylert et al. 2016; Salas et al. 2019), although a lack of effective education are also thought to contribute to a poorer understanding of individual risks for cancer (Marmot 2010; Noor et al. 2013; Lamb et al. 2014; Eylert et al. 2016; Marmot 2015). In the United Kingdom 1.2 million people from Black Asian Minority Ethnic (BAME) communities live in the most deprived 10% of neighbourhoods (ONS 2020), therefore increasing exposure to the problems of deprivation.

Of interest to this research is the effect of social constructions of prostate cancer risk amongst black men living in these areas, and how their understandings compare with those of white men also living in areas of deprivation. The embodied impact of prostate cancer in men has been documented previously (Kelly 2009) but further insights of how prostate cancer risk is perceived in different cultural groups is now needed.

This research explores knowledge of prostate cancer risk amongst men without having previously experienced a diagnosis of prostate cancer, to complement existing knowledge on the experiences of black and white men with prostate cancer and the effect of deprivation and culture on treatment choices, quality of life and life expectancy (Corben et al 2017, Pederson et al. 2012). This study also explores the role of social and cultural networks in shaping views of prostate cancer risk and the ways that cancer itself is perceived, to build on previous research (Forbat et al. 2014).

THE STUDY

Aim:

The aim of the research was to explore differences in the social construction of prostate cancer knowledge between Somali, African Caribbean and white men living in areas of deprivation, which could provide insights into factors that may contribute to the lower diagnosis rates of prostate cancer amongst black men in the United Kingdom.

Design and methodology:

This was a cross-sectional multi-method study, using semi-structured and focus group methods for data collection. A constructivist grounded theory approach to data collection and analysis was used. This framework reasons that reality is a subjective construct created by an individual's experiences (Guba and Lincoln 1989) and was used to investigate how men construct their understanding of prostate cancer risk based on their everyday experiences. This approach was appropriate for an inductive exploration of the perceptions of men who have not experienced a diagnosis of cancer, and how their social understanding of health and illness may influence their perception and acceptance of prostate cancer risk.

Additionally, of interest was the constructivist approach to grounded theory and the consideration of the position of the researcher in the research process. The first author was working as a prostate cancer nurse specialist at the time of data collection, therefore by using a constructivist grounded theory approach the role of the researcher remained transparent in the research process (Charmaz 2014). This was achieved using researcher reflexivity by maintaining memos during data analysis to interrogate the researchers influence and to acknowledge potential preconceptions of the primary researcher (Enosh and Ben-Ari 2016). The flexibility of data collection in this method was also thought to be of benefit to the research as any emerging social themes could be subject to ongoing exploration.

Participants

The geographical focus of this research was a city of approximately 363,200 people in the United Kingdom (ONS 2018). The research area was chosen because it included areas of deprivation, measured by the Welsh Index of Multiple Deprivation (National Statistics 2015). One location was chosen because it was known to be highly populated by African and African Caribbean communities, and another was chosen as it was known to be populated mainly by white communities. There was a very large population of men of Somali origin in one study area, who lived alongside men of African Caribbean origin. It became clear in the early stages of recruitment that the black men (Somali and African Caribbean men), should actually be treated as two separate groups for the purpose of the research. The research was focused on socialised knowledge of prostate cancer, and it was felt that grouping African Caribbean and Somali men together as black men would be ignoring cultural differences in the way knowledge is socially constructed, which was important for this research. As far as is known from current evidence, the risk for prostate cancer is the same for Somali men as it is for African Caribbean men in the UK (Ben-Shlomo et al 2008, Benarif and Eeles 2016, Perez-Cornago et al 2017), so recruitment of men from these populations was thought to be relevant to the research aims.

