Factors that may influence black men and their partners' knowledge and awareness of prostate cancer screening: a literature review.

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Abstract

Background: Prostate cancer is the most commonly diagnosed cancer in men in the UK with 46,690 new cases in 2014. While there is sufficient research on this topic in the USA, there is no review in the United Kingdom regarding both black men and their significant others' perspectives on prostate cancer screening.

Aim: To identify and explore factors that may influence black men and their significant others' knowledge and awareness of prostate cancer screening.

Method: A literature search revealed seven relevant articles.

Results: Six of the seven articles were conducted in the USA. The results are described using four themes: perception of prostate cancer screening, fear, anxiety and discomfort, misinformation about prostate cancer screening procedures and communication and decision-making.

Conclusion: The evidence suggests that some black men and their significant others had knowledge and awareness of prostate cancer screening. However, their views were influenced by misperceptions, misinformation, fear, anxiety around screening procedures and mortality. Communication and spousal support were important in decision making.

Introduction

Prostate cancer is the most commonly diagnosed cancer in men in the United Kingdom (UK), with 46,690 new cases and 11,287 in 2014 (Cancer Research UK, 2014). It is the second most common cause of death in British men with 10,837 deaths in 2012 (National Institute for Health and Care Excellence, 2014). A person's risk of developing prostate cancer depends on many factors, including advanced age, ethnicity (black men), family history and obesity (Cancer Research UK, 2017a). In the UK, black men are two to three times more likely to be at risk of developing prostate cancer compared to their Caucasian counterparts, with a 30% higher mortality rate (Jones and Chinegwundoh, 2014).

In the UK, the highest incidence of prostate cancer occurs in black men (Cancer Research UK, 2017a). Approximately, 1 in 4 black men will experience the disease at some point in their lives (Prostate Cancer UK, 2016). The lifetime risk of being diagnosed with prostate cancer is 13.2-15.0% for white males, while in black males it is significantly higher (23.5-37.2%), and in Asian males it is significantly lower (6.3-10.5%), according to data for 2008-2010 in England (Cancer Research UK, 2017b).

Currently, there is no national screening in the UK. However, in 2002, the Prostate Cancer Risk Management Programme was introduced, which provides patients and clinicians with balanced information on the pros and

cons of Prostate Specific Antigen (PSA) testing. The PSA test is available in the UK to any man aged 50 or over who requests it, and may lead to the detection of prostate cancer before symptoms develop or at an early stage when the cancer could be treated (Public Health England, 2016). GPs, however, are not permitted to proactively raise the issue of PSA testing with asymptomatic men. The PSA test may give false-positive results which can lead to misdiagnosis of prostate cancer. A single PSA test is a simple test used to determine if a man has prostate cancer. However, it is used in combination with other tests such as MRI scan and transperineal biopsy to confirm tumour type (Schroder et al, 2009).

Pickles et al's. (2015) qualitative study shows that there still remains a high amount of inconsistency in PSA testing. A study by Nderitu et al (2016) was the first to show a modest 2% rise in rates of PSA testing amongst black men in the UK from 6.2% to 8.2%. They found that PSA testing among black men was higher compared to that among White men, but remained relatively lower compared to other EU countries and the USA. This is possibly driven by increased awareness of prostate cancer risks by patients and GPs (Nderitu et al., 2016). However, there has been a decrease in PSA testing rate among Caucasian men which may reflect the reduced incidence of mortality risk of prostate cancer among this group (Kazuto, 2014).

Some black men prefer to take a passive role in their health care and tend to rely strongly on female relatives for prostate cancer screening decisionmaking (McFall et al., 2009). Some tend to have difficulty understanding

cancer prevention information and most women often act as their overall health advocates (Friedman et al., 2009). It has been reported consistently that some women are influential on their men's decision to pursue prostate cancer screening reflecting the important role they play in men's lives regarding their health (Dean et al., 2015). Men preferred to discuss prostate cancer with their partners rather than their doctors (Friedman et al, 2012). There has been more research into prostate cancer and the lessons from the experiences of black men and their significant others can be translated into UK practice.

