EXPLANATORY MODELS OF RECOVERY FROM STROKE WITHIN THE AFRICAN-CARIBBEAN COMMUNITY IN CANADA

by

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Abstract

Stroke is the most common serious neurological condition worldwide. Members of the Black population are at an increased risk of suffering a stroke due to several risk factors which are more prevalent in this racial group. The purpose of this qualitative research study is to describe how African-Caribbean stroke survivors, who live in Canada, understand their illness and manage their care during the early recovery period.

Eight participants who were of African-Caribbean origin who were living in Canada and recovering from a stroke were interviewed. Results of the study indicate that participants were not knowledgeable about the risk factors for stroke, they did not recognize the warning signs of a stroke as a medical emergency, and they did not always follow treatment regimes recommended by their physicians. Participants in the study described stroke as a catastrophic event, resulting in feelings of intense fear, being out of control, uncertainty, yearning for their old self, and feelings of detachment from their own body. Motivating factors in their recovery from stroke were the support of family, their own individual personal determination, and the acceptance of the illness by the participants. Nurses and physiotherapists were valued by the participants due to the role they played in improving their functional abilities.

Participants expressed a desire for nurses to become knowledgeable about the African-Caribbean culture, in order to provide them with education pertaining to diet as well as steps they can take to reduce their risk of having another stroke.

Responding to the care needs of this population will require individualized nursing care which considers the influence of culture on how the illness is perceived.
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Chapter 1

Introduction

Stroke is the most common serious neurological condition worldwide (Lindsay, Kapral, Gladstone, Holloway, Tu, Laupacis & Grimshaw, 2005). It is the third leading cause of death and the number one leading cause of serious long-term disability (Heart and Stroke Foundation of Canada, 2003). The disease poses a serious health threat, as demonstrated by results obtained from the Canadian Stroke Quality of Care Study (Lindsay et al., 2005) which estimates that every ten minutes someone in Canada suffers a “brain attack” requiring hospital admission. The cost to our healthcare system is calculated at $2.7 billion dollars per year (Lindsay et al., 2005). In large part, the growing burden of stroke will result from what is termed the “greying of Canada” (Heart and Stroke Foundation of Canada, 2003). In 2003, an estimated 4.6 million Canadians were 65 years of age or older; a number that is expected to double in the next 25 years (Statistics Canada). With the growing problem of rising healthcare costs, many people worry that an aging population will put an extra burden on the Canadian healthcare system.

The incidence of stroke is higher in Blacks as compared to Caucasians (Gillum, 1999; McGruder, Malarcher, Antoine, Greenland & Croft, 2004; Howard, Prineas, Cushman, Kellum, Temple, Graham & Howard, 2006). In a study of the variations in mortality rates for stroke in Black communities, it was found that Blacks have more than double the risk of stroke compared to Caucasians, regardless of the country or ethnicity of the Black group (Wolfe, Corbin, Smeeton, Gay, Rudd, Hennis, Wilks & Fraser, 2006). Worldwide, stroke is considered to be an important cause of mortality and morbidity in Blacks (Gillum, 1999).
In examination of the needs of stroke survivors, the Canadian Stroke Best Practice Recommendations (CSS, 2006) indicate that information and education be provided to all stroke patients and their families, at all stages of care in a timely and interactive manner, in a variety of languages and information formats that are specific to patient and family needs and impairments. Despite the importance placed on education in clinical practice guidelines, many research studies have found that stroke survivors and their families are frequently dissatisfied with the content, quantity and quality of information received from health care professionals while in hospital, regarding all aspects of stroke and the support available to them in the community (Garrett & Cowdell, 2005; Hanger & Wilikinson, 2001; Rodgers, Bond & Curless, 2001). Such dissatisfaction could be remedied by improved communication between patients and health professionals.

Communication has been shown to be a major determinant of patient compliance, satisfaction and appropriate use of health facilities. In addition, the influence of culture on the illness response must be given equal consideration. When cultural influences are not taken into consideration, substantial problems have been shown to arise in patient care (Kleinman, 1978).

Purpose of the Study

Worldwide, stroke is considered to be an important cause of mortality and morbidity in Blacks (Gillum, 1999). As a result of the tremendous burden stroke poses to the economy and the health status of patients, education pertaining to the needs of stroke survivors is regarded as being of paramount importance (Ovbiagele & Levine, 2006). However, no serious attempt at reducing the economic burden of stroke can be made without specifically targeting the groups at the highest risk (Ovbiagele & Levine, 2006). Understanding the illness experience from the patient’s
perspective is deemed to be an essential component in the development of appropriate strategies to facilitate recovery (Burton, 2000). It is due to these reasons that this study was undertaken.

The purpose of this study is to describe how African-Caribbean stroke survivors, who live in Canada, understand their illness and manage their care during the early recovery period.
Chapter 2

Literature Review

A review of the literature reveals a large body of research on stroke, primarily having to do with etiology. Gaps in the literature exist on the psychosocial effects of stroke, the educational needs of stroke patients, the recovery process, and the experience of stroke in particular ethnic groups. The literature review presented here will highlight some of the major themes found in the literature related to the experience of stroke among Blacks, issues pertaining to the recovery process and the use of the explanatory model of illness framework to assess the influence of culture on the illness response.

Search Strategy

In order to gain a better understanding of the effect of stroke within the Black population, a search of the literature was undertaken. The following key words were used: stroke, cerebrovascular accident, explanatory models, health beliefs, recovery, African-Caribbean, African-American, Black, quality of life, self-care, and lived experience. Searches were limited to peer-reviewed studies published between 1978 to 2009. Databases accessed were: the Cochrane Collaboration of Systematic Reviews, CINAHL, Medline, Embase, and PsychInfo. In addition to these search engines, information was obtained through the Statistics Canada website.

The Caribbean Community in Canada

Results of an Ethnic Diversity Survey conducted by Statistics Canada (2003) indicate that Canadians of Caribbean origin make up one of the largest non-European ethnic origin groupings in Canada. In 2001, over half a million people of Caribbean origin lived in Canada. That year,
they represented almost 2% of the total population of Canada. The Canadian population of Caribbean origin is largely concentrated in Ontario and Quebec. In 2001, 91% of people who reported being of Caribbean origin lived in one of these two provinces; Ontario was reported as being home to 69% of the overall Canadian Caribbean community, while 22% lived in Quebec. The Caribbean community in Canada is also growing considerably faster than the overall population. Between 1996 and 2001, the number of people who reported being of Caribbean origin rose by 11%, while the overall population grew by only 4% (Statistics Canada, 2007).

The effect of a stroke on the economic status of Caribbean Canadians is apt to be greater than that of other Canadians for the following reasons: only 37% of Canadians of Caribbean origin are married, compared with approximately 50% of adults in the overall population; people of Caribbean origin are less likely to have a university degree; the average incomes of Canadians of Caribbean origin are approximately $4,000 lower than the national average; 69% of senior women of Caribbean origin who live alone are considered to have low incomes. The Caribbean community in Canada is relatively young; in 2001 people aged 65 and over made up only 6% of the Caribbean community in Canada compared with 12% of all Canadians (Statistics Canada, 2007). These statistics help to illustrate the financial burden stroke may pose on the socioeconomic status of Caribbean Canadians.

Significance of Stroke in Blacks

Studies undertaken on the topic of racial disparities in stroke are well documented within the United States compared to Canada. While the Canadian government reports on demographics related to stroke, reports according to race are unavailable. In the U.S., of the three leading causes of adult death – heart disease, cancer, and stroke – the disparity in the ratio of black to white mortality is greatest for stroke (Gorelick, 1998). Blacks are reported as having a higher
incidence of stroke, more severe strokes and higher stroke mortality than Caucasians (Bravata, Wells, Gulanski, Kernan, Brass, Long & Concato, 2005).

Studies examining the rehabilitation outcome of Blacks following stroke has shown that Blacks have worse functional status after stroke than Caucasians (Bhandari, Kushel, Price & Schillinger, 2005; Horner, Swanson, Bosworth & Matchar, 2003; Kuhlemeier & Steins, 1994). Blacks experience less functional improvement from in-patient rehabilitation compared to Caucasians, even though both groups received similar intensity of rehabilitation services. Possible explanations provided for the observed difference may be in the patient experience with rehabilitation or the quality of services provided (Bhandari et al., 2005).

In a study examining racial and ethnic disparities in the prevalence of stroke, the overall death rate for stroke for all Americans in the year 2000 was 60.8 per 100,000, the rates for black males and females were considerably higher at 87.1 and 78.1 per 100,000 (McGruder et al., 2004). What is equally disturbing is the age at which stroke occurs in members of the Black community, being most pronounced at younger ages (Gorelick, 1998). In a U.S. population based study of stroke (Kissela, Schneider, Kleindorfer, Khoury, Miller, Alwell, Woo, Szaflarski, Gebel, Moomaw, Pancholi, Jauch, Shukla, & Broderick, 2004), stroke risks in Blacks were shown to be higher at all ages but excessively so in the younger age category of 35 to 54 years of age. U.S. stroke-related mortality rates in 1998 among individuals 25 to 64 years of age were three times higher in blacks than whites; it is not until >65 years of age that the rates become similar between the groups (Kissela et al., 2004).

Two possible explanations have been provided for the excess stroke mortality among Blacks: stroke occurs more commonly among Blacks, particularly among the young and middle-aged or Blacks have a higher likelihood of case fatality following stroke (Kissela et al., 2004). In
terms of the racial differences in stroke subtype, Blacks have been shown to have a higher incidence of subarachnoid hemorrhage and intracerebral hemorrhage (Gorelick, 1998; Wolfe, et al., 2006). The substantial excess burden of stroke incidence among Blacks represents one of the most serious health problems facing the United States (Kissela et al., 2004).

While the majority of the literature detailing the disparities in stroke originates in the U.S., the United Kingdom also considers the higher stroke incidence of Blacks compared to Caucasians to be a major public health issue (Wolfe et al., 2006).

