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ORIGINAL ARTICLE

“…It might not have occurred to my husband that this woman, his wife who is taking care of him has some emotional needs as well…”: the unheard voices of partners of Black African and Black Caribbean men with prostate cancer

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Abstract

Purpose Evidence suggests that partners of men with prostate cancer (CaP) experience greater psychosocial distress compared with men themselves. However, the experiences of partners of high-risk (1 in 4) Black African (BA) and Black Caribbean (BC) men with CaP remain poorly understood as existing research has predominantly focused on Caucasian populations. This study aimed to address this gap by exploring partners’ experience and support needs as influenced both by the specific impacts of CaP, treatment side effects and socio-cultural context.

Methods Using a constructivist grounded theory approach, eight face-to-face, two Skype and one telephone interviews were conducted with eligible partners ($n = 11$). The interviews were analysed using constant comparison following key stages of open, focused and theoretical coding.

Results Three broad categories emerged which described participants’ experiences: ‘partner in the passenger seat’, ‘care-giving on an isolating journey’, and ‘coping as a partner’. Findings showed that BA and BC cultural marital context influenced how partners experienced and traversed the CaP journey. Peripheral involvement in decision-making, communication restrictions, limited access to support and lack of recognition for their experiences and needs further contributed to partners’ psychological and emotional distress.

Conclusions Cultural beliefs, behaviours and values should be taken into account when developing psychosocial support for partners and their men with CaP. Specifically providing information focused on partners and including them in the CaP care pathway could help ensure that partners’ needs are recognised and improve marital communications. This could potentially help partners and their men to identify acceptable ways of supporting each other throughout the CaP experience.

Keywords Prostate cancer · Black African · Black Caribbean · Partners · Wives · Experience · Grounded theory

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Introduction

Prostate cancer (CaP) is the most common male cancer and affects Black African (BA) and Black Caribbean (BC) men at disproportionately higher rates (1 in 4) than Caucasian men (1 in 8) [1, 2]. Despite improving survival rates, treatments for CaP often come with adverse side effects (such as sexual dysfunction, fatigue, incontinence issues, hot flashes) which significantly alter the psychosocial well-being of affected men and their partners [3, 4].

Describing CaP as a couple's disease, Wittmann et al. [5] highlight the significant role partners play in providing practical and emotional support for men along their recovery pathway. However, there is limited research on how partners themselves are supported to navigate the psychosocial challenges associated with CaP. The currently sparse literature has focused on Caucasian [4, 6, 7] and African American [8, 9] partners and indicates they often experience greater psychosocial distress than the men themselves due to feelings of isolation, communication constraints and unmet support needs. Partners' experiences within higher-risk BA and BC populations remain poorly understood.

Evidence suggests the existence of cultural influences on how men and partners experience and cope with the impact of CaP [9, 10]. Socio-cultural definitions of gender role and identity have also been shown to underpin the existing power structure in BA and BC relationships in which traditional hegemonic masculinity constructs culturally situate men in a more dominant position than women [11]. These, coupled with the younger age and advanced stages at which BA and BC men are diagnosed with CaP, further suggest that partners within these populations may have unique psychosocial needs which should be addressed in a culturally sensitive way [12, 13]. Therefore, an in-depth exploration of the experiences of partners of BA and BC men with CaP could help inform the provision of appropriate support to improve their psychosocial well-being along the CaP journey.

This article reports partner data from a larger study which focused on exploring the experiences, psychosocial needs and how best to address them after CaP treatment for both BA and BC men and their partners. The aim of this article is to highlight these partners' experiences and support needs, uniquely influenced by the interaction of CaP, treatment side effects and socio-cultural context.

