

Introduction

- ▶ My research relates to cancer services, from cancer screening through to palliative care.
- ▶ Narrowing the scope to Africans and African-Caribbeans:
 - ▶ –provided the opportunity for gaining an in-depth critical account of individual experiences, the outcome of which may have implications for other minority ethnic communities
 - ▶ and
 - ▶ –identified a dearth of literature relating to cancer specifically in relation to these two communities in the UK.

Introduction

- ▶ To my knowledge, narrative research has not been applied to these communities in relation to cancer in the UK; hence, as part of the research thesis, I aim to explore whether such a research approach has value as a research tool for these communities.

Cancer

- ▶ A major illness across the globe.
- ▶ In the UK the most recent statistics indicated that 320,000 (Cancer Research UK, 2012).
- ▶ Accurate data for the numbers of Black and Minority Ethnic groups diagnosed with cancer has been hampered by the lack of consistent data collection on ethnicity by hospitals, (National Cancer Intelligence Network and Cancer Research UK, 2009).

Common cancers in African & African-Caribbean communities

Prostate cancer	More common in Black men
Cancer of the stomach	More common in Black population
Multiple myeloma	More common in Black population
Adult T-cell leukaemia (HTLV-1)	Disproportionately high in Jamaicans
Ca cervix(related to HPV)	More common in Black women
Ca bladder due to the parasite Schistomiasis	Common in Africans
Ca uterus	More common in Black women
Ca breast incidence	Incidence lower in Black women but they have a higher mortality rate

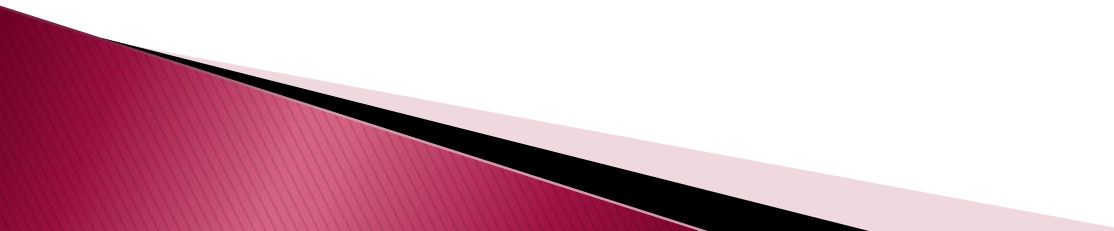
Cancer

- ▶ Incidence of cancer is expected to increase amongst minority ethnic communities for a number of reasons including:
 - ▶ an aging minority ethnic population
 - ▶ and
 - ▶ changes in that population's lifestyle and environment.
- ▶ Socio-cultural dynamics may play a role in health and illness & HCP's need to understand these dynamics from the perspectives of African and African-Caribbeans to ensure they receive positive experiences of cancer services.

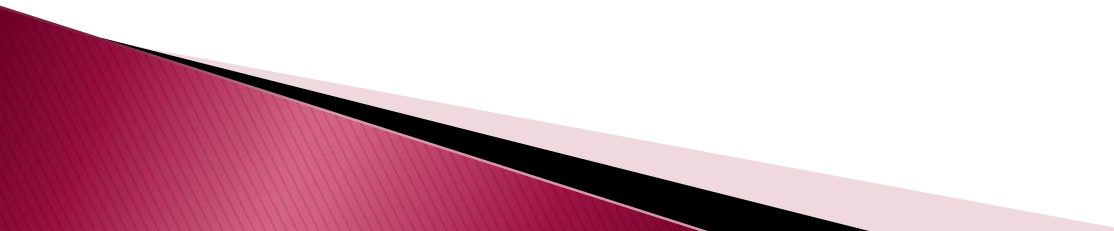
Why London?.....

	2001	2011
Total London population	7, 336, 900	8,173,941
White	5,216,100	3,846,258
Black Caribbean	351,000	344,597
Black African	389,700	573, 931
Total South. Asian	446,600	998,772

Why London?.....

