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# Accepted Manuscript

Black and Minority Ethnic women's decision-making for risk reduction strategies after *BRCA* testing: Use of context and knowledge

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**Black and Minority Ethnic women's decision-making for risk reduction strategies after BRCA****testing: use of context and knowledge****Abstract**

Within the field of breast cancer care, women concerned about their family history are offered genetic testing and subsequent treatment options based on several factors which include but are not limited to personal and family cancer disease histories and clinical guidelines. Discussions around decision-making in genetics in Black and Minority Ethnic (BME) groups are rarely documented in literature, and information regarding interactions with genetics services is usually discussed and linked to lack of scientific knowledge. As such, counselling sessions based only on scientific and medical information miss out the many reasons participants consider in making health decisions, information which can be used to encourage BME women to engage in cancer genetics services. 10 BME women with a mixed personal and family history of breast and ovarian cancer backgrounds, were interviewed in a study exploring issues of knowledge about familial breast cancer syndromes, to understand how they created and used familial knowledge for health decisions, with a particular focus on attitudes towards risk reducing strategies.

Study results show that our participants are not unique in the ways they make decisions towards the use of cancer genetics and risk reduction strategies and as such, there are no specific ethnically defined pathways for decision-making. Our participants demonstrated mixed biomedical, social and individual cultural reasons for their decision-making towards risk reduction surgeries and treatment options which are similar to women from different ethnicities and are individual rather than group-specific. Narratives about suspicion of scientific utility of genetic knowledge, the perceived predictive value of mutations for future cancers or the origin of mutations and family disease patterns feature heavily in how participants evaluated genetic information and treatment

decisions. The diversity of results shows that our participants are interested in engaging with genetic information but use multiple sources for evaluating the extent of involvement in genetic services and the place of genetic information and treatment options for themselves and their families. Genetic information is considered within various bio-social scenarios before decision-making for risk reduction is undertaken. BME women are shown to undertake evaluative processes which clinicians are encouraged to explore for better patient support. Continuing to focus on links between superficial and un-representative meanings of ethnicity, ethnic identity and attitudes and behaviours by only searching for differences between ethnic groups, are unhelpful in further understanding how women from those diverse backgrounds make decisions towards risk reduction interventions. Future research must find ways of investigating and understanding populations in ways that are not focussed *solely* on ethnic differences but on how meaning is created out of social circumstances and experiences.

### **Background**

The advance of medical knowledge and technology within the field of cancer has led to new ways of knowing, understanding, treating and interacting with the disease. Although a multi-factorial disease, there is increased understanding of the genetic basis of cancer, and genetic variation has been identified which increases the likelihood of developing certain types of cancers. For example mutations in the *BRCA1/2* genes, increase one's likelihood of developing breast, ovarian, prostate and pancreatic cancers (Wiesmuller, 2011). Identifying those who are likely to be affected by, or carry these gene mutations, is undertaken in various ways, including assessing individuals' personal and family cancer disease histories and conducting genetic testing. Once those at increased risk of developing cancer are identified, several clinical interventions to reduce that risk are offered (National Cancer Institute, 2015; National Institute for Health and Care Excellence, 2013; USA Food and Drug Administration, 2017) dependent upon age, other relevant biological information and care systems (Gadzicki et al., 2011; Leonarczyk and Mawn, 2015).

In the UK (National Institute for Health and Care Excellence, 2013), some of the interventions that patients could be offered include medical and surgical interventions such as chemoprevention medication, mastectomy and oophorectomy, as well as to which degrees the surgical interventions will be carried out (Godet and M. Gilkes, 2017). These interventions bring several issues of concern; for example efficacy, physical side effects, social and psychological impacts which women need to consider (Bradbury et al., 2008; Cappelli et al., 1999; Leonarczyk and Mawn, 2015; Underhill and Crotser, 2014). Throughout all the articulation of patient concerns, the subsequent clinical and risk assessments and considerations for interventions, genetic counselling is an imperative step that is or should be offered to patients to help them navigate through all the scenarios they find themselves in (Ciarleglio et al., 2003; Skirton and Patch, 2002; Vig and Wang, 2012).

Although the offer and availability of cancer risk reduction strategies, genetic testing, genetic counselling and surveillance and treatment services differs across Western societies as per the different health care systems, inequality trends in use of those services appears common (Mehta 2005, Allford *et al.* 2014, Daly & Olopade 2015). Among diverse patient populations, ethnic minority women, black women in particular, are visibly under-represented in who accesses the various cancer genetics services, including in uptake of interventions to reduce risk of developing breast and ovarian cancer (Armstrong *et al.* 2005, Mehta 2005, Salant *et al.* 2006, Halbert *et al.* 2006, 2010, Kinney *et al.* 2006, Ellington *et al.* 2007, Bradbury *et al.* 2008, Allford *et al.* 2014, Robinson *et al.* 2015, Lynce *et al.* 2015, Underhill *et al.* 2016, Cragun *et al.* 2017, Jones *et al.* 2017). In general, various reasons have been offered for the reduced presence in cancer genetics services by women from ethnic minority groups and the subsequent inequalities in health outcomes resulting from the patterns of use of related services.