This leads one to ask the question Why the disparity in stroke? Indeed many researchers have asked this question and have carried out studies in an effort to understand some possible reasons for this excess stroke burden. Let us now consider how stroke risk factors vary between Blacks and Caucasians, which may account for the differences observed.

Differences in Stroke Risk Factors

Several explanations have been proposed for the excess stroke mortality and risk in African Americans: higher prevalence of cardiovascular risk factors, greater severity of risk factors or greater sensitivity to the risk factors, and lack of access to care (Gorelick, 1998). Modifiable cardiovascular disease risk factors such as hypertension, diabetes mellitus, smoking, and obesity have been found to be more prevalent in African Americans (Gorelick, 1998). While the number of strokes attributable to hypertension and diabetes are higher in Blacks, the number attributable to atrial fibrillation is higher in Caucasians (Bravata et al., 2005; Gorelick, 1998; McGuruder et al., 2004).

In a U.S. study looking at the racial and geographic differences in awareness, treatment, and control of hypertension (Howard et al., 2006), researchers found that although the prevalence
of hypertension was substantially higher in Blacks, they reported poorer control of the illness compared to other racial groups.

Similarly, in a Canadian study conducted to evaluate the prevalence and management of hypertension among adults in the province of Ontario (Leenen, Dumais, McInnis, Turton, Stratychuk, Nemeth, Lum-Kwong & Fodor, 2008), researchers found that while the prevalence of hypertension was greatest among Blacks, this group also reported the least control of their illness. For the purpose of this study, hypertension was defined as a mean systolic blood pressure of 140 mm Hg or higher, a mean diastolic blood pressure of 90 mm Hg or higher or current treatment with antihypertensive medication. Hypertension, including inadequate control of hypertension, has been suggested as 1 of the 3 most likely causes of stroke (Howard et al., 2006).

With regard to severity of risk factors and possible sensitivity to risk factors, there is evidence to suggest that the occurrence of hypertension in Blacks may in part be due to salt sensitivity, leading to the occurrence of a volume type of hypertension (Gorelick, 1998).

Some potential reasons stated for poorer hypertension control in Blacks are: there may be racial differences in the aggressiveness of treatment or the quality of follow-up, it is possible that specific medications are less effective in Blacks than Caucasians due to genetics or reasons related to diet or lifestyle, it is also possible that Blacks find the side effects associated with the treatment of hypertension less acceptable (Howard et al., 2006). In a U.K. study, hypertensive patients of Afro-Caribbean ethnicity were found to be less likely to use anti-hypertensive medication than European patients (Kaplan, 1994).

While cardiovascular disease risk factors, such as hypertension and diabetes mellitus, account for some of the disproportionate stroke burden in African Americans, studies conducted have found that socioeconomic status is an additional factor which may play a role (Bravata et al.,
Poverty can shorten the average person’s life span by up to 10 years (Kleindorfer et al., 2006). Socioeconomic status (SES) and its relation to stroke mortality have been extensively investigated within the literature. Lower SES has been associated with a higher mortality after stroke in both Europe and the United States (Kleindorfer et al., 2006).

The primary measures of SES have been education, occupation and income (Gorelick, 1998). In a U.S. population based study looking at the impact of socioeconomic status on stroke incidence (Kleindorfer et al., 2006), researchers found that 39% of the racial disparity in stroke incidence for Blacks was associated with poorer SES; the remainder was unexplained. There is likely significant overlap between the prevalence of risk factors and SES, and there may also be differences in medical control of risk factors associated with SES (Kleindorfer et al., 2006). The study by Bravata et al. (2005), support the hypothesis that ethnic disparities in stroke are caused in part by lower socioeconomic status. Results of their research showed that low income was independently associated with stroke; however, ethnicity was not independently associated with stroke. Ethnicity was independently associated with stroke after adjustment for having no insurance.

Traditionally, African Americans have had less access to medical care (Gorelick, 1998). Reasons cited for this are inequalities in the distribution of healthcare insurance, utilization of procedures, treatments, and surgery, and mistrust of health institutions. In addition, African Americans have faced other barriers to healthcare participation such as economic factors, social isolation, lack of awareness of disease risk factors, lack of knowledge of warning signs, treatment programs, and communication barriers (Gorelick, 1998). Access to medical care and lack of
knowledge would appear to be a logical explanation of the excess stroke burden in African Americans. Unlike the United States where SES and limited access to medical care has been listed as potential factors contributing to the higher incidence of stroke in Blacks, the literature points to different factors possibly at play within the Canadian population.

In a study by the Heart and Stroke Foundation of Ontario on the prevalence and control of hypertension in ethnic Canadians (Leenen et al., 2008), it was reported that while Blacks have the highest prevalence of hypertension, they report the least control of their illness. Failure to receive treatment does not appear to be a reason for this tragedy, since 90% of Blacks having hypertension report receiving treatment for their illness (Leenen et al., 2008). Discovering the reasons for Blacks having such poor control of their hypertension, is not an easy task to undertake, considering that the literature as it relates to ethnicity and health care access in Canada is limited.

Canada, as well as western European countries are said to have efficient, publicly funded health care systems (Leenen et al., 2008). The universal health care system which exists in Canada appears to be a factor in minimizing health implications due to SES, as shown in the study by Wu and Schimmele (2005). The purpose of the research carried out by Wu and Schimmele (2005), was to investigate whether racial/ethnic disparities exist in Canada and whether behavioral differences between minorities and non-minorities account for such disparities. Results of their study showed that socioeconomic and behavioral perspectives fail to explain racial/ethnic health patterns in Canada.

In an effort to understand the possible links between ethnicity, income and access to health care in the Atlantic region of Canada, authors Sharif, Dar & Amaratunga (2000) completed
a synthesis of the literature which exists on the topic in Atlantic Canada. The major points which were highlighted as affecting the access to healthcare by ethnic groups included: the lack of effective ethnic representation of healthcare professionals on bodies providing healthcare or involved in making policies, cultural differences in the perception of health and hence the need for healthcare, language and communication barriers resulting in ethnic groups being unclear about the health care services that are available to them, racism within the healthcare system which may affect the care that minorities receive as well as the extent to which they may utilize healthcare services. The literature review carried out also points to the knowledge gap which exists in the health care system; the lack of awareness on the part of professionals about the health care perceptions and needs of ethnic individuals.

Renewed efforts for secondary prevention of stroke are stated to be particularly needed (McGruder et al., 2004). Creating culturally appropriate public health messages and intervention strategies for persons with stroke, is recommended as an avenue to reduce the morbidity and mortality among high-risk ethnic groups (McGruder et al., 2004).

*Stroke Recovery Process*

The experience of recovery from stroke receives limited description within research studies. As a disease process the biomedical interpretation of stroke appear to predominate (Burton, 2000).

Doolittle (1992) suggests that patient and professional interpretations of recovery can differ significantly; consequently, the reference frames for the evaluation of recovery can be at odds with each other. In a phenomenological study, Burton (2000), tracked the experience of six patients admitted to a rehabilitation unit in north-west England for a period of twelve months. The
The aim of the study was to identify the lived experience of recovery from stroke from the patient’s perspective.

Results of the study point to stroke being an intensely personal experience, involving the rebuilding and restructuring of an individual’s world. The social context of recovery was found to be extremely important to participants, where the focus of recovery was on adaptation and the development of coping skills, rather than simply improvement in physical function alone. This suggests that professional interpretations of recovery may have limited relevance to the concerns and experiences of the individual (Burton, 2000).

Additional studies reporting patients’ concepts of recovery have also found a mismatch between their views and those of professionals (Doolittle, 1991; Hart, 1998; Dowswell, Lawler, Dowswell, Young, Forester & Hearn, 2000). While professionals measure recovery in terms of regaining function, for patients, recovery can mean a return to their pre-stroke life. Current methods of assessing progress after stroke have been criticized for failing to take into account patients’ ideas about what recovery means to them (Dowswell et al., 2000).

The impact of stroke on survivors has repeatedly been described as “loss” in the qualitative research literature with the significance of decreased functional ability being explained in terms of loss of activities, abilities, personal characteristics and independence, emotional and social loss, and a loss or change in the individual’s own identity (McKevitt, Redfern, Mold & Wolfe, 2004).

In a qualitative descriptive exploratory study conducted to enhance understanding about quality of life after a stroke from the patient’s own perspective (Pilkington, 1999), suffering emerges with unaccustomed restrictions and losses after a stroke. Quality of life was shown to be
enhanced through participants developing a new appreciation for the ordinary hopes and dreams of new possibilities, and relationships that uplift the self.

Since returning to one’s previous lifestyle and activities may be improbable following a stroke, changing how the situation is perceived appears to be the most effective way of coping, in order to enhance one’s quality of life (Rochette, Tribble, Desrosiers, Bravo & Bourget, 2006). Studies suggest that it is more important for individuals who have had a stroke to adapt to and accept their new situation rather than to recover specific abilities (Burton, 2000; Bendz, 2003).

It is not surprising to discover that motivation plays an important role in maximizing the recovery process of stroke survivors (Robinson-Smith & Pizzi, 2003). One important concept that is believed to influence people’s motivation is self-efficacy (Dixon, Thornton & Young, 2007). Self-efficacy is a person’s belief about his or her capabilities to perform an activity that has influence over events affecting his or her life. Self-efficacy influences motivation by determining the goals people set, how much effort they invest in achieving those goals, and their resilience when faced with difficulties or failure (Dixon et al., 2007). The degree of belief in one’s capability affects the manner in which challenging activities are approached (Robinson-Smith & Pizzi, 2003).

An important component of self-efficacy is self-care. The World Health Organization defines self-care as the activities individuals, families and communities undertake with the intention of enhancing health, preventing disease, limiting illness and restoring health (W.H.O, 1983).

In a study examining self-care behavior among chronically ill African-Americans (Becker, Gates & Newsom, 2004), self-care practices were found to be culturally based. African-Americans integrated basic cultural approaches to self-care with the development of specific
biomedical self-care approaches and applied them to their chronic illnesses. Central to the development of self-care approaches were spirituality, social support and advice from relatives and close friends, and the use of traditional medicine. In the face of ongoing health disparities, public health efforts to build on the cultural aspects of self-care, is regarded as one step toward reducing morbidity and mortality among racial/ethnic minorities (Becker et al., 2004).