Aim

The aim of this review was to identify and explore factors that may influence black men and their significant others' knowledge and awareness of prostate cancer screening, thereby recognising gaps in knowledge and awareness that can be used to improve UK practice.

Study design

To achieve the aim of this study, a literature review was conducted to summarise the body of evidence on black men and their significant others' knowledge and awareness of prostate cancer screening.

Inclusion and exclusion criteria

Only qualitative and mixed method research papers published in English from 2006 to 2016, addressing black men and their significant others' knowledge and awareness of prostate cancer screening were included in this review.

Articles not published in English or that were solely quantitative studies or that included white and Hispanic men were excluded. This is because the authors are only fluent in English and also to ensure in-depth qualitative information was obtained to fully address the research question. Four databases (MEDLINE, CINAHL, PUBMED and PsycINFO) were searched using the keywords as identified in the search strategy.

Search Strategy

Keywords were developed and some were combined with truncation to allow for a wider range of results. Articles were sourced using the keywords "Black men OR African men OR non-Caucasian men OR ethnic minorit* men AND Significant other* OR Partner OR Spouse OR Female* AND Knowledge OR Culture OR Understand* OR Information AND Prostat* cancer OR Prostat* neoplasm* OR Prostat* tumor AND Screen* OR Assessment* OR Test OR Diagnosis."

A total of 123 articles were identified through a systematic search of computerised databases (MEDLINE, CINAHL, PUBMED and PsycINFO) using the above keywords. Once duplicates were removed, 115 articles remained. After reviewing their titles and abstracts, a further 72 articles were excluded for failing to meet the inclusion criteria. Out of the remaining 43 eligible articles, 36 articles were reviewed and excluded for not meeting the inclusion criteria. This left 7 articles which were to be included in the review (see search outcome in figure 1).

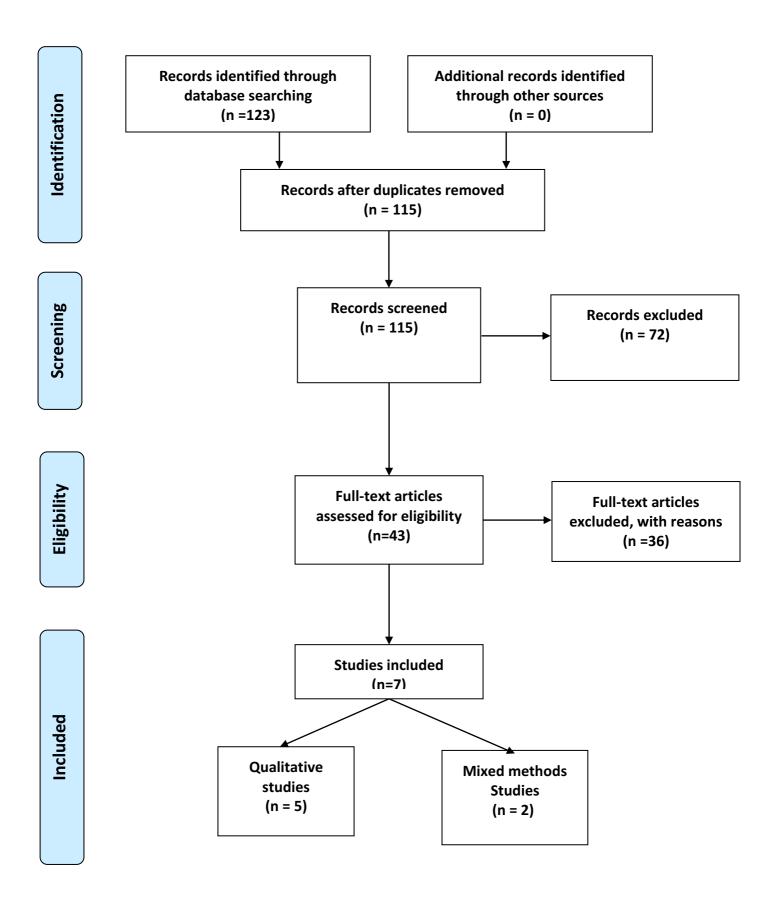


Figure 1: Search outcome of literature review

Quality Appraisal

In order to ascertain the quality of each of the seven relevant articles, the criteria from the validated Critical Appraisal Skills Programme (CASP, 2017) tool for qualitative appraisal and Long et al.'s (2002) evaluation tool for 'mixed methods' were used. All of the studies were rated as high quality and so were acceptable for analysis.