Methods

Study design

A qualitative design using constructivist (co-construction of knowledge through researcher-participant interactions) grounded theory methodology was used [14]. Purposive sampling (including snowball) enabled the identification and initial access to the 'hard-to-reach' (difficult to access) [15] study participants at different locations in England (Greater London, South and East Central England). Theoretical sampling (in-depth exploration of initial data in later interviews until fully conceptualised) was subsequently used. Between October 2016 and March 2018, potential partners were identified through men who participated in the study, by healthcare professionals (HCPs) at three National Health Service (NHS) hospitals in England and by networking with other colleagues. Regardless of their ethnicity (self-reported by participants) and gender, partners were included if they were in intimate or marital relationship with BA and BC men who had undergone at least 3 months' active treatment for their CaP; resident in the United Kingdom (UK); aged 18 years and above; and able to read, speak and understand English. Partners of men receiving palliative care were excluded because their needs were perceived to be beyond the scope of the study. Eligible and willing partners were provided with an information pack explaining the implications of their involvement. Once written informed consent was received, interview arrangement was agreed with the participant. The study is reported following the Consolidated Criteria for Reporting Qualitative Research (COREQ)'s guidelines [16].

Ethical considerations

Institutional and national ethical approvals were obtained. Interview transcripts were anonymised (using pseudonyms), and all necessary data protection procedures were observed to protect participants' confidentiality.

Data collection

Semi-structured interviews were used to collect rich, in-depth data. A semi-structured topic guide was developed (Table 1) which was informed by the literature and study participants themselves. After the initial interview, the topic guide was subsequently modified to enable in-depth exploration of emerging categories in further interviews. Theoretical sampling guided data collection until saturation was achieved (when emerging categories were fully conceptualised and no further data was required) [14]. Interviews were conducted face-to-face at different locations in England either at each participant's home or place of work (private office), or via telephone or Skype. The interviews, which were audio-recorded and lasted between 30 and 90 min, were conducted by the first author (OB) who is a BA woman with no prior relationship to any of the study participants.

Table 1 The semi-structured topic guide

Sample initial open-ended questions based on research aims and objectives

1. Experience of being a partner to someone diagnosed and treated for CaP
2. Impact of men's CaP on self and marital relationship
3. Cultural implications of husband's CaP within their and husband's (if different) cultural contexts
4. Support experience and psychosocial needs for self as a partner
5. Suggestions on how to address the needs identified in 4
6. Demographic details

Sample open-ended questions on modified topic guide as informed by emerging categories

1. Marital communications and decision-making process in cultural context
2. Personal coping mechanisms
3. Impact of limited disclosure of the CaP on support experience
4. Dealing with sexual challenges

Data analysis

Interview transcripts were organised using NVivo 11 software [17]. Using constant comparison, open coding of the first interview using gerunds (action words) in participants' narratives helped to identify gaps requiring further exploration in subsequent interviews. A more conceptually focused coding followed where relationships, similarities and differences between concepts were iteratively explored and compared with new data, thus probing participants' psychosocial inclinations, responses and processes. Theoretical coding enabled the grouping of similar concepts into categories which were explored in greater detail until theoretical saturation was achieved [14].

Rigour, credibility and trustworthiness

To ensure rigour, credibility and trustworthiness, data were independently analysed by four of the authors (OB, BML, HM and EMcC). Differences in opinion were discussed in-depth and triangulated through expert validation [18] involving a fifth author (DW) to consensually agree on findings. Keeping reflexive and analytical memos enhanced theoretical sensitivity whilst iterative data collection and analysis facilitated the validation of the researchers' interpretation of emerging categories from participants to ensure findings were grounded in their data [14].

Results

Overview

Theoretical saturation was achieved after 11 interviews. All the 11 partners approached for the study consented to be interviewed. Of these partners, seven were recruited by snowballing through men with CaP who participated in the larger study, whilst four were recruited by purposive sampling through HCPs ($n = 3$) and researcher's networks ($n = 1$). Eight of the interviews were held face-to-face, two were conducted via Skype whilst the remaining one was conducted over the phone. Although gender was not applied as an eligibility criterion, no male partners was identified. All partners were female, aged between 41 and 88 years old and married to either a BA or BC men with CaP. The majority of the women ($n = 7$) were of the same ethnic background as their husband with CaP. Table 2 presents the partners' demographic details.