The process of adjustment after stroke has been described as difficult and slow, presenting survivors with unexpected obstacles (McKevitt et al., 2004). It was argued in one study that previous experience of illness and hardship helps some people accept the difficulties of life after stroke in an unproblematic way (Pound, Gompertz & Ebrahim, 1998). With the many challenges that stroke presents in the lives of individuals, it has been suggested that further qualitative research be undertaken to shed light on patient’s experience of being ill with stroke, and the process of recovery (Hafsteinsdottir & Gryndonck, 1997). Such research may help nurses to individualize nursing care designed to meet the stroke patient’s physical as well as psychosocial needs. By doing this, I believe that as health professionals we will be on the road to truly providing patient centered care, a necessary component in today’s health care arena.

Cultural Explanations of Illness

Nurses are constantly seeking to understand how people’s cultural beliefs of health and illness affect their experience and yet there is sparse literature about how to elicit cultural beliefs or incorporate them into healthcare practice (Meetoo & Meetoo, 2005). According to Kleinman (1980), illness is culturally shaped in the sense that how one perceives, experiences and copes with illness is based on one’s explanation of sickness.

Kleinman suggested that exploring the patient’s explanatory model of illness facilitates effective health communication which is a major determinant of patient compliance, satisfaction
and appropriate use of health facilities (Kleinman, 1978). The concept of explanatory models emphasizes understanding the illness from an individual’s perspective. Explanatory models are personal beliefs used to recognize, interpret, and respond to a specific illness experience; these models help people cope with and make sense of an illness (McSweeney, Allan & Mayo, 1997).

The use of the explanatory model of illness framework captures both the individual as well as the cultural group’s understanding of disease and illness. Since clients and health professionals frequently have different ways of viewing illness, it is important that discussions take place to increase understanding and identify commonalities (Kleinman, 1980).

Explanatory models are subjectively and personally constructed, reflecting the culturally situated meaning of an illness (Meetoo & Meetoo, 2005). The five components of explanatory models include: beliefs about etiology, onset of symptoms, pathophysiology, course of illness and treatment (Skelly et al., 2006). The explanatory model determines the meanings and expectations associated with the illness (Srivastava, 2007).

Of particular importance is the finding that health professionals and patients frequently have different explanatory models and their differing views often result in conflicting expectations concerning treatment, outcomes and evaluations (McSweeney et al., 1997). Conflicting models between health professionals and patients are said to impede health care, leading to substantial problems in patient care (Kleinman, 1978). This can result in non-adherence, dissatisfaction, inappropriate treatment, and overall poor quality of care (McSweeney et al., 1997).

Studies of explanatory models of illness were first used by medical anthropologists to understand health practices in a variety of cultures (Meetoo & Meetoo, 2005). The model has been
used in many disciplines as a foundation for research studies with both sick and healthy individuals.

In a study examining the explanatory model of Filipino Americans with hypertension (dela Cruz & Galang, 2008), researchers discovered several misconceptions that the participants possessed regarding their illness. They claimed that they could detect when their blood pressure was high through a variety of symptoms. In addition, the study revealed that many of the participants believe in the role of spirituality in relieving stress and therefore reducing high blood pressure.

The explanatory model of illness framework has been used in studies undertaken to explore the cultural beliefs of ethnic groups regarding diabetes (Heuer & Lausch, 2006; Jezewski, 2002; Meeto & Meeto, 2005). The studies described the usefulness of the explanatory model of illness framework as a foundation for clinical practice. It is an avenue whereby nurses can access important data such as: similarities and differences between patients’ explanation of their illness and that of the healthcare professional, as well as bringing to light point of views related to treatment which may inhibit the plan of care.

In a qualitative descriptive study by Skelly, Dougherty, Gesler, Burns & Arcury (2006) to examine the beliefs of African Americans about diabetes, the use of the explanatory model of illness framework was shown to be an effective means for informing the development of culturally sensitive diabetes prevention programs specific to the needs of this ethnic community.

The explanatory model of illness framework is regarded as relevant when assessing, planning, implementing, and evaluating care (Meeto & Meeto, 2005). It enables nurses to
provide culturally appropriate care for their patients, targeting treatment plans which addresses lifestyle, illness concerns, and the priorities of the individual (McSweeney et al., 1997).

As a sensitizing framework, Kleinman’s explanatory model of illness (1978) was used to explore the perspective of African Caribbean Canadians who have had a stroke. The questions contained within the model, have the potential to assist the researcher in gathering rich descriptions of the illness perception of African-Caribbean people on the topic of stroke and the recovery process.
Chapter 3

Method

The rationale for undertaking this study is to provide a description of how stroke is experienced within the African-Caribbean community of Canada. The information generated from this study will be useful in the design of educational interventions to increase the awareness of individuals within this community to the risks of stroke as well as to assist in their recovery process. Following are the research questions which arose from a review of the literature on stroke in the Black community, the research design of the study, the sampling technique and the steps to recruit participants for the study. Challenges to recruitment and the steps taken to deal with this issue are also presented. The chapter concludes with the sources of data collection, analysis of the data, and the process by which the researcher ensured trustworthiness of the study.

Statement of Purpose

The purpose of this qualitative research study is to describe how African-Caribbean stroke survivors, who live in Canada, understand their illness and manage their care during the early recovery period. Challenges encountered in self-care in addition to cultural aspects of care that African-Caribbean stroke survivors consider important are also explored. The results of this study and the information generated may help in the design of educational interventions which are culturally appropriate for members of the Black community.
Research Questions

The study addressed the following research questions:

1. What are the thoughts and beliefs of African-Caribbean Canadians about stroke?
2. What do they identify that was helpful during their first months of recovery from a stroke?
3. What cultural aspects of care do they consider important in their recovery process?
4. What challenges have they encountered in self-care during the early recovery period?

Research Design

A qualitative descriptive study was designed to explore the early illness experience and early recovery period among stroke survivors in the African-Caribbean community. The strength of a qualitative descriptive design is the ability to identify meanings and to develop concepts of the phenomenon in question (McKevitt, Redfern, Mold & Wolfe, 2007). Since participants in the study were being asked to provide a description of their post-stroke illness experience, and highlight challenges they face around self-care, it seemed fitting that a qualitative descriptive study amenable to obtaining straight and largely unadorned answers to questions (Sandelowski, 2000), would be a good fit towards answering the research questions.

The study was guided in part by Kleinman’s explanatory model of illness (Kleinman, Eisenberg & Good, 1978), as it relates to the cultural meanings attached to the illness experience.
**Sampling**

A purposeful sampling technique was used in conducting the study. The aim of this technique is to select appropriate sources of information (i.e. people, places, events), which will address the research question and serve to best inform the study (Fossey, Harvey, McDermott & Davidson, 2002). The population for the study was African-Caribbean stroke patients living in the Greater Toronto Area. The inclusion criteria were individuals self-identified as African-Caribbean, 1st incident of stroke, adult; able to give informed consent, diagnosed within the past two years and capable of giving adequate descriptions of their experience.

The term African-Caribbean usually refers to people with African ancestral origins who migrated via the Caribbean islands. African Caribbean people have cultural values, which are different from other African populations in terms of language, diet, customs, beliefs and migration history (Agyemang, Bhopal & Bruijnzeels, 2005). Given the variations even within the African-Caribbean community, lumping them together with African populations from Africa as one homogenous ethnic group, leads to differences between them being ignored. Based on this knowledge, as well as recognizing that explanatory models of illness are culturally shaped, the researcher chose to narrow the classification of Black to individuals fitting a specific cultural background.

**Recruitment and Data Collection**

Participants were recruited through the out-patient stroke clinics of two teaching hospitals within the Greater Toronto area (GTA), the out-patient rehabilitation unit of a community hospital in Mississauga, Ontario, and stroke recovery associations in the GTA. The researcher met formally with the medical director and the nurse clinicians of the out-patient stroke clinics, to
explain the rationale for the study and to respond to any queries. The nurse clinicians were asked, by the researcher, to approach potential participants who met the criteria for the study during their follow-up appointments. If the individual was agreeable, the nurse clinician provided contact information to the researcher, who arranged to meet with the stroke survivor at a mutually agreeable time and place.

Recruitment through the out-patient rehabilitation unit consisted of the researcher meeting formally with the manager of the unit to advise her of the study and to respond to any queries. The manager conducted a search of her database, of past clients meeting the criteria of the study. She then contacted the individuals personally to advise them of the study and gain their verbal consent for their contact information to be relayed to the researcher. The researcher then contacted each individual to explain the study in greater depth and arrange a private interview session with each person who agreed to participate.

There were some challenges encountered with respect to recruiting participants for the study. Due to the study being limited to individuals from a specific cultural group, it took several months to recruit a few participants. A request for an amendment to the study was made to the Research Ethics Board of Queen’s University to include Stroke recovery associations in the GTA as potential sources of recruitment (see Appendix I). Stroke Recovery Canada and Next Step to Active Living Program were added as sources of recruitment. A written overview of the study (see Appendix A) was submitted by the researcher to the Coordinator of each organization.

Stroke Recovery Canada advertised the study in their community newsletter, which was forwarded to each of their members. The coordinator of Next Step to Active Living program forwarded an overview of the study to each individual within their program who met the
inclusion criteria. It was then left to the individual to contact the researcher directly to express their desire to take part in the study.

Participant recruitment continued to be difficult. Following a meeting with members of the thesis committee, it was decided that the time frame of diagnosis with stroke should be extended from the initial inclusion criterion of six months to two years, as a way of increasing the number of participants. An additional request for an amendment to the study was made to the Research Ethics Board of Queens University (see Appendix J). During the course of five months, seven participants were recruited for the study. Following three months of no additional individuals being recruited, a final participant was added to the study who had sustained a prior stroke. It was decided to include this individual in the study since he did not have any lasting disabilities as a result of his first stroke. Following nine months of recruitment, a total of eight participants agreed to take part in the study. During the period of recruitment, three additional individuals were referred by the nurse clinicians of the out-patient stroke clinic of one of the teaching hospitals. These individuals were not included in the study since one had a speech impairment making it difficult to communicate his experience of stroke, a second who had expressed a desire to take part in the study could not be contacted for an interview, and the third individual subsequently decided she was not ready to share her experience of having sustained a stroke.