Recruitment to the research

The men were recruited to this research using extensive community engagement. There were concerns before recruitment that accessing men who did not have prostate cancer would be difficult. It was also thought that this would be particularly challenging when recruiting the Somali and African Caribbean men, as identified in previous research (Odedina et al. 2011; Vrinten et al. 2016); the female identity of the researcher could have created reluctance from the black men to talk to a female about a uniquely male complaint (Kelly 2009). To overcome this, community engagement activities were developed to build a trusting relationship with men in the black communities. These activities involved attending activities at a community centre local to both the African Caribbean men and Somali men, such as a weekly dominoes club, health fairs and summer fetes. Access to the white working class men also involved attending health fairs and summer fetes, as well as regular meetings with a volunteer-led group for people aged over 50 years.

Working with key stakeholders

Key stakeholders were used to help the researcher to identify possible participants and approach these men to take part in the research.

Working with key stakeholders is a recognised method for recruiting participants who might otherwise be considered challenging to access by a research team (Odedina et al. 2011; Kessing 2013; Vrinten et al. 2016). In this study, key stakeholders were identified as individuals who were respected within the targeted participant's social environment. For the Somali men, the key stakeholder was a male community leader who managed a local male only restaurant used by Somali men after daily prayers. The key stakeholder for the African Caribbean men was a caretaker at a local community centre, who was respected by the local African Caribbean population for being trustworthy and knowledgeable. The key stakeholder for the white working-class men was a woman. This woman organised a social group for individuals aged over 50yrs and had a good working relationship with older men in her community.

The key stakeholders were informed of the nature of the research and the characteristics of the men who were sought and would be invited to take part. Men that met the characteristics given in table 1 were recruited to the study; the men were identified by the key stakeholders and introduced to the researcher during community engagement activities.

The men involved in the focus groups were not the same as those interviewed during the study. It was felt important to involve other men who had not engaged in previous conversations about prostate cancer with the researcher. All the men were over the age of 40yrs, and six men worked full-time or part-time, with the remainder being retired. To further characterise the sample self-reported educational attainment data were collected from each participant, using the 2011 census education questions (2011 Census Questions). The White working class men reported the most overall qualifications, and these were mostly classified as 'other/vocational qualifications. There were four men who reported no educational qualifications, with three of these being in the Somali group.

Eligibility criteria for men of African and African Caribbean origin	Eligibility criteria for white British men
1. No previous diagnosis of cancer	1. No previous diagnosis of cancer
2. Adult aged over 40 years	2. Adult aged over 40 years
3. Self-reported ethnic origin Black Caribbean, Black African, Black British	3. Self-reported ethnic origin Welsh, English, Scottish, Irish
4. Currently resident in area of low socioeconomic status, according to Welsh Index of Multiple Deprivation	4. Currently resident in area of low socioeconomic status, according to Welsh Index of Multiple Deprivation
5. Resident in study area for more than five years	5. Resident in study area for more than five years
6. Has permanent residency status in the United Kingdom	6. Has permanent residency status in the United Kingdom
7. Able and willing to provide informed consent	7. Able and willing to provide informed consent

Table 1: Participant characteristics

Use of translation

There was a language barrier identified between the researcher and the Somali men. A translator from a local charity supporting diversity and BAME communities was asked to help with translation during the interviews and focus groups; the recordings were transcribed in English with sections of Somali speech back translated to English and included in the final transcription, to minimise loss of meaning. To prepare the translator the purpose of the study was explained as being an exploration of men's awareness of health and prostate cancer risk. The translator had previous experience of talking about health and illness but required further information about the prostate, which was provided using written and visual information from third sector prostate cancer literature sources. The translator was advised about the format of the interviews and focus groups but was not shown the interview schedule.

Ethical considerations

Ethical approval for the research was given by the local University Ethics Committee (approval date: 28.03.2014). It was acknowledged that the participants were going to be asked questions about prostate cancer that may raise concerns that the men may not have previously considered. The

researcher went to each interview with a range of information about prostate cancer, including translated literature for Somali men, and set-up an agreement with a local third sector charity as a point of contact if the men had any specific concerns about cancer. All men were given this information at the end of their interviews or focus group participation.

Potential participants were provided with written information to read about the study and were given time to ask questions about the research before consent was taken. To maintain confidentiality each man had a given pseudonym, which was used throughout analysis and during the write up of the research findings.