For instance, despite the availability of guidelines to help clinicians act on patient concerns, clinical assessments or referrals to specialist cancer genetics services, based on a person's age, number of affected relatives and types of cancer for example (National Cancer Institute, 2015; National Institute for Health and Care Excellence, 2013), for various reasons, the use of those guidelines is varied. It has been reported in some cases that clinicians have limited knowledge of the relevant cancer referral pathways or of cancer genetics itself (Watson *et al.*, 2002) which affect the timing, quality and effectiveness of their clinical assessments and subsequent decisions. Additionally, Daly and Olopade (2015) highlight that in other cases, even when clinical assessments have been considered, delays in referrals and poor follow-up patterns compound the issue of inequalities in uptake and use of cancer genetics services. Other reasons affecting use of cancer genetics services discussed in the literature include, but are not limited to, medical mistrust, and worries about confidentiality and discrimination (Singer *et al.* 2004, Kinney *et al.* 2006, Sheppard *et al.* 2013, Jones *et al.* 2017), lack of knowledge or awareness about services (Halbert *et al.*, 2005; Hann *et al.*, 2017; Jones *et al.*, 2017; Sheppard *et al.*, 2014) and insurance concerns or payment for services (Catz *et al.*, 2005; Sheppard *et al.*, 2014; Singer *et al.*, 2004).

When barriers such as insurance and payments to cover costs for treatment; or lack of education and awareness have been addressed, the patterns of use among ethnic minority groups have remained largely unchanged. The trends of reduced service use become even more noticeable post genetic counselling and testing where women from Black and Minority Ethnic (BME) groups are reported in some research as not taking up risk reduction at similar rates to Caucasian counterparts (Kinney *et al.* 2006, Susswein *et al.* 2008, Pagán *et al.* 2009, Saulsberry & Terry 2013). In BME women, there appears to be a stronger preference for surveillance such as through MRI, ultrasounds and breast self-assessment over surgical options, even when those preferences are not always adhered to or as effective in detecting early disease (Kinney *et al.* 2006, Bradbury *et al.* 2008, Lynce *et al.* 2015, Cragun *et al.* 2017). Although some information can be found about reasons people

undertake or forgo risk reduction (Bradbury et al., 2008; Cragun et al., 2017; Grimmer et al., 2015; Klitzman and Chung, 2010), for countries such as the UK where issues of insurance and payment structures are generally not as pertinent as they may be in the USA, there is little information about those decision-making processes by BME women. This article thus adds to the growing literature exploring why such trends of under-use of certain genetics services exist and focusses particularly on how women from BME backgrounds make decisions for risk reduction strategies. The results provide a different perspective towards health service use, suggesting that women who have had breast and/or ovarian cancer and genetic testing hold diverse reasons for choosing, preferring or rejecting risk reduction interventions.

### **Aim**

Taken from a broader research project discussing women's perspectives and knowledge of familial cancers, the aim of this article is to present qualitative findings about how a group of patients use that knowledge and understanding to navigate concerns and decisions around risk reduction strategies. While previous discussions and interventions to encourage use of cancer genetic services among minority groups have overwhelmingly focussed on the role of awareness and knowledge of genetic cancers as discussed by Armstrong *et al.* (2005), Kinney *et al.* (2006), Brewster *et al.* (2007) and Underhill *et al.* (2016); when it comes to decisions around risk reduction, various studies attest to the complex processes of evaluations and decision-making that are inherent in discussions and decisions for participating in those interventions (Bradbury et al., 2008; Daly and Olopade, 2015; Klitzman and Chung, 2010). It is towards this complex knowledge that this article aims to add. The evidence presented here will be drawn from a qualitative study of a group of women who underwent genetic testing following cancer diagnoses and will explore their perspectives and concerns towards risk reduction strategies.