Six themes were identified which were theoretically coded into three broad categories: (1) partner in the passenger seat, (2) caregiving on an isolating journey and (3) coping as a partner. Relevant quotes are provided in Table 3 to support findings reported under each of these themes.

Table 2 Demographic details of partners interviewed for the study ($N = 11$)

		Partners (n)
BA (3)	Nigeria	1
	Ghana	2
BC (4)	Jamaica	2
	Barbados	2
White (4)	British (WB)	2
	Irish (WI)	1
	Spanish (S)	1
Age (years)	< 45	1
	45–55	5
	56–65	2
	66–75	2
	> 75	1
Length of time married to their husband with CaP	< 20 years	4
	21–30 years	2
	31–40 years	3
	> 40 years	2
Educational level	Below graduate	3
	Graduate	4
	Post graduate	4
Type of treatment husband had for his CaP	Robotic surgery	5
	Brachytherapy	3
	Surgery + radiotherapy	1
	Radiotherapy + hormone therapy	1
	Cryotherapy + hormone therapy	1
Length of time since husband was treated for CaP	Ongoing long term treatment	3
	< 1 year post treatment	5
	1–5 years post treatment	3

Table 3 Some relevant quotes from study participants

Main themes	Supporting quotes
1. Partner in the passenger seat	
a. The unrecognised co-patient of prostate cancer	[i] *"…I would prefer, my husband to be more interactive, more communicative than he is, something is poking you then talk to me about it but I tend to be the one that has to draw out everything … I guess any problems will be on his side because he tends to hold his feelings back… (long pause), it hurts…"* (*Mrs Freda, BC, 62*) [ii] *"… I was very worried but I did not show it to him at the time because he needed a supportive person… I wasn't sure how it will affect him being a man because, you are not really told about that sort of thing… I think information is important and especially if you know some people em especially women if they are younger, if they do have quite a good sexual relationship with their husband, how it will affect their relationship, you know because nobody really tells you anything like that, you are not really supported with that…"* (*Mrs Beth, 51, WI*) [iii] *"…he was acting as if he was the only one who had been through the diagnosis…I could argue my stress has been more, I used to say to him, we have both been very very stressed and he said well you do not know what you are talking about, I do not think he ever, I do not think he ever grasped the level of stress I was under the whole time…"* (*Mrs Grace, 50, BA*) [iv] *"…I think if we have an avenue, perhaps as you have come, for the person to talk to the two of us so as to extract this type of conversation, because when you are in a situation you want to see that pain from your own point of view alone, it might not have occurred to him that this woman that is taking care of him has some emotional needs as well, has some needs that are not being met as well, if it comes from an outsider, it will be very effective because if it comes from me, he will say you this woman you have come again, you are always complaining and whining, but if someone else says it, if a counsellor or psychologist says that in the presence of both couple I think it will be very helpful…"* (*Mrs Julie, 61, BA*)
b. Partner position in the back seat in decision-making	[i] *"…he had pretty much made his decision before he came to me, he had already made his decision, he very much owned the illness and did not want to share, I will say did not want to share the burden …"* (*Anna, 49, WI*) [ii] *"…I do not think African men, I do not think they like being told because, culturally it's like they tell people what to do, they do not like being told so …'* (*Mrs Grace, 50, BA*)
c. Partner acknowledging an 'elephant in the room'	[i] *"…and I think because we had a very straightforward sexual relationship which was based on penetration and mutual satisfaction, neither of us was particularly skilled in any other kind of play really, I find that I am actually very anxious, because he is not getting an erection very quickly, maybe he is not finding me attractive or I am not doing what I should be doing I feel that I have not got the skills to help him, so that makes me extremely anxious, I guess anxious is not good for your libido but yea I am struggling with that…"* (*Mrs Helen, 52, WB*) [ii] *"…I was obviously very worried because I knew then he had to have operation, I knew then that would affect us, because in many respect not just as a man but he is a very active, strong person, he is also the main breadwinner, you know he's also head of the family…he was always the strong male of the family, you know, so it was how it would affect everybody else and that was quite you know, worrying for me…"* (*Mrs Beth, 51, WI*) [iii] *"…how long will he have to live, for instance the issue of will, what is going to happen to me, in African set up, you dare not mention it to your husband at that time, because it would mean you are thinking ah ah so that was the major one but with an English person they are free to talk about it, they can seek help, but I have not been able to, with him you dare not, so I was, I felt boxed in …"* (*Mrs Julie, 61, BA*)
2. Care-giving on an isolating journey	[i] *"…he did put an embargo on me discussing it with my friends… because my natural instinct would have been to discuss it, I think it was so sensitive to him, you know to his identity really, he did not want me to be talking about it with them so I really had to take it inwards, there wasn't anybody to talk to about it…"* (*Mrs Helen, 52, WB*)
3. Coping as a partner	[i] *"… well in the Caribbean to be quite honest, you just stick together, so I guess it's the same thing there as it would be here you know, you just have to stick together, support each other...that's it…"* (*Mrs Debbie, 88, BC*) [ii] *"…because I was reassured that he would be ok, he would be fine and through prayers...having prayers… we believe er, I believed in healing…"* (*Mrs Freda, 62, BC*)