Data Extraction

Data extraction is a process that enables the reviewer to extract the relevant information from the papers included in the review in preparation for subsequent analysis (Aveyard et al., 2016). Braun and Clarke's (2006) stepby-step guide for doing thematic analysis was adopted to analyse and synthesise the data. The authors independently read and reread each paper to gain an overall understanding of the study's findings. The characteristics of these studies are given in Table 1 below. The authors then met and combined different codes to form overarching themes identified through the findings of all seven studies. Figure 2 shows the subthemes and their corresponding overarching themes.

Table 1: Critical appraisal of the selected studies					
Author (Year), country	Title	Aim	Study Design	Sample size	Main findings
Webb et al.	An evaluation of the	To explore the	Qualitative	18 African American	Some male participants were
(2006)	knowledge, attitudes	knowledge, attitudes	6 Focus	men aged ≥ 40	misinformed about PC.
	and beliefs of	and beliefs of African-	groups were	years,	
	African-American	American men and	conducted	14 women of any	Existing confusion between PC
	men and their	their female significant		race aged ≥ 30	and colon cancer screening.
	significant others	others regarding		years.	
	regarding prostate	prostate cancer		One focus group was	The female significant others
	cancer screening.	screening.		a convenience	were motivators for the men.
				sample	
				The other	
				participants were	
				recruited via gender	
				specific flyers and a	
				television interview to	
				publicise the study.	

Hunter et al.	African Americans'	To examine	Qualitative	38 African American	Participants had knowledge on
(2015)	perceptions of	perceptions regarding	Focus groups	men and 8 women	how helpful PSA screening test
		susceptibility and		aged ≥18 years were	was.
	prostate-specific	screening of prostate		recruited using word	
	antigen prostate	cancer.		of mouth and flyers.	Participants perceived biopsies
	cancer screening.			Sample included	could interfere with sexual
	g.			prostate cancer	functioning.
				survivors and their	
				loved ones. Married	Women were identified as
				(n=35), divorced or	partners in PC screening
				separated (n=6), or	decision-making.
				single (n=5)	

Hughes et al.	Prostate	cancer	To investigate factors	Qualitative	54 African American	Fear of cancer.
(2007)	community		which influence	Ten Focus	males aged 55-79,	
	collaboration	and	African American men	groups (6	37 females aged 48-	Testing process viewed as
	partnership:		and their significant	male only	77. Potential male	compromising masculinity.
	education,		others' decision to	and 4	participants who had	Stigma of having PC influenced
	awareness,		take part in	females only)	been diagnosed with	willingness to undergo
	recruitment	and	screenings.		prostate cancer	screening.
	outreach	to			within the past 10	
	Southern-Ame	erican			years were randomly	
	males.				selected from lists	
					generated by a local	
					urological clinic.	
					Female partners of	
					the eligible males	
					were recruited for the	
					study.	
Blocker et al.	Knowledge,	beliefs	To assess attitudes	Qualitative	Convenience sample	Good knowledge and
(2006)	and	barriers	and behaviours linked	Four focus	of 14 African	awareness of PC screening
	associated	with	to prostate cancer	groups	American men and	shown by both men and

	prostate cancer	prevention activities		15 women aged 34-	women.
	prevention and	that could be used to		68 years. 41% had	
	screening behaviours	develop culturally		college degrees and	Issues of masculinity deterred
	among African	relevant intervention		95.5% were married,	black men from getting
	American men.	for African American		22% had prostate	screened.
		church-based		cancer screening	
		population.		test.	
Owens et al.	Prostate cancer	To assess African	Multiple	81 participants	Most participants had limited
(2015)	knowledge and	American men's and	methods	recruited by word of	information regarding risks,
	decision making	their female relatives,	Focus groups	mouth & media	benefits and uncertainties of
	among African	friends and significant	Quantitative	approaches.	PC screening.
	American Men and	others' knowledge	Survey	Participants included	
	women in the	and cancer related		African American	Both men and women received
	Southeastern United	decision- practices		men aged ≥40 with	information from different
	States.	within the context of a		no history of prostate	sources.
		prostate cancer		cancer and women	
		education program.		aged ≥ 21.	Men often relied on their female
			-		significant others for guidance.
Ng et al.	Factors influencing	To evaluate the	Qualitative	23 African Barbadian	African Barbadian men
(2013)	prostate cancer	knowledge, attitudes	design	men and 10 women	perceived visiting a healthcare