### **Methodology, theoretical underpinning and participants**

Understanding patients' perspectives and concerns enables practitioners and researchers to better explain and work with those patients' in decision-making processes. Context is thus an important factor for any health decision that people make, as no decisions or actions are undertaken in isolation (Calnan, 1987; Geertz, 1973; Heath, 2013). Busby *et al.* (1997) discuss the concept that there exist bodies of knowledge, where contexts and various sources of information are brought together to make sense of scientific concepts, thus creating lay perspectives which are useful to inform action and decisions. A similar approach to use of contexts and understanding process was applied in the broader research study, where the theoretical underpinnings of social construction (Berger and Luckmann, 1966) and symbolic interaction (Blumer, 1986) provided a philosophical lens with which to view the decision-making processes for the particular cohort of BME women under discussion. Social construction is premised on the idea that people's understanding and knowledge of an object or concept are shaped by how they make use of that concept, with meanings and realities 'constructed' by those within that social group. This means that meanings and perspectives are likely to differ from group to group, as what influences social meanings will also differ. There is no one correct or fixed meaning of a concept because the different interactions with it by different people, create new and diverse meanings upon that object or concept. Social construction is notable in how people use words and language to communicate the meaning they hold and can thus make claims about the way the world is or their experiences of it (Berger and Luckmann, 1966; Gergen, 2010, 1999a; Hacking, 1999).

The second theory of symbolic interaction privileges the creation of meaning through people's interactions with others around a concept or object. The meanings that individuals create are constantly changing based on their contact with an object, but additionally, their evaluation of others' behaviours towards the same object (Blumer, 1986; Carter and Fuller, 2015; Denzin, 1992; Pascale, 2011). By interpreting other people's behaviours and actions, the individual can form a perspective, understanding and opinion about what something means and in turn, how they might



modify their behaviour in line with any new interpretation they make. Together, theories of social construction and symbolic interaction argue for an interpretive way of investigating meaning, one that acknowledges that objects and concepts are likely to bring different truths and different perspectives for diverse societies. To make full use of the theories within the over-arching study from which this discussion arises, a constructivist grounded theory approach (Charmaz, 2017, 2008, 2006) was used, where knowledge reported is understood to be contextual and time-bound, and is potentially a version of the general perspectives some BME women hold, which they share with the researcher through interviews. Acknowledging the fluid nature of knowledge means one gains an insight into others' minds, insights which are highly useful for future interrogations into the multiple or main factors and complex ways in which those factors are brought together to make sense of scientific and medical concepts and related clinical concerns (Busby et al., 1997; Calnan, 1987; Lipworth et al., 2010; Walter et al., 2004).

The focus of the article are results reported from a sub-group of 10 women who had undergone genetic testing, out of the 15 women who had participated in the bigger qualitative study. Participants for the overall qualitative study were recruited from a tertiary hospital in the South of England. The hospital provided a range of cancer genetics services in a wide range of settings, including community and satellite clinics, in addition to routine hospital-based care and services. Coverage of sites was predominantly within London and the South East of England. Participants had in the past been clinically assessed for personal and family histories, which included breast, ovarian, lung and prostate cancers. As such, women who had attended any of the clinical cancer services between 2013 and 2016 were eligible for participation in the study with further eligibility based on documented ethnic group affiliation. The study dates coincided with the publication of the latest clinical care guidelines on familial cancers (National Institute for Health and Care Excellence, 2013) and when the bigger qualitative study commenced. Invitations to participate were sent out by letter, with those interested responding as appropriate.

Despite the documented ethnic groups, women in the study were asked to self-describe, as an acknowledgement that ethnicity was a subjective concept whose membership carried different meanings (Bhopal, 2004; Jones, 2008; Sheldon and Parker, 1992). We acknowledge, however, that our use of the term BME is itself contentious but chosen as a working albeit inadequate descriptor between the potentially different and subjective ways in which people define themselves or are defined by others. Despite this use aligning with discussions in some policy and research documents (Baker, 2013; Jacobs et al., 2007; Thompson and Van Der Molen, 2009), other terms such as Black, Asian and Minority Ethnic (BAME) or ethnic minority have also been used in research and questioned by others (Okolosie et al., 2016).

Nonetheless, the women broadly self-identified as coming from South Asian, Black African and Black Caribbean backgrounds, although what each of those categories meant was noted to be fluid and heterogeneous (Table 1). Of the 10 women, who all were the first to be tested in their families, 6 had returned positive *BRCA* mutation results, while the remaining had uninformative/negative/inconclusive results (Table 1).

Participant and age	Ethnicity	Place of birth	Cancer history	<i>BRCA</i> 1/2 mutation history
P1, 40s	Black African/British	Nigeria	Breast cancer, no family history	Positive
P2, 30s	Black African/French	Congo	Breast cancer, family history of breast cancer	Positive
P3, 30s	Black British	UK	Breast cancer	Positive

			and family history	
P4, 60s	Black Caribbean	Jamaica	Breast cancer, family history of prostate	Inconclusive
P5, 50s	Black African	Congo	Breast cancer, Family history of breast and ovarian cancer	Positive
P6, 50s	British/Pakistani	UK	Breast cancer, family history of breast cancer	Positive
P7, 40s	British/Indian	Africa	Breast cancer	Positive
P8, 40s	Black British	UK	Breast cancer, sarcoma, lung cancer, family history of cancer	Inconclusive
P9, 50s	Black African	Africa	Breast cancer	Inconclusive
P10, 50s	British/Indian	Africa	Breast cancer	Inconclusive

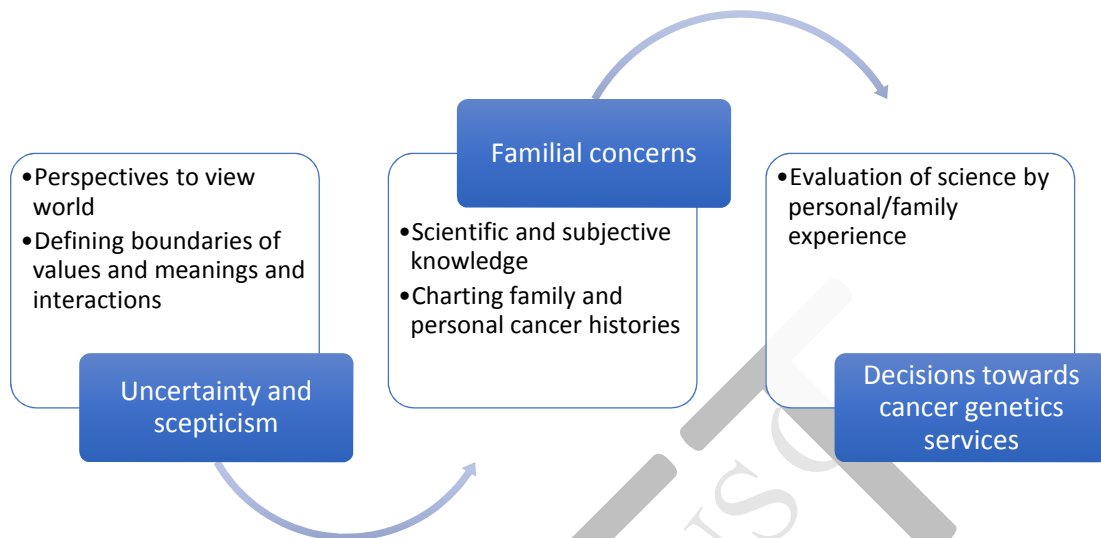
*Table 1 – Participant details (NB Participants numbered by their entry into the study)*

Finally, relevant research and ethical approvals as well as individual informed consent had been sought and obtained prior to participation. Each participant was interviewed once and all agreed to have their interviews audio-recorded, each lasting between 60-150 minutes. Data was stored in a de-identified way, on a password-protected computer, with de-identified transcripts uploaded onto a computer software programme, Nvivo, for data management and analysis. Analysis was conducted manually and in line with grounded theory methodology. While data analyses were conducted using line-by-line coding techniques of grounded theory (Charmaz, 2006; Saldaña, 2009), the results presented here emerge from part thematic analysis (Braun and Clarke, 2006) and part grounded theory analytic processes, since the objectives of this article were not themselves the main objectives of the main qualitative study. Results are presented in a descriptive manner, with

participants' quotations provided verbatim to highlight the themes under discussion (Sandelowski, 1994).

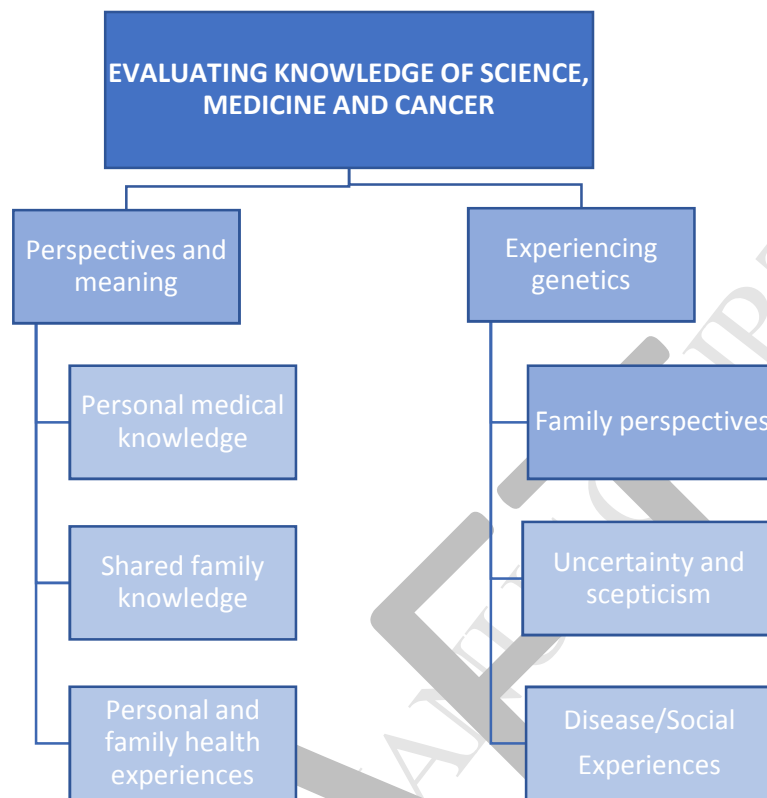
### **Results**

To understand how these participants interacted with genetics-related health services, it is important that the various influences and ways to interact with and evaluate genetics as a scientific concept be explored in more detail. In line with the theoretical underpinnings of symbolic interaction and social construction, results show that the knowledge and meaning of genetic cancers that underpinned and guided women's ideas around risk reduction strategies, were created out of various individual medical and social concerns and interactions with cancer. Social and medical situations created functional and contextual knowledge and understanding of genetic cancers that helped our participants decide for or against certain risk reduction strategies. Functional knowledge was a constructed knowledge that one could draw upon through lived experiences of the disease and which itself took into consideration the entirety of one's personal, social and medical life. The context that influenced one's final decision towards risk reduction was a mix of historical and current medical practices and outcomes which enabled the participants to navigate the options on offer and their own personal understanding and concerns of familial or inherited cancers (Figure 1).



*Figure 1 - Interactions leading to cancer genetics decisions*

As such, this cohort of women ascribed social meanings to scientific and medical concepts and based those social meanings on prior experiences and interactions with family. The knowledge that the participants used to underpin their decision-making processes was thereby constructed from various evaluations of science, experiences of health as well as to what extent medical genetics explained women's and their families' disease histories (Figure 2). Within their evaluations, scientific knowledge emerged as a knowledge filled with flaws and uncertainties, which in turn created multiple reasons for individuals to accept, decline or even prefer risk reduction strategies when at times that offer was not available to them. In the end, making decisions about risk reduction was not only about accepting knowledge that surgeries would aim to reduce one's risk, but finding a way in which that medical knowledge would fit with one's wider personal expectations and one's personal ideas about familial and inherited cancers.



*Figure 2 - Knowledge base for decision-making*

Varied perspectives were formed as the participants grappled with what they presumed was the interface between medical knowledge and their own and significant others' health experiences. As medicine and science were not stand-alone entities or sources of information, any related medical/scientific knowledge was related to previously held meanings of the concepts, but meanings created in different bio-social circumstances. Medical knowledge was imported from those previous circumstances and used in diverse and imaginative ways, to account for past or preferred decisions for risk reduction.

**“When they said to me it's in the beginning and we gonna remove the cancer you so far have, you gonna keep your breast. And I spoke to my sister in France, she said to me: ‘get rid of your breast.’ Yea, because I know that many woman got ovarian cancer or breast cancer and when it spread on you, you can die. So I decide that because I got big fibroid in**

**my womb, I want them to remove it, I don't want to keep it anymore - I don't want to get cancer that way.” (P8, BRCA Positive, aged 50s)**

Not only was the above participant's medical knowledge based on her own understanding of risk factors for future disease, she also sought medical opinion from family. Medical knowledge became a symbolic object that was shared and passed around for others to think on, provide opinion and return for a final social meaning. That this same participant had already had breast cancer, with a significant family history, meant that she perceived fibroids as something with more medical meaning in her life, on which she prescribed risk for developing further cancers. Her personalised and social understanding thereby meant she symbolised her fibroid as a risk that had to be removed.

It is worth noting that even if some of the participants had returned mutation negative results, that is a known pathogenic mutation was not identified, this did not stop them from wishing the offer for risk reduction surgeries for instance had been made to them. The excerpt below shows how the symbolic meanings ascribed to fibroids are also ascribed to other medical factors in new ways and used to give more intensive clinical assessments.

**“I was prepared to have my ovaries removed, because yes, not only because of the oestrogen production but breast and ovarian are all linked apparently. So I, personally I have nothing to lose if I had to have my ovaries removed.” (P14, BRCA Neg, 50s)**

Similar to P8 above, this participant, P14, also used her own medical understanding of risk factors to explain how she would have been willing to undergo surgery to reduce what she saw as a significant risk. Also, having undergone treatment for a previous breast cancer, this participant used various sources of medical knowledge, and infused them with her own health experiences thus reducing the role of mutation testing and her negative result in her decision-making. She later conceded, in a

different point in her interview, that the result she received for her test results had not meant much to her, as there was always a chance that future technologies would provide a genetic link to the cancers recorded in her family – a chance for which a current decision to undergo surgery would be justified.

Uncertainty was a common theme among different participants, where scepticism and uncertainty surrounding the non-deterministic relationship between having a mutation and developing cancer was a considered factor in scientific evaluations and related medical decisions. Some participants, for instance, displayed their scepticism and justified delaying risk reduction surgeries based on their family histories of disease progression post surgeries. Despite being mutation positive, the meaning given to the mutation was less influential than what their loved ones had gone through. This weighing of pasts and futures at times negated one's personal evaluated risk and medical risk and gave weighting to family experiences instead. As noted by the next participant, decision-making was a thought-out and personally rationalised process.

**“Yes, because even you have the gene, it doesn't mean that you can get sick. [...] I saw women like my mum having her breast removed. But the cancer came back in the same place. So for me, it's not the first choice. If nothing happens, don't do anything. It's my point of view. [...] it's not easy thing to do, you know?” (P4, Pos, 30s)**

One had to continually balance these competing influences of science, genetics results and health and disease experiences, something P4 noted was ‘not an easy thing to do’.

For other participants, however, rationalising decisions meant going wider to the media portrayals of the impact of having a disease predisposing mutation, and evaluating instead the media messages



of risk reduction against the likely physical effects and what various parts of their body which might be affected meant to them. For this, breasts and ovaries did not hold similar importance to women, as shown next by P12 who says she would firmly base her surgical decisions on how she views her body *and* how those views would impact her psychological health.

**“I always said to myself, even if I've got the BRCA gene, I'm not gonna go and take my breasts off [...] not gonna be an Angelina Jolie... I will have to wait until the cancer happens. About my ovaries? Without a doubt, get rid of them. I don't need them. I'm not having a baby! That breast would affect your life. I know you don't physically use it for anything but it's there. And you can see the scars, you look in the mirror and you can see what's going on there.” (P12, Neg, 40s)**

By understanding how some women gave social meaning to their body parts and the subsequent values and uses they imbued on them, one can then start to see how the creation of meaning and symbolic values influences decision-making process. For instance, if something holds considerable value, then someone might be more likely to preserve that value than lose it. A case in point is participant P5 who initially seemed set on her decision for undergoing surgery as the most rational thing to do, having tested positive for a *BRCA* mutation in addition to her personal and family history of early onset breast cancers. Yet, when faced with changes in her social life, what mattered to her at that point stopped being about reducing risk, but delaying that decision until such a point where she had fully assessed her new childbearing circumstances and future plans:

**“My social circumstances is different. Do I actually want another child? [...] I still want to have that choice. It would be far easier if, when I went to the assisted conception unit,**

**they had said actually you haven't got any follicles left and you're starting menopause.**

**Because I'd be like right. [...] you just whip them out, the ovaries.”(P5, Pos, 30s)**

The possibility of wanting more children loomed larger and more urgent than current evaluations of future risk, which led to a change of mind about when and if to undergo further risk reduction interventions. As such, not all women in similar medical backgrounds made the same choices and instead were guided by social circumstances. As participant P9 indicated, quite similarly to P5, social meanings and circumstances were vital for decision-making. Even if the end point was similar to what medical practitioners might have advised, the reasons for P9's decisions were not entirely for the same medical reasons.

**“And I thought well, I'm not gonna have any more kids, why am I going to worry about protection? Have the ovaries and tubes removed, don't want to get pregnant. That was done more for that really, rather than ... I know they called it preventative surgery coz they were preventing it. But me, I was preventing a pregnancy.” (P9, Pos, 40s)**

However, offered a mastectomy to remove her remaining breast that was not affected by breast cancer, the above participant had declined, believing that having that breast was more important to her as she equated it with the only 'womanly thing' she had left. For P9, feeling womanly appeared far more significant and important to her than her personal risk of future cancer, a sentiment voiced by P12 above.

Despite these decisions impacting their personal health, as these BME women made considerations for their own health, they also thought about and provided advice to their kin, providing possible future layers of complex decision-making for those in their families who would be in similar predicaments, specifically their daughters. Asked what advice they would give to their children in

similar circumstances, once again, the participants portrayed a mix of personalised rationality based on varied evaluations and contextualisation of health and disease experiences in relation to scientific information.

**“I won't want them to go through that. So therefore I would say, while they are young and a lot of people with good health, they have false parts anyway, if it happens I would implant, I would ask them to go for implant. I would advise them.” (P15, Neg, 50s)**

**“If you want a child, have your child. I don't care whether you married or not. Just have your child and then decide after that if you want to get your ovaries removed, breasts removed [...] it's not the end of the world, there is formula milk now. Lots of children have been on formula and they are fine. So she can have RRS and there is lots of implants and things.” (P10, Pos, 40s)**

#### Discussion

Making decisions for or against risk reduction strategies is shown as a complex endeavour. The decisions these women made were not easily traced or predicted, but had to be understood as decisions that were personally rational and guided by certain frames of thought. As Cragun *et al.* (2017) argue, ongoing differences between provision, management and use of cancer genetics services for and among ethnic minority women, increase inequalities in health outcomes, especially as there are high rates of variants of uncertain significance discovered in genetic testing, of almost four times the average rate, in Black women when compared to non-Jewish White women (Nanda *et al.*, 2013; Pal *et al.*, 2015). There are also more aggressive breast cancers and poor health outcomes in those groups already which increase the health disparities noted (Daly and Olopade, 2015; Pal *et al.*, 2015; Saulsberry and Terry, 2013; Seiler *et al.*, 2017). As such, failure to cater to people's diverse ways of thinking, compounds an expectation that patients must use only scientific knowledge of

genetics to make decisions which ignores the many reasons that might bring BME women into the genetics environment, and misses chances to find ways to improve their genetics related health outcomes.

Finding ways to make the entirety of genetics services - not just screening, counselling and testing – more inclusive of diverse ways of interacting and knowing genetic cancers will provide new thinking towards ways to reduce current differences in cancer genetics services uptake and provision. While quantitative studies such as those by Schwartz *et al.* (2012) and van der Aa *et al.* (2015) for instance, are useful for making predictions by patient characteristics and histories of who might use risk reduction strategies, qualitative work similar to Salant *et al.* (2006) and Bradbury *et al.* (2008) enable a deeper understanding of some of the factors associated with the various decisions that those patients make, particularly in ethnic minority women. Exploring women's concerns around cancers that may have an inherited component leads to several points of interest, some of which are explored here, which must be considered if health practitioners are going to successfully engage BME women at increased risk of cancers to consider risk reduction strategies over surveillance.

Exploring what information is important, when it is important and why it is important to individuals as well as how it helps them understand and interact with a situation, are some of the most fundamental factors that health care providers must be attuned to when engaging in clinical consultations. The idea that individuals act rationally in decision-making begins to take on a new meaning, where rationality is about the best outcome in a certain context for that person. Within that, direct scientific knowledge may be inadequate as presented by medical practitioners, to assist patients in making what might be considered as rational decisions for risk reduction. Rationality is then acknowledged as itself not having universal meanings (Pescosolido, 1992), but contextual and individualised ones instead. Rationality becomes something differently experienced and evidenced

by those having to make those various health-related decisions and for the BME women reported in this article, their actions and evaluations are shown as rational to them. Therefore, as shown in this article, in considering their influential factors that guide preferring, taking or rejecting interventions, patients act rationally as they weigh up the various bio-social effects of the strategies on offer. The patients evaluate any perceived benefits and negative effects against medical opinion.

The personal and family experiences of cancer and the meanings and values of science influence the scientific evaluations which our participants carry out. They then use those evaluations to understand scenarios and situations as shown above, processes which are highlighted in symbolic interactionist and social constructionist theories and are shown to underpin our participants' decision-making. This means that, in the end, genetics investigations into service use must stop being about categorising health decisions by BME women as different to dominant populations, or being about lack of genetic knowledge, but about the process in which all knowledge is created and used, results similar to work by Hallowell et al., (2001) and Howard et al., (2011) which are arguably universal across disease and patient groups. Such a perspective is useful for translating previous literature on non-BME populations around their decisions for accepting or rejecting risk reduction, to BME women and finding common solutions to all ethnic groups. What Figure 1 and 2 show is that knowledge construction regarding familial cancers is not a strange process specific only to BME women, but can be noted in various clinical situations across all ethnicities. This is an important consideration since instances of such decision-making evaluations are noted in various literature, and should thus not aim to make BME women necessarily 'other' or different from non-BME women.

Miller *et al.* (2010) for instance, in a general literature review, suggest that several reasons affecting uptake of interventions revolve around issues such as menopausal side-effects and one's age when they have to consider such effects, similar considerations mentioned by some of the ethnic minority

participants under discussion. However, while Miller *et al.* (2010) go on to suggest that surgeries might be a way to reduce uncertainties, the BME women's evaluations presented in this article regarding scientific uncertainty, which were juxtaposed with their family histories at times led to these women framing surgical interventions as something to be avoided. Despite that, if other concerns, such as being healthy for one's family was more important, the uncertainties seen within these medical interventions in relation to family experiences would then at times be diminished, leading the participants to take up interventions. Incidentally, the article findings go against those in Miller *et al.* (2010)'s review where the suggestion was that for women with positive genetic mutations, strong family history of cancer might enhance one's intent to undergo surgical interventions themselves since the BME participants above did not use family history as reason for deciding around risk reduction interventions.

The meanings of genetic disease and associated risk must be understood to carry different levels of importance at different times in women's lives. Decisions to undergo surgery can, as shown above, be delayed or diminished by thoughts around childbearing and breastfeeding, as well as what gives one their self-worth and identity. The various reasons that women have to consider are invariably a mix of clinician advice and experiences of cancers within the family, to name a few (Lifford *et al.*, 2013). In fact, Dew (2016) shows that decisions for health, and how people understand various health related concerns are played out in many locations, and not just the clinic, as shown by the narratives and reasons given by these women. As such, our participants, in deciding on risk reduction strategies, evaluate their concerns using information gathered from their clinical consultations but placed within the context of their homes and social environments. Such concerns for various aspects of one's personal and social life - for instance feeling like a woman, wanting to breastfeed or starting a family – all merge with perspectives towards the gene for cancer and its place in future health management.

All these factors have been shown to create ways in which one shapes their interaction with health services (Bradbury et al., 2008; Crew, 2017; Hallowell et al., 2004; Skirton and Eiser, 2003) and should thus be part of the discussions clinicians will have with their patients from diverse ethnic groups. The concept of genetics therefore has multiple meanings (Atkinson et al., 2013; Featherstone et al., 2006; Hallowell et al., 2004; Richards, 1996; Salant et al., 2006) which will each influence people's perspectives towards how to interact with any related health maximising decisions and what advice they may give to family. Given the diversity of meanings that participants held about the same concept, the construction of knowledge shows that the sources of influence that patients use in determining their next course of action are also diverse but importantly, hold very deeply rooted and significant associations for their health and decision-making (Burr, 2015; Gergen, 1999b; Mellon et al., 2013; Saleh et al., 2012).

Fields of interaction and diverse meanings given towards familial cancers can at times mean that some women might place higher concern on their family and personal histories than clinical evaluations might give, leading those who may not be eligible for risk reduction interventions to express an interest and willingness to undergo those interventions. This was shown earlier by women who had negative/uninformative/inconclusive results following BRCA testing who reported willingness to undergo surgery, had it been offered to them. These issues must be considered in the light of Black women specifically who are known to have high rates of results of unknown significance, or whose family members may not have had a chance for genetic testing if those family members live outside of Western countries. Thus, contexts in which health decisions are evaluated and made are key. Just as Willis *et al.* (2016) note, the importance of understanding sources of knowledge helps explain how patients navigate health systems. As such, women's contexts are highly influential to how they create their functional knowledge of familial disease. Additionally, and importantly, decisions over how to engage with risk reduction strategies and cancer genetics services are related to that functional knowledge that women hold. Navigating health systems is

therefore a matter of what knowledge one holds and privileges at specific times *and* how much negotiation can occur between them and their health providers.

Bradbury *et al.* (2008) and Howard *et al.* (2009, 2010, 2011) have shown such a knowledge usage in action, by detailing some of the concerns influencing rejection or uptake of risk reduction strategies such as fear of death, wanting it to be the right time to decide against possibility that different options may arise in the future. Thus, although ethnic minority women remain under-represented in interventions to reduce cancer risk, they are shown to hold similar routes to evaluations of concerns to those raised in studies by Hallowell *et al.* (2001), Meiser *et al.* (2003, Garcia *et al.* (2014), Rosenberg & Partridge (2015), Padamsee *et al.* (2017) and Padamsee *et al.* (2017). In the end, creating non-judgemental zones of interaction in clinical practice which enable women to fully explore the options available to them against the options they would prefer, will ensure that women from diverse backgrounds are supported and guided in their decision-making in ways that will consider all their factors of concern while providing the best chances for better health outcomes.

### Conclusion

While the use of risk reduction interventions remains for some, a contentious strategy for managing cancer (Klitzman and Chung, 2010; Long Roche *et al.*, 2017; Salant *et al.*, 2006; Tschernichovsky and Goodman, 2017), BME women's evaluations of the factors that lead them to request, reject or accept such interventions remain an area in which more information can be gathered. Although a small study for which no generalisations to the wider population can be made explicitly, this article goes some way to provide extra information on the contexts and thoughts of a group of women who had undergone genetic testing and details the way the participants navigated discussions and decisions for reducing future risk of cancer. Results are interesting in their similarity to non-BME focused studies, suggesting that the systems and processes patients use to make



decisions are likely to be more similar than researchers and clinicians sometimes acknowledge. It is important to recognise that not all women rejected or accepted interventions outright, based on medical opinion alone, but that as Busby *et al.* (1997), Dew (2016) and Willis *et al.* (2016) have highlighted, women created specific and functional forms of social knowledge to help them make sense of their clinical situations and construct rational motives for their decisions around risk reduction strategies. Helping clinicians understand those rational motives will be useful in helping women engage deeper in discussions around future health maximising. More importantly, it will help identify how BME women might want to interact with genetics services and how those attending to those interactions will find ways to ensure when women make the decisions to request, accept or reject risk reduction, all the pertinent concerns, both medical and social are discussed and women can make the right choices for them, given their different ways of knowing familial cancers.

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