Data collection

Interview data were collected using purposeful sampling and until theoretical saturation was reached. Saturation was achieved after constant comparison of the data from 17 interviews, which did not produce any new properties in the emergence of theory. To be certain that data saturation had been achieved, theoretical sampling was employed after the analysis of the interview data. This was the point at which the data were identifying the same or similar theoretical categories, which revealed important, and sometimes different, community understandings of cancer risks between the groups of men, and which seemed to be influencing individual understanding. To explore this in more depth the decision was made to conduct focus groups to develop theory generation and gain insight into the way men talked to each other about prostate cancer, as well as health and illness generally. The decision was made to conduct one focus group with each of the different groups of men. Saturation was reached when data from the focus groups were analysed and compared to the interview data, at which point the emerging grounded theory was seen to be fully developed (Charmaz 2014).

Semi-structured interviews

Semi-structured interviews allowed the researcher flexibility in gathering a range of rich data (Kvale 2010), by exploring how the men were interpreting and understanding questions about their knowledge of prostate cancer and prostate cancer risk factors. Although a degree of flexibility and reflexivity was required for this research, the use of an interview schedule meant broad interview topics (Table 2) were drawn from the initial review of the literature.

Broad interview topics	
1.	Background of self, family, pattern of migration (if required)
2.	Knowledge and experience of cancer
3.	Beliefs about cancer diagnosis and treatment
4.	Knowledge and experience of prostate cancer
5.	Understanding of personal risk for prostate cancer
6.	Methods of access to healthcare services
7.	Preferred education strategies

Table 2: Broad interview topics

Interviews were conducted in a location of the participant's choice, apart from their own home, so that the researcher complied with the University Lone Worker policy. Via the key stakeholders, the

researcher also had access to meeting rooms at community centres and a Somali male only café, where the interviews were conducted.

Focus groups

The focus groups were conducted in the same facilities as the interviews. In order to explore how the men talked to each other about health generally, card games were used to help generate interaction (Fry et al., 2020). A similar approach was used by Kitzinger (1993) in a study of people's understanding of HIV media coverage, to enable group conversation. In the current study, men were asked questions about prostate cancer symptoms, preferred health education strategies, and who they would prefer to talk to about prostate cancer issues. They were given possible answers on cards, which they were then asked to place in order of preference. They did this task as a group and one person was nominated to read out a question and organise the response. This method created conversation amongst the group and included quieter members who were also asked to read a question aloud.

During the card games, the researcher facilitated the use of the cards but otherwise did not influence the men's talk. A focus group moderator accompanied the researcher to the groups to take notes of the men's responses and their physical interactions with each other. Throughout the focus group with the Somali men there was a translator present. The presence of the translator did not appear to impact the nature or content of talk within the group.

Data Analysis

The interviews and focus groups were recorded using a hand-held digital recorder and were transcribed verbatim; Somali speech was translated to English and included in the verbatim transcription. Each transcription was read by one researcher on two occasions whilst listening to the accompanying interview or focus group recording, to ensure the transcriptions were an accurate representation of participant's meaning. It was considered an important part of data analysis to record hesitations, pauses, laughter, and character of the participants speak so that, as far as possible, meanings as well as words were recorded (Kowal and O'Connell 2014). The interview and focus group data were analysed by hand; there was no software used to store and sort these data. Figure 1 shows a representation of data analysis, which was completed using the guidance of Charmaz (2014).

Initial coding

Each incident of data collection was analysed after recording and transcription of the data, which continued throughout the data collection process. This allowed a depth of analysis to be achieved by challenging the researcher's theoretical thinking (Charmaz 2014).

Initial line-by-line coding was done using the application of gerunds to generate a deep understanding of the data and avoid analysing the data at face value. Line-by-line coding allowed analytical codes to be generated, which were then subjected to constant comparison across participants and within interviews and focus groups. This allowed for similarities and differences to be identified, which was important for the discovery and confirmation of patterns within the data.