	healthcare practices	and practices of	Interviews	aged ≥ 18 were	professional as a sign of
	in Barbados, West	African Barbadian		recruited via	weakness.
	Indies.	men in relation to		telephone. 27 of	
		prostate cancer and		participants had	Fear and anxiety about the
		discover factors that		personal experience	
		hinder PC screening.		with prostate cancer	nature of the DRE influenced
				and 23 participants	screening decisions among
				with other cancer.	both men and women.
Carter et al.	Increasing prostate	To identify facilitators	Mixed	74 African American	Male participants did not
(2010).	cancer screening	and barriers to	methods	men (aged over 40)	discuss health issues with
	among African	screening.	Six focus groups.	and their spouses/ significant others.	anybody.
	American men.				Both men and women
					associated PC with death.
					Women were identified as sources of support in cancer decision-making.

GROUPING OF FINDINGS INTO THEMES

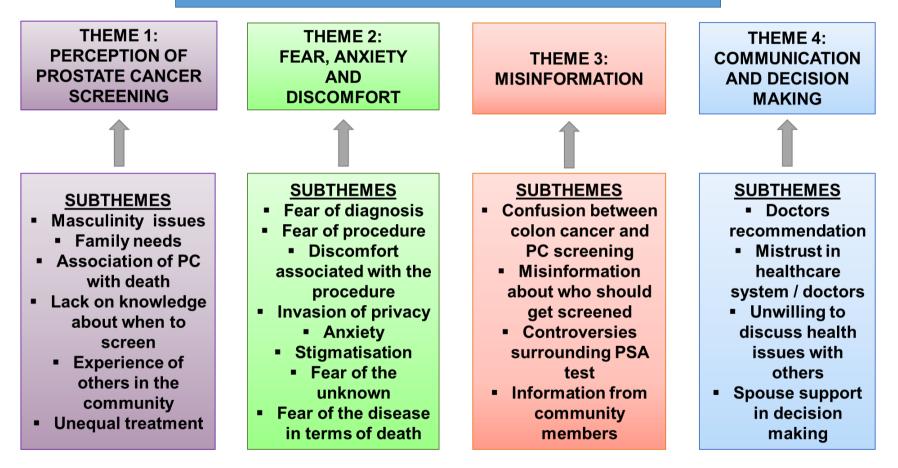


Figure 2: overarching themes

Results

The coding process highlighted 22 subthemes, which were then aggregated into 4 overarching themes (figure 2). These are as follows: 1). Perception of prostate cancer screening 2). Fear, anxiety and discomfort 3). Misinformation 4). Communication and decision-making. Each theme is explored in detail. The first paragraph of each theme pertains to the views of the men, while the second paragraph details the views of their significant others.

Perception of prostate cancer screening

The review highlighted that men were concerned that undergoing rectal examination might decrease men's masculinity and could lead to being perceived as homosexual, feeling less of a man or having their manhood taken away (Blocker et al., 2006; Webb et al., 2006; Hughes et al., 2007; Ng et al., 2013; Hunter et al., 2015; Owens et al., 2015). The majority of the men in Ng et al.'s (2013) study indicated that African Barbadian men had the perception that visiting a healthcare professional was a sign of weakness. In general, men were portrayed as 'macho' and to seek medical care was a 'feminine thing' (Ng et al., 2013, p.655). The word 'macho' or 'machismo' was also used by Blocker et al. (2006, p.1289) to denote toughness.

The women also expressed concerns related to sexual identity and manhood as a deterrent to having the DRE performed (Webb et al., 2006). It was also highlighted that most women were discouraged by the thought that biopsies or screening procedures could affect sexual functioning (Webb et al., 2006; Ng et al., 2013; Hunter et al., 2015). However, some of the women thought that

prostate cancer screening is recommended only for those with a family history of the disease (Hunter et al., 2015).