Partner in the passenger seat

This category describes the peripheral position in which partners of BA and BC men with CaP were placed along their husband's disease journey. The three themes which contributed to this category are: 'the unrecognised co-patient of CaP', 'partner positioned in the back seat in decision-making', and 'partner acknowledging an elephant in the room'.

The unrecognised co-patient of CaP

Findings showed that the majority of the participants felt unrecognised and excluded from their husband's newly diagnosed cancer journey. This was mostly attributed to the men not sharing their concerns about their CaP illness with their partner and also lack of information from HCPs to specifically address partners' needs. Narratives from some of the women showed that although they accompanied their husband to his clinical appointments, they were minimally involved in the conversations that took place. Other women noted they did not attend clinical appointments with their husband because the men preferred to attend alone, insisting that they could take care of themselves. Only a few of the women reported being actively engaged e.g. scheduling their husband's appointments, taking notes for them during consultations and helping the men to search for information online when asked. For many of the women, they reported that they only were given information as much as their husband was willing to share about his CaP. Such women described this as emotionally hurting (see supporting quote at Table 3, 1a[i]).

The majority of the women highlighted their desire to be well-informed along the CaP journey as they felt psychologically impacted by the diagnosis as much as the men themselves. The women described how they were psychologically affected in terms of feeling shocked at their husband's CaP diagnosis; worried about the potential consequences of the disease on their individual, marital and family lives; having uncertainties around recovery outcomes and processes; and lacked information on how best to support themselves and their husband through the disease trajectory (see supporting quote at Table 3, 1a[ii]).

The psychological and emotional impact of the CaP on partners was not recognised by the men or HCPs. For example, a participant expressed disappointment at her husband's exclusive focus on his illness without showing much insight or acknowledging how the CaP had significantly affected her as his partner (see supporting quote at Table 3, 1a[iii]). Women's perceptions were also that HCPs showed limited awareness and interest in partners' experiences and needs. This seemed to compound the women's distress as they were further pushed towards a peripheral position on the CaP journey. Clarifying this further, the women said they were frustrated at the current lack of information and professional support focused on them to help deal with their psychological and emotional concerns as partners of BA/BC men with CaP. The women suggested that HCPs specifically engaging and supporting partners of CaP patients could facilitate coping by reducing isolation and uncertainty and also help sensitise men towards the unmet needs of their partners (see supporting quote at Table 3, 1a[iv]).