Focused coding, theoretical coding, and categories

Focused coding was used to generate codes that had analytical relevance. The researcher used an analytic process to decide which initial codes related to theoretical thinking, and for understanding how the data were fitting together to generate a plausible theory (Glaser 1992). At this point, theory generation was derived from the data using a process of theoretical coding. The researcher then raised the focused codes into categories that formed the theory emerging from the data.

Transcript	Line by line coding	Focused code	Sorting
P03: So we're not talking about let's say somebody who's only just coming in for a fortnight and so on, we're talking more a proper partner.	Giving a timeline. Correcting the group.	Correcting	Democratic talk
P01: You can have a proper partner but you can have a friend okay, that's been with you longer than your partner.	Giving a timeline. Correcting the group.	Correcting	Democratic talk
P02: Yes but the point is that see, a friend and a partner are two different things.	Clarifying roles.	Correcting	Democratic talk
P04: Could be, not all the time, some it's the same.	Disagreement	Disagreeing	Democratic talk
P02: It's different, but you can say to your partner or you can say it to a friend.	Clarifying communication	Disagreeing	Democratic talk

Figure 1: Representation of data analysis

Use of memo writing

The researcher supported data analysis with memo writing, which was used during theoretical thinking and theory generation. In this research, memo writing was also used as a space for the researcher to be reflexive about their thinking and ask questions of the emerging theory and how their thinking developed during analysis (Charmaz 2014).

Findings

A total of 35 men took part in this research. The total men in each distinct cultural group can be seen in table 3. Seventeen men were interviewed for this research and eighteen men took part in three separate focus groups.

Participant groupings	
White men:	14
Somali men:	10
African Caribbean men:	11

Table 3: Number of participants by cultural group

From the process of data analysis, a number of dominant themes were identified. From these a theory, grounded in the evidence, was proposed (see box 1). The theory proposes that men's understanding of their body is constructed via individual experiences and in relation to their social

context. The men's experiences were embodied in their individual social journeys, which in turn influenced the ways that the body was then understood in relation to health or illness.

The social construction of the body is important in helping men understand their body in society, which mediates the way in which men are socialised to understand and accept their risk for prostate cancer.

Box 1. Grounded theory of the body in the social context and the relationship of this with the acceptance of prostate cancer risk.

This grounded theory was developed from two dominant categories, which are presented below. Pseudonyms are used in the presentation of these findings.

Category 1: Identity by difference or similarity

Seminal work by Berger and Luckmann (1966) introduced the idea that identity is a phenomenon constructed from the social interactions experienced by individuals. The way in which an individual understands their place in society is influenced by social structures, and the way in which an individual places him or herself in relation to these structures will influence how they self-identify (Berger and Luckman 1966).

In this research the men certainly talked about their identity having been created from their social experiences. When the men were asked about their personal understanding of prostate cancer risk the African Caribbean men contextualised this answer as black men and the experiences of social interactions with individuals from outside of their own communities. For example, one retired African Caribbean man talked about the impact of his experience of social interactions with white people as he grew up:

White people, they're always sort of made out that we're stupid...and we're down the food chain and stuff like that and evolution and all that rubbish. So, we like to be proud of ourselves, black people are very proud people you know.

(Patrick, interview transcript)

Patrick also describes the way in which his social experiences of being seen a less capable had affected the way black people have sought to protect their social identity. Patrick experienced black people as identifying themselves as being equal and proud, perhaps to differentiate from a hostile social environment. Other participants also talked about such experiences when discussing prostate cancer risk and the threat of illness that would come with this. As a young adult Leon had faced feelings of not belonging to his social group, and felt that his body could be used to protect him from hostile experiences:

The average guy thought that for some reason we didn't belong, yeah, and that was a massive barrier ... what broke that barrier is that I was a tougher, better athlete than them, that's what broke that barrier.