Fear, anxiety and discomfort

It was identified that black men associated prostate cancer with death and a fear of knowing something was wrong and consequently were not getting screened (Webb et al., 2006; Carter et al., 2010; Ng et al., 2013). Some of the participants from men's group expressed fear that they might have prostate cancer (Webb et al., 2006; Carter et al., 2010). The study by Ng et al. (2013, p.655), found that most men would avoid going to the doctors, as they 'fear discovering exactly what may be wrong'. Also, the men stated that the DRE procedure was uncomfortable (Webb et al., 2006). The stigma associated with prostate cancer was an issue of concern for all the participants (Hughes et al., 2007; Ng et al., 2013). Additionally, participants stated that the DRE made them uncomfortable and they feared intrusion into their privacy and bodies (Blocker et al., 2006; Webb et al., 2006; Hughes et al., 2007). They feared that the DRE might impact on their manhood (Blocker et al., 2006).

Women expressed their fear that the disease could lead to death (Blocker et al., 2006; Webb et al., 2006; Hughes et al., 2007; Ng et al., 2013). One female participant stated that she always reflected on how her family members and people she knew who were diagnosed with prostate cancer suffered and died (Blocker et al., 2006). Another female participant said "men have the tendency to have that fear of going and finding out there is something wrong" (Webb et

al., 2006: p.236). Most women reinforced the men's distaste for the DRE as one woman remarked "he came home walking a little strange" (Webb et al., 2006: p.236). Another female participant reported her husband did not like the DRE (Webb et al., 2006).

Misinformation about PC screening procedures

There were confusions between prostate and colon cancer screening (Carter et al., 2010). In one study, while 51% of participants had been screened for prostate cancer at some point in their lives, only 33% indicated they had been screened within the previous 12 months (Carter et al., 2010). However, 12% of those respondents who indicated they had been screened stated they received neither PSA nor DRE indicating lack of knowledge regarding the type of test given for prostate cancer screening (Carter et al., 2010). Similarly, a number of men in the group were misinformed in regard to prostate cancer screening procedures (Webb et al., 2006). When asked if he was familiar with PSA blood tests, one of the participants stated he did not have a blood test but rather a colonoscopy, believing that, as they used their hands, they were checking the prostate (Webb et al, 2006). Regarding misinformation, one male participant said " what is PSA? I hear different ones discussing it and now I do not have no idea what that is" (Webb et al., 2006, p.236). However, a few of the participants in one study were aware of the controversies surrounding the suitability of the PSA test as a screening tool for prostate cancer (Hunter et al., 2015). One participant reported that he had heard that the doctors were unable to agree on the same thing as every doctor said

something different in respect of prostate cancer screening (Hunter et al., 2015).

Communication and decision-making

This review highlighted that the men's overall decision making about prostate cancer screening varied, but was often related to a decision by their doctor (Blocker et al., 2006; Owens et al., 2015). However, most of the male participants stated they did not trust non-black doctors in the diagnosis of prostate cancer as they felt they treated them differently compared to other races (Blocker et al., 2006; Hughes et al., 2007). Equally, Carter et al (2010) and Ng et al. (2013) found that most of the participants were not comfortable discussing their health issues with friends, but stated they "kept it within the family" and spoke only to their doctors for advice or information (Ng et al, 2013: p.657). Women were identified as partners of men in decision-making regarding prostate cancer screening (Carter et al., 2010; Hunter et al., 2015 and Owens et al., 2015). One male participant stated, "even though we feel macho we do listen to our wives and obey" (Webb et al., 2006, p. 237).

The role of wives in men's health issues was inconsistent among the Barbadian families, as four of the wives stated they were not involved in the medical decision-making processes of their husbands (Ng et al., 2013). In contrast, most of the women in the other studies reported that they were fully involved in the decision making process from start to finish, and reminded men of their appointments (Webb et al, 2006; Carter et al, 2010; Ng et al, 2013).