Partner positioned in the back seat in decision-making

Partners noted that treatment decisions and management of post treatment side effects were led by their husbands who also discretionally determined how much they (partners) were involved in these processes. The women's level of involvement varied in this regard. Few partners acknowledged that there was shared decision-making which enabled them to provide side-by-side guidance and support, making them feel included in their husband's disease journey. However, many partners expressed feelings of exclusion as they reported that their husbands took sole ownership of their CaP and exercised an autonomous right to steer treatment and recovery decisions along their preferred routes whilst they (wives) assumed a background supporting role (see supporting quote at Table 3, 1b[i]). Some women explained that their husband's controlling attitude towards their illness mirrors the men's position as the head of the family and natural leaders in their nuclear and extended family settings (see supporting quote at Table 3, 1b[ii]).

Partner acknowledging 'an elephant in the room'

The partners reported that their husband's sexual dysfunction after CaP treatment had impacted on the intimacy of their relationship and they found communications on this subject very difficult. Some women reported a substantial decline in the frequency of their sexual relationship since their husband was treated for CaP and felt uncomfortable initiating conversations with their husbands regarding this impact, therefore the subject was not discussed. This resulted in feelings of frustration for the women. The women mentioned that before CaP, their husbands had always taken the lead in the sexual relationship. The women felt reluctant to initiate sex and change this routine as they felt their husbands' personal self-esteem could be affected. The current lack of psychosexual support to help couples deal with anxieties related to sexual problems in their marital relationship was also a source of concern for many partners (see supporting quote at Table 3, 1c[i]).

Within the marital relationships, women commented that there were communication challenges about certain issues. For example, some women (across the White and Black ethnic origins) noted they felt insecure thinking about the possible economic impact on them and the wider family if their husband died from his CaP illness (see supporting quote at Table 3, 1c[ii]). These issues however were not discussed. Describing their husband as the strong male and main breadwinner for the family, some women's concerns were heightened where the man had not prepared a will prior to his diagnosis and they (women) perceived the subject as too sensitive to discuss (see supporting quote at Table 3, 1c[iii]). Whilst open communication continued to be a priority need for the women, they expressed frustration that their husbands seemed unprepared to take this on.

Care-giving on an isolating journey

Partners consensually described that although they actively provided moral and practical support for their husband through the CaP experience, they themselves had limited support. The women reiterated that their husband's reluctance to disclose the CaP diagnosis among wider members of their social network constrained their (women's) access to the much-needed support for themselves and increased their feelings of isolation. When probed further, the women attributed such reluctant attitude towards disclosure, to the men's ego and personal decision to self-manage their CaP. The women also explained that the CaP threatened their husband's cultural identity as a BA/BC man (see supporting quote at Table 3, 2[i]).

Although most of the women admitted they felt obliged to agree with their husband on this stance, having to contain their personal anxieties and concerns without betraying their feelings made the CaP experience very difficult for them. Where their husbands allowed some disclosure, it was limited to immediate family members, employers, close friends and church pastors, all of whom provided moral and spiritual (church pastor) support for them. The women described the support received from such avenues as excellent.

Coping as a partner

Although the women felt 'restricted' in gaining support from family and friends, they had their husband's needs at the centre of their lives. Many of them reported that recognising the impact that CaP had on their husband made them feel sympathetic towards the man. The women further expressed that their unconditional love and loyalty towards their husband made them feel obliged to prioritise his well-being over their own psychological and emotional needs. Older women (aged over 65 years old) reiterated that couples staying with each in good and bad times is culturally ideal within BA and BC marriages (see supporting quote at Table 3, 3[i]).

Narratives from many of the women showed that their faith played a central role in helping them cope with their psychological and emotional concerns. They prayed to God that their husband would not die from the CaP and drew strength from believing their prayers were answered. This gave the women comfort and peace of mind from their greatest fear of cancer fatality (see supporting quote at Table 3, 3[ii]). Women also stated that they coped by keeping themselves busy with different activities which diverted their minds away from their husband's CaP. Such activities mostly included taking on additional work loads such as journal writing, reading, exercising, watching television and caring for their own children, and in few cases, grandchildren.