(Leon, interview transcript)

Like the African Caribbean men, the Somali group also talked about the importance of maintaining their identity, although cultural heritage was more important when talking about prostate cancer risk and the threat of illness. The Somali men in this research came to the UK for work or to flee a civil war, and they talked repeatedly about wanting to return to Somalia; their social identity seemed to be related to maintaining their cultural differences, rather than finding ways to assimilate, to retain their Somali heritage. The men all discussed their desire to return to Somalia, and the prospect of this not being possible as their body aged, or they became unwell, was a concern to them. When asked about how he would access a healthcare professional if he was concerned about possible prostate cancer symptoms, Hamza talked about already having a health condition and how this restricted his travel back to Somali:

SF: You don't go now because you need to have your medication?

H: Yes, I can't leave here.

SF: Do you miss Somalia?

H: I miss everything, I miss everything.

(Hamza interview transcript)

This desire to return home also seemed to influence the men wanting to establish a social space which allowed them to maintain their cultural identity, including not accessing western healthcare. For example, two Somali men talked about how they had experienced illness but used non-western treatment to cure themselves:

I have cured my...; I will tell you sometime how I did it. Not with your medicine.

(Abdi, interview transcript)

It's very cheap what they use, garlic or something like that, ginger...lemon I used myself...I get better.

(Farah, interview transcript)

For Abdi and Farah maintaining their Somali identity meant managing illness in a culturally appropriate way, viewing themselves as "cured" and "better", but also by maintaining important social and cultural boundaries. This may serve to limit the acceptance of medical interventions that fall outside of what they might perceive as culturally acceptable healthcare and might reduce the possibility of an early diagnosis of prostate cancer.

This group of men also talked about their experiences of cancer when living in Somalia, and this seemed to inform their identity and sense of risk. For example, when talking about his experiences of cancer in Somalia Mohammod talked about cancer being "fairly bad illness", clarifying this by saying "[in Somali] if somebody said Oh, they've got cancer, they think that's it". These experiences may have established powerful cultural beliefs about cancer, and together with cultural views of treating illness in general, could serve to prevent, or delay, seeking healthcare for prostate cancer symptoms (such as problems with urine flow).

Conversely, the white working class men did not talk openly about cultural identity being so important to their personal understanding of prostate cancer risk. In this research, the white working class men did not actually refer to themselves as white or White British but talked openly and with freedom about their experiences of illness. Discussions about the body seemed to bring these men together in transitional social situations. For example, when the men were asked who they would talk to about problems with their prostate Ken and Pete talked about conversations they had had in everyday social environments about how their bodies were changing:

I mean down the allotment ... there's one or two down there with bowel problems and we talk about it and I've told them I've got an enlarged prostate, you know.

(Ken, interview transcript)

I do hear of it; I mean some of my colleagues...they have got prostate problems

(Pete, interview transcript)

It is thought that these differences in health-related social identity, as well as threats to identity, are mediated by the acceptance of the body gradually becoming unwell and the willingness to accept risks for illnesses of age, including prostate cancer.

Category 2: The everyday social body

In early work on the social construction of health knowledge, Labonte and Robertson (1996) proposed that ideas about health are generated from the everyday realities experienced by an individual. These individual constructions of everyday reality in turn influence the way people construct ideas about the healthy or the unhealthy body.

In this study there were differences in the way the men talked about their everyday lives in relation to health. When asked about their knowledge of prostate cancer specifically, the black men were most likely to identify their understanding as developed from their everyday social and cultural experiences, and this had an influence on the way that illness in general was accepted, which seemed to also affect social opportunities to learn about prostate cancer. Marvin, one of the African Caribbean men, talked about illness being abstract or distant to people's lives:

Most people in these communities ... diseases and death is abstract to their life ... that's nothing to do with me.

(Marvin, interview transcript)

Marvin relates this to his own experience of people in his community and the social constructions of illness beliefs. Men in the focus group discussed community feelings relating to prostate cancer education and felt that black men would not be likely to take up opportunities to seek help if they thought it was needed:

Noah: Just a minute, the education part of it is still there...but people don't want to do it [rectal examination for prostate cancer]

Leon: People just don't, if they don't want to do it then they just going to have to die then...