Ethical Considerations

The study was approved by Queen’s University Ethics Board, prior to data collection. Permission and ethics approval was also obtained from the institutions from which the participants were recruited.
Prior to any interviews taking place, informed consent (see Appendix B) was obtained in writing from each participant. The researcher informed the participants that their involvement in the study was completely voluntary, and that they could withdraw from the study at any time.

Each participant was given a copy of their signed consent form as well as informed that the researcher would be available throughout the study to answer any questions they may have. The rationale for this was based on the results of a qualitative study by Corbie-Smith, Thomas, Williams and Moody-Ayers (1999) describing barriers to participation of African Americans in research. Study participants recommended that copies of all signed documents related to their involvement in the research be distributed to them as well as the assurance of health professionals conducting the research, to be available for questions during the course of the study.

To ensure confidentiality, the names of participants were not used on any documentation or transcripts. Recordings were stored in a locked drawer when not in use and computerized files were encrypted, with only members of the research team able to access them.

Socio-demographic data (see Appendix D) were collected by way of a self-report, at the beginning of the interview. Interview sessions were held at a location of the participant’s choice, often taking place within the clinical setting or within the individual’s home. If requested, the presence of a family member was permitted.

*Interviews*

Semi-structured interviews, with the use of open-ended questions relevant to the research objectives were used (see Appendix E). The reason this method was chosen, was to allow participants free expression; to tell their story without restrictions. A major benefit of such a method is the richness it brings to the data being collected (Burton, 2000). Interview questions
were developed based on Kleinman’s explanatory model of illness (1978) to elicit participants’ thoughts and beliefs about their illness. They were also asked to describe their daily self care and what was helpful in the early months of recovery (see Appendix E).

Prior to actual data collection, the researcher conducted two practice interviews for the benefit of refining the questionnaire as required. Lessons learnt during the practice interviews were to refrain from using clinical terms, but rather make a point of using layman terms. For example instead of using the term ‘hypertension’, the term ‘high blood pressure’ was used, when discussing the two different types of stroke, the term ‘ischemic’ was replaced with ‘blood clot or interruption of oxygen to the brain’ and the term ‘hemorrhagic’, was replaced with ‘bleeding in the brain’. Another lesson learnt was to allow more time for individuals to expand on their thoughts. The researcher would use the technique of prompting to assist individuals to expand or clarify their thoughts. This technique was applied primarily when questioning participants concerning what they thought caused their illness, their hopes regarding treatment that they were receiving, what they found helpful in the first few months of their recovery as well as the ways in which nurses can assist someone of their culture recovering from stroke. During the period of data collection, interview sessions lasted a range of 30 to 60 minutes with an average of 45 minutes. The interviews ended when participants finished what they had to say about their experience.

Data Analysis

Interviews were tape recorded and transcribed verbatim. The researcher also included the non-verbal cues of the participants such as gestures, laughter, sighs, and crying. It has been said that meaning is partly created by how a message is communicated (Graneheim & Lundman (2003). Therefore, when transcribing interviews and observations into text, it is valuable to
notice non-verbal cues seeing that they may influence the underlying meaning of the text (Granehim & Lundman, 2003). Transcripts were closely examined and read as a whole several times, to gain a full description of the illness perception of each participant. Key phrases were coded by the researcher and the thesis supervisor. Throughout the research process the researcher met face to face with the thesis supervisor for the purpose of comparing codes. Qualitative content analysis was used as a means for establishing codes; from which themes could emerge. Qualitative content analysis is data-derived, meaning that codes are systematically applied which are generated from the data themselves during the course of the study (Sandelowski & Barroso, 2002). The approach of choice was conventional content analysis, in which themes emerged directly from the data collected. Information from the literature was used in the process of reducing codes and developing themes that described the main findings of the study.

A major challenge noted in the literature in performing content analysis is the fact that it is very flexible, with no simple guidelines for data analysis (Elo & Kyngas, 2007). This speaks to the subjective nature by which researchers may interpret the data. For this reason, dialogue between the researcher and thesis supervisor was most important throughout the study, to discuss the labeling of the data. In conducting qualitative content analysis, it is most important to ‘let the text talk’ and not impute meaning that is not there (Graneheim & Lundman, 2003, p.111).

Analysis was carried out soon after each interview was completed; allowing the researcher the opportunity to explore themes discovered in subsequent interviews. For example, the topic of the Caribbean diet, as a contributing factor in having a stroke, was commented on by participant number two. Following this interview, the researcher made a point of exploring this topic in subsequent interviews. NVivo 8, a computer-assisted qualitative data management system, was used in the analysis of the data.
Trustworthiness

To ensure trustworthiness of the study, the researcher implemented several steps over the course of the study. Throughout the study, journaling and field notes were kept by the researcher, to provide an opportunity for active reflection in addition to expanding on themes that arose from the actual data. The field notes contained the impressions of the researcher regarding such things as the environment the interview took place in and the conduct of the participants, i.e.: cues regarding their emotional state, eye contact, body language, tone of speech, and gauging the tiredness of the participants. Through reflective journaling the researcher was able to examine any biases she had, her role in the research process and her conduct of the interview itself. An additional step the researcher took to limit any biases she had which may influence the study, was to write an overview of her background and experience (see Appendix K) for the benefit of acknowledging how this may relate to her thoughts and views on the topic of stroke in the African-Caribbean community.

At the completion of each interview, the researcher spent a prolonged period of time reviewing the transcripts, observing the verbal and nonverbal behaviors of the participants and peer debriefing with the thesis supervisor. Dialogue between the researcher and thesis supervisor took place throughout the study for the purpose of determining what questions warranted further exploration with the participants. Themes were discussed with the thesis supervisor, who checked the data for accuracy. To verify the study’s dependability, results of similar and related studies were compared with the findings of this study. In addition, review of the raw data, the findings and the interpretation of the results were conducted by a researcher knowledgeable on qualitative research methods.
The use of open ended questions as an interview technique provided rich data from the participants. The analysis of the data was kept on a secure database. This formed part of the audit trail which included the written summaries and analysis of the interviews from which codes were established as well as the reflective journal kept by the researcher.

At the end of the study, the researcher mailed a letter outlining the key findings of the research study to three of the participants. This was done as a way of seeking confirmation from the participants that the findings presented was a representation of their experience. This process known as member checking is according to Lincoln & Guba (1985), the most crucial technique for establishing credibility. Individuals were invited to contact the researcher if they wished to discuss any aspect of the study or to clarify any of the information presented. No responses were received from the participants following the receipt of the letters.
Chapter 4

Findings

In this chapter a description of the participants has been provided in addition to the findings of this research study. The research findings are presented under the major headings of the explanatory model of illness framework: etiology, pathophysiology, time of onset, symptoms, treatment, and course of illness. Information obtained pertaining to self-care, the recovery process and the view of the participants on the cultural aspects of care they deem important follows.

Quotes from the participants have been included within this chapter, that best illustrate the key findings of the research study. Within the quotes, bold print is occasionally used to emphasize words which were stressed by the participants during the interview process.

Characteristics of the Participants

All of the participants were diagnosed with stroke within the past two years. The participants ranged in age from forty-one to seventy-two years. Of the eight participants in the study, seven were male and one female. All the participants report being born in the Caribbean; their years in Canada range from six to forty years. Further descriptions of the participants are presented in Table 1.
Table 1. Profile of the Participants (N=8)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>N</th>
<th>%</th>
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<tr>
<td>Place of Birth</td>
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</tr>
<tr>
<td>51-60</td>
<td>2</td>
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</tr>
<tr>
<td>Female</td>
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<td>12%</td>
</tr>
<tr>
<td>Time Since Stroke</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;6 months</td>
<td>5</td>
<td>62%</td>
</tr>
<tr>
<td>&gt;6 months - 2 years</td>
<td>3</td>
<td>37%</td>
</tr>
<tr>
<td>Marital Status</td>
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<td></td>
</tr>
<tr>
<td>Single (never married)</td>
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<td>25%</td>
</tr>
<tr>
<td>Married/Common Law</td>
<td>5</td>
<td>62%</td>
</tr>
<tr>
<td>Widow/Widower</td>
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<td>12%</td>
</tr>
<tr>
<td>Employment Status</td>
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<td></td>
</tr>
<tr>
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<tr>
<td>Unemployed</td>
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<tr>
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<td>12%</td>
</tr>
<tr>
<td>Part-Time Employment</td>
<td>1</td>
<td>12%</td>
</tr>
<tr>
<td>Full-Time Employment</td>
<td>1</td>
<td>12%</td>
</tr>
</tbody>
</table>
Descriptions of Illness Perceptions using Explanatory Model Framework

The following is a description of the illness perceptions provided by the participants, as it relates to the major headings of Kleinman’s explanatory model of illness framework.

Etiology

The response of participants with respect to what they believed caused their stroke were centered on either stress or their underlying medical health condition. Contributing factors for stress leading to the experience of stroke included: stress due to loneliness, the process of immigrating to Canada from the Caribbean, stress due to the many demands they experience within their personal lives and within the workplace. One gentleman described the cause of his stroke as “things going over the top”:

- …it’s things that were resting on my brain; things that I’ve been thinking about, problems issues that’s been bothering me…Prior to this, I didn’t feel any form of illness sickness; so, I figure that whatever was bothering me like financial, female, children, were issues that I could deal with. Not thinking that it’s gonna go over the top (Participant T.M.).