Discussion

Findings from this study suggest that the BA/BC cultural marital context uniquely influenced participants' experiences as they traversed the CaP journey. Unlike a related study involving Caucasian participants [7] where partners were very much involved in their men's health, steering them to seek help and taking centre stage in their care, findings from this study highlight a peripheral involvement of partners in the CaP journey of BA and BC men. Such peripheral involvement was more profound in the area of decision-making, accessing information and communication with the men and HCPs. Their husbands' insistence to maintain secrecy around the CaP diagnosis and cultural restrictions in discussing their anxieties, especially as regards wills and sexual intimacy, also contributed to the participants' emotional distress.

Reiterating the cultural expectations that the man is the head of the family who leads in core areas such as decision-making, sex and bread-winning [19, 20], our study participants recognised how these influenced their husbands' behaviour towards their CaP and the expectations they had of their partners. Evidence highlights the therapeutic effect of open communications in helping couples cope with the psychosocial challenges of CaP through shared decision-making and mutual understanding [6]. However, it seemed that adherence to traditional hegemonic gender ideals which predominantly underpin the cultural beliefs and values of BAs and BCs [20, 21] may have made such open communications very difficult for participants in this study.

Whilst it has been suggested that marital intimacy can be improved post treatment for CaP where partners feel comfortable to take the lead in initiating sexual activity [5], previous evidence showed that partners are often reluctant to assume this role so as not to further upset the man whose self-esteem may have already been affected by the side effects of the CaP treatment [6]. Such reluctance to change roles also resonated with partners in this study. Despite their desire for improved marital intimacy, the women perceived that trying to lead sexual discussions and activities affected their husband's self-esteem, as this seemed to have hit the core of the men's masculine identity (which is culturally defined by sexual virility and performance) [20]. Moreover, traditional cultural expectations for women to prioritise nurturing roles over pursuit of sexual goals whilst men lead core activities and decisions (including sex) may have further constrained partners of BA/BC men with CaP from taking the lead in this regard [19].

It is also pertinent to note the younger age at which CaP occurs in BA/BC men [1], which further suggests that their partners may be younger, as evidenced in the majority of women in this study being below the age of 65 years. This indicates that many of these couples may be at the age where sexual activity is a significant part of their routine lives. Hence, the psychosexual impact of sexual dysfunction on the man and consequently on his partner cannot be under estimated. The World Health Organisation (WHO) defined sexual health as a state of physical, mental and social well-being in which individuals are capable of having pleasurable, mutually acceptable and satisfying sexual experiences and relationships [22]. Therefore, empowering partners to help their men navigate post treatment sexual challenges through mutual understanding and resolution without undermining their cultural values could potentially enhance couples' psychosexual well-being after CaP treatment.

Whilst the use of religious faith and physical distractions as coping strategies are consistent with previous reports on partners among African American [9] and some Caucasian [23] populations, women's description of sympathy and loyalty as coping strategies may be novel in this study. Hegemonic feminity constructs within BA and BC cultures epitomise women as natural caregivers who are expected to be subordinate, submissive, dependent and more emotionally expressive than men [21]. Such feminine ideals combined with being in long-term marital relationships with their husbands may have enhanced our participants' sensitivity to the men's illness experiences and enabled them to prioritise men's well-being over their own need for improved marital communication and sexual intimacy. Contrary to findings from previous studies where some BA and BC men with CaP had expressed fear of being abandoned by their wife if they were unable to meet their sexual obligations post treatment [24], expressions of sympathy and loyalty in this research suggest that wives' opinions may differ in this regard. Cultural values placed on marriage within the BA and BC cultures propounds that married couples are highly regarded and respected within these communities [11, 25]. Despite acculturation assumptions [26], findings from this study indicate that women married within and into the BA and BC communities may continue to uphold existing idealistic cultural values regarding marital commitment and loyalty regardless of living in a western society (UK). Although serving as coping mechanisms, such traditional cultural values may have further undermined the women's feelings of unhappiness, isolation and exclusion.