[...]

Leon: If you're talking about black people.

Pete: What I'm trying to say is if we don't want this

Leon: No that's what you're talking about. We're not talking about men in general, we're just talking about black people, there's a difference.

(African Caribbean men focus group transcript)

Leon made the distinction between black men and other men, recognising that their identity as black is central to their attitudes towards prostate cancer itself and necessary rectal investigations to screen for this. However, some men also recognised the risk of not seeking help and the benefits of sharing knowledge and experience with each other. In the same focus group, when asked who the men would talk to if concerned about symptoms of prostate cancer, Patrick was clear that the community should help each other:

...whatever you've learnt, pass it on because it helps the community, it helps people along and then somebody else will come and improve on that see, that's what's going on.

(Patrick, focus group participant)

This seems somewhat contradictory to Marvin saying that "death and disease" is "abstract to their lives", and it may be that the social situation of the focus group generated talk about how their community would manage a threat such as prostate cancer. It may also suggest that change is possible through discussion and education.

Similarly, the Somali men also constructed their realities of illness based on everyday community needs. The focus group participants, when discussing where they would prefer to find health information about prostate cancer, showed a strong emphasis and agreement on the sharing of knowledge:

Assad: Yes, an uncle, a brother, or a friend, if it is good for them.

Mohammad: What's good for you is good for others.

Bahir: It will help with others.

Mohammad: Like if you get information, health information, because if it happens to you, or about your body, you can advise your brother, cousins, brother-in-law, father, do you know?

SF: So, you've got this community feeling of helping each other.

Abdulrahim: Exactly

(Somali men focus group transcript)

According to their theories of the social construction of health information, Labonte and Robertson (1996) would agree that this sharing of knowledge is part of the construction of the reality of illness, and in this case perceptions of prostate cancer risk that need to be attended to. For the Somali men this seems to be best mediated by their strong cultural views of identity as being linked to belonging to a Somali community.

Talk of illness in the social environment was different for the white working class men. These men talked more about having had chance conversations about prostate cancer, rather than being part of

a community. The reality of health for these men was also constructed from their everyday experiences, such as the example discussed previously from Ken, during his social time at the allotment when men talked about their prostate problems.

These everyday discussions in groups were also confirmed by Dave when he said:

Elderly people when they get on, they tell you all their problems...no matter what you've got wrong with you there's always someone who will out-ill you.

(Dave, interview transcript)

Dave clearly articulates the ease with which white men talk about their bodies as unwell during everyday interactions. His view that someone will "out-ill you" were also evident in the focus group discussion between the white working class men when discussing what they thought the main symptoms of prostate cancer were. These men talked about this based on their own experiences:

Evan: I go to the toilet just before I go to bed, like last night I went to the toilet before I went to bed and I woke up at about four o'clock and went to the toilet...

(...)

Graham: I used to be able to do a little job and think I'll go to the toilet now...I hardly make it sometimes. I've got to squeeze the end of my penis to stop it.

(White working class men focus group transcript)

The white men were known to each other but the ease at which they talked about their bodies and the urinary symptoms they were experiencing seemed at first rather surprising, when compared to the other groups. The white men talked very openly with each other about intimate body experiences, constructed, it appears, by the acceptance of social talk about intimate health and illness between the men. This is different to the generation of knowledge in everyday talk between the Somali men and between the African Caribbean men, who constructed identity as being physically strong and generally well, or via maintaining a collective identity based on their country of origin, which seemed to influence the less immediate perception of prostate cancer risk, this despite the fact that their lifetime risk may actually be highest.

Discussion

The aim of this research was to explore cultural differences in perceptions of prostate cancer risk. The findings suggest that men's experiences of their social body mediate the way in which health and illness are understood, including prostate cancer risk. The findings have shown that in order to try and understand the men's beliefs about prostate cancer, the body in its social context must be considered during development of health-related information. This is perhaps most relevant in understanding how men at the highest risk of prostate cancer (black men) may need to understand this risk differently to white working class men.