- ▶ 32 London boroughs.
 - ▶ 9 London boroughs have minority ethnic population, which comprises 50% or more, meaning some London boroughs have an ethnic majority (ONS, 2012).
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NHS Cancer Plan (2000)

- ▶ Set out the government's strategy to not only reduce mortality but to improve survival and quality of life.
 - ▶ Importance of cancer screening and early detection were seen by the government as fundamental in improving outcomes as well as wanting to reduce inequalities through the provision of excellence in access and treatment provision for cancer.
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NHS Cancer Plan

- ▶ Amongst many recommendations the NHS Cancer Plan, emphasized the need for good communication between patients and their healthcare practitioners to enable high quality care and for the patient to be involved in the process and decision-making.

Qualifying what is meant by the concept 'experience'?

- ▶ Stories reflect experiences and experiences are shaped through interactions which are influenced through history and socio-cultural dynamics, (Andrews, 2007).
- ▶ Scot (1991) 'Making visible the experience of a different group, exposes the existence of repressive mechanism...we need to attend to the historical processes that, through discourse, position subjects and produce their experiences. It is not individuals who have experience, but subjects who are constituted through experiences' (p.9).
- ▶ My thesis is focussed on two BME'S groups, known to have historical issues in relation to migration, racism and discrimination, therefore their stories about cancer care, may draw attention to negative as well as positive experiences, which need to be made 'visible'.

Research method & theoretical underpinning using illness narrative

- ▶ One of our most powerful forms for expressing suffering and experiences related to suffering is the narrative. Patients' narratives give voice to suffering in a way that lies outside the domain of the biomedical voice, (Hydén, 1997, p.49).

Research method & theoretical underpinning using illness narrative

- ▶ Illness narratives enable an understanding of what has happened to an individual and give a picture of the journey of recuperating, which in the case of cancer can either be full recovery or a means to understanding how someone can adjust to morbidity.

Tailoring with illness narrative concepts

- ▶ I combined Hydén's (1997) 'illness as narrative' with Bury's (2001) 'moral and contingent narrative' categories, widening their focus to address the significance of ethnicity in illness experiences.

Why the adaptation of Bury and Hydén?

▶ Illness is:

▶ Expressed

▶ Discussed

and

Framed

- ▶ within a social, historical and cultural context in which ethnicity is a significant component.
- ▶ Neither Bury's (2001) nor Hydén's (1997) ideologies specifically incorporate ethnicity but their conceptual framework allows for such an adaptation.
- ▶ Ethnicity can play a significant part in illness narrative and it is of particular relevance when the narrators are from minority ethnic communities.
- ▶ Building ethnicity into the combined adaptation of these illness concepts provided me with a way to consider another element which plays a crucial role in healthcare interactions and was relevant for this research.

Why the adaptation of Bury and Hydén?

- ▶ Anticipated that participants' narratives would straddle Bury's (2001) moral and contingent illness narrative and Hydén's (1997) illness as narrative type.
- ▶ Therefore seen as valuable to utilise both frameworks to minimise any loss of meanings and;
- ▶ Support interpretations and to increase the reliability and persuasiveness of the meanings produced from the analysis.

