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Using Card Games to study men's social talk about prostate cancer

ABSTRACT

Aim: To report the Card Games approach used to study men's talk about their risk for prostate cancer, and as a method of data collection to analyse patterns of talk amongst distinct cultural groups.

Design: A constructivist grounded theory approach using focus groups to analyse men's social talk about prostate cancer

Methods: Data were collected using three focus groups with African-Caribbean, Somali and White British men. The focus groups were conducted in a location of the men's choice with a focus group facilitator and observer. Four Card Games were given to the men to encourage social talk.

Results: The African-Caribbean men had the most democratic talk with the use of agreement and disagreement and the Somali men were the most inclusive of others and used the most humour. The White British men were competitive in their talk and the least inclusive of each other's views.

Conclusion: The Card Games revealed differences in the pattern of talk, which provided insight into how men may use social talk to develop their understanding of prostate cancer risk. This is useful for healthcare professionals as it provides a grounding for structuring discussions with men about prostate cancer, whilst having an understanding of how risk-related knowledge may be reconstructed in social talk and interactions.

Impact: The methodology discussed in this paper addressed the use of focus group to analyse talk of men from culturally diverse groups. The use of Card Games allowed the talk between the men to take centre stage, and this allowed differences in the social talk of the men to become apparent. The use of this methodology could have an impact on approaches to researching cultural understandings of cancer risk, which may provide evidence on effective delivery of sociocultural relevant health education relating to cancer screening.

Keywords: Cancer, men's health, focus groups, cultural issues, sociology, grounded theory, research methods, nursing, BME, BAME

INTRODUCTION

In the developed world the lifetime risk of developing prostate cancer is 13.2-15.0%, (Cancer Research UK 2019). However, when data is extrapolated for black men the risk increases to 23.5-37.2% (Cancer Research UK 2019). Siegel et al. (2018) go as far as to say that men of African and African Caribbean origin have the highest risk of all men, which has also been suggested by oncogenetics experts Benerif and Eeles (2016). Despite this increased risk these men are underrepresented in prostate cancer clinics in the UK; African and African Caribbean men in the UK are less likely to be diagnosed with prostate cancer, and after diagnosis have an increased risk of death (Ben-Shlomo et al. 2008; Perez-Cornago et al. 2017).

To investigate why these men appear to be under-diagnosed with prostate cancer, research by Fry (2017) explored men's perceptions of their risks for prostate cancer by studying the everyday lives of men without a diagnosis of prostate cancer (the focus group method discussed in this paper are part of this larger study). Men from three distinct cultural groups were recruited to the research, which used a constructivist grounded theory methodology to develop insights and theory into how men's perception of prostate cancer risk is constructed, and whether differences may exist in terms of the influence of cultural structure.

BACKGROUND

In the field of mass communication research focus group methods have historically been an accepted form of data collection (Merton and Kendall, 1946; Kitzinger 1993). Merton and Kendall (1946) first introduced the term 'focused interview' when discussing a method of data collection in which interviews had a central focus based on the researcher's analysis of pre-existing data. Mass communication researchers wanted to understand why certain stimuli appeared to produce effects on a person's behaviour, by understanding what it was about specific stimuli that people responded to (Philo 1993; Kitzinger 1993). This is now of interest to health researchers who are working in the field of cancer screening; the views of different groups can be useful in determining the usefulness of health information (Barbour 2018). Examples of such research include the effect of mass communication in health messages and the interpretation of these by the intended audience (Eldridge 1993; Kitzinger 1993; Kitzinger 1994; Odedina et al. 2004; Woudstra et al. 2017; Lewis et al. 2018).

Methods of data collection using focus groups alone have been criticised for being a quick and easy method of collecting oral data from large numbers of people (Lambert and Loiselle 2007), and this is particularly true if the method of analysis focuses on individual responses and not group interaction (Barbour 2018). For example, in 2017 Woudstra et al. used focus groups to study the decision-making process in colorectal cancer screening. Their research involved using focus groups with individuals entitled to colorectal cancer screening, as well as health literacy and decision-making experts, and provided recommendations relating to the individual decision-making processes. However, these authors do not address how the use of focus groups reflects individual decision-making; the focus group methodology may have produced data that reflected group derived understandings of colorectal cancer rather than that of the individual decision-making process.

AIM

The aim of using Card Games was to analyse the patterns of talk between the groups of men, rather than the content of their talk about prostate cancer per se. Primarily the goal was to explore if there were social influences in the way the men reached conclusions about prostate cancer risk.

DESIGN

The methodology discussed in this paper applied focus group methods to analyse the pattern of talk between men, to generate data on how social learning of prostate cancer risk may differ between distinct cultural groups of men. Using a constructivist grounded theory approach this research took the position that the data should not be forced into pre-existing concepts (Glaser 1992), and rather was open to how the data led to theory generation (Thornberg 2012). Data to construct the Card Games were collected from a larger study (Fry 2017), in which interview data was collected with men from three cultural groups (Somali, African Caribbean and White British men).

This study focused on differences in perceptions of prostate cancer risk between African Caribbean, Somali and White British men. Whilst it is clear that differentiating the men in this way mixes race and ethnicity, it is difficult to know how to identify which men had taken part in the research, whilst maintaining the focus on social constructions of prostate cancer knowledge amongst men at the highest risk compared to those who are not. For this reason the term White British men is used to identify the white men.

During analysis of the interview data it became clear that men from these cultural groups talked differently about community-based relationships within their conversations about illness (Fry 2017). For example, the White British men talked about the influence of their friendship groups on their acceptance of ill health, which seemed to be based on their desire to share their experiences of illness, whilst the African Caribbean men explained they would be less forthcoming about experiences of illness, unless it would be of some benefit to educating the community. This opinion was also voiced by the Somali men, but there appeared to be more influence of social acceptability in general talk about illness.

Insights such as these led to the decision to use focus groups to study the social talk of these men. The focus groups were designed to allow the men to talk to each other, with minimal interaction with the researcher. In order to do this, the methods of Kitzinger (1993) were studied. Kitzinger (1993) used focus groups to examine the effect of media messages about acquired immune deficiency syndrome (AIDS). Her research examined how and why people accessed media about AIDS, with an interest in how social networks influenced peoples thinking about AIDS. In order to generate rich data Kitzinger (1993) used News Games to provoke talk, an example of which was providing the participants with a pack of cards with statements about who may be at risk from AIDS. The participants were asked to sort the cards into piles indicating the degree of risk (Kitzinger 1993). These games were used to minimise interactions between the researcher and the participants, and to generate interaction rather than focus on the final categorising of the cards (Kitzinger 1994). Kitzinger (1993) examined the language used by the focus group participants when reproducing media messages, which provided insights into the use of media language and disregard of health education terms provided in mass communication.

In order to engage the participants, Card Games were created using data analysed from earlier semi-structured interviews (see boxes 1 - 4), following the principles of constructivist grounded theory. The card games were created to convey cultural differences based on the interviews and were considered to include topics that men could feel comfortable talking about in a group.

Participants

Somali, African Caribbean and White British men living in areas of social deprivation took part in the research. Cancer and social deprivation are known to be linked in ways that make it less likely for people to be diagnosed with cancer (Surbone and Halpren 2016). It was therefore felt important to this research to ensure that all the men involved had, as much as possible, similar experiences that may impact on their access to healthcare, and this is why men from areas of deprivation were recruited for this work.

The men were recruited using convenience sampling. The researcher had developed good relationships with the communities from which men were recruited, see box 5 for the number of men in each focus group. The men were aged between 45-60yrs. Two men in the Somali group were in work and the men in the African Caribbean and White British focus groups were retired. All men were given questions from the 2011 census regarding education achievement. All men had completed school and any education after this was mostly in the form of apprenticeship or other work-based qualifications. No men in the focus groups had taken part in the interviews for the study.

Data collection

The focus groups were conducted in a natural environment chosen by each group. For all three groups these were community centres specific to community identities. For example, the White British men preferred to be involved in a focus group at a local council-run community facility. The men were taking part in an over 50's group, who met weekly for access to advice, education and company.

The focus group with the African Caribbean men was conducted in a community centre, which the men used for their weekly dominoes club. The men took part in the focus group in the early evening prior to this club activity.

The focus group with the Somali men took place in a male-only restaurant, used by the men after daily prayer. Despite the researcher being female, the Somali men were happy for her to be present in the restaurant, and this may be based on the importance of reciprocity amongst the Somali community (Fry 2017); having previously worked in a clinical role as a prostate cancer specialist nurse, the researcher was able to provide access to prostate cancer information if the men asked for this.

Management of the focus groups

The focus groups were managed by the researcher. The researcher gave the men one Card Game at a time and asked one participant to read the task aloud before placing the card on a table in the centre of the group. The men were asked to discuss the task, taking as long as they needed. The researcher had minimal input with the discussions taking place amongst the men. In the role of group facilitator, the researcher allowed the talk between the men to take centre stage. This was important as it allowed the normal structure of conversation, including agreement and disagreement, to emerge. Maximising this type of talk provided

insights into how the men used each other's opinions and experiences to conduct conversations about health issues. Despite the researcher taking a 'back seat' during these interactions they were not passive. The use of Card Games gave the opportunity to bring out the quieter members of the group by asking them to also read aloud the instructions of the Card Game for the rest of the group to consider.

The focus groups were conducted with a focus group observer. The role of the observer was to capture non-verbal interactions between the participants, which were used to complement recorded and transcribed records of the focus groups, such as used by BreAnna et al. (2019) in their focus group research exploring gendered racial socialisation among black women. The observer notes were particularly important in the methodology discussed in this paper, for noting non-verbal cues that can manifest actions such as inclusion and exclusion. The focus group observer worked for a national cancer charity and had experience in conducting focus groups, having completed such research in the past.

The focus group with the Somali men also included a translator to translate from English to Somali and Somali back to English. The transcript of this focus group was then transcribed in English and back-translated to Somali to ensure accuracy. The translator did not participate during the group's interactions.

The focus groups lasted between 60-90 minutes; the longest in duration was with the African Caribbean men.

Ethical considerations

Ethical approval was given by Cardiff University. The translator involved in the focus group with the Somali men was informed of the purpose of the research and the nature of the tasks. The translator was from a local diversity charity and was educated on health-related research having been involved in similar research in the past.

The research studied men's perceptions of prostate cancer risk, and therefore carried with it the risk of group discussion involving topics that some men may find embarrassing. Rubin (2004) used focus groups to study men's attitudes to Viagra and found that the men talked easily to each other but that the conversation lacked depth, possibly due to concerns about revealing too much in a group setting. In this research the focus was on the style of talk, rather than the depth of talk, and it was felt important to generate talk on a topic that may be socially awkward due to the uniquely male nature of this cancer (Kelly 2009).

Prostate cancer literature was made available for the men, and the researcher was able to offer information for ongoing support if needed, having come from a background in clinical uro-oncology. A national cancer charity had agreed to be a point of contact if the men had any concerns. The prostate cancer literature was provided in Somali language for the Somali men.

Data Analysis

The focus group talk was analysed following the coding in grounded theory approach of Charmaz (1995; 2014). Coding was focused on the use of language that defined the relationships between the men in each group, rather than the content of the talk (see figure 1). The use of the Card Games allowed the use of language to become the centre of the focus group as the men worked through each game. The data were analysed initially using line-by-line coding for patterns of talk, for example: interruptions, agreements and disagreements and the use of humour. Focused codes were derived from comparisons between the groups of men, based on the patterns derived in step one, before analytical categories were developed to explain social differences in health-related talk.

Validity and reliability

The use of Card Games to collect focus group data has been tested in previous health related research (Kitzinger 1993), and methodologies involving interviews and follow-up focus groups, using a constructivist grounded theory approach to data analysis, have been successful in studying men's views of ageing and health (Liechty et al. 2014). Qualitative research has been criticised for having a lack of transferability and dependability due to small numbers of participants and the capturing of data that may only reflect a few people's views at a certain place and time (Blaikie 2010; Morse 2015). Charmaz (2014) argues that rather than dependability a constructivist grounded theory approach should look for the resonance of categories created through data analysis, aimed at creating a full portrayal of the participant's reality to offer deeper insights into their world. The methodological approach discussed in this paper used Card Games based on the analysis of interview data, to provide a further source of in-depth data informing us of men's social understanding of prostate cancer risk. Care was taken to ensure the card games were constructed using themes derived from analysis of individual interviews with each cultural group (Fry 2017), to provide resonance on the sociocultural understanding of risk, and inform transferability of the findings.

RESULTS

The importance of focus groups to study difference in cultures

The focus groups demonstrated differences in the structure of the talk between the men, and how this might help to understand how ideas about health and illness are developed from social influences. The impact of cultural norms in understanding of health and illness are part of this process of social construction and using Card Games in this research allowed men to generate social talk that brought cultural differences into sharp focus. Comparisons were made between the patterns of talk between men. The men were given the same games which made comparisons more credible, and useful, to the overall research findings.

To protect confidentiality pseudonyms have been used for the discussion of the results.

Patterns of talk

African Caribbean men

The focus groups highlighted characteristics of interaction between these men, which differed in their nature. The African Caribbean men were the least disciplined in their group

conversation. This group had the most democratic style of talk with both argument and agreement occurring. No noticeable leader of the group emerged, and the men seemed comfortable in confronting each other. For example, in the extract below the men felt that one of the participants was not taking the task seriously when discussing the image shown in task 4:

Noah: You'd just walk past, you don't, it looks like a chimney (laughter).

SF: That's interesting, okay.

Patrick: Saying what it is on there, and then you'll stop and you'll think about what it signifies, you'll look at it in a better, in a better light.

Pete: I've got a new one for that.

Noah: What

Pete: Don't die a virgin

Leon: That's what I'm talking about, you know. People wouldn't see it as something educational, they'll see it as like this dickhead sees it.

Confrontation seemed to be comfortable for these men. Patrick appears to be taking on the role of educator in this conversation, explaining how the 'Don't Fear the Finger' picture could be better represented. On the other hand, Pete wants to make a joke out of this, and this seems to generate ideas about how other men might react to this image. Leon put the focus on the reaction of people in general and used his confrontation with Pete as an opportunity to speculate on the thoughts of others. Here the men seem to be developing constructive talk from a process of confrontation and disagreement.

The African Caribbean men also demonstrated their ease with confrontation when discussing how they might access prostate cancer health literature. They made reference to their heritage and based some of their talk on their shared past and how this might influence the acceptance of health literature by men like them:

Leon: What I'm trying to say is this was years ago, a lot of education has gone back there now since we left home, we left, I left home in 61. When did you leave, '64?

Noah: I left in '65 but you must remember I came from the West Indies in March, I was there I just came back in March.

Leon: But I'm saying (overlapping speech).

Noah: Just a minute, the education part of it there still, right, but the actual doing, people don't want to do it.

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

Pete: No (name given), also,

Noah: I'm telling you (overlapping speech)

Leon: If you're talking about black people.

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

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

Here, Leon is identifying that black men would approach their health differently and this is a consensus of the group through the use of the word 'we' when referring to how they may approach health messages. Some academics have theorised that identifying as different has been a protective barrier against past experiences of racism when individuals moved to the United Kingdom (Marriott 2000; Sellers and Shelton 2003; Case and Hunter 2014). The democratic style of talk amongst these men may also be as a result of their experiences of being held back (Edwards 2006), leading to attempts to have their voice heard when the opportunity arises (Staples 1995). The work of Staples, in studying masculinity amongst black men, is still relevant today; men who migrated in the Windrush period, during which African Caribbean people migrated to the United Kingdom to help reconstruct the country after the war (Levy 2020), experienced such extremes of racism during their formative years that the barriers they seem to have erected in their everyday lives will be hard to dismantle (Fry 2017).

Somali men

The Somali men also identified each other as a unique group. Similarly to the African Caribbean men, these men used the pronouns 'we' and 'us' and were inclusive in the pattern of their group talk. During ranking exercise 1 the men considered who they would talk to if they had concerns about possible prostate cancer. The men quickly agreed that they would first talk to each other:

Abdi: If you know someone who knows about the symptoms you have, but it is not your doctor, you will speak to him.

Hamza: Yes, yes, that is mostly what we do.

SF: Mostly what you do?

Hamza: Mostly what the Somali's do is they come to ask someone about their health before they would go anywhere.

SF: Ah, okay.

Hamza: We do that.

Overlapping Somali speech: Yes, yes, Somali's we do. We tell each other. We talk to friends. Culturally we speak to friends.

Here, Abdi and Hamza identified that they listen to each other when talking about health. The men agreed that their pattern of social talk means they would confide in each other, and this ease in their talk is demonstrated by agreement. There was no disagreement during the focus group with the Somali men, the flow of their talk was not interrupted by individual opinion and these men were the most likely to use humour. This use of humour seemed to come from their alliances, and this was particularly obvious during task 4:

Hamza: I do not like that. It is not that valuable. It is not good. It is a doctor; no, it is up to the doctor. If the doctor wants to do it then it's fine, but what if this picture is used as a board? It will make people run (laughter).

Abdi: You see this finger its going up your.... You run away (laughter).

SF: So this makes you fearful?

Farah: It doesn't make sense.

Overlapping speech (laughter).

Abdi: He said it's too long (laughter).

This laughter may be a manifestation of embarrassment amongst these men and this was not examined further in this work. The image generated conversation and despite Hamza starting the discussion, by saying he did not like it, he seemed comfortable with humour that was reciprocated. Reciprocity is held in high regard amongst the Somali men and this is coupled with interdependence (Lagace et al. 2012). This is evidenced in the content of these men's talk and may have been exacerbated amongst Somali men after travel to the United Kingdom during the civil war in the 1980's. The recreation of home in the United Kingdom, including the importance of maintaining everyday cultural language in social talk, may come from the reasons for migration and the view that these men often want to return to Somali (Carter 2017; Neilsen et al. 2017; Lagace et al. 2012)

White British men

Unlike the African Caribbean and Somali men, the White British men were the most individual in their style of talk, and this seemed to come from these men placing value on their interactions with healthcare services. The men spoke about their own experiences, rather than how this may relate to one another. When considering ranking task 1 the men talked to each other about their own health problems, and seemed comfortable sharing their health experiences and even competing with each other:

Evan: I go to the toilet just before I go to bed, like last night I went to the toilet before I went to bed and I woke up at about four o'clock this morning and went to the toilet and then I got up at half past eight and went to the toilet then.

Dave: I have a good night sometimes.

Graham: I used to be able to do a little job and think I'll go to the toilet now, now I've got to hurry.

SF: So that's a change?

Graham: Yes, I hardly make it sometimes. I've got to squeeze the end on my penis to stop it.

These men were also the most competitive in the pattern of their talk. There was confrontation in the same way as with the African Caribbean men, but this was less 'banter-like' and seemed more a form of disagreement. It was not obvious that the men were sharing their opinion or experience as friendship, and there did not seem to be any motivation to learn from each other. This was characterised by the use of the pronouns 'I' and 'me', rather than 'we' and 'us'. This was more clearly demonstrated during ranking task 1 when discussing how they would gain access to a doctor:

Dave: [...] I'd try and get an appointment with the doctor. I say try because it's a nightmare.

Evan: If you do it at half past ten Friday

Dave: You see a nurse

Evan: No, you will see a doctor

Ken: It all depends which practice you're in

Dave: Down here you see a nurse.

Evan: Down here I go.

This competitiveness was also noted by the focus group observer who commented that one man seemed to be excluded by the other men. The observer noted this as follows:

Ken seems to be viewed as an outsider... he shared a story about being examined by Army doctors when he joined up... the Army doctors thought he had good muscles. This is not well

received by the group. They groan when he starts talking about the Army and laugh out of politeness at his story.

This pattern of speech amongst these men seemed to give them some degree of social status that the other men in this research did not express when talking about health. Liechty et al. (2014) comment that for some men it is accepted that ageing will inevitably be accompanied by health decline, and this could mean the men are more comfortable talking about their health problems; including intimate details. Browne-Yung et al. (2013) consider that people from areas of a low socio-economic status may be more likely to look for personal status in social interactions, which they may not obtain from their actual economic position, by finding ways to position themselves in a given social situation. This could explain the competitive nature of talk amongst the White British men in this research, as they seemed to find some degree of status from experiencing poor health.

DISCUSSION

Unlike focus groups used in research to conveniently collect data from large numbers, for example Woudstra et al (2017), this research used the focus group method as a way of analysing styles of talk and interactions. This has added to knowledge about the pattern of men's talk about cancer risk rather than assuming collective agreement. For example, findings from the interview data, which led to the focus groups, provided an insight into the men's social talk derived from their cultural background (Fry 2017). These data were useful in informing the theoretical direction of the research, but the interviews alone would not have revealed how the men reacted to each other and how these social exchanges may inform health literature and avoid a culturally-blind approach to prostate cancer education. The use of a constructive grounded theory means the subjectivity of the researcher is recognised (Charmaz 2014), and therefore the focus groups have been used to develop the researchers thinking about the emerging theory of socially mediated understandings of prostate cancer risk.

The use of card games have drawn on the work of Kitzinger (1993) in the development of materials to use in focus groups, as well as the ideas of Lambert and Loiselle (2007) in using a focus group to contextualise interview data and generate new insights into interactions between study participants. This research has shown that the use of focus groups with card games does allow comparison *between* groups of a distinct cultural nature. In the case of this research, this was important in developing new understanding of how knowledge of prostate cancer risk may be socially constructed.

Limitations

The Card Game methodology was used with a small number of men in three focus groups. The games worked well in promoting talk amongst the men and the content did not seem to generate concerns. However, these men had been socialised in a particular geographical environment, South East Wales, and had been aware of the research the researcher had been conducting. The men in the focus groups had not taken part in a research interview but due to extensive community engagement the researcher was known to them and this may have prompted less formal talk amongst the men.

CONCLUSION

The use of Card Games in focus groups demonstrated the differences in the way these groups of men talked to each other about prostate cancer risk, based on their everyday experiences of group talk. Using Card Games to generate talk allowed the natural patterns of talk to materialise and the characteristics of this became clearer during the study.

The Somali men were the most amenable in their use of social talk. The men did not disagree and gave each other time to speak. Their use of the Card Games generated a shared understanding of the health concern being discussed, and the group talk brought into focus the importance of each other in gaining health related knowledge. These men were also the most likely to use humour, and this seemed to reflect the ease of their everyday relationships. The African Caribbean men were also inclusive of community views in their talk but had the most democratic style of talk, possibly from their background experiences of racism. For both these cultural groups, healthcare professional need to consider discussing prostate cancer risk using community inclusive language, for the men to be aware of the possibility of educating their own local community.

The White British men were the most excluding and competitive. They also seemed to be most likely to value ill health when in a group conversation. It seemed that these men had not been socialised to consider themselves as part of a wider community, as the Somali and African Caribbean men had, and so used illness to give themselves status. This may be related to living in an area of social deprivation, which could engender the men to find social status in ways other than from economic position.

The differences in the patterns of talk between these men will be useful for healthcare professionals, as well as third sector providers, in developing new understandings of how to raise awareness of prostate cancer amongst the men who may be most at risk. Accepting cultural differences is more than producing literature in different languages; as this research has shown it is also pertinent to understand how health education messages will be understood when incorporated into socially-constructed talk. For example, a healthcare professional could use inclusive talk such as suggesting sharing prostate cancer knowledge with the community, which may mean the information has more resonance.

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