Implications for practice

When compared with some previous related studies among Caucasian [7] and African American [9] populations, it appears that the implications of CaP may be more complicated for partners within BA and BC populations due to complex socio-cultural influences. This suggests the need for increased cultural awareness and competency among health and support care providers in the development and delivery of psychosocial support (such as information, counselling services) to these populations. In a clinical setting, it is important to recognise men's culturally informed leadership roles and at the same time acknowledge the significant impact of CaP on partners' psychosocial well-being. Without undermining their role as the head of the family, BA/BC men can be educated about the needs of their partners to be actively involved and also supported along the CaP journey. Inclusive support care which involves partners and incorporating comprehensive psychosexual support could potentially encourage willing men to develop empathy for their partners experiences; help couples to engage in open communication to mutually understand their concerns, and identify how they can support each other through the most challenging aspects of their CaP experiences.

Bearing in mind the centrality of their husband's recovery, and the well-being of their partner's, there is further need for holistic interventions delivered in a culturally sensitive manner to address the influence of CaP on the sexual health and mental well-being of men and partners both as individuals and as a couple [22]. This could help ensure that the sexual rights of both the man and his partner are still respected and preserved amidst inevitable limitations imposed by the man's CaP illness [22]. These measures could potentially help to improve the psychosexual and psychosocial well-being of the women and also that of their husband with CaP.

Study limitations and directions for future research

This qualitative study makes a significant contribution to knowledge by being one of the first to bring to fore the unheard voices of some hard-to-reach partners of BA and BC men with CaP. Insights from this study can inform the provision of culturally sensitive support for these under-researched population. Although a qualitative design does not make these findings generalisable, clinicians can refer to them for potential transferability to similar settings. The lack of availability of same-sex partners limits the transferability of the findings to such BA/BC couples. Whilst the women were heterogeneously distributed across BA, BC and White ethnic backgrounds, the majority of them being younger, well-educated and in long-term marriage with a BA or BC man may have contributed to the observed homogeneity in their narratives. Concepts identified in this study can serve as a starting point for quantitative research that can help explicate how much of partners' experiences can be attributed to culturally informed gender, socio-economic and marital stereotypes.

Conclusion

This study identified the cultural definitions of masculine and feminine roles and identities within the BA and BC marital context as influential on partners' psychosocial experiences of CaP. In addition to previous research findings that partners may feel isolated and have limited psychosocial support, these female partners were further handicapped by cultural norms such as men's assumption of a leadership role and restrictions on public disclosure of the CaP illness. Regardless of having unmet communication, information and psychosexual support needs, the women coped by prioritising their husband's well-being over their own needs. Psychosocial support should engage couples in problem-solving that would recognise this socio-cultural context and help them navigate their communication and sexual challenges after CaP treatment. Areas for further research were also identified.

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Compliance with ethical standards

Ethical statement All procedures performed in this study were in accordance with the ethical standards of the institutional and national research committees and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Informed consent was obtained from all individual participants included in the study.

Conflict of interest The authors declare that they have no conflict of interest.

References

1. Jones AL, Chinegwundoh F (2014) Update on prostate cancer in black men within the UK. Ecancermedicalscience 8:455–455
2. Prostate Cancer UK (2014) Remember, remember: four things all black men should know about prostate cancer. Prostate Cancer UK. http://prostatecanceruk.org/about-us/news-andviews/2014/10/four-things-every-black-man-should-know. Accessed 20 April 2018
3. Nelson CJ, Kenowitz J (2013) Communication and intimacy-enhancing interventions for men diagnosed with prostate cancer and their partners. J Sex Med 10:127–132
4. McCaughan E, McKenna S, McSorley O, Parahoo K (2015) The experience and perceptions of men with prostate cancer and their partners of the CONNECT psychosocial intervention: a qualitative exploration. J Adv Nurs 71:1871–1882
5. Wittmann D, Carolan M, Given B, Skolarus TA, Crossley H, An L, Palapattu G, Clark P, Montie JE (2015) What couples say about their recovery of sexual intimacy after prostatectomy: toward the development of a conceptual model of couples' sexual recovery after surgery for prostate cancer. J Sex Med 12:494–504
6. Wittmann D, Carolan M, Given B, Skolarus TA, An L, Palapattu G, Montie JE (2014) Exploring the role of the partner in couples' sexual recovery after surgery for prostate cancer. Support Care Cancer 22:2509–2515
7. Pinks D, Davis C, Pinks C (2018) Experiences of partners of prostate cancer survivors: a qualitative study. J Psychosoc Oncol 36:49–63
8. Rivers BM, August EM, Gwede CK, Hart AJ, Donovan KA, Pow-Sang JM, Quinn GP (2011) Psychosocial issues related to sexual functioning among African-American prostate cancer survivors and their spouses. Psycho-Oncology 20(1):106–110
9. Rivers BM, August EM, Quinn GP, Gwede CK, Pow-Sang JM, Green BL, Jacobsen PB (2012) Understanding the psychosocial issues of African American couples surviving prostate cancer. J Cancer Educ 27:546–558
10. Wootten AC, Abbott JM, Osborne D, Austin DW, Klein B, Costello AJ, Murphy DG (2014) The impact of prostate cancer on partners: a qualitative exploration. Psycho-Oncology 23:1252–1258
11. Arugu LO (2014) Social indicators and effects of marriage divorce in African societies. Bus Manag Rev 4:374
12. Mulugeta B (2014) The influence of culture on the views of black African/African-Caribbean men living in the UK towards Cancer. Doctoral thesis, University of Central Lancashire
13. Bamidele O, McGarvey H, Lagan B, Ali N, Chinegwundoh F, Parahoo K, McCaughan E (2017) Life after prostate cancer: a systematic literature review and thematic synthesis of the post-treatment experiences of black African and black Caribbean men. Eur J Cancer Care. https://doi.org/10.1111/ecc.12784
14. Charmaz K (2014) Constructing grounded theory, 2nd edn. Sage, London
15. Mulugeta B, Williamson S, Monks R, Hack T, Beaver K (2017) Cancer through black eyes-the views of UK based black men towards cancer: a constructivist grounded theory study. Eur J Oncol Nurs 29:8–16
16. Tong A, Sainsbury P, Craig J (2007) Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. Int J Qual Health Care 19(6):349–397
17. NVivo Qualitative Data Analysis Software (2018). QSR International Ltd Version 11
18. Noble H, Smith J (2015) Issues of validity and reliability in qualitative research. Evidence-Based Nursing 18:34–35
19. Coomarsingh K (2012) "Tie the heifer, loose the bull": gender inequality in the Caribbean. Available at: http://www.whatispsychology.biz/gender-inequality-in-caribbean. Accessed 20 April 2018
20. Case AD, Gordon DM (2016) Contextualizing the health behaviour of Caribbean men. In: Roopnarine JL, Chadee D (eds) Caribbean psychology: indigenous contributions to a global discipline. American Psychological Association, Washington DC
21. Kolawole TO, Abubakar MB, Elizabeth O (2012) Gender and party politics in Africa with reference to Nigeria. Online J Educ Res 1:132–144
22. WHO (2017) 'Sexual health and its linkages to reproductive health: an operational approach'. Available at: http://appswhoint/iris/bitstream/handle/10665/258738/9789241512886-engpdf;

jsessionid=0F2FF45F77BE9E275F30391EAF4B52CF?sequence=1 Accessed 25 April 2018

23. Tanner T, Galbraith M, Hays L (2011) From a woman's perspective: life as a partner of a prostate cancer survivor. J Midwifery Womens Health 56(2):154–160
24. Anderson B, Marshall-Lucette S, Webb P (2013) African and afro-Caribbean men's experiences of prostate cancer. Br J Nurs 22: 1296–1307
25. Bhugra D, Pathare S, Nardodkar R, Gosavi C, Ng R, Torales J, Ventriglio A (2016) Legislative provisions related to marriage and divorce of persons with mental health problems: a global review. Int Rev Psychiatry 28: 386–392
26. Randall D, Rosenberg JP, Reimer S (2017) Solid and liquid modernity: a comparison of the social geography of places to die in the UK and Australia. Death Stud 41:103–111