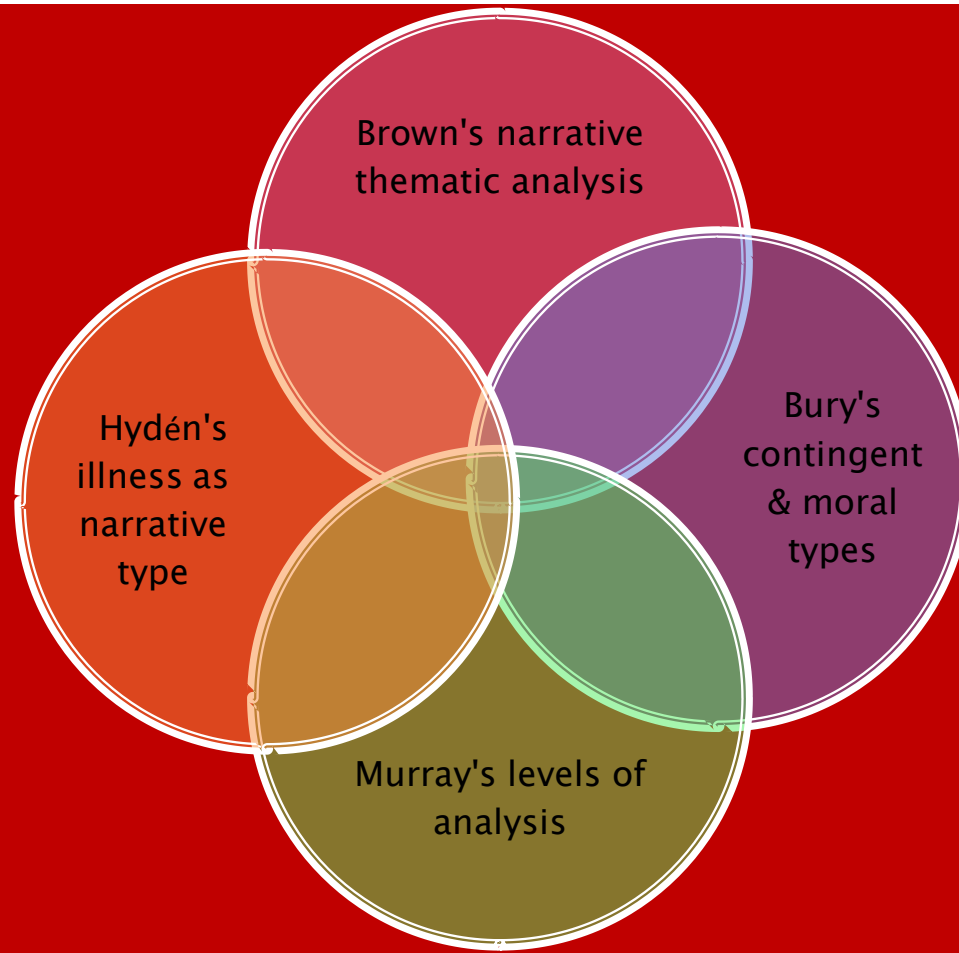
Why the adaptation of Bury and Hyden?

- ▶ Within multicultural context of the UK society, issues such as migration and 'race' are significant and illness narratives frameworks could be expanded to incorporate.

Research method

- ▶ Murray's (2000) proposed four levels of analysis, namely personal, interpersonal, socio-political and positional, form the foundation to provide an integrative approach to discussing the findings.

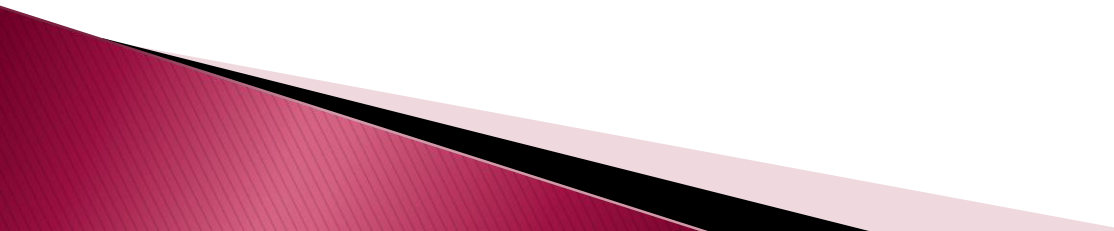
Brown's narrative thematic analysis



Dialogic analysis

- ▶ Thesis influenced by the work of Bakhtin (1981) and Riessman's (2008).
- ▶ Dialogic analysis emphasises communication as interactional and is placed within a socio-cultural context and that those interactions can have diverse meanings to the various participants, illustrating that individuals do not live within a vacuum.

Dialogic analysis

- ▶ A dialogic process between a teller and listener where storyteller and questioner jointly participate in conversation is the emphasis in dialogic analysis.
 - ▶ Socio-cultural dynamics between the narrator and listener shapes the meaning from dialogue, a fundamental platform and basis of dialogic analysis.
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Dialogic analysis

- ▶ Riessman refers to dialogic analysis as examining how talk is dialogically produced as narrative.
- ▶ Bakhtin (1981) believed that people are interconnected and influenced by each other
- ▶ This creates the potential for multivocality
- ▶ Words and phrases used have historical meaning, which indicates how dialogic analysis incorporates wider contextual meanings to the interpretation of the narrative.

