

Identifying through illness narratives, the power of pastors in parishioners decision-making in accepting cancer treatment.

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Overall focus of the study

- ▶ African and African-Caribbean Londoners' experiences of cancer services
- ▶ Ethnicity and culture, in relation to cancer and the Africa and African-Caribbean communities, was also explored,
 - ▶ to
- ▶ provide an understanding of the complexities of how those social constructs impact on utilisation, access and acceptance of cancer services and treatments.

Theoretical underpinning & narrative approach

- ▶ Dialogic analysis & adaptation of illness narrative typologies.
- ▶ I combined Hydén's' (1997) 'illness as narrative' with Bury's (2001) 'moral and contingent narrative' categories

Why the adaptation of the typologies?


- ▶ Ethnicity can play a significant part in illness narrative and it is of particular relevance when the narrators are from minority ethnic communities.
 - ▶ Within multicultural context of the UK society, issues such as migration and 'race' are significant and illness narrative frameworks could be expanded to incorporate
 - ▶ Support interpretations and to increase the reliability and persuasiveness of the meanings produced from the analysis
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The research process

- ▶ A combination of convenience and judgement sampling was used
- ▶ The storytellers came from the four geographical areas of London
- ▶ All participants had been living in London for over five years.
- ▶ 12 African and African-Caribbean storytellers
- ▶ Age between 34-79,
- ▶ 4 Africans, 8 African-Caribbean
- ▶ 3 MEN, 9 WOMEN

- ▶ In-depth interviews were conducted
- ▶ Interviews recorded and verbatim transcription & research journal

Forming narrative themes

- ▶ Narratives themes were formulated through loosely using and adapting a thematic framework developed by Braun and Clarke (2006).
 - ▶ Narrative themes display the a plot of the story being told
 - ▶ Therefore, the analysis is presented as lengthy extracts to illustrate how a narrative theme was identified
 - ▶ 5 narrative themes were identified
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Examples of narrative descriptions leading to narrative themes

<p>‘I just gave it over to him [God]’ (Sara)</p>	<p>Narrative theme</p>	<p>The narrative on religion, spirituality and faith</p>
<p>‘People just believe everything the pastor says’ (Ngozi)</p>		
<p>‘Its nice to know people are praying for you, it’s comforting’ (Jennifer)</p>		
<p>‘Her faith I am sure was what kept her with us a lot longer’ (Joseph)</p>		

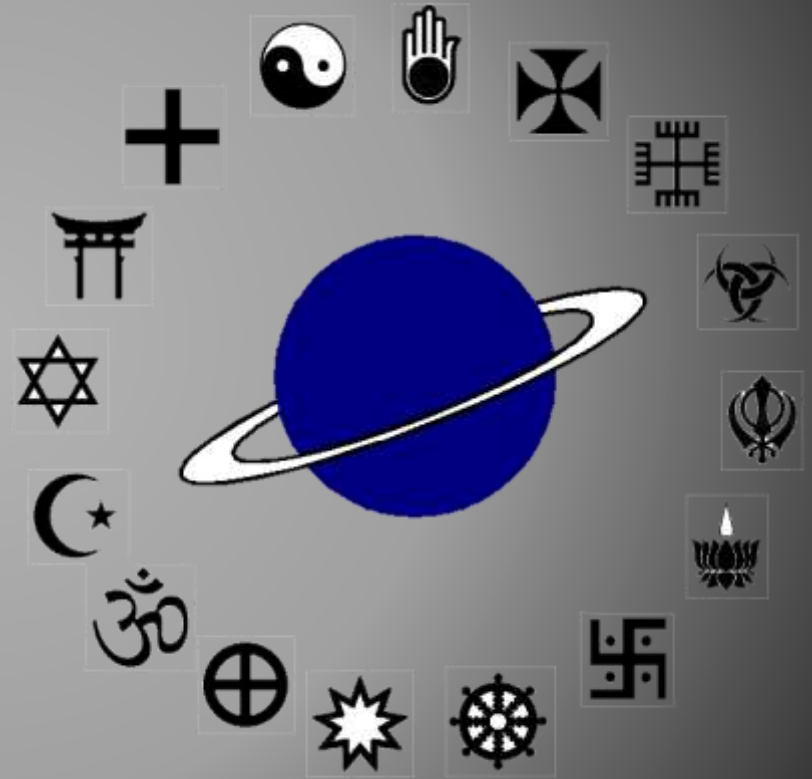
The 5 narratives themes

- ▶ 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
- ▶ **Within these sub–narratives emerged**

How deep is my faith; divine power versus accepting medical interventions (the power of the pastor)

Ngozi's story

- ▶ *" 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."*



Ngozi's story

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 it.”*



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.***
- ***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.”***

Ngozi



- MB: *“So are you saying there is a cultural issue at play .*
- **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.”*

An extract from Sharon's story

- *“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 over flow 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). “*
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Sharon's story

- *“ the pastor gave me an understanding of why I was drawn to that scripture and I felt light and clear about what I would do. “*



Summary

- ‘Cancer is a great equalizer’ (Sharon).
- The research illustrated that like all patients with cancer, the cancer experience is an individual phenomenon but the narratives had demonstrated those experiences are bound up in historical, cultural, social, religious and spiritual perspectives.