The African Caribbean men involved in this research were clear about viewing their body with a sense of pride, a position which stems from their everyday social interactions. In a seminal text discussing black men and health, Staples (1995) draws a parallel between black men taking pride in their bodies and maintaining feelings of strength and experiences of racism. More recent evidence has suggested that this history means black men may be particularly vulnerable to threats that could affect their physical health (Campbell et al 2012), and this is likely to be the case when confronting the risk of a serious illnesses, such as prostate cancer. In relation to this, Maliski et al. (2008) studied African American men after receiving a diagnosis of prostate cancer. They found that these men

may maintain a silence about their prostate cancer experience because of concerns about losing their strength, control, and independence. Drawing on the findings of the research presented here, it is possible that this silence is related to concerns the African Caribbean men had about being perceived by others as physically vulnerable, which seems to be an important consideration for these men.

For the Somali men in this study their social identity was instead based on a desire to maintain the cultural expectations of their heritage. In a study of perceptions of ageing among Somali men in Canada, Lagace et al. (2012) also found the creation of community was importance for these men, so that they could lead their life through the lens of their country of origin. It is suggested here, however, that Somali men may also feel more drawn to traditional support from their own community, primarily in order to maintain their socially constructed Somali identity, and thus may consider healthcare services (including prostate cancer screening or diagnostic services) as threats to this ideal.

The white working class men shared their health knowledge and experiences in a very different way to the Somali and African Caribbean men, and this mostly involved sharing intimate health experiences in transient groups. This may be related to the apparent and long held stereotype that being old is related to being ill (Stewart et al. 2011). There was also an element of competition in 'out-illing' amongst these men, and it is suggested here that this may also be related somewhat to the socioeconomic status of these men. A study of white men by Springer and Mouzon (2011) found that men from areas of low deprivation were less likely to access preventative healthcare, such as cancer screening, compared to men from areas of high deprivation. Springer and Mouzon (2011) suggest that the threat of illness may be less salient for men from areas of high deprivation because declining health is not seen as a threat to maintaining an image of health and wealth, and the findings of this research suggest that illness can be a way of gaining social recognition, even if the illness is prostate cancer. These findings could be relevant by helping to explain why the white working class men were less concerned about being perceived as vulnerable and accept the inevitable effects of growing older, which becomes part of their everyday lives via the social construction of the ageing body.

It is also interesting to consider how this point may relate to African Caribbean men. Based on the findings of Springer and Mouzon (2011), as well as from this research, African Caribbean men may hold similar values about the social context of the body as white men from areas of low deprivation regardless of cultural identity; illness being primarily a social concern, although the concern for the African Caribbean men seems to be based on the threat of illness, in this case prostate cancer, rather than illness being a possible driver for social recognition, as with the white men. This is yet to be explored fully but may give insight into how the complexities of socially constructed ideas of the body influence perceptions of risk for prostate cancer.

All of the men in this research seemed to have developed some knowledge of prostate cancer mediated by everyday cultural influences. For the white men this seemed to make access to healthcare with concerns about prostate cancer acceptable, and possibly have social value, as opposed to the Somali and African Caribbean men who seemed to have socially constructed reasons for not wanting to seek health advice.

Relevance to practice

The findings of this research suggest that a greater understanding of the importance of the social constructions of health, particularly on the acceptance or rejection of health risks, could contribute greatly to the understanding of how prostate cancer is perceived by different ethnic groups. Cancer services and third sector organisations may wish to consider the relevance of these findings when

reviewing the wording and images used in their prostate cancer awareness campaigns, directed at different groups of men. These organisations may usefully discuss the evidence with lay-person/ user-groups to consider directing health-related literature to different ethnic groups in society. Perhaps culturally focused approaches to prostate cancer education and support would be more effective in engaging men at the highest risk. This new evidence on the importance of community, reported by the African Caribbean and Somali men, could lead to developments of health education strategies for communities to generate their own health literature in their own way.