Discussion

By using thematic analysis, it was shown that black men and their significant others' knowledge and awareness of prostate cancer screening were influenced by their perceptions, fears and anxieties, misinformation and issues of trust. Six of the studies included in this review were conducted in America and one study in Barbados. However, the findings from these studies were remarkably similar with regards to the themes that emerged. The majority of the papers included in the review used a qualitative approach, with only two using a mixed method approach.

It was discovered that although black men and their significant others demonstrated acceptable general knowledge and awareness of prostate cancer screening, most of the male participants said they were unaware of the increased risk among black men (Ng et al., 2012). Jones et al. (2009) stated that some African American men did not perceive themselves as being of high risk to prostate cancer unless a close relative had the disease or there was a family history, clearly indicating a lack of awareness in their susceptibility to prostate cancer. It stands to reason that black men must be made aware of the need to be tested regardless of their family's medical history.

The difficulties in getting black men to undergo screening are further exacerbated by the level of misinformation surrounding screening procedures. It appears that most men listened to their peers, and were not gleaning facts but rather hear 'say. Colon cancer screening had been mistaken for prostate cancer screening in one study, as the doctor had used their hands to check

(Webb et al., 2006). Additionally, the controversies surrounding PSA screening and doctors' differing opinions were also found to affect black men's willingness to undergo screening (Hunter et al., 2015). In this respect, medical practitioners in the USA may have added to the confusion by not being consistent in their approach. NHS guidance should ensure consistence in the UK. Kim and Andriole (2015) suggested that doctors should have a complete discussion of the potentially limited benefits and the harms associated with early detection of prostate cancer with men and their partners in order to keep them well informed. This would do well to cut through the fog of misinformation surrounding the issue.

Concerns about how their masculinity would be affected, such as sexual difficulties, invasion of privacy, and being perceived as gay, were also seen as reasons as to why black men were not getting tested (Blocker et al., 2006; Hughes et al., 2007; Ng et al., 2013). The data indicates how seeing a doctor was not considered manly, nor was undergoing the DRE which was disliked by a number of men and their partners. These attitudes need to be challenged in order to encourage more men to take up screening. A report by the Prostate Cancer in BME Communities Parliamentary Stakeholder Group (2012: 6) pointed out that one could request the DRE to be performed either by a man or woman. The reasons for highlighting this option are not expanded on, but one possibility is alleviating the perception of being seen as gay. It is also important for nurses to take into consideration how treatment could have an adverse impact on sexual function and cause impotence. This was clearly an issue for some men and their spouses, one that deterred them from getting

screened (Webb et al., 2006; Ng et al., 2013; Hunter et al., 2015). A holistic response must be adopted in order to sensitively handle the effects on masculinity and any adverse impact on sexual function that may occur after treatment.

It was identified that both men and women equated prostate cancer with death (Carter et al., 2010). There was the belief that a diagnosis of prostate cancer was a death sentence. A separate study also reinforces the data from the review, in that black men perceived being diagnosed with prostate cancer as synonymous with death (Oliver, 2007). A fear of receiving a positive diagnosis prevented screening, fomenting a cultural taboo around prostate cancer. UK medical practitioners will need to work to dispel any notion of death surrounding a prostate cancer diagnosis, showing that men can recover from prostate cancer and still live long lives, while being clear about any adverse side effects caused by treatment.

Little is known about how black men and their significant others access information about prostate cancer in the UK (Prostate Cancer UK, 2016). Currently, as there is no national prostate cancer screening programme, it is believed that improving access to balanced information for both black men and their significant others from Black communities could assist in improving prostate cancer detection (Louie, 2016). Culturally sensitive information targeted to modify perceptions should be made available to improve prostate cancer screening behaviours among both black men and women in the UK (Allen et al., 2007). Rajbabu et al. (2007) reported that knowledge about

prostate cancer risk factors among black men in the UK were fairly high, but only 5% of them had been tested for prostate cancer.