The Research Questions

- ▶ What factors affected their experiences of cancer services?
- ▶ How culture, ethnicity and societal factors influenced the experiences?
- ▶ How did those factors influence the stories they told and the way they told them?
- ▶ What were good and bad practices which affected their experiences?
- ▶ What is the value of narrative approach in research related to cancer focussed on African and African Caribbeans?
- ▶ In addition, within these questions existed sub-categories which reflected:
 - ▶ Reactions to the diagnosis of cancer
 - ▶ The impact of the diagnosis on relationships with family, friends, their communities
 - ▶ Coping strategies adopted to manage the effects of treatment and long term consequences of cancer and the treatment

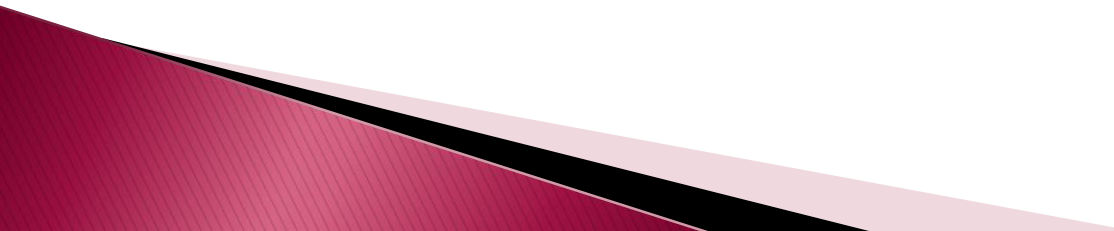
Study process

- ▶ Pilot
- ▶ Recruited from all 4 parts of London
- ▶ Convenience/snowballing
- ▶ 12 participants (9 women, 3 men)
- ▶ Age bet 35–79
- ▶ In–depth interviews took place between March 2010 and August 2011.
- ▶ Participants who had a cancer diagnosis had been diagnosed between three and eight years prior to taking part in the study.
- ▶ Analysis of the data took place from September 2011 to April 2012

Recruitment sources

Recruitment source	Flyer	Personal contacts
Recruited numbers	4	8

Study process

- ▶ Interviews taped & verbatim transcription
 - ▶ Challenges with ethical approval
 - ▶ Challenges with transcription
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Identifying narrative themes

- ▶ Narrative themes was based on adapting Braun and Clarke (2006) framework;
- ▶ familiarisation, generating initial codes, searching for a theme, reviewing themes, defining and naming themes.
- ▶ referred to as ‘keyness’ relating to relevance of the theme in answering the research question.
- ▶ In establishing ‘keyness’, I based this on the narrator demonstrating a particular issue as important or I judged its importance when other narrators made similar reference to that issue.

Identifying narrative themes

- ▶ In addition Linde (1993) concept on coherence systems was also utilised.
- ▶ Linde (1993, p164) defines coherence systems ‘as systems which claim to provide means of understanding, evaluating and constructing accounts of experiences’.
- ▶ The underlying tenet is that there is a link with shared beliefs and cultural understandings between individuals from the same communities. The participants shared with me some cultural context, have a shared socio-historical past and in some cases community, and have a shared socio-political past within Western society.
- ▶ This linked well with Braun & Clarke (2006) concept on ‘Keyness’ and both acted as a platform for supporting the reliability of the data presented by the participants in my research.

▶ Narrative theme v theme

Theme

small phrases or sentences or other pieces of text together on the basis of theme

Narrative theme

narrative themes display the plot of the story being told, rather than simply presenting a short element of meaning. Using pieces of text to show the characteristics of narrative.

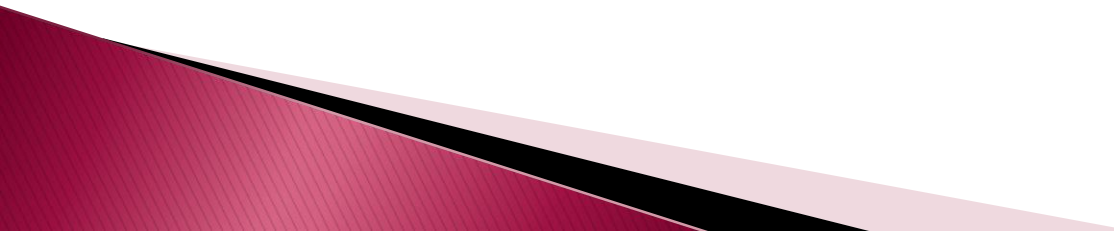
Narrative theme

The reader is presented with lengthy extracts to illustrate how a narrative theme was identified