With recent and ongoing changes to the nursing workforce (Leary et al. 2016), nurses in primary care should also be aware of how men from different cultural groups may engage with opportunities for education about prostate cancer. Feasibility studies of primary care interventions, for men receiving long term follow-up, have shown that follow-up from nurse-led clinics is acceptable to men with prostate cancer (Clarke et al. 2020), and for nurses leading these clinics recognising the cultural differences in social constructions of prostate cancer risk could help inform the language and approaches used. For example, black men may prefer to consider talking about prostate cancer as a community concern which could open conversations about prostate cancer risk on a more general level.

This research also suggests that black men may have different needs for cancer survivorship support, when compared to white men. Cancer survivorship is now a recognised pathway for cancer patients and all men with a diagnosis of prostate cancer are offered a place on a survivorship programme in the UK (Macmillan Cancer Support 2017). Survivorship programmes already offer group education sessions about living with a prostate cancer diagnosis, and the findings of this research suggest that a group situation may be preferable to white men who appear more accepting of a public arena to discuss their bodies and the impact of cancer. However, black men may find this public environment a threat to cultural constructions of the body. Nurses delivering these survivorship programmes should consider how they can be adapted to accommodate for this. This could include finding safe places for men to talk about living with prostate cancer, for example neighbourhood community venues such as barbershops or cafés. Nurses will need to be flexible in delivering survivorship programmes and supported in this by service providers.

Strengths and limitations of the study

This research involves a small number of participants, which may affect the transferability of the research findings. However, the constructivist approach rejects the idea that social organisations operate by a single set of rules (Guba and Lincoln 1989), and instead advocates a thick description of the research data, which has been achieved in this research using theoretical sampling. A thick description has also been achieved through prolonged engagement with the research areas and multiple methods of data collection to test theory development. A constructivist grounded theory methodology puts the researcher at the centre of data analysis, and this means the researcher has been reflexive and paid attention as to how their thinking might influence analysis of the data collected in this work. The data have been through close scrutiny using manual coding, which allowed the researcher to become submerged in the data during data analysis and theory generation.

Due to concerns about the researchers own clinical experience in prostate cancer nursing, which could weaken this study by influencing the course of data collection and analysis, reflexivity was used to create transparency of the involvement of the researcher and to scrutinise any preconceptions the researcher may have.

Conclusion

This research adds new knowledge about the importance of the cultural understanding of prostate cancer and contributes to the literature about culture, cancer risk and men's health more generally. The research also adds to our understanding of the cultural relevance of information provision and accessing those men most at risk for prostate cancer. The research suggests that practitioners and third sector organisations should acknowledge how illness is defined differently across cultural groups and consider how to use these differences in the provision of prostate cancer risk education.

The findings of this study have been discussed in relation to the theoretical positioning of the research process and comparisons have been made with recent literature focusing on men's health in the social context. The men's views of the male body were influenced by their social background, and it is theorised that this, in turn, influences the perceptions of prostate cancer risk as experienced by the men in this research.

Importantly, this research has demonstrated how men operate in their social world and adds to an understanding of how social constructions are important in developing ways to access the men at the highest risk for prostate cancer. However, achieving this understanding alone is not the only solution needed to improve prostate cancer awareness. This research has shown that more knowledge is needed of health perception in the wider context of the social field and how men's individual experience has shaped their understanding.

The limitations of this research have been recognised. It is understood that the findings of this research reflect a moment in time for these groups of men, but this work also provides new insights into understanding the socially constructed body, and the influence this may have on the way the men perceive their risk for prostate cancer. The strengths of this research are in the methodological approach used to collect and analyse these data, and in the flexibility and reflexivity of the researcher to develop an insightful grounded theory.

Nurses can consider how the knowledge generated from this research may help them to engage men about prostate cancer from the position of men's social experiences, being careful to acknowledge the individual concerns that men may have are dependent on their individual social and cultural backgrounds and expectations.

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