

Title Life after Stroke, African Caribbean women voices: you have to make it up, I pray, I do what the doctors say, I am fine, I'm ok, thanks be to God

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Title: Life after Stroke: Coping mechanisms among African Caribbean Women

Abstract In the UK stroke is the third most common cause of death for women and the incidence in African Caribbean women is higher than the general population. Stroke burden has major consequences for the physical, mental and social health of African Caribbean women. In order to adjust to life after stroke individuals affected employ a range of strategies which may include personal, religious (church) or spiritual support (i.e. prayer), individual motivation, or resignation to life with a disability. This study explored these areas through the coping mechanisms that African Caribbean women utilised post stroke in the context of stroke recovery and lifestyle modification efforts needed to promote healthy living post stroke.

A qualitative approach using Interpretative Phenomenological Analysis was adopted. Eight women were recruited into the study. Semi structured in-depth interviews were audio recorded and were transcribed verbatim. Data were analysed using a four-stage framework: familiarisation, sense making, developing themes and data refinement and analysis.

Three main themes on coping emerged: the need to follow medical rules to manage stroke, strength and determination, and the use of religion and faith to cope with life after stroke. These findings illustrate both a tension between religious beliefs and the medical approach to stroke and highlight the potential benefits that religion and the church can play in stroke recovery. Implications for practice include acknowledgement and inclusion of religion and church based health promotion in post stroke recovery.

Key words: Stroke, life after stroke, culture, religion, church, health, African Caribbean Women

What is known about this topic

- Stroke causes about 7% of deaths in men and 10% of deaths in women. It is the 3rd most common cause of death for women in the UK.
- There are approximately 1.1 million stroke survivors living in the UK and stroke remains the leading cause of adult disability
- The medical model is the most dominant model used in stroke care

What this paper adds

- An understanding of how African Caribbean women follow medical guidance and rules post stroke.
- A social and cultural understanding of the place that religion and faith based organizations play in recovery from illness
- The role religious institutions could have as spaces for post stroke recovery and secondary stroke prevention efforts

Background

Stroke is a global health concern and remains one of the main causes of acquired adult disability (Norris et al. 2012). In the UK stroke is the third most common cause of death for women, and the incidence for African Caribbean women is greater than the general UK population (Stroke Association, 2013).

The burden of stroke has far reaching consequences for physical, mental and social health (Burton et al. 2014). In a Caribbean island based study at 12 months post stroke follow up a 29.4% mortality rate was observed and 70.5% of survivors presented with hypertension (Sophie et al. 2014). This finding indicates that post stroke care is important in reducing co-existing morbidities that increase stroke mortality along with management of the consequences that stem from stroke. Consequences of stroke include low physical fitness levels (Saunders et

al. 2013) which may lead to restricted mobility and stroke survivors with low levels of mobility who are dependent on others also report reduced quality of life (Sprigg et al. 2013). There are a number of challenges facing those who have experienced stroke, for example, the desire to return to work can be hampered by physical weakness and neurological deficits or impairments such as speech and cognition (Wang et al. 2013). **These deficits can also impact on daily living, for example Guidetti et al. (2014) noted that at 3 and 12 months post stroke, difficulties are experienced in daily activities of living. Issues around sensitive topics such as urinary incontinence, which may continue long after discharge, also impacted on daily functioning (White et al. 2014). Concerns such as finance or dependence on others are also important and may impact on social and mental health. In addition patients' perceptions of their everyday life situation is essential in rehabilitation (Guidetti et al. 2014) as this can act as a catalyst or barrier to engaging in activities aligned to recovery.**

The inability to be able to engage with others, and continue life as before remains a constant challenge for some and adjusting to life post stroke may evoke loss for a past life. In the UK the medical model is the dominant response to stroke, **as** stroke requires medical treatment, compliance to medical rules, and adherence to medication in the management of the disease state. This response rests on the assumption that compliance to medication or treatment regimens as specified by a medical team will prolong life, and improve quality of life post stroke. This may also be coupled with suggested lifestyle modifications such as changes to nutrition and diet or increased physical activity.

In order to adjust to life post stroke **those** individuals affected employ a range of strategies to mobilise or communicate with others, to cope with everyday living, and adapt to the changes recommended by modern medical support. It has been suggested that coping strategies are linked to emotions and behaviours that are influenced by ethnicity and cultural beliefs or expectations (Smith, 2012; Bache et al. 2012). This idea suggests that different population

groups are likely to utilise different coping strategies to deal with the consequences of stroke and the management of their new life post stroke.