One participant attributed his stroke from the stress he experienced in part as a result of his ‘guilt complex’ following the death of his wife:

- I was drinking almost two bottles of rum a day. Part of it could have been a guilt complex because I kind of blamed myself for not being at home a lot more often…my attitudes were partly responsible for her dying… my wife was an alcoholic. She died from cirrhosis of the liver. I think that maybe one of the reasons she drank so much was because she was lonely because I used to go out a lot. I’m accustomed as a male going out on a weekend… I never saw her [wife] as a companion, as somebody to be with, like somebody to go out with, to go to dinner with and what not. She was there at home, she took care of my needs, but she was not a companion. (Participant L.S.).
The following participant believed that his stroke was caused from having overexerted himself while on vacation.

- ......my estimation is my activities [indicating activities he did while on vacation] was above board, my holiday in Cuba four weeks ago (Participant N.P.).

For participants who attributed their stroke to their underlying medical condition, hypertension was stated as the main illness. One gentleman blamed the result of his stroke from hypertension resulting from inadequate medical management.

- Well I was told it was the continuous high blood pressure and I wasn’t getting enough blood thinner at that time… maybe the milligram wasn’t enough or something (Participant M.S.).

Pathophysiology

When asked to describe the action stroke has on the body, participants were only able to give a limited response. All the participants knew that having a stroke implied an adverse event having to do with the brain; however they all struggled to understand what actually happens to the body during a stroke.

- Cholesterol is when after it go into your brain, the fatty tissue stops your brain (Participant Y.D.).

- What happens to the body when you have a stroke is that it makes your head; your head don’t function as it were before. Once they talk to you in that short period of time you totally forget everything (Participant M.S.).

For some participants, seeing the diagnostic image of their stroke resulted in their ability to better understand what had actually happened to them.

- I just knew that it had to do with blood vessels and veins running through your head… seeing the pictures of the MRI of my brain…I’m slowly coming to terms with how it works and prevention and cures (Participant T.M.).
• Actually, you see right here? (pointing to front of head), after me stroke, had a black spot here. It come out now, it was visible, you could see, see right here (points to spot again) had a black spot.....they show me when I did my M.R.I. (Participant Y.D.).

**Time of Onset**

In discussions about the warning signs of a stroke, it was found that none of the participants had knowledge of this prior to having a stroke. Since many of the participants did not seek medical attention in a timely manner, this may have resulted in increased disability since treatment was delayed.

• My foot went limp, like I started hopping but I didn’t pay it no mind…drink a beer, went to sleep. When I get up in the morning, I feel no way different. Went to work, in fact I work half day and the boss send me to the doctor. When I went there the doctor said, well I had a stroke. At the time I really didn’t pay it no mind…the doctor told me if I had went to hospital the same night, I wouldn’t be walking like this (Participant Y.D.).

• Got up the morning to go to the washroom and I find that the right side sort of a little bit lazy, that lazy feel. You think that maybe it’s because you were sleeping on the one side. It wasn’t much of an alarming situation…when I got up again, when I got up this time I just couldn’t sustain myself on the right side at all, I just collapsed. So that means that something was happening; but even then I did not figure it as a stroke, I didn’t know what was happening…I wish I had gotten help in that window that…3 or 4 hour window that they suggest…you get attention…It took a while. So, I think by then, you know, the job was done…my wife rushed me off to the hospital. You know, drove me to the hospital. I think what we should have done, this is in hindsight, is that we should have called the EMS (Participant C.N).

• It started at swimming when I had that bad headache, migraine. It was a bad headache, it’s a headache you could never forget. It’s like something is going on wrong in your head o.k, and it’s a hard throbbing very very hard pounding, pounding. I start throwing up. Just out of the blue, I just started throwing up, throwing up very thick brown coloured vomit …at that point that’s when they called the paramedics…I do remember they saying to me, saying to my husband…what took you so long to call?; because I think there was some time between when it happened and when he actually called because he figured nothing was wrong (Participant N.S).
Participant L.S. reported that even after his second stroke, he was still unsure of the warning signs of a stroke.

- I don’t know the warning signs; I still don’t know the warning signs. Even with this stroke…nobody has ever sat down and talked to me about like what to look for with a stroke. I still don’t know what the warning signs are and I don’t think I’ll ever know unless I ask (Participant L.S.).

The following participant reported never having heard of stroke, and what could cause it.

- I never took very close or pay very close attention to stroke before. I never knew or heard of it…what could cause that (Participant N.P.).

In recounting their experience of having a stroke, many of the participants described feelings of intense fear and being at a loss in trying to understand why it happened to them.

- I didn’t even know what was happening to me. I feel something very strange. I never feel like that before…and my knees they were buckling (Participant N.P.).

- I find it was very frightening, very scary. I’ve never had anything like that happen and just the way it happened, it was no warning, just the headache; and I didn’t think much of that headache (Participant N.S.).

- There were so many things, I’m still even trying to figure where did I go wrong? type of thing. It just goes to show, it can happen to anybody (Participant C.N.).

Symptoms due to a stroke

The two most common symptoms experienced by participants as a result of their stroke were of a mental or physical nature. Problems with executive functions, such as concentration and memory, were the most common complaints.

- I think the major issue was my brain. Just, you know, not being able to comprehend. Just to remember stuff that was my major issue; yes, just to concentrate. Sometimes I’m saying something and sometimes I just switch off I forget what I’m saying (Participant N.S.).
• Say someone said something to you, tomorrow you might remember other things. With stroke now, say something now and if I don’t write it down another 2 hours or so, I totally forget what you say; although I try, I don’t remember (Participant M.S.).

Of a physical nature, numbness and lack of sensation dominated the list of symptoms experienced by participants.

• I’m not saying I don’t have feeling on the right side. I can pick up a pencil and know that I’m picking up something, I can walk and know I’m walking, but it’s minimum compared to my left side, and then it has like I don’t know pins and needles; like your foot fell asleep and it’s waking back up, that feeling throughout me, the top of my head to the tip of my toes on the right side, that’s what I feel; every movement it’s pins and needles; every touch pins and needles. Back, side, every part of me (Participant T.M.).

For participant H.B., a primary concern of his due to the numbness he is experiencing in his hands is the worry that he may not be employable since he was a chef by profession.

• ...my hands get numb, stay numb ever since. Steady numbness and make me really concerned. Both hands, numbness (Participant H.B.).

Treatment

In discussions about treatment received for their stroke, participants commented on medication prescribed, rehabilitation and goals of therapy.

All of the participants in the study reported receiving treatment for their stroke. Treatment included medication in conjunction with rehabilitation to improve their functional outcome. While rehabilitation measures were regarded in a favorable light by the participants, medication for secondary prevention of stroke resulted in mixed views. The theme uncovered here could be termed ‘medication aversion’. Participant Y.D. commented on the medication Lipitor™ (atorvastatin) which he has been prescribed to lower his cholesterol level; his belief is
that the medication he has been prescribed, due to its’ large size, is beyond what he needs for treating his condition.

- I don’t like that big big tablet like a horse. I can’t wait for it to finish to go to a doctor. I hate those tablets. I don’t like the tablets at all... I tell you the truth I don’t like tablets The only thing I suggest, I suggest that Lipitor™ (atorvastatin) be reduced, cause I... that’s too much tablet, they’re giving me a tablet for a horse, for a horse and it taste bad (Participant Y.D.).

The same participant when diagnosed with diabetes, prior to his stroke, reported having not followed his doctor’s orders and taken the medication prescribed to treat his diabetes. He admits to being mistrustful of medications, believing that they can harm the body.

- I didn’t take the tablets...in fact I didn’t take any tablets for about 2 years...it never bother me. I was taking a tablet called metformin. I was, but I stop because I used to get a pain in my leg (Participant Y.D.).

Upon further probing in an attempt to understand the reason that Y.D. refuses to take his medication, including his blood thinner to decrease his risk of another stroke, he reveals that his financial situation limits his ability to be compliant with his medications. Y.D. also commented that a second reason for not taking his medication is that he believes his blood pressure is stable and that he does not actually feel unwell.

- Blood thinners. I don’t take them you know...I ain’t taking them...they’re too expensive, number two to me they serve no purpose cause my blood pressure is stable (Participant Y.D.).

For participant M.S. his reluctance to take his antihypertensive prior to his stroke was also due to not actively feeling unwell:

- I wasn’t so regular in Jamaica, I wasn’t even checking on the pressure. You get the medication, you take the medication, that’s it...Sometimes I stop, or like I get a prescription and it finish, maybe I don’t even refill it until the next week...don’t question that when I get up each day, even if my head feel giddy [dizzy] or whatever, I wasn’t sick as such from the pressure (Participant M.S.).
For participant L.S. his aversion to taking medication has to do with his desire to maintain control over his life:

- In a way what I don’t like is the fact that I’m regimented or controlled, by having to take a tablet everyday or tablets everyday. One of the things in **my life** is that I don’t like control. ..What I hate above all is routine, I hate anything that is routine, anything (Participant L.S.).

This same participant in an effort to maintain control of his life went against his doctor’s orders and returned to playing rugby following his first stroke.

- I went back to Trinidad, and in Trinidad I was playing rugby…some of them [players] were aware that I was a stroke victim…they used to be in awe of me, they say, “you play rugby boy?, you not supposed to be playing rugby” …[Stroke] is not something that is known or accepted in the Caribbean population (Participant L.S.).

A further response given by Participant L.S. for not following his doctor’s orders was that he has not been educated on the importance of taking medication to prevent stroke.

- I don’t take medication, because again, the Caribbean man is not told of the importance of taking drugs to prevent stroke… it’s only now with this second stroke that I am kind of partly aware of the importance of taking medication.

All of the participants reported taking part in the rehabilitation process and valuing the role physiotherapy played in increasing their mobility.

- After my physio…everything moves…even my head (moving neck side to side). I don’t like to miss these therapists it’s doing me a whole lot of good… It’s no fun to lay in this bed for 24hrs a day (Participant N.P.).

- I can’t write very good the first 2 weeks, you couldn’t understand a word I say because my mouth was twisted and my tongue was too heavy….you see my hand (lifting his right hand), my hand is swollen from exercise…I don’t feel any pain except when I exercise it cause me fingers couldn’t move ….I exercise every week I have nothing else to do (Participant Y.D.).
For Participant C.N, he believes that working collaboratively with health professionals, to be the best approach towards facilitating the rehabilitation process.