Across the studies, significant others and doctors were found to play a pivotal role in prostate cancer screening decision making amongst black men (Blocker et al, 2006; Carter et al., 2010; Ng et al., 2013; Hunter et al, 2015; Owens et al., 2015). Toles (2008) postulates that including their significant others in healthcare decision-making processes could help influence men's decision to get screened for prostate cancer. Thus, it is imperative to relay information about screening to the spouses or partners of black men. Doctors' recommendation for prostate cancer screening was also identified as a significant predictor in convincing black men to be tested (Blocker et al., 2006; Owens et al., 2015). The recommendation of their doctor therefore carries considerable weight, a factor that cannot be considered in the UK due to the current policy. Problems have arisen in the USA due to historic institutionalised racism that has culminated in mistrust towards the healthcare system and non-black doctors (Blocker et al, 2006; Hughes et al., 2007). Some black men and women felt that non-black doctors treated them differently compared to other ethnicities. Adegbembo et al. (2006) reported that personal negative experiences and perceived racism can cultivate mistrust in the healthcare system among African American men and women. It is unknown if the same views are as widespread in the UK, and whether this is a detriment to screening. A study looking at the experiences of African Caribbean fathers in England found that many believed that health professionals did not understand their needs, and that black boys and young

men were feared by white middle-class professionals, inferring that perhaps there is an underlying prejudice being perceived (Williams et al., 2011). Nurses must work to establish trust in Black communities, particularly through community outreach programmes.

Limitation of the review

A major limitation of this review was that most of the studies were undertaken in the USA. The differences between the USA and the UK health systems regarding access to healthcare and their national guidelines for prostate cancer screening must be taken into account. Also, there could be the possibility of language bias as the studies were conducted in English. This might have limited participants whose first language is not English from giving accurate information or expressing themselves accurately. The key word 'tumor' used in the search was the American spelling, and is recognised as a limitation. Although the term 'significant others' was used during the literature search, 'wife' was omitted and there was no literature found that included gay men, thereby limiting the scope of the review.

Conclusion

The evidence suggests that some black men and their significant others had knowledge and awareness of prostate cancer screening. However, perceptions were influenced by beliefs and misinformation. Based on the data

drawn from the US studies, UK Healthcare professionals must provide patients and their significant others with accurate, pertinent details about screening procedures, and be clear and cohesive in their strategy to avoid creating misconceptions. Black men are more likely to develop prostate cancer than their white or Asian counterpart and therefore require particular consideration, with awareness of their possible beliefs and ethnicity treated with sensitivity. Nurses should adopt a holistic approach in their practice, recognising the impact screening can have on a patient's masculinity, and guide patients and their significant others to make informed choices. The shared decision making aid for PSA testing (NHS Right Care, 2017) can be consulted to aid patients through the process, while ensuring their own beliefs and values are considered. However, nurses should be aware that patients' needs may vary with age, culture and sexual orientation. Work is already being done in the UK to improve screening rates, especially among black men. For instance, in 2014, Public Health England (PHE), in partnership with the Department of Health, NHS England and Cancer Research, introduced the 'Be clear on cancer' campaign in six London boroughs to improve early diagnosis of prostate cancer by raising public awareness of the increased risk among black men (PHE, 2014). Prostate Cancer UK (2016) has also undertaken programmes, such as setting up local support groups, giving awareness talks, training specialist nurses and conducting one to one support to improve PSA screening uptake. Nurses should therefore engage in outreach programmes and campaigns to help facilitate trust and awareness by overcoming reservations in Black communities, dispelling taboos and countering misinformation, and being aware of potentially racist undertones to

health information. Additionally, education of male youths about prostate cancer screening would prepare them for a sensitive encounter with their future clinicians. This review has highlighted a need for further research in the UK to ascertain black men and their significant others' perceptions and knowledge of prostate cancer screening.

CPD reflective questions

- What more could healthcare professionals do in order to provide black men and their significant others with accurate information regarding prostate cancer screening in the UK?
- What could be done to encourage black men to undergo screening?
- How could nurses and other healthcare professionals alleviate fear of prostate cancer screening in black men?

Key Points

- Black men and their partners' perceptions of prostate cancer screening were influenced by beliefs and misinformation.
- Nurses should adopt a holistic approach in their in caring for black men with prostate cancer.
- Nurses should be aware that black men's needs may vary with age and sexual orientation.
- Education of black male youths about prostate cancer screening will prepare them for sensitive encounters with health professionals.

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