Individual coping strategies for stroke may include personal, religious (church) or spiritual support (i.e. prayer), individual motivation, or resignation to life with a disability. Group coping strategies may include the use of supportive networks such as family, medical, religious, health or community groups. **Research in the area of stroke has noted the importance of the environment and the presence of external support that may aid stroke recovery (Boger et al. 2014) but this has not been specifically connected to religion or the church as an organisation in promoting stroke recovery.** There is currently no research around African Caribbean women and how they cope (either using individual or group strategies) with life post stroke. There is however some research in the areas of chronic disease in similar ethnic groups that can **offer** guidance as to what we may expect to find when exploring this condition with this group of people.

Current research that examines the role of the medical profession and the adherence to medication or treatment in coping with chronic disease does not give a clear picture. For example, in diabetes management, Brown et al. (2007) suggested that African Caribbean people mistrust advice, medication and services provided to them by health professionals. Abubakari et al. (2013) found that **Black** Africans reported better adherence to self-management recommendations for type 2 diabetes than other ethnic groups. Caregivers such as spouses have also been connected to better medication adherence in long term chronic conditions such as COPD (Trivedi et al. 2012). Family social support may be a key group coping strategy in chronic disease, for example Koffman et al. (2012) found that in advanced cancer patients spouses and partners were considered to be essential support mechanisms and noticeable in African Caribbean women was the presence of church communities as a main support system.

Specific coping strategies that have been linked to chronic disease in diverse ethnic groups have focussed on the role of religion or religious practices. Religion and religious practices such as prayer may provide varying levels of social support, psychological comfort or reassurance (Blumenthal et al. 2007). The role of religion and spirituality and health in stroke has been investigated in terms of influences on stroke outcomes, and influences on mental health although the physical health benefits remains controversial (Blumenthal et al. 2007). It is difficult to separate out whether some **stroke survivors** turn to religion because of stroke, or whether religion is relied on more heavily after stroke to help individuals manage and assume a new identity.

The term “religious coping” is a multidimensional construct, made up of both positive and negative aspects. Positive religious coping includes for example working with God to seek guidance and utilizing methods (i.e. prayer). There is a positive correlation between the role of religion and positive mental health, supported by authors such as Giaquinto et al. (2007) who suggest the stronger the religious belief, the more they were protective against emotional distress, and Holt et al. (2014) who notes the relationship between positive religious coping and higher self-esteem. Negative religious coping, such as anger at God or lack of forgiveness, may be adversely related to health, particularly emotional health (Rippentrop et al. 2005).

Despite the fact that stroke is one of the major causes of mortality in the UK, there is a lack of evidence that investigates the coping mechanisms used by UK based African Caribbean women in stroke. Uncovering these mechanisms could help facilitate and tailor stroke prevention efforts to this group of women and identify challenges that may be hindering the post stroke rehabilitation or recovery processes. **One of the objectives of** this study was to identify the coping mechanisms that African Caribbean women used post stroke and the implications of these coping mechanisms for stroke recovery and lifestyle modification efforts.

Methodology

A qualitative approach was adopted for this study using the principles of phenomenology captured by Smith & Osborn (2004) in Interpretative Phenomenological Analysis (IPA). A common assertion of qualitative research is that the researcher and participants are co-authors in the process of knowledge production and the knowledge claims that emerge (Flick et al. 2005). In this approach the participants' voices are represented. In our study this was achieved via the narrative accounts derived from the semi- structured in-depth interviews carried out. In the interview situation the researcher allowed participants the opportunity to fully share their experience by active listening giving rise to prompts and probes that led to a narrative that the participants were happy to share. This co-authorship served to facilitate greater clarity and awareness of participants' situation as well as sense of empowerment for the participant as they were able to retell their stroke experience in their own time and words. IPA is rooted in psychology and has emerged as a methodological approach that can be used for exploring in depth how individuals experience and ascribe meaning to a specific phenomenon (Smith et al.1999). In our study we set out to understand the lived experience of life after stroke, we examined the day to day experience of living with stroke among African Caribbean women.

Ethical approval for the study was granted by the University of East London and Barking and Havering Local Research Ethics Committee. Participants were recruited by advertising locally in community halls, hospital areas and using a snowball approach. The latter approach was used as the group proved hard to reach. An information pack contained a letter with information on the study, which included contact details of the researcher and a consent form. Good ethical practice adopted the use of pseudonyms for all participants reported in the study. Any identifying marks were removed to ensure anonymity for example if women referred to their church or general physician by name it was removed or replaced by a letter.

Semi structured in depth interviews were audio recorded and all interviews were transcribed verbatim by the researcher CM. The interview schedule was used as a guide during the interviews rather than as a prescription. The questions were open-ended, which created an opportunity for the participants to tell their story. The interview schedule consisted of four sections including the background, concepts of health, own understandings of illness and the patient experiences of living with stroke. All interviews were conducted in the participants' home at a time convenient to them and lasted between 60-90 minutes. Data were analysed using a four stage framework: familiarisation, sense making, developing themes and data refinement and analysis.

Analysis

The study took place in the London borough of Newham, set in the East End of London. Seven women were recruited into the study; small numbers are advised when using IPA. It is worth noting that the ideographic emphasis of IPA means that the focus is not on large quantities of data but on gathering in-depth data that allow a richer understanding of the participants' experiences. Seven women were interviewed totalling 10 hours of interview time. All participants were born in the Caribbean in St Lucia, Jamaica or Trinidad and are now permanently living in East London. They had all experienced at least one stroke from between four years to twenty years ago. They were a mixture of single and married women aged between 47 to 82 years. They all expressed Christianity as their religious faith (see table 1). There were no language deficits and all were able to communicate in English.

Three main themes on coping mechanisms emerged from the in depth dialogue with African Caribbean women on their day-to-day life and living with stroke. The first was the need to follow medical rules to manage stroke, the second was strength and determination, and the third was the use of religion and faith to cope with life after stroke.

Medical rules to manage stroke

From the participants' talk that the role of medicine and particularly medical doctors was perceived as important in the management of their stroke. The women **highlighted** the need to follow rules and guidance in their rehabilitation. In addition they expressed satisfaction and comfort from what their medical team, usually in reference to 'the doctor' had told them.

Well I am healthy and living and doing everything I want to do and I listen to what my doctor have to say. So I am Ok. I am fine. I'm alright. (Marie)

They also discussed the need to take medication to retain control of their health, in some cases, exhibiting a good understanding of why medication is needed. Queenie notes that she *has to* take medication, and knows why she has to take this:

I have to take a whole barrage of drugs, to keep my blood pressure to what is an acceptable level coz I have what is called malignant hypertension (Queenie)

Participant's talk suggested that they were compliant in relation to taking their medication and followed the guidance of their medical team. In staying true to IPA subjectivity we noted that one of the women in the sample expressed breaking the rules in order to follow the rules:

Ah just get up in the morning and I say chuts, give it a break, Every day the same ting, de same ting, I must cah skip ah day, sometimes taking all these tablets is not easy. Chuts man I say enough is enough and I must can skip one day, so I skip one day...I don't do it regular ...I have been taking these tablets for years day in day out, day in day out. You must can skip one day at least one in ah month I is not saying you have to do it regular (Doris)

Even in breaking the rules she has created her own rules to following the rules of medication. She was keen to **say** that you don't have to do it regularly but you can have one day off medication. Adhering to the rules of taking medication was not easy for Doris; it was a

monotonous, tiring routine. Therefore as with most tedious routines taking a risk makes it exciting, a rule that she has created to maintain her mental and physical health.

The other women discussed how they were comfortable and accepting of their doctors, and how they listened to the medical guidance that was given to them. This suggested a high level of trust in the medical team. Mildred talked of doing what the hospital asked her to do:

I exercise as my doctor in the hospital say to do, and take the treatment from the doctor (Mildred)

The women trusted their medical team, which in some cases included nurses, health visitors and physiotherapists; there was a **sense of trust** that if you followed the rules of the medical team you would be rewarded with good health.

...because if you let it worry you or let yourself go you will not be alright as the doctor says.. They speak to me they say you must not worry about anything you are carrying on good you are alright. Doctor tell me you should not worry too much. Well I am healthy and living and doing everything I want to do and I listen to what my doctor have to say, so I am ok I am fine I'm alright (Marie)

In most cases this group of Caribbean women embodied the notion of the doctor knowing best, and noted that there was nothing else that they could do in terms of controlling their illness, signifying a belief that the doctor had told them all they needed to know in order to control their health.

I am comfortable with what my doctor tell me, there is nothing more I can do (Mildred)

Mildred's talks demonstrated the perception of the control of illness resting in the hands of the medical profession, and that there was nothing more that she could do to help herself apart

from follow this guidance. This indicates a level of slight passivity (and being a ‘good patient’ who follows the rules) but also of satisfaction with how her illness was being managed.

Strength and determination

It was noticeable in this group of African Caribbean women that their determination and strength to overcome stroke was high. They spoke of a desire to get better and talked of focussing on making their minds up to get themselves well. They also considered that getting better was something that was linked to individual responsibility. Marie talked of the individual being responsible for developing a will to regain some level of health post stroke but she also acknowledged that in some cases this may not be possible

Well you have to make it up, some people can't make it up at all...wanting to get better (Marie)

The women's talk indicated this need and desire to get better and Lucy noted that this requires concentration. Lucy also expressed the notion that she needed to get as well as she could in her new capacity post stroke.

I just think I need to get more fit, you know get better, right now I am just concentrating on getting as well as I could (Lucy)

A thread identified in the women's talk was the motivation to get well. We could argue that this was linked to **this group of** women having strong self efficacy and a high desire to have control of their illness (**acknowledging that not all African Caribbean women share the same experiences**). It was also reflected in their attitude towards getting on with life, no matter what happened. Doris speaks of her determination to go on, no matter what:

If you don't have the determination you are not going to move from where you is then you right back at square one...you have to go on no matter what (Doris)

Participants appeared to work very hard to get better, and this assertion was evident in their talk. Margo highlighted that she had been working hard to get better because that was who she was, it was part of her identity and personal make up. This suggests perhaps that Margo felt that some people might not cope in the same way and that you had to be strong and be in control to keep your health:

I have been working really hard to help myself. I haven't sat about doing nothing. Cause I am not the type of person to sit around and do nothing (Margo)

Mildred also echoed Margo's beliefs when she noted that health was in the control of the individual and health is what you make it. **Again, this reflects assertiveness over health and illness demonstrating a determination to work to improve health status.**

Health is what you make it (Mildred)

The strength and determination to get better, and to keep working at getting well shows that the participants in this group were determined and had an inner strength which increased motivation and allowed them to cope day to day with stroke.

Yuh have to just make your mind up and try, and not to make it a hindrance to you and take one day at a time (Doris)

Strong will and determination are fundamental precursors to self efficacy which are used by this group of African Caribbean women as coping strategies for stroke.

The role of religion and faith

The participants identified the importance of religion, mostly positive, in coping with stroke, and it was clear that religion and spirituality were **essential** in assisting in daily life and coping with life post stroke.

Some of the women aligned health closely with the concept of religion, and considered their health to be created and granted through God. God was generally a positive life-force whom many participants frequently acknowledged as being part of their day-to-day life post-stroke. Doris and Lucy expressed gratitude to God, and Lucy added that faith was what was keeping her alive:

I thank God for what I can do (Doris)

Whats keeping me alive is my faith and the one I cannot see (Lucy)

In addition, participants were thankful to their God that their health had been spared, a view that was sometimes reinforced by their medical practitioners: Marie said:

..... my doctor say you have a stroke a bad stroke and God still spare you life (Marie)

There was a strong link between the belief that God created health, and that he had given these women a chance to carry on their life. He was both responsible for life, and could grant recovery from illness. It was also acknowledged that he could test faith and dedication to God.

Because if I wasn't believing in God I wouldn't be here today, I would be six foot deep. Oh yes, oh yes, he (God) has tried me and bring me back (Lucy)

Health may be seen as 'justly deserved' in this context, through following rules, and proving one's own faith. Ill health as a test or trial from God has its roots in Christianity where one may experience ordeals and be rewarded at the end. On recovering from her stroke Doris said:

So I am happy God is still giving me breath to breathe (Doris)

Among this group of African Caribbean women there was a belief that God might also grant wealth and strength. He was seen as the provider and controller of health, and was able to supply or meet participants' physical and financial needs. This included the concerns associated

with being a burden on one's family post stroke when their might be a restriction in mobility, or an increased in dependence on the family financially. Doris noted that God would help her to ensure that she was not any trouble to her family:

I say to them (her children) I eh go be no trouble to none of yous, fuh God help me fih I don't have to say lend mih a penny or ah doh have this and I doh have that (Doris).

Participants frequently acknowledged the role of prayer and church in maintaining health, and using prayer or attendance at a religious group or organisation was frequently cited:

I go to church on Sunday's to keep me spirit clean (Mildred)

And for Jenny:

I go to church twice on Sundays and during the week I lay and pray and meditate and say me prayers. My son got me some Caribbean tapes of gospel songs (Jenny).

Unfortunately, due to the physical and functional effects of a stroke some women were not able to continue the same religious habits as before. It is important to note that this does not mean that they were any less religious or faithful in their belief. Lucy noted that even though she used to attend church frequently she could not attend anymore, and so had turned to personal prayer:

I went to the same church for 27 years, like I am an Anglican and de vicar never come and see mih since I get de stroke but I pray for myself I have got my Holy Bible, I got lickle books I can read and pray (Lucy).

Marie also said that she used to go to church frequently, but as she now had a problem with her leg post stroke she was unable to attend.

I used to go to church a lot I am Catholic but since I have the sick leg I don't worry, I know that there is a God I pray (Marie).

She further confirmed her faith with the rewards of good health:

I know there is a God and I pray and things like that and I feel alright to tell you the truth (Marie)

Trust in God may be reaffirmed in times of illness. God may be a guide during times of illness. The type of trust and guidance the women talked of was one that was often shared by good friends who acted as a supporter and confidant in times of need. Lucy noted how God was her guide in time of need and danger.

I tried to come down the steps to call the doctor. I said God lead me downstairs with your eyes so I can see the phone to call the doctor (Lucy)

Discussion

This study had set out to understand the lived experienced pertaining to life after stroke among a group of African Caribbean women living in the East End of London. This paper reports on the coping mechanism used to live with stroke among this group. We recognise that the group African Caribbean in this study is not homogenous and our participants' description reflects some of these differences. However there were commonalities; the women all lived in a similar geographical area, and shared an immigration experience from the Caribbean to the UK. They were also all middle to older aged women who had experienced a stroke. The results of this study illustrate a range of coping strategies post stroke linked to medical professionals, religion and the role of the church. The main themes are linked to individual behaviours such as compliance to medication and medical rules and the desire to change their lifestyle. Personal

beliefs such as attribution of health status and recovery from stroke to God, and the importance religion and the church play in stroke recovery are also a main theme.

Health to **some of the women was seen as** deserved if you followed the rules of healthy behaviour as dictated by the medical profession – in the case of this study, take your medication, exercise or attend treatment centres. The group of women in this study were generally compliant in their taking of medication, and they listened to the advice from the medical team. These experiences are similar to findings in other small scale qualitative studies in different illness areas, for example Bache et al. (2012) found that African and Black Caribbean origin cancer survivors generally had positive views of treatment provision, and hospital services. Schoenberg et al. (2008) found in a multi-ethnic sample of US adults with diabetes respect and trust in authority of physicians was also deemed to be high as participants quotes were linked to conventional self-care approaches to lifestyle modifications. It is unclear if the similarities are due to management of a chronic condition, or ethnicity and further research would need to investigate this particular area. Medication compliance was also linked to self-efficacy and social support by Rimando (2013) in a study on compliance in hypertension in older African-Americans. This is interesting as our study found very positive views of control, and the desire to get better and having control over one's health may indicate fairly high levels of self-efficacy and may also be linked to increased medication or medical compliance.

Our participants reported their desire to remain in control or stay strong in the face of illness. **This suggests a positive link to the self-management of stroke and suggests a desire to get well and remain healthy**, which is reflected in compliance to medication treatment and guidance. Leach & Schoenberg (2008) found in the US that older adults with mixed ethnicity with multiple chronic conditions expressed a strong desire to stay in control of their health, and used a variety of strategies to do this such as self-care activities reflected in the participants in our

study. This is positive, as it suggests that coping strategies may reflect higher self esteem and feelings of control over illness, which in turn is linked to positive self-care behaviours such as lifestyle modifications, or medication adherence. This may in turn have a positive outcome for stroke rehabilitation and prevention of subsequent stroke.

Recent NICE (National Institute for Clinical Excellence) guidance that makes recommendations for returning to work and long term health and social care need, however these guidelines are for healthcare professionals and are generally linked to functional rehabilitation (NICE 2013). Recent research in stroke suggests people would like more psychological and emotional support in the self-management of stroke (Satnik et al. 2014) and Boger et al. (2014) noted that not only is the concept of self management not recognised in those post stroke, but that many people consider they are ill prepared to self manage post stroke. This is problematic as post discharge self-management of stroke and reintegration into community or work environment will generally require some degree of stroke outcome management both emotionally and psychologically.

Maintaining a positive spiritual life can contribute to positive mental health, alongside prayer which may seek solace, peace or forgiveness. This may have a positive correlation to health, which has been noted by other authors for example Johnstone (2008) noted that spiritual belief in a higher power, assisted in the recovery process of stroke and was linked to better mental health outcomes. Prayer is also an important way to express dedication to a specific religion. Norris et al. (2012) noted that prayer was maintained despite the physical limitations of stroke. Prayer is the most common form of religious coping (Giaquinto et al. 2007) and this is highlighted by nearly all the African Caribbean participants in our study. Becoming unwell may lead to increased interest and involvement in religion and spirituality (Ironson et al. 2006). Rippentrop et al. (2005) for example noted that those experiencing worst health were more

likely to engage in private religious activities suggesting that this may be a way of coping with ill health.

Predominately the participants in our study utilised positive religious coping mechanisms including prayer, listening to religious media, attendance at church and they spoke of God in positive and optimistic ways. Positive coping strategies are associated with better mental health outcomes and private religious practice and spiritual coping has been found to help improve health status in immigrant older adults (Lee et al. 2014). Thus participants in this study who use private religious practice and spiritual coping maybe better placed to improve their health post stroke.

There is an understanding that the stronger the religious beliefs, the better the individual's ability to cope after a stroke event (Giaquinto et al. 2007). In addition as stroke has some associations with poor mental health such as depression, this suggests that this particular group may have religious beliefs which protect them against possible negative emotional experiences.

A range of studies have noted that higher levels of spirituality and spiritual support experience less depression. Bennett & Shepherd (2013) and Sternthal et al. (2012) examined the benefits of meaning and forgiveness from religious involvement and indicated that religious involvement facilitate mental health benefits in a range of ethnic groups. Given the links between stroke and poorer quality of life the positive relationship to spirituality in these participants may have additional positive benefits post stroke.

Participation and attendance at church is a small underlying theme, which some participants noted through their attendance at church, although equally some participants noted they no longer attended church due to effect of their stroke. The focus on personal use of religion is a stronger theme, rather than the caring or supportive role of the church through social activities.

This group of African Caribbean women asserted their strength and determination to get well, although it is not clear if this was because they utilised positive religious coping styles, or whether their coping styles without the use of religion would remain strong. However, as this group of women had particularly strong religious beliefs which they were using to maintain health, there is potential for a much stronger role of the church and church partnerships in the rehabilitation and maintenance of strong spiritual support for post stroke women. It is also important to consider how to engage those who are isolated due to physical challenges, especially as some of the women report difficulties in accessing their church post stroke. The view of spiritual and religious beliefs in coping with life after stroke may not always fit into the health professionals' view, which can sometimes be based on assessments and ability to function in a set way. **There is some research to support health professional's views on inclusion of religion into stroke rehabilitation with Muslim stroke patients and that health professionals could support religious patients to enhance self-efficacy in stroke rehabilitation (Omu & Reynolds et al. 2014). The evidence base for the inclusion of religion in rehabilitation of stroke however is very small.**

For some of this group of African Caribbean women, spirituality and religion guided health and recovery and was seen as granted by God. This concept has implications for healthcare workers because if the individuals believe that their health is granted by God, they may adopt a fatalistic approach and opportunities for health promotion could be missed or ignored by placing health into the hands of fate. **Morgenstern et al. (2011) noted the relationship between negative health outcomes and fatalism in stroke. This is usually due to the suggestion that events that are attributed to God's will or destiny are essentially pre-determined and cannot be changed. However other research has disproved this and indicated that potential fatalism influencers such as religious beliefs may actually encourage health service use and self-care in areas such as cancer prevention (Leyva et al. 2014; Florez et al. 2009). Our findings show that**

there was a tension between a religious belief in God and individual agencies (outside of religion), but that individual action and the external will of God was utilised in a positive manner.

This finding suggests a number of potential implications for practice. There was a strong element of religious coping in the African Caribbean women in this study. This is supported by other works in different ethnic groups in areas of illness such as cancer (Kristeller et al. 2011) and multiple morbidities (Leach & Schoenberg, 2008). Religion and spirituality clearly provides an important role in the coping strategies of African Caribbean women post stroke. As there is a strong religious and spiritual element to nearly every participants' interview the potential for the church or church partnerships to be involved in stroke prevention is strong. This is supported by authors such as Skolarus et al. (2012) who also considers the potential for stroke based interventions that involve local church based settings and partnerships one that should be investigated. Currently most of the evidence for using church based health promotion is centred on the African American community (Corcoran et al. 2013), and the potential for UK churches is predominately under investigated. The church has strong leadership and social interaction which places them in a prime position to be part of health promotion programmes. This includes both outreach and in-house programmes. At the very minimum programmes that aim to increase medication compliance and adherence or that provide social or emotional support may be beneficial in post stroke care. **Recent research around using peer support to support and reintegrate stroke survivors back into the community (Kessler et al. 2014) may also be an ideal intervention for church based outreach work.**

The notion that religion and spiritual beliefs can contribute to perception of illness and recovery needs to be acknowledged when caring for groups that exhibit such beliefs, health care professionals need to be taught that religious and spiritual beliefs together with medical treatment can co exist and this can lead to understanding better the experiences of life after

stroke and other illnesses. Therefore health professionals could be trained to confidently provide culturally competent care that acknowledges religious or cultural beliefs and how these can be used by individuals from different backgrounds as coping mechanisms particularly in recovery of stroke and similar chronic illnesses.

Study limitations

The main limitations of this study are the small sample size which only allows us to make comparisons within a specific ethnic group. In addition our study was conducted on inner city women in East London and those in a rural area may experience and use different coping mechanisms as the levels of community and medical support may be different. Findings might also be different for various ethnic or younger age groups. We could have also triangulated our data by interviewing church leaders or stroke health professionals who work with this group to get their views. However, research in the area of stroke and African Caribbean women still remains sparse, and this study gives us some key areas to focus on in terms of future research, and secondary prevention opportunities.

References

Abubakari AR, Jones MC, Lauder W, Kirk A, Anderson J, Devendra D and Naderali EK (2013) Ethnic differences and socio-demographic predictors of illness perceptions, self-management and metabolic control of type 2 diabetes. *International Journal of General Medicine* 29 (6) 617-28

Bache RA, Bhui KS, Dein S and Korszun A (2012) African and Black Caribbean origin cancer survivors: a qualitative study of the narratives of causes, coping and care experiences. *Ethnicity and Health* 17 (1-2) 187-201

- Blumenthal JA, Babyak MA, Ironson G, Thoresen C, Powell L, Czajkowski S et al. (2007) Spirituality, religion, and clinical outcomes in patients recovering from an acute myocardial infarction. *Psychosomatic Medicine* 69 (6) 501-508
- Bennett KS & Shepherd JM (2013) Depression in Australian women: the varied roles of spirituality and social support. *Journal of Health Psychology* 18 (3) 429-38 & Shepherd 2013
- Boger EJ, Demain SH, Latter SM (2014) Stroke self management: A focus group study to identify the factors influencing self-management following stroke. *International Journal of Nursing Studies* May 24. doi: 10.1016/j.ijnurstu.2014.05.006. [Epub ahead of print]
- Burton CR, Fargher E, Plumpton C, Roberts GW, Owen H and Roberts E (2014) Investigating preferences for support with life after stroke: a discrete choice experiment. *BMC Health Services Research* 14 (1) 63
- Brown K, Avis M and Hubbard M (2007) Health beliefs of African–Caribbean people with type 2 diabetes: a qualitative study. *British Journal of General Practice* 57 (539) 461–469.
- Corcoran N, Bone A and Everett C (2013) Using settings pp 112-133 in Corcoran N (Ed) *Communicating Health strategies for health promotion*, 2nd edition. Sage, London.
- Flick U, Von Kardoff E, and Steinke I (2005) *A companion to qualitative research* (2nd Edn) Sage, London
- Florez KR, Aguirre AN, Viladrich A, Cespedes A, De LA Cruz AA & Abraido-Lanza AF (2009) Fatalism or destiny? A qualitative study and interpretative framework on Dominican Women's breast cancer beliefs. *Journal of Immigrant Minority Health* 11 (4) 291-301
- Gioquinto S, Spiridigliozzi C and Caracciolo B (2007) Can faith protect from emotional distress after stroke? *Stroke* 38 (3) 993-997

Guidetti S, Ytterberg C, Ekstam L, Johansson U, Eriksson G (2014) Changes in the impact of stroke between 3 and 12 months post stroke, assessed with the stroke impact scale. *Journal of Rehabilitation Medicine* Sep 3. doi: 10.2340/16501977-1865. [Epub ahead of print]

Holt CL, Clark EM, Debnam KJ and Roth DL (2014) Religion and Health in African Americans: The Role of Religious Coping. *American Journal of Health Behaviour* 38 (2) 190-199

Ironson G, Stuetzle R and Fletcher MA (2006) An increase in religiousness/spirituality occurs after HIV diagnosis and predicts slower disease progression over 4 years in people with HIV. *Journal of General Internal Medicine* 21 Suppl 5: S62-8

Johnstone B (2008) Relationships among religiousness, spirituality and health for individuals with stroke. *Journal of Clinical Psychology in Medical Settings* 15 (4) 308-313

Kessler D, Egan M, Kubina LA (2014) Peer support for stroke survivors: a case study Disability Rehabilitation. *BMC Health Services research* 14: 256

Koffman J, Morgan M, Edmonds P, Speck P and Higginson IJ (2012) ‘The greatest thing in the world is the family’: the meaning of social support among black Caribbean and white British patients living with advanced cancer. *Psycho Oncology* 21 (4) 400-8

Kristeller JL, Sheets V, Johnson T and Frank B (2011) Understanding religious and spiritual influences on adjustment to cancer: Individual patterns and differences. *Journal Behavioural Medicine* 34 (6) 550-61

Lee KH & Hwang MJ (2014) Private religious practice, spiritual coping, social support and health status among older Korean adult immigrants *Social work and public health* 29 (5) 428-43.

Leach CR and Schoenberg NE (2008) Striving for Control: Cognitive, Self-Care, and Faith. Strategies Employed by Vulnerable Black and White Older Adults with Multiple Chronic Conditions. *Journal of Cross Cultural Gerontology* 23(4) 377-99

Leyva B, Allen JD, Tom LS, Ospino H, Torres ML, Abraido-Lanza AF (2014) religion, fatalism and cancer control: a qualitative study among Hispanic Catholics. *American Journal of Health Behaviors* 38 (6) 839-49

Morgernstern LB, Sanchez BN, Skolarus LE, Garcia N, Risser JM, Wing JJ, Smith MA, Zahuranec DB & Lisabeth LD (2011) Fatalism, optimism, spirituality, depressive symptoms, and stroke outcomes: a population-based analysis. *Stroke* 42 (12) 3518-23

NICE (2013) Stroke rehabilitation; Long term rehabilitation after stroke CG162, Nice UK available at www.nice.org.uk/guidance/cg162

Norris M, Allotey P and Barrett G (2012) 'It burdens me': the impact of stroke in central Aceh, Indonesia. *Sociology of Health and Illness* 34 (6) 826-840.

Omu O & Reynolds F (2014) Religious faith and self-efficacy among stroke patients in Kuwait: health professionals' views. *Disability Rehabilitation* 36 (18) 1529-35

Rimando M (2013) Factors influencing medication compliance among hypertensive older African American adults. *Ethnicity and Disease* 23 (4) 469-73

Rippentrop AE, Altmaier EM, Chen JJ, Found EM and Keffala VJ (2005) The relationship between religion/spirituality and physical health, mental health and pain in a chronic pain population. *Pain* 116 (3) 311-321.

Satnik T, Cup EH, de Swart BJ, Nijhuis-van der Sanden MW (2014) How is self management perceived by community living people after a stroke? A focus group study. *Disability Rehabilitation* May 14:1-8. [Epub ahead of print]

Saunders DH, Sanderson M, Brazzelli M, Greig CA and Mead GE (2013) Physical fitness training for stroke patients. *Cochrane Database* Oct 21 10: CD003316.

Schoenberg NE, Travick LS, Jacobs-Lawson J and Kart CS (2008) Diabetes Self-care among a Multi-ethnic Sample of Older Adults. *Journal of Cross Cultural Gerontology* 23 (4) 361–376

Skolarus LE, Burke JF, Brown DL and Freedman VA (2014) Understanding stroke survivorship: expanding the concept of post stroke disability. *Stroke* 45 (1) 224-30

Smith CA (2012) Living with sugar: influence of cultural beliefs on type 2 diabetes self-management of English speaking Afro-Caribbean women. *Journal of Immigrant and Minority Health* 14 (4) 640-7

Smith J and Osborn M (2004) Interpretative phenomenological analysis. In G. Breakwell (Ed) *Doing social psychology research*. Oxford BPS Blackwell.

Smith J, Jarman M, and Osborn M (1999) *Doing interpretative phenomenological analysis*. In M, Murray and K, Chamberlain (Eds) *Qualitative health psychology: Theories and methods* Sage, London

Sophie G, Benoit T, Annie L, Patrick F, Cosmin A (2014) Factors influencing prognosis and functional outcome one year after a first time stroke in the Caribbean population Archives Physical Medical rehabilitation. Jul 29. doi: 10.1016/j.apmr.2014.07.394. [Epub ahead of print]

Sternthal MJ, Williams DR, Buck AC (2012) Religious practices, beliefs and mental health: variations across ethnicity. *Ethnicity and Health* 17 (1-2) 171-85

Sprigg N, Selby J, Fox L, Berge E, Whyne D and Bath PM (2013) Very low quality of life after acute stroke: data from the Efficacy of Nitric Oxide in Stroke trial. *Stroke* 44 (12) 3458-62

Stroke Association (2013) Stroke statistics available at <http://www.stroke.org.uk/sites/default/files/Stroke%20statistics.pdf> last accessed 03 04 14

Trivedi RB, Bryson CL, Udris E and Au DH (2012) The influence of informal caregivers on adherence in COPD patients. *Annals of Behavioural Medicine* 44 (1) 66-72

Wang YC, Kapellusch J and Garg A (2013) Important factors influencing the return to work after stroke *Work* Mar 26 [Epub ahead of print]

White JH, Patterson K, Jordan LA, Magin P, Atia J & Sturm JW (2014) The experience of urinary incontinence in stroke survivors: a follow up qualitative study. *Canadian Journal of Occupational Therapy* 81(2):124-34.

Table 1 Description of participants
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Lucy: A 80-year-old woman from St Lucia. She had a right-sided stroke six years ago and lives with her husband and two sons. She can no longer attend church due to her stroke disability.
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Jenny: A 72 year old woman from Jamaica. She has a history of TIAs and she had a right-sided stroke three years ago. She lives with her second husband. She has three children and although none of her children live at home they are all within driving distance. She attends church regularly twice on Sundays.
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Doris: A 65-year-old woman from Jamaica. She has had a left sided stroke for more than five years. She now lives on her own, but her children are all within driving distance.

Believes in God but not a regular church attendee.

Margot: A 47 year old woman originally from Trinidad. She suffered a single stroke attack seven years ago. She is a single parent and lives with her teenage daughter. Did not express any religious beliefs.

Marie: A 82-year-old woman from St Lucia. She had a left sided stroke five years ago. She is single and lives in sheltered accommodation, with no close family or relatives. She believes in God and attends church regularly

Queenie: A 49-year-old woman from Jamaica. She had her first stroke in 1994 and then subsequent strokes in 1998 and 1999. She lives with her husband and has three children. Did not express any religious beliefs.

Mildred: A 67-year-old lady from St Lucia. Married with a husband and 4 adult children. She had a right-sided stroke 4 years ago, she is able to mobilise and communicate all her needs with minimal assistance. She believes in God but does not always attends church.