Narrative theme

<p>'we don't talk about it (cancer) in our community' (Ngozi)</p> <p>'I don't think ethnicity is a problem, more class'(Ngozi)</p> <p>' I felt like I was something on the bottom of her shoe' (Kahn)</p> <p>'I think there is more openness to talk about cancer in the West Indian community' (Sharon)</p>	<p>Narrative theme</p>	<p>The narrative on culture, ethnicity & race</p>

Identifying narrative themes

- ▶ Narratives of reliving the cancer diagnosis
 - ▶ Narratives of health care professional–patient communication
 - ▶ Narratives of culture, ethnicity and race
 - ▶ Narratives of religion, spirituality and faith
 - ▶ Narratives about screening
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Narratives of religion, spirituality and faith

- ▶ **Ngozi:** I'm a Christian, and I've got really strong faith, absolutely, believe 100% in the Lord, and I'm Pentecostal. My diagnosis was opportunistic. That was God's miracle for me. For me, the way I see it after the Lord has actually caused it to be exposed [the cancer], I'm not still expecting him to come down from heaven to take out the cancer. I just was appreciative that it was exposed and I got rid of it. But, for lots of people in the Pentecostal faith, particularly Nigerian, you have an operation, you're saying God can't do it, and they believe in healing so even accepting surgery, for some people, they would deny. I'd call it denial because it's there if it's been diagnosed, I think that's God's grace.

Narratives on religion, spirituality and faith (the power of the pastor)

- ▶ **MB:** So would you say that the belief may affect people's decision to go for screening for cancer?
- ▶ **Ngozi:** Sure. For many, many people, they wouldn't engage with the service (screening) to start with because they would pray against it, end of. Not many of us have regular checks, not many of us actually believe in the GP at all, you understand, cause when we are ill, we speak a word of faith, a word of prayer, and we believe that the Lord will deal with it. So much so, to a point that, yes, I don't think people from where I come from really access the services that are available to them because it is seen as giving up and it's a downward spiral from there. So you just need to stand on your own feet and be strong. You must have faith. So if it's a niggling pain you curse it, and you keep on cursing

Narratives on religion, spirituality and faith (the power of the pastor)

- ▶ **MB:** So are you saying there is a cultural issue at play as well?
- ▶ **Ngozi:** It's culturally an issue, yes, and it is religious. In the religious bit it's like maybe they've sinned and that's where cancer's crept in. It was a sin, the hedge is broken. The serpent can seep in, so maybe there's sin, or maybe there's lack of faith, again, this person's supposed to be a strong person, but that happened, because even if they had the faith, even if it was cancer, then they'd be able to pray to it. And what happens towards the end, and this is not, I'm not speaking about this lightly in any way, death is a heavy blow, but what happens to the end with some of the Christians who have refused treatment, they've been, umm, kind of looked at as martyrs. They've stood their grounds in the faith. They refuse it because of God and they die and they go to heaven. It's like I live, I die, I die for God, which is individual choice, but the way I see it I beg to differ a bit, the fact that God provides doctors, provides us with herbs to get better. I think the facilities God has given us need to be tapped into and I see it as a blessing.

Narratives on religion, spirituality and faith (the power of the pastor)

- ▶ **MB:** And in your experience, this is a common practice?
- ▶ **Ngozi:** The way I've experienced things, with regard to church, is the fact that many of us, appropriate pastor's to be God. So anything they say is what God is saying, and they lose like you said themselves, and they hang on to the word of their pastor without questioning and I think it's a very dangerous thing not to question, and I'm not saying question the word of God, but find God yourself, find. And another thing that I have noticed operates in the community, and in the church, is the fact that when you actually say someone from the family's got cancer, it's kind of it's like a curse. You want to show the world that your family's blessed and blessings and prosperity, good health. So suddenly we have cancer in the family, we must not let anybody know or hear that we have a curse in the family. God forbid, not in our family.