- I try to work with the professionals around me because I know if I just sit in a corner poor me, poor me, poor me, it’s not going to help (Participant C.N.).

When questioned about the goals the participants had regarding treatments they were receiving, the most common theme uncovered was a yearning for the old self. Since a decline in mobility was the main issue faced by the participants as a result of stroke, it was not surprising to find that increased mobility dominated the goals participants had around treatment.

- What I do know is that I would like to be back on my feet, back on my feet yesterday. But it’s not gonna happen, it’s not gonna happen in the real world (Participant C.N.).
- I want me hand. I want me hand moving again (cradling his swollen right hand). Me hand.....not there (Participant Y.D.).

The following participant admitted to not wanting anything less than a full return to his pre-stroke life.

- A hundred percent (laughs). That’s just plain straight out, a hundred percent. I just want to get back to what I used to do (Participant T.M).

Participant L.S. states his desire to have his doctor confirm that he is healed from his stroke:

- …no doctor or nobody never tells you that you’re healed. It’s not like a cut where your body could show signs that you’re healed. A stroke is something I feel very undetected unseen, as this happens inside your brain. It’s not something with MRI or whatever you may call it, that they can pinpoint that they can see that you’re healed and that is one of the problems I feel. I would like confirmation from the doctor or somebody to be able to tell me o.k., you had a stroke you were taking tablets, continue taking the tablets and your blood pressure will become controlled but you are healed (Participant L.S.).

Course of Illness

The term course of illness otherwise known as consequences of sickness refers to the meaning and significance of a condition which provides clues to the ways in which individuals deal with that condition (Meetoo & Meetoo, 2005). For nearly all the participants the
event of having a stroke was spoken of as a catastrophic event, leaving them with feelings of being out of control, emotional distress, and unable to embrace the new self.

- I tell a friend a couple weeks ago the same thing you asking me; how would I describe what happened to me...said.....like a hurricane pass through your body and left you as a shipwreck, every moveable part is broken. I mean that’s a very rough case I can give you of my feeling on this thing (Participant N.P.).

Many of the participants commented on a feeling of loss as a result of having sustained a stroke. Categories of loss included loss of mobility as well as loss of self.

- I find it [stroke] very restrictive...taken me down a notch in terms of my mobility, stuff like that. That is the part of it that really has affected me as an individual (Participant C.N.).

- It’s an experience that basically took away half of my body and for a person that never was really per say ill to an extent, it’s hard for me to adjust...What do I do from here?, You know that kind of hit me hard (Participant T.M).

For participant N.P, his limited mobility is nothing less than demoralizing, due to the extent to which he is reliant on others:

- Just imagine you can’t get up and go to the washroom as you like, can’t get up and have a drink of water, it’s demoralizing (crying).

N.P. further exemplifies his feelings of loss related to his body by the use of the term detachment to convey the manner in which he sees his body:

- I find myself somewhat detached to my normal self, you know? To what my normal self used to be...so, then I feel it is very severe (Participant N.P.).

In commenting on how severe the participants view their illness, it was of interest to note that the extent to which the participants were immobile mirrored how severe they regarded their illness. The following are comments participants made when asked how severe their illness is:
Quite severe you know; cause after I had the stroke I could not use my left side too good. If I’m walking, I could only walk straight for a little while; I tend to lean a little. I could not hold my strength along, the whole part of the left body start to let go ( Participant M.S.).

It is very severe because it has reduced my mobility. I had to change my whole way of life a lot like from the moment, because I can’t run…one of my joys was running. I can’t run, I can barely walk (laughing), I can’t dance anymore; and I love to dance (Participant L.S.).

For Participant L.S. his functional mobility is linked closely with the way in which he perceives himself.

…the Caribbean culture sees illness as the end of mobility.

In terms of the reaction of the participants to their diagnosis, a common reaction was that of emotional distress when considering what had happened to them.

It took me all of about 2 days to stop crying in my pitty pat [my little corner]. I said well, this is what I’ve been dealt and I better deal with it. I think that has helped me a lot…I know if I just sit in a corner poor me, poor me, poor me, it’s not going to help (Participant C. N.).

In the past, I never cried you know. I’m a person who finds it hard to cry… I hope this will change as I begin to recover… I never used to cry, never used to cry. But I never expected that I would be hit with this thing…I mean never (Participant N.P.).

In considering ways in which the participants have coped with their illness, a common theme identified was that of acceptance.

I have accepted it. What are you going to do? We all are going to be dealt a pack of cards, and we’ve just got to use them. (Participant C.N.).

I don’t really sit down and have too much expectations…I had a stroke I realize what caused the stroke, so I’m hoping that I’ll be better (Participant M.S.).

Participants displayed personal determination in the manner in which they responded to the challenges which stroke presented in their lives. This is best depicted in the statement made by the following individual  when asked what has been most useful in assisting him to deal with his illness:
• Determination, it’s better than medicine (Participant Y.D.)

To gain a better understanding of the effects of having a stroke on the lives of the participants, they were asked to comment on their concerns/worries about their illness. While their experience of having limited mobility dominated the list of concerns, due to the restriction placed on their activities, other common concerns were financial in nature as well as the possibility of the illness reoccurring. In the following statements, the stress experienced by the participants, due to worries about finances, are quite apparent. For participant T.M. his concern about his current financial situation also brought with it fears of not being a desired worker to future employers.

• My biggest worry is that if I do not get back even close to a hundred percent of feeling, it’s gonna drastically affect my financial status. It’s hard enough right now to even get into a work force, never mind going in with an illness like this. Nobody’s gonna hire a forty year old, forty-one year old pre-stroke, prior stroke, because I read through the information that they [healthcare professionals] gave me, and they’re saying that you know most stroke victims within five years get another stroke if not taken care of or monitored. (Participant T.M.).

The stress of having limited financial resources was also apparent in the following comment made by participant Y.D as he awaited his unemployment cheque.

• One concern I have...is when these people [government] paying me my money?. I haven’t worked in 2 months...I can’t get anywhere. Tomorrow I go into the office. When I go at home and there’s no cheque in the mailbox, I’ll be in the office early morning...I need to pay my rent at the end of this month... (Participant Y.D.).

In considering the possibility of sustaining another stroke, participants reported that while it is not something they actively thought about, it was indeed a matter of concern.

• I’m concerned about it recurring again...although I’m not, I don’t go around thinking about it; but occasionally, I try to hopefully do the right things to ensure that it doesn’t happen again (Participant C.N.).
In discussing worries about their illness, the following participant commented on his hope of getting back his health. When asked what being healthy means to him, he made the following comment to communicate his underlying concern of the possibility of sustaining another stroke:

- Well, I can move around; not being nervous that I’m gonna fall over one day, things like that, and get a second stroke (Participant H.B.).

This completes the description of the participants under the major headings of the explanatory model of illness framework. In the next section, responses to questions explored with the participants regarding self-care, the recovery process and cultural aspects of care they deem important will be described.

*Self-Care Practices*

Participants were asked to describe challenges they face with respect to self-care following their stroke. Various self-care practices were reported by the participants in the study, the most prevalent of which was the inclusion of physical activity to promote independence in terms of mobility. Three of the participants reported taking part in an organized therapeutic recreation program developed for adults with acquired physical disabilities. The program was designed to improve the physical, social, emotional and mental well-being of the participants.

- Well, the Next Step program essentially is to teach you, or to assist you really in reaching a higher level of independence progressively, and that is really what I need to do. I think I’m getting there (Participant C.N.).

- I do the bicycle riding or you do the pool, whichever you want to do. You do the ball; whichever you want to do…If I’m feeling o.k., I could manage those exercises quite alright and I did not have to use the cane anymore for my balance, I balance (Participant M.S.).
Self care involves a great deal of effort and relearning to recapture former skills and abilities. The following participant described the experience of going through the program as similar to returning to school. This displays the great deal of re-learning which stroke survivors undergo in an effort to master simple skills.

- …at home I did homework, it was like back to school, that’s what it was; mathematics, you name it…everything we did here. We did like little games and stuff, we did some cooking, yes, had to learn to handle the hot stove and stuff like that…you know trying to walk. I started out with a walker, and just trying to balance you know, do a lot of balancing and stuff (Participant N.S.).

In an effort to maintain optimum wellness, participants reported consulting with a physician for their health care needs. Relationships with physicians were mostly seen in a favorable light, with many of the participants commenting on their trust in the medical community.

- I ask the doctor, the neurosurgeon, just a couple weeks back, Doctor how am I doing? He said you’re doing good but you’re slow. I understood this, you know, because I can feel that way (Participant N.P.).

- I don’t think any doctor will leave anything out, so there’s nothing else I think that they can do other than just to monitor it [stroke] and still find out what caused it (Participant T.M.).

Self-care behavior related to diet was cited by some of the participants as a necessary component in improving their general health.

- I don’t eat what I ain’t [am not] suppose to...some people eat white rice and sugar....I stay away from it and I maintain me own cholesterol level with a tablet they gave me, Lipitor™ (atorvastatin)...I smoke me weed [marijuana]...I don’t drink (Participant Y.D.).
The following excerpts are from participants who commented on the desire for health care professionals to provide them with information pertaining to diet in order to decrease their risk of illness.

• …they [doctors]) should be aware of it [diet], not just tell say you have high blood pressure and then give you medication for that high blood pressure. Don’t tell you what to eat from what not to eat or whatever. From the time that you know that you’re not really sick, you know it [high blood pressure] put you in bed, they don’t really emphasize on what you should eat or such (Participant L.S.).

• Nobody has really given me a diet. Nobody has really…say hey…I know you West Indian eat this and Caribbean eat this, like curry chicken and you know, stew peas and rice, jerk chicken you know, all this…no diet education. They just say hey listen your cholesterol is high, take this pill, you know check your blood and that, just basic. So I never really got educated on it [diet], even after the stroke. They just gave me paperwork and said read this (Participant T.M.).

The most significant aspect of diet which participants felt required addressing within the Caribbean culture was the intake of salt.

• Caribbean’s on a whole…like their stuff spicy and tasty; with that I guess you got to use a lot of spices and salt, blandness is not in there (Participant C.N.).

• …they [Jamaicans] eat a lot of salt (Participant M.S.).

• …blood pressure is a major problem. Cholesterol is a problem for us [Caribbean’s] too; but blood pressure mainly is our problem, that I know…and you know, that sometimes can be caused from our diet (Participant T.M.).

For the following participant, a focus on diet was seen as a step towards preventing another stroke.

• I try to hopefully do the right things to ensure that it doesn’t happen again…hopefully, eating right, I didn’t think I was before…honestly, I pay a little bit more attention now, cause even the intake of salt stuff like that (Participant C.N.).

In terms of the degree to which the participants exercise independence in caring for themselves, all of the participants report being able to carry out their activities of daily living
without the assistance of others; albeit challenging. The challenges noted largely centered on the limited mobility many of the participants report following their stroke; often due to issues around balancing oneself. To compensate for this, participants reported making use of assistive devices such as a walker, cane, or wheelchair to provide them with the confidence needed to mobilize safely.

For participant L.S., although he comments on feeling able to safely walk without the use of his cane, he admitted to feeling a sense of dependence on its use. This dependence stems from not knowing at which point he is considered to be ‘healed’ from his stroke. In addition, he admitted to being cautious in performing certain activities such as bathing himself.

- It could be I have an innate caution about going to the bathroom because I am afraid that I will slip. It’s not that the bathroom is not secure, it’s just something within me, It’s just like I could walk 90% unaided, but I walk with the cane... it’s not that It’s needed, I know that I could walk by myself but I’m accustomed to the cane because I am not told well look now, you see no doctor tells you that your cerebellum cortex is healed now...so most probably I might be using this cane on and off for the next year or until my body feels that I am independent of the cane (Participant L.S.).

- I used to use the chair thing…the walker. When I could manage good now, I start use the cane. Walking straight and you just suddenly list [meaning to become weakened] on the left side you know? Cause I don’t have enough strength, but now I can balance myself o.k. I don’t bother with the cane (Participant M.S).

A common theme identified in relation to the mindset of the participants in facing the challenge of maintaining independence, in light of their illness, was that of relying on one’s self.

- No one does nothing for me…No, I don’t like getting anything…because if you take care of me I depend on you and when you’re not there I can’t do it myself (Participant Y.D).

The following participant, who continues to work full-time as a chef, admits that although he exercises independence in caring for himself, he could use the assistance of others. He nevertheless continues to be self-sufficient in attending to his needs; commenting on the
challenge of having to remain employed even though he continues to experience tremendous difficulty with his feet.

- I manage on my own, I could use a lot of assistance but I manage on my own right now. I had to push it, I had to push it, to make ends meet I had to push it. I’d rather not … because right now I have a lot of problem with my feet (Participant H.B.).

**Recovery Process**

A main focus of this research study was on gaining a description of the recovery process experienced by the participants. Participants in the study were asked what they considered to be most helpful during the course of their recovery from stroke.

Family support was stated by the participants as the most significant factor in their recovery process. Second to this was the care they received from members of the healthcare team which primarily included nurses and physiotherapists. Spirituality was also a factor in the ability of participants to cope with their illness.

The following participants described ways in which they have benefitted from the assistance of family members during their recovery process.

- …my husband he’s very good; but the nurses were saying they’d never seen a husband like that. He’s here every day, he brings whatever I want even sometimes it’s the wrong stuff [laughs], brings me the wrong housecoat or the wrong stuff but you know he brings it. He’s my support and my two daughters and grandchildren (Participant N.S.).

- Well, if I’m going anywhere my wife is beside me… my wife have helped me a lot. There’s nothing I’m to do…I get up in the day and I go and I play domino [a board game], or play a game of cards or something. It’s really helpful (Participant M.S.).

- Actually, thank God for my mother. She is a fiend when it comes to herbal medicine and she’s basically my nurse right now. She’s been on the rampage, she’s all out finding remedies…I’m illiterate where herbal medicine is concerned. All I know are the basics drink your cerasee [Jamaican bush tea] and you’ll be all right. Every now and again you take your wash-out [laxative] you know what I mean, your herb wash-out and senna pod. These are things that we grew up knowing…there’s a whole vast …area where herbal is concerned that can decrease pills (Participant T.M.).
For Participant T.M. while the motivating factor to his recovery is family, particularly his young
daughter, this also creates a burden on him to continue to provide for his family.

- Definitely family, definitely family. My mother and my wife, they’re there, watching my
daughter grow, that’s an option that I didn’t want to…[laughs] compromise…recovery is
definitely brought by my daughter, sure, I always said to myself just give me twenty
more years, you know, ten more years. Just let her finish school, so I can see her on her
own, you know. That’s put a lot on my table right now (Participant T.M.).

Participant C.N. commented on being able to rely on his wife to keep him on track with what
needs to be done as part of his recovery process.

- …I remember before I was discharged this nurse, she sat me down and she said you
know make sure you do this and do that and do that, cause I don’t want to see you back in
here, and that type of thing…She said come back and look for me but not as a patient
(laughs). …then I could go home and say to my wife make sure that this [is done] because
the nurse told me that.

While family support was stated as the most significant factor in the recovery of the
participants, a close second was that of working with the healthcare team. The assistance of
nurses as well as rehabilitation specialists, most notably physiotherapists were considered as
being very influential during the first few months following the incident of stroke.

- First few months, I would say you cannot discount the help you, services you are
provided in the hospital; but I think next to that would be the support of your family,
especially my spouse…not everybody was at their best everyday but they [health care
team] did what they could, with what they had (Participant C.N.).

- I would say that the nurses and the therapists were more helpful than the doctors because,
put it this way, the doctor’s like God, you only see God once in a while [laughs] but the
nurses you see every day. That nurse attends to you… you move a lot, the nurses make
you move… they cause me to think (Participant L.S.).

The statement made by Participant L.S. concerning the way in which he is helped by the
healthcare team, in causing him to think, is echoed by Participant N.S. in recalling what she found
helpful during the first few months of her recovery. The action of therapists in promoting activities which stimulated the participants on a cognitive level was spoken of in a very favorable light. The satisfaction felt by participants is evident in the following statements:

- I was fighting with concentration. Just remembering things and detail. These stories that they [rehabilitation therapists] used to tell me they weren’t easy, they were complex, made you really have to think. They’re really smart things that help you to think and, you know, listen, pay attention (Participant N.S.).

- I do remember nurses coming in and say watch me and they will say what is the day today?; to force me to have to remember certain things...no nurse ever pampered me, they always say if you want it go for it (Participant L.S.).

In comparing his stay within the hospital to being at home, L.S. makes the following statement which communicates the limited motivation he feels being away from the hospital setting:

- They [nurses] cause me to move, they cause me to think …my normal day at home I get up about one o’clock in the afternoon because…I don’t move, I don’t have to move, so the most I will do is go to the bathroom, but apart from that I don’t really move’, so I will sleep a lot in the day… because I’m bored…12 hours is a lot of time in a day and to occupy that fully is very very hard’ (Participant L.S.).

Religious values were expressed by three of the participants within the study. One participant commented on the strength she derives from her church, another participant stated that although he is not a Christian; he believes in leaving it to God in terms of what will transpire in his life. While not openly discussed, I noted during an interview with a participant that within the home were objects on display related to spirituality. These objects included a bible as well as various figurines depicting Christ.

- …my sisters them was here from the States to visit and knowing that someone was in the house…that cut a little bit of the nervousness, you know, and other than that just leave it to God… I’m not a Christian but I believe (Participant H.B.).
A term which could be used to describe the action of many of the participants during the course of their recovery is that of ‘resiliency’. While challenging, there is a tendency for the participants to undertake activities which will assist them in their attempt to return to as much normalcy as possible in light of the disabilities they face following their stroke.

- I had to hold my foot like this [cradling his weakened right foot]...I get up on me one foot, limp, limp until I get up and start to move, I never stop moving it…determination, it’s better than medicine (Participant Y.D.).

- I wasn’t going to the gym until I got the o.k. from my neurologist…he looked at me and I said can I go back, and he said oh sure!...I just keep my fingers crossed as I stay away from here [hospital] as long as I can; which is why I do everything to try to help me to be strong, my body to be strong, and to stay healthy for as long as I can (Participant N.S.).

Participant N.S., whose stroke occurred as a result of her sickle cell disease, sees great importance in being an advocate for the sickle cell community and sharing her knowledge with others.

- I’m doing a walkathon for sickle cell…I’m really involved. I’m a member now…so when they have meetings and so on, I take part in that. I’m learning, I’m learning a lot more (Participant N.S.).

Cultural Aspects of Care

The final question of the interview process was centered on gaining an account of ways in which the participants felt nurses could positively influence the care of individuals within the African Caribbean community, during their recovery from stroke. The provision of education was stated as the most significant manner in which nurses could influence the care of African Caribbean stroke survivors. Areas cited for education concerned lifestyle changes such as diet-particularly modifying salt intake - as well as education regarding underlying illnesses, most notably hypertension, which are prevalent in this racial group.
• …you know, I think that Caribbean’s on a whole…they like their stuff spicy and tasty. With that, I guess you got to use a lot of spices and salt, blandness is not in there (laughing) not part of the makeup. (Participant C.N.).

• …blood pressure is a **major** problem. Cholesterol is a problem for us too; but blood pressure mainly is our problem, that I know. So…that sometimes can be caused from our diet...Nobody ever really base anything around my culture to say you know, hey stay away from this, you can have that but in moderate. They just say hey listen your cholesterol is high, take this pill, you know check your blood and that, just basic (Participant T.M.).

For Participant M.S., who was diagnosed with hypertension in Jamaica, education he was provided concerning his illness merely consisted of certain foods to stay away from as well as to take his medication. Due to this, he did not understand the significant risk factors he had for stroke and the potential consequences of not following his doctor’s advice.

• I didn’t take it too serious when they [doctor’s] say you have high blood pressure, don’t eat a lot of salt… they [Jamaicans] eat a lot of salt you know …and you’re not to drink Red Stripe beer…they say it has in a lot of hops, I don’t know what the h__ hops is (Participant M.S.).

In the following statement made by Participant N.S., concerning her mother, she gives an overview of the difficulty, as she sees it, of Jamaicans making lifestyle changes which will affect their diet.

• …my mother she still uses milk and sugar, like condensed milk and she still cooks her chicken with oil and I’m trying to tell her Mom you put it in the oven, use the oven, you don’t have to use any oil. You know, just the way that they [Jamaicans] cook and they eat…so it’s just having to make the change. It’s not easy for them to make the change, very stubborn, very hard. I think that’s their pitfall right there, just to realize what’s happening, what it’s [diet] gonna do to you (Participant N.S.).

According to participant L.S, and C.N, an important aspect of nurses working successfully with individuals of African Caribbean heritage, is for nurses to take the time to get to know more about the culture.
• [Stroke] is not something that is known or accepted in the Caribbean population… I think the nurses have to know their patients a little more. They have to understand the culture from which the patient comes and they have to try and give in to the culture (Participant L.S.).

• I think if nurses have an understanding of the Caribbean culture… they can impart to them [patients] some of the things that they need to do and stay away from. I think, you know, it’s really not that the doctors are not saying it, but sometimes because they [nurses] are there at the frontline, if they impart it to them [patients] it sort of sticks to them (Participant C.N.).

Summary of Key Findings

Participants in the study reported that they were not aware of the warning signs of a stroke, prior to its occurrence. Some of the participants expressed regret and disappointment that this lack of knowledge delayed their seeking medical attention. Participants felt that this may have been a factor in the severity of their disability.

The experience of having a stroke was described as a catastrophic event. Participants described feeling a sense of loss as a result of their bodies not functioning as it did prior to their stroke. The two most common types of symptoms experienced by participants as a result of their stroke were mental or physical. Reduced concentration and memory or numbness and loss of sensation were most common.

In discussions about treatment, participants commented on the value they found in receiving physiotherapy due to the positive effects it had on increasing their mobility. Medication prescribed by physicians was not always taken as directed because of the cost or concern about reliance on pills, as well as an aversion to taking medication.

Ways in which the participants coped with their illness were by accepting what had happened to them as well as displaying personal determination in the manner in which they responded to the challenges which stroke presented in their lives.
Self-care practices of the participants consisted of adopting a healthy diet and taking part in activities to promote their sense of independence.

Participants reported the most significant factor to their recovery as being the assistance received from their families. Family support meant a great deal in the ability of participants to deal effectively with their illness as well as their hopes for the future.

The healthcare team primarily nurses and rehabilitation therapists were praised with providing for the needs of the participants while they were in the hospital as well as in the follow-up care that they received. These individuals were seen as contributing in a favorable light towards assisting the participants on their road to recovery.

In discussions pertaining to the ways in which nurses can assist the African-Caribbean community in their recovery from stroke, participants reported that nurses should make attempts to familiarize themselves with the Caribbean culture. The feeling here is that if nurses could learn more about the Caribbean culture, they could better assist the population in their recovery from stroke. The most important aspect of care that participants wanted from the healthcare team was education pertaining to stroke. An important aspect of this education concerned diet. Participants stated that there are many aspects of the Caribbean diet which are unhealthy. Education related to diet, most notably what foods to eat in moderation and which to avoid, was stated as information which participants expressed a keen desire to become knowledgeable about.
Chapter 5

Discussion

In this chapter, the key findings of this study will be discussed, linked to the literature and previous research. The chapter is divided into four sections: the explanatory model of illness framework to elicit descriptions of participants illness perceptions, self-care practices, the recovery process and cultural aspects of care.

**Description of Illness Perceptions using the Explanatory Model of Illness Framework**

The use of the explanatory model of illness framework was beneficial to guide this research study, as it provided an avenue whereby the researcher could communicate with stroke survivors to gain a description of how they perceived their illness as well as the challenges they faced in self-care and the recovery process. Similar to studies carried out to explore the cultural beliefs of ethnic groups about diabetes (Heuer & Lausch, 2006; Jezewski, 2002; Meeto & Meeto, 2005) the use of the explanatory model of illness framework was beneficial in eliciting the perception of participants regarding their illness as well as their views related to treatment. In addition, the use of the model uncovered several misconceptions the participants possessed regarding their illness.

These misconceptions included: one participant was convinced that his stroke was due to being overly active while vacationing, another participant believed that his diabetes, which was uncontrolled, was not a factor in his illness of stroke, another participant prior to his stroke did not see the importance of taking his medication prescribed by his doctor for managing his high blood pressure. He believed that his blood pressure was under control, seeing that he did not
actually feel sick from having high blood pressure. A final misconception came from a participant who felt that having to take his medication in order to manage his high blood pressure, represented a form of control by the medical community.

Participants described the event of having a stroke as being a catastrophic event wherein they had feelings of being out of control and overall emotional distress. These feelings are similar to those reported within the literature where the effect of having a stroke was vividly imprinted in the memory of the stroke survivors as an incident which they were not prepared for as well as having changed their life irrevocably (O’Connell, Hanna, Penney, Pearce, Owen & Warelow, 2001; Lamb, Buchanan, Godfrey, Harrison & Oakley, 2008). These feelings precipitated a range of emotional responses by individuals which were often extreme in nature (Rochette, et al., 2006; Jones, Mandy & Partridge, 2007). The perception of dependency, especially with personal tasks such as going to the toilet is thought to spur on these emotional responses (Jones, et al., 2007). This knowledge should not come as a surprise considering that aspects of a person’s life which used to be under their control, is suddenly taken away, with little opportunity to adjust to the change.

Participants attempted to regain control of their lives in ways which were positive as well as problematic. Positive actions included following the treatment regimes ordered by their physician and undergoing rehabilitation measures to regain their strength and improve their functional outcome. The most problematic account was made by three of the participants with respect to their non-compliance with medication. Reasons for non-compliance stemmed from an aversion to medication, the need to exercise control over one’s life, the inability of participants to financially afford their medication as well as having not been educated on the importance of taking medication to prevent stroke.
Within the literature, a rational given for African-Caribbean people being mistrustful of medication is the belief that medication could bring about more harm than good, or cause complications (Brow, Avis & Hubbard, 2007).

The fact that none of the participants knew the warning signs of a stroke, prior to the event, mirrors the wealth of literature which exists on the knowledge gap concerning the topic of stroke in the general population (Hux, Rogers & Mongar 2000; Panioli, Broderick, Kothari, Brott, Tuchfarber, Miller, Khoury & Jauch 1998; Pratt, Ha, Levine & Pratt, 2003; Reeves, Hogan & Rafferty, 2002).

In a study by Panioli, et al. (1998), to assess the general public’s knowledge of risk factors and warning signs of stroke, only 57% of telephone respondents were able to identify one of the five warning signs with only 8% of individuals able to identify three signs.

As a result of the physical decline experienced by many of the participants, coupled with a lack of control experienced over an affected limb, comments arose related to feelings of detachment from their actual bodies. This speaks to the intensely personal experience which Burton (1999) equated with having a stroke. While the physical effects of a stroke often varies from person to person, there is a tendency on the part of stroke survivors to view the physical effects of their stroke as being detached from their body as a whole (Burton, 1999). The loss of body control, associated with weakness and feelings of uncertainty, set the scene for what Doolittle (1992) describe as a shocked immobile self. The experience of a split between one’s self and body appears to be the focus of life for many stroke patients at least a year following discharge from hospital (Ellis-Hill, Payne & Ward, 2000).

Yearning for the old self, is a feeling echoed by many of the participants in the study. Keep in mind that the event of a stroke has altered the physical functioning as well as the
cognitive abilities of many of the participants. The main goals for therapy are therefore centered on regaining lost abilities. Within the literature, it is stated that recovery for patients often mean a return to their pre-stroke life (Mckevitt, et al., 2004); however, effective adaptation is thought to be best achieved when individuals are able to reset their expectations to fit with their new reality (Rochette et al., 2006). It is nevertheless the tendency of stroke patients to discuss the impact of their stroke in the context of their descriptions of life before the event or in relation to others who have been affected by the illness (Dowswell, et al., 2000).

Statements made by the participants related to acceptance of their illness, is similar to the theme ‘appreciating the ordinary’ which emerged from Pilkington’s (1999) study, which sought to enhance understanding about quality of life after a stroke from the patient’s perspective. Within that study, appreciating the ordinary was reflected in comments such as “accepting it” or “feeling fortunate to be alive” (Pilkington, 1999). Similar comments made by participants within this research study included ‘I have accepted it’, and ‘we are all going to be dealt a pack of cards’. According to Pilkington (1999), comments related to appreciating the ordinary seemed to shift participants’ perspectives of their lives.

The fear expressed by some of the participants concerning the possibility of sustaining another stroke is said to be particularly overwhelming especially in the initial period post-stroke (Rochette et al., 2006). Perhaps it is this fear which causes many of the participants to vocalize their desire to gain information related to the causes of stroke and preventative measures they can take to minimize the risk of a reoccurrence. Information such as this is thought to be beneficial in helping people to better understand what happened to them, as well as assist them in regaining a sense of control over their lives (Wiles, Pain, Buckland & McLellan, 1998).
*Self-Care Practices*

The key findings related to the self-care practices of the participants included taking part in physical activity to promote independence and relying on one’s self to overcome the challenges their illness presented.

Physical activity for the participants largely included formal rehabilitation with the assistance of a physiotherapist. Out of the eight participants interviewed, six reported having received physical rehabilitation to assist them in improving their mobility. The remaining two participants were in the process of being referred for formal rehabilitation. Those having undergone physiotherapy viewed the experience in a positive light, having contributed to their sense of independence. Within the literature, stroke survivors are said to consider rehabilitation services as being an important aspect in their physical functioning (Carin-Levