

Experiences of UK African-Caribbean Prostate Cancer Survivors of Discharge to primary care

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Abstract

Objective: Black men are three times more likely to develop prostate cancer (PCa), to do so at a younger age and to experience a more aggressive form than White men. This study aims to understand the experiences of African-Caribbean men with respect to their discharge to primary care following successful PCa treatment and the challenges associated with survivorship.

Design: Eight African-Caribbean men, who had been successfully treated for PCa, were recruited through the charity BME Cancer Communities. They participated in a focus group, which took place on the premises of the charity and was audio-recorded. The recording was transcribed and the data were analysed employing thematic analysis.

Results: Three overarching themes were developed: Discharge - misconceptions and uncertainties; Survivorship - challenges and ways of coping; Black men and PCa: real and potential discrimination. Participants expressed concerns regarding the lack of information and clarity about what discharge meant, the quality of follow-up care, especially the levels of specialist knowledge among GPs, and the impact of side-effects, particularly erectile dysfunction (ED). Participants linked ED with stereotypes of Black male sexuality, particularly in relation to difficulties of expressing their emotions and psychological distress. African-Caribbean men face particular challenges in dealing with the side-effects of treatment for PCa, which are linked to socially-constructed ideas of masculinity.

Conclusion: There needs to be a greater focus in primary care on understanding these issues and providing individualised culturally-sensitive care. In particular, GPs should be aware of sensitivities concerning help-seeking related to culturally-mediated understandings of masculinity.

Keywords: prostate cancer; discharge; Black men; follow-up; cancer survivorship; primary care

Introduction

Prostate cancer (PCa) is the most common cancer in men in the United Kingdom (UK) and constitutes a quarter of all new cases of cancer among males. There are approximately 47,700 new PCa cases in the UK every year (Cancer Research UK [CRUK] 2018). It is uncommon before the age of 50 but increases rapidly thereafter. There were 11,631 deaths in the UK from PCa in 2016 (CRUK 2018) and it is a global health concern.

There are important ethnic variations in the incidence, progression and outcomes of PCa. Most notably, Black African and African-Caribbean¹ men have incidence rates approximately 2-3 times those of White (Caucasian) men (Pedersen, Armes, and Ream 2012). The first UK-based multicentre, population-based study comparing PCa incidence rates of Black and White men reported that Black African and Black Caribbean men were three times more likely to be diagnosed with PCa than White men (Ben-Shlomo et al. 2008). They tend to develop the disease at an earlier age than White men (Shenoy et al. 2016) and in a more aggressive form (Powell et al. 2010). Improved survivorship rates across a range of cancers have prompted interest in the experiences of survivors, including in relation to their return to primary care services. In the UK in 2011 the one-year survival rate for PCa was 94% and the five-year rate was 84.8%. These survival rates were the highest among the 21 most common cancers in the UK (CRUK 2018).

Virtually all treatments for PCa, both localised and metastatic, are associated with significant side-effects (Siegel et al. 2012; Lavery and Cooperberg 2017). Men's responses to these are determined in great part by culturally determined norms of masculinity and this can result in challenges to men's masculine self-image, particularly in response to impacts on sexual function and urinary continence (Chambers et al. 2016). Most survivors of PCa

¹ We recognise that there are important cultural and other differences between groups of members described as "Black".

The participants in this study self-described in this way and for simplicity, this term has been employed throughout this paper except when referring to the findings of particular studies.

(PCaSS) report long-term treatment side-effects, including ED but Matthews et al. (2012) found that, compared with White patients, Black men had significantly poorer physical and emotional functioning after their treatment. The latter has been linked with feelings of embarrassment and shame associated with urinary, sexual and bowel dysfunction (Zaider et al. 2012)

Rivers et al (2011) reported that Black men rarely discussed sexual dysfunction with their spouses, indicating that an unwillingness to speak openly about these matters might be a barrier to seeking medical help. Guidance from the National Institute for Health and Clinical Excellence (NICE) (2014) suggests that patients with a stable PSA² level at least 2 years after the completion of their radical treatment for PCa and patients who are undergoing “watchful waiting”³ should be discharged and offered follow-up care in primary care settings. A number of studies have identified issues in relation to the cancer-specific knowledge of Primary Care Physicians (PCPs) (known as General Practitioners [GPs] in the UK). For example, a US cross-sectional survey of cancer survivors (Nyarko et al. 2015) reported that 43% perceived their PCP as knowledgeable about cancer follow-up and 45% viewed them as knowledgeable about late or long-term effects of cancer therapy. Although it did not address issues in primary care, an analysis of UK National Health Service (NHS) cancer patient satisfaction that focused specifically on respondents from minority ethnic groups found that they reported statistically significantly lower levels of satisfaction with care and with their communication with healthcare professionals compared with those from the majority White population (Pinder, Ferguson and Moller 2016).

However, this analysis did not specifically examine the experiences of Black men with PCa that might explain their comparatively lower satisfaction rating. A report by the charity

² Blood tests for Prostate Specific Antigen (PSA) carried out to detect increases in PSA, which can indicate the presence of PCa.

³ Watchful waiting is offered for asymptomatic PCa to avoid treatment side-effects, is more suitable for men with comorbidities, and involves regular follow-up in primary care (Prostate Cancer UK 2016).

Black and Minority Ethnic (BME) Cancer Communities (Thompson 2013) highlighted both a lack of cultural competence amongst healthcare professionals and a lack of cancer awareness in Black communities as likely contributors to poor outcomes from PCa in Black men. Bamidele et al. (2018) carried out a systematic review of the post-treatment experiences of Black African and Black Caribbean men with PCa. They reviewed four qualitative studies published between 2005 and 2013; three based on a UK sample and one on a Canadian sample. Across the studies, men discussed the impact of treatment side-effects on sexual activity, their involvement in decision-making concerning treatment, their experiences of healthcare and communication with healthcare professionals as well as a range of other issues. Many of the comments related to experiences with secondary care professionals and there was little about primary care or the experience of discharge.

There continues to be a shortage of evidence about the experiences, knowledge and beliefs of Black men in the UK concerning side-effects, survivorship and sources of information and support following successful treatment for PCa and discharge back to primary care. A number of recent studies (e.g. Nanton and Dale 2011; Anderson, Marshall-Lucette, and Webb 2013) have addressed issues relating to cancer and PCa survivorship and masculinity in Black men, but this study differs from them in some important respects. Those studies focused on a wide range of issues such as pre-diagnostic knowledge, treatment-related decision-making, survivorship, risk perceptions and screening but did not address the experience of follow-up in primary care.

Previous research has reported concerns among mixed groups of cancer patients (including men with PCa) who had been discharged to primary care following treatment (Harrison et al. 2012; Hudson et al. 2012). The current study aimed to investigate specifically this experience among African-Caribbean men in the UK and sought to answer the following questions:

- What are the experiences of Black men with respect to their follow-up in primary care after successful PCa treatment?
- What are the challenges faced by Black men in the transition to survivorship?

In attempting to answer these questions we will draw on the concepts of hegemonic masculinity and intersectionality. The term hegemonic masculinity (Courtenay 2000) refers to institutionalised and culturally dominant representations of particular ways of being a man that emphasise physical dominance and toughness, emotional reticence and sexual prowess. It is not necessarily the only possibility for being a man, but it is a standard against which other versions of masculinity are evaluated. Scott-Samuel, Stanistreet and Crawshaw (2009) argued that hegemonic masculinity can act to establish social and political relationships that are harmful to the health of men and women. The concept of intersectionality was developed by Crenshaw (1989) and is increasingly used to facilitate understanding of how factors such as gender, race and socioeconomic status interact to determine inequalities in health outcomes (Kapilashrami, Hill, and Meer 2015). Together these concepts provide a useful framework for examining the experiences of Black men.

Method

Research design

To address hegemonic masculinity and intersectionality as they apply to Black men we adopted a qualitative approach based on focus group methodology with Black PCaSS. Qualitative research methods enable an in-depth understanding of the experiences and feelings of research participants and the significance of these experiences to them (Sullivan, Gibson, and Riley 2012).

Men recruited to the study (see below) were familiar with speaking openly about PCa in a group setting, so the approach was consistent with their previous experience. A focus group drawing on pre-existing groups (i.e. support groups) allows an interpersonal interaction that is more realistic and natural because participants feel comfortable commenting on each other's experiences and expressing their own views (Krueger and Casey 2014), particularly in relation to sensitive topics such as sexuality and ED. This permits spontaneous interactions and responses, thereby generating rich data in a short time period (Krueger and

Casey 2014; Then, Rankin, and Ali 2014).

Focus group methodology is widely used for examining people's understanding of illness and health behaviours and experiences of health services (Bowling 2014; Odedina et al. 2004).

Recruitment procedure and participants' characteristics

The inclusion criteria stipulated that participants be Black African or African-Caribbean men, under 75 years old who had been successfully treated for localised PCa and were attending their GP for post-treatment follow-up. The age-range was based on the need to examine the impact of the side-effects of treatment while reducing the likelihood of comorbidities. There were no exclusion criteria.

Participants were recruited through a convenience sampling strategy from Friends and Bredrins (F.A.B.), a support group in Nottingham organised by the charity BME Cancer Communities (BMECC) aimed at African-Caribbean men and their families in the East Midlands region of the UK. We employed this approach because of difficulties in identifying participants based on NHS records. Access to the group was facilitated by the Chair of BMECC. Current members of the group were approached by the Chair and asked to participate; all agreed. No financial or other incentives to participate were offered.

Ethical considerations

Ethical approval for the study was obtained from the University of East London Research Ethics Committee. All participants were provided in advance with an information sheet giving details of the study and their right to withdraw and completed a consent form at the start of the focus group. Ground rules were developed in conjunction with participants, which covered issues such as confidentiality, respect for the views of others and allowing participants to speak without interruption.

Data collection

The focus group was facilitated by the first author. The topic guide was developed in consultation with staff of BMECC and covered a range of issues, including the process of discharge from hospital-based care, anxieties about discharge, the side-effects of treatment and the support they received in connection with these, their experiences of GP care and the challenges of life as a survivor (see Table 1 for a sample of interview questions). The focus group lasted 90 minutes and was audio recorded. The researcher kept field notes. The field notes enabled reflection on the researcher's experience as a facilitator, her facilitative skills and her influence on the researcher-participant relationship.

The recording was transcribed by the first author employing the semantic-level approach advocated by Banister (2011). Participants were given pseudonyms to ensure anonymity. (INSERT TABLE 1 ABOUT HERE)

Data analysis

Data were analysed inductively by the first author using thematic analysis, a qualitative method that identifies, describes and reports themes within the data (Braun and Clarke 2006). The stages of analysis outlined by Braun and Clarke (2006) were followed, including familiarisation with the data by repeated reading, the generation of initial codes and combining these into themes based on shared features. Each individual transcript was read and re-read and data were coded. These codes were then grouped into potential themes which were reviewed, refined and named in conjunction with the other authors. Developing themes were checked against the constituent codes and linked quotations in order to ensure fidelity to the data while following an interpretative approach. Theme development ceased when the existing themes captured the codes.

In order to ensure the quality of the study, we drew on the criteria outlined by Tracy (2010), including the importance of the topic, the rigour of the analytic process, transparency concerning procedures and the contribution of the study. Verbatim transcription was followed

by rigorous data analysis that permitted the transformation and organization of the data into themes enabling meaningful claims to be made.

Results

A total of 8 participants was recruited and the focus group was conducted on BMECC premises. Table 2 shows the key demographic characteristics of the participants regarding their age, relationship and employment status. All the participants self-identified as African-Caribbean and the majority was married or had a partner. Their ages ranged from 51 to 75 years. (INSERT TABLE 2 ABOUT HERE)

The following main themes were identified from the data; 1) Discharge - misconceptions and uncertainties, 2) Survivorship - challenges and ways of coping and 3) Black men and PCa: real and potential discrimination. Table 3 shows the main themes and their sub-themes developed in the analysis. (INSERT TABLE 3 ABOUT HERE)

1. Discharge: misconceptions and uncertainties

The meaning and consequences of discharge from secondary to primary care were viewed as unclear. Participants described a lack of information and a lack of clarity about what discharge actually meant and the role of the GP. They reported feeling insecure and uncertain about care in the future.

'Well, it's (discharge) a very common phrase that they use, and they mean that "we've done basically what we can, you had your operation, and you had your radiotherapy and now we will discharge you back to your GP"... And you've got to make your own conclusion what the GP is all about.' (P2, 71)⁴

⁴Each quote is presented with the participant's identifying pseudonym and age.

'They don't say that "you will go to your GP and you have to do this and that", they just say "we will discharge you back to your GP" and you think "wow is the service is going to be the same as I am getting here?" (P4, 59)

All agreed that there is a common misconception that discharge means cancer has been cured. P5 explained that there is a lack of information about the risk of recurrence and the importance of follow-up care.

'Well, you know it is not like "Ok, I am discharging you, you can go back to your GP but you can still get it again, it can still come back", it's not like that, they don't tell you that. I know that this is not a good thing for them to tell you or they could just say that there is a possibility but you go to your GP and you think "oh yes great! So, they never tell you the seriousness of what might happen next.'" (P5, 75)

P2 stated that 'the discharge means nothing' to him. He explained that misunderstanding the nature of discharge could be dangerous and emphasised the importance of men being properly informed. Some men, such as P7, were offered a choice between being followed up by the hospital or the GP. He explained that he chose hospital-care because he did not trust the GP in this context.

'They gave me a choice "would you like the hospital to contact or your doctor?" and to me it makes sense the results and everything be taken care of the hospital and why to go to the doctors and then feel like "oh my god he lost my notes" or the doctor may forget and I felt more comfortable with the hospital sending me a reminder and going to the hospital and those people take blood more regularly' (P7, 67)

All participants were concerned about the level of expertise and resource issues in primary care.

'And you think "wow is the service going to be the same as I am getting here (in the hospital)?" and you know that the service is not gonna be the same because that's a hospital and that's a general practitioner.' (P4, 59)

'They don't have enough information, they just don't know. I think it is about time and resources, isn't it?' (P6, 64)

Participants were frequently concerned about continuity of care in general practice, believing that it could be easier to raise potentially difficult topics with a familiar GP or with a female GP.

'Yes, that's true in a health centre it is very, very hard to see the same doctor all the time and you don't have this familiarity and you don't feel comfortable to say or mention something (...) if you have a preference to see the doctor you want to see, it is more difficult. I may feel better speaking to a woman, and you can't get to see who you want.' (P7, 67)

Concerns about the side-effects of treatment and the expertise of the GP in addressing them were also important.

'I spent a bit more time with them (hospital specialists) and I explained more things in more depth so when I didn't have the answers from GPs or I felt that I wasn't given enough information (...) because of the consultant's expertise who is specialised especially in erectile dysfunction, that was his speciality whereas you get a GP who looks at everything and they are not specialised in that particular area.' (P5, 75)

2. Survivorship: challenges and ways of coping

There were two aspects to this theme. One concerned the process of dealing with the long-term side-effects of treatment and difficulties in obtaining help and support for these. The other was related to the challenges in managing information within their families.

2a. Dealing with the long-term side-effects of treatment and difficulties in obtaining help and support for these.

All agreed that there was a lack of support regarding the psychological aspects of the side-effects.

'I am going to my GP every 6 months to have my PSA but ... no one asked me "how are the things with you? How you are feeling?" there is no occasion about that and I am going through this since 2008.' (P1, 55)

Following diagnosis and treatment initial concerns focused on survival, but once the immediate crisis was past the side-effects became more salient, particularly as old routines were re-established.

'The first thing is "I don't want to die" and then the second thing is "I've to get it (cancer) out" and then you don't think about anything else until you get the operation and then after the operation, you just care if it is a success and then after that then the side-effects start kicking you because now you want to start to do what you used normally to do.'
(P4, 59)

Urinary incontinence was common in the group but generally considered a relatively minor inconvenience.

'Well the thing with me is that I am OK but I could still have incontinence when I am work or if I am at the gym, but apart from that I am fine.' (P8, 73)

All participants agreed that the biggest challenge after treatment was their sex life and gave accounts of how for some men they knew, sexual potency was more important than surviving.

'When you can't perform sexually, you will think "Oh my God what I will do?" so he feels a failure and he doesn't try anything else and that's a shame really because the psychological part is a killer as well.' (P4, 59)

'Some men said to me "I'd rather be dead than live without sex", that's some people's mindset, their personality' (P8, 73)

For some men, the loss of a body part was a source of distress and required a period of adjustment.

'The psychological thing for me was the removal of the prostate, not the sexual thing because someone was taking something out of me when I think about it, I feel like this is part of me, that's been taken away.' (P5, 75)

The support group was seen to fill the gap in the service provision and was described as an 'after-care service' (P5, 75) that provided 'a sort of counselling' (P2, 71). All agreed that the support group was the most significant source of help and support, describing it as a safe place where they could find information, comfort, exchange thoughts and be open about their concerns and worries.

'There are so much knowledge and information and you feel so comfortable around the group because you know that they've gone through similar and you have that degree of understanding as well, cause your people can be understanding at a certain level but they have not been through it, you know.' (P4, 59)

2b. Challenges in managing information within the family

While these men desired psychological support from services and valued the group as a place they could share their feelings, several described how they often had to hide feelings at home. This happened for a number of reasons. P7 felt that he had to present a

strong role model for his sons in case they developed PCa in the future, explaining that he had to remain strong and calm for them so it would be easier and less stressful for them.

'I've got two sons and I can see that both of them handle my situation differently so I have to be careful at the same time, how they perceive me, how my treatment goes, how I am handling, because they will see how they would handle it, how dad was handling it so if I am gonna pass it to them, they may get it so I've got to put them in a position that they will feel safe and secure, and if it is necessary to have the operation themselves, not worry about the side-effects and remember how bad their dad was.' (P7, 67)

There was also a desire to protect their families from further anxiety about them.

'I don't talk about it with my kids. They got too much to deal with, I talk to my wife, she is my soulmate, the person who understands me but for the rest of my family they say "dad are you ok?" and I say yes. But I don't discuss that.' (P2, 71).

'I think most people because you know by telling them everything, by telling your kids, your partner, your wife everything, it puts them in a state of worry and I mean, if you don't tell them everything, they think you are reasonably ok. But if you tell them everything, then it is another worry for them "oh my god why he is leaking again? He is going to the toilet because he is leaking, not because he wants to go to the toilet" so I just avoided that and I kept a balance.' (P5, 75)

3. Black men and PCa: real and potential discrimination

There was a consensus that the lack of knowledge among GPs regarding the greater risk of PCa in African-Caribbean men could lead to discrimination and inadequate provision of health care services and support.

'The GPs probably whether they are not aware or they won't admit and treat, you know, Black men as an actual special case given the statistics. In other words, from them to be more aware and more informed about the risk, the increased risk of PCa in Black men so when they have Black men as patients, and when they reach a particular age, 50 or whatever it may be, they should be aware of considering, you know, to refer them and tell them to do a PSA test to start with or be more aware that they could have PCa and I think this is a problem with the GPs, not be aware of that as much. It's not actually miscommunication, it is probably lack of information.' (P6, 64)

Some men believed that racial stereotypes might make it difficult for African-Caribbean men to disclose their sexual problems to their doctors and ask for help or support.

'I think there is a perception that Black men they supposed to be sexual human beings and that every Black man is a sex icon, which is a lot of rubbish. So, having that stereotype running around, that's probably why some of the men are afraid to talk openly because they have this image to live up to. I mean, I am in the gym, in the shower, and the other guys say "Oh I bet you have 3 women". Hold on a minute, what does that mean? I am married but this is the perception, that all Black men must have a big penis.' (P4, 59)

The particular needs of Black men and variability in provision were also seen as potentially contributing to inequalities.

'In order to get another size for your vacuum penile pump device, you have to pay for it and that's a good point. I have to take another size as well and my GP was alright and he ordered a new one. So, the differences within the GP practices is that when I ask something to my GP he says yes and it is not a problem, but for many people could be a problem because the GPs say that you have to pay for it so it could an issue. So, there is a real issue if you look at it as an after-care, you know what you can access, in terms of that this is a side-effect and you have to pay for it. That can't be right.' (P5, 75)

In spite of these limitations in GP knowledge and service provision, all agreed that they had never experienced any direct discrimination from healthcare professionals and believed they were treated similarly to any other patient.

'I didn't experience any specific racist incidents. I can say that the guy who was dealing with me, he was good and I felt really comfortable, he told me that about the operation, that he is going to do the operation, he gave me his number and all that was very reassuring so for myself I can't say that I felt any racist behaviour.' (P7, 67)

Discussion

PCa is an arena in which masculinity and minority status intersect in ways that can influence the experience of discharge to primary care and the transition to survivorship. Masculine norms can affect men's response to PCa (e.g., Hoyt, Stanton, Irwin, and Thomas 2013) and it is recognised that men from minority groups, both racial and sexual, have negative experiences of the healthcare system (e.g., Halbert et al. 2009; Eaton et al. 2015). In the present study, the experience of transitioning from hospital-based to primary care and subsequently to survivorship was shaped by the impact of treatment side-effects on masculine identity. This identity was located within a particular culturally determined framing of masculinity and interacted with systemic and structural processes of healthcare.

The transition from secondary back to primary care was experienced as challenging and problematic in a number of ways. Comments concerning the way in which discharge is frequently misunderstood as indicating that the disease has been cured demonstrate the impact of a perceived lack of clear and accurate information in preparing patients for discharge. Without this, the transition process is already potentially compromised, as the role of GPs will not be clearly understood. These men's interactions with GPs during the process of diagnosing cancer also played a role in shaping expectations about returning to their care.

Lack of knowledge among GPs of risk factors relevant to African-Caribbean men and a consequent failure to recommend or support PSA testing contributed to a lack of confidence in the ability of GPs to manage the side effects of treatment. Comments about the possible loss of notes, failures to send appointment reminders and lack of resources also indicated a lack of confidence in the ability of GP practices to provide adequate care. Previous studies have shown that lack of trust in the healthcare system was one of the reasons why Black men did not see their doctor regularly (Metcalfe et al. 2008; Odedina et al. 2004). Our participants did not consider that they had been the victims of racist attitudes or values but they believed that lack of knowledge among GPs about aspects of PCa that were of particular relevance to the African-Caribbean community was problematic. This applied to all aspects of diagnosis and treatment, from awareness of risk factors, in particular, the elevated risk for African-Caribbean men, to appropriate advice and sensitivity relating to the management of social and sexual side-effects. The fact that both African-American and African-Caribbean men can develop PCa at a younger age and in a more aggressive form than White men means that they often experience side-effects such as ED at an age when sexual activity is still a significant aspect of their lives. Our participants believed that counselling and psychological support should be provided in relation to ED, but they were only able to obtain this support informally in the FAB group and not via their GP, who participants considered to be more focused on PSA testing than on their psychological welfare. The contrast between seeing familiar clinicians when attending hospital appointments and the lack of continuity of care in the GP practice was also a source of concern and they expressed reservations about raising sensitive topics with a GP who was unfamiliar to them. Together with a perceived lack of relevant expertise among GPs, this led some men to opt for ongoing hospital-based care when given a choice.

Participants described how culturally powerful and influential constructions of masculinity within their community rendered ED, and fear of ED, particularly salient. Perceptions of Black male identity that, in their view, foregrounded sexuality and penis size were seen as potential barriers to open communication with GPs. The complexities of both

recognising the importance of sexuality while managing difficulties at a personal level is apparent in distancing devices whereby "other" men are described as choosing death over the loss of sexual potency while participants also acknowledged a desire to return to how things were before surgery. Anderson et al. (2013) examined the experience of PCa among African and African-Caribbean men in the UK and found that fear of not being able to perform sexually after treatment was a major theme. Rivers and colleagues (2011) examined concerns about sexual functioning in African-American PCaSs and their wives and reported that for the male participants ED was perceived as the most important side-effect of treatment. The reduced sexual performance and desire were described as being key factors impacting their masculinity and manhood.

Our participants felt constrained in relation to what they were able to share with their partners and children. They withheld information from them to avoid upsetting them and fears that their sons might, in turn, develop PCa led them to adopt a stoic demeanour in order to provide reassurance that both the disease and the side-effects of treatment could be managed. This is consistent with work by Hammond and Mattis (2005), who found that for African-American men masculinity was related to family leadership and the perception that they had to be a role model. Emotional control and reluctance to seek help is also a component of the construct of hegemonic masculinity (Courtenay 2000). Non-disclosure of concerns, resulting in diminished support, may place Black men at risk of a greater psychological burden (Rivas et al. 2016), and our participants acknowledged this, which again emphasizes the need for adequate support and advice post-discharge.

Clinical implications and future directions

GP training should contain a greater focus on the needs of minority ethnic groups, specifically the risk factors and vulnerabilities of African-Caribbean men, regarding PCa. This could also be included in CPD courses in Urology. In a similar way, GPs and practice nurses need to be aware of sensitivities concerning help-seeking related to culturally-mediated understandings of masculinity, particularly in the area of sexuality.

Future studies should recruit a larger and nationally representative sample of African-Caribbean men. The perspectives of GPs in areas of diverse ethnicity and of GPs from African-Caribbean background would also be valuable in developing our understanding and knowledge of the issues identified in this study.

Strengths and limitations

Although the aim and the findings of this research are novel in the particular field of PCa and transition to primary care in the UK, some findings were consistent with those of previous relevant studies. This kind of triangulation suggests that the study was sufficiently sensitive and appropriately designed to enable it to identify issues that previous researchers had highlighted, such as side-effects and masculinity. While sexual orientation was not an inclusion or exclusion criterion, all the participants were heterosexual. Even though the aim of this study was not to achieve a statistical generalization of its findings, the challenges that participants described could be relevant to other cancer survivors or patients and could help the NHS to gain an insight into the problems and challenges concerning the process of discharge and survivorship in general.

The researcher was self-reflective about her role and potential influence she may have had during the focus group and in the analysis process such as the identification of themes.

The inclusion of quotes as representations and illustrations of each theme and sub-theme provides a clear insight into the theme's context and description.

The men in this study may have been better informed about PCa than is typically the case and they benefitted from the support of a close-knit group of fellow survivors. All participants were recruited via the same support group. However, the use of a non-random and selective sample is common in qualitative approaches, which focus on identifying individuals who have lived specific experiences or have specific characteristics (Tuckett 2003).

Conclusions

The experience of discharge from secondary to primary/GP care can be anxiety-provoking. It seems likely that the issues described by our participants are not unique to African-Caribbean men and that the process overall needs to be made more clear and transparent, with explicit information about its meaning and what will happen next. African-Caribbean PCaSs face many of the same challenges as all PCaSs. However, in their case, these are compounded by fears that their GPs do not fully understand the additional risk factors in this population and by particular assumptions concerning Black male sexuality among healthcare professionals as well as in wider society. The role and position of men in African-Caribbean families is also an issue here. GPs and other primary healthcare providers would benefit from access to information and educational materials about the added burden of risk for African-Caribbean men as well as about their specific emotional and social needs.

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