Narratives of religion, spirituality and faith (putting my life in the hands of God: the power of prayer)

- ▶ **Sharon:** Going through treatment, you know God gave me another scripture that prepared me for treatment and it was Isaiah, Chapter 53 and 1 and 2 and it says when you go through the waters I will be with you and when you go through the floods they will overflow you and you will not be burnt or not scorched and again the water theme was all entwined there so I really took it personally. That was the point where I was unsure as to whether I should be treated and my pastor interprets it for me and he said some people get through their healing in the beginning but some people have to go through and you know my portion (situation) was to go through and those are the words I hold onto. I know it was never about me and always about Him (God).



Narratives of religion, spirituality and faith (putting my life in the hands of God: the power of prayer)

- ▶ **Sharon:** To me it was almost a vision of the perseverance and what is actually coming at the end is me coming over that. Not too long after that dream, I heard of two people who had died from cancer so it came true as well that there will be people who would have died who would not have survived and I had heard of more as well. Another thing one day, I think they had just told me, probably the same day they told me about the cancer; I was lying down after the bone marrow biopsy and it is quite a painful procedure and I was looking out of the window and I saw the name of the window blind was defiant so God was telling me how my case was going to be so and it has been you know, would defy what the doctors think and those are the two things I really hold onto. The source of my strength from God really is undeniable. I felt at peace when I started my treatment. The doctors put me at ease and I believed I was in good hands.

Culture, ethnicity and 'race' (seeing me for who I am)

- ▶ **MB:** During your treatment do you think there was any consideration given to meeting your cultural needs?
- ▶ **Ebony:** No, erm, not really. When I was being told about chemotherapy and the nurse mentioned something about scalp cooling cap. This is meant to cool your head and reduce your hair loss.
- ▶ **MB:** Yes I am familiar with that.

Culture, 'race' and ethnicity (seeing me for who I am)

- ▶ **Ebony:** I asked the nurse if I needed to prepare my hair being a black woman. Did I need to do anything? She said I needed to wait until when Monica was on duty. I guessed before I saw her that Monica was a black nurse.
- ▶
- ▶ **MB:** Was she able to help?
- ▶
- ▶ **Ebony:** Yes but was it right that I should have to wait for a black nurse? Why wasn't there any information about this? When I asked about prosthetic breasts I was given white prosthesis, which I felt were unsuitable and quite frankly an insult. I thought what I do with these? How insensitive. I asked about breast prosthesis for black women, I was told there weren't any. I know now things are better now but for me at the time there were no options.

Culture, ethnicity and 'race' (accepting me)

- ▶ **MB:** What are your feelings about how you have been treated by the doctors and nurses?
- ▶ **Sharon:** I felt no prejudice at all from being black, you know I wasn't born here so not being born here and being an immigrant even though I have paid my dues, I pay taxes you know, I am entitled to the services as everyone else but parts of you feel that maybe you I know it is a silly feeling really but you kind of feel that you are probably using the resources of people who should be getting it.



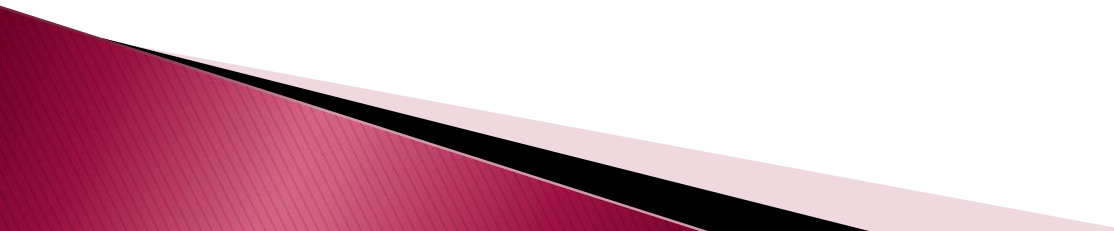
Culture, ethnicity and 'race' (accepting me)

- ▶ **MB:** That's an interesting view. What makes you feel that way?
- ▶ **Sharon:** I guess maybe it's because I wasn't born here and although like I said I have paid taxes never claimed anything, I have at times felt a little guilty. But I have never felt prejudiced in any way by the doctors and nurses... When I was referred to the specialist hospital I was given top-notch treatment. They spared no expense really in terms of the all the tests and scans they have given me you know, erm, the professor referred my case to people in Europe and America you know. I mean I am a black person with cancer but I have never seen myself as a black person with cancer you know so maybe that is the way I just think. Coming here and coming out of being a majority (referring to black people being the majority in Trinidad) to being a minority, I do see colour as being an issue here but personally (p), I don't know I just feel more grateful.

Culture, ethnicity and 'race' (accepting me)

- ▶ **MB:** When you say grateful, grateful about what?
- ▶ **Sharon:** That is probably the wrong word. I am grateful for the kind of care you get and you grateful that people treat you as a person and not as a colour you know, erm, and that has been my experience and I know for many people it would be different; if people have had prejudices then I didn't feel it. I have always felt respected really in the whole scheme of treatment and in terms of the medical side of things I have always felt that you know I was treated with a high degree of respect. They were interested in me as a person.

Interpreting meaning..gaining insights into experiences

- ▶ Courage, strength and resilience
 - ▶ Religion: testing faith and the power of religious leaders
 - ▶ Culture, ethnicity, race
 - ▶ Black men as carers
 - ▶ Talking to 'me', the carer
 - ▶ Personal narratives and their place in researching African and African-Caribbean communities
- 

'I' as the researcher: sharing
cultures

Limitations of the study

- ▶ The numbers of participants was no more than twelve and the study was focussed only on one city.
- ▶ Widening the study to include another city to compare experiences of African and African-Caribbean communities may have alluded to variations in experiences.
- ▶ Including a sample of white participants.
- ▶ Could have provided comparative analysis to ascertain similarities and differences in cancer care experiences.

Limitations of the study

- ▶ Increasing the number of men may have presented wider gender issues surrounding cancer care experiences.
- ▶ A focus group of healthcare professionals to ascertain both their experiences and perceptions of African and African-Caribbean individuals' behaviour in relation to cancer care could be combined with in-depth interviews of participants.
- ▶ Setting narratives into narrative themes, posed some challenges at not being able to look across at how a theme impacted on another (for example the screening, religion and the power of pastors). However, using Murray's levels of analysis in the discussion allowed for crossing across themes, enabling the opportunity for demonstrating links and integration of narratives.

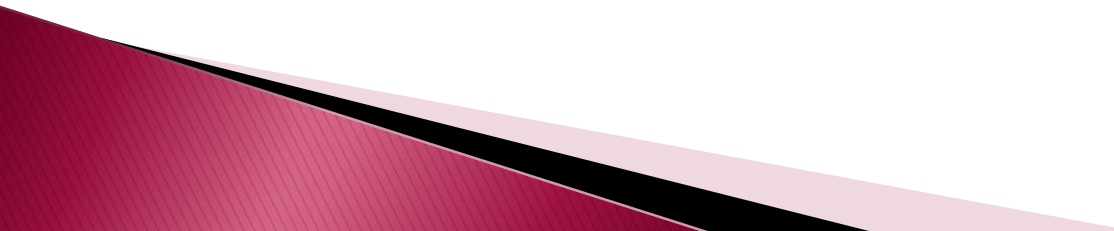
Conclusions

- ▶ ‘Cancer is a great equalizer’ (Sharon).
- ▶ Courage, defiance, positivity, overcoming adversity, deepening and re-connection to God are descriptors which depict the narratives.

Conclusions

- ▶ Positive experiences of cancer services included:
 - ▶ clinicians apologising for mistakes
 - ▶ clinicians creating an environment which encouraged a positive relationship between themselves and the patient.
- ▶ Evidence of good practice of interrelations between clinicians and participants demonstrated what Hurst and DasGupta (2003) termed 'clinical empathy'

Conclusions

- ▶ Interlinks between migration, cultural adaptation, racism, social class, gender and religion coalesce in affecting and accepting healthcare interventions.
 - ▶ Religion was a central focus for all but one of the participants, many participants gaining immeasurable support from prayer.
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Conclusion

- ▶ Both Bury's (2001) and Hydén's (1997) frameworks provided a guide to delve into an understand illness from the perspective of the individual with the illness.
- ▶ The importance of recognising that Africans and African-Caribbean people are not a homogenous group is key to establishing health strategies which best suit these communities to effectively articulate health information

Conclusion

- ▶ Considering the multicultural demographics of the UK, illness narrative frameworks may need to be adapted to take account of factors such as 'race', migration & ethnicity.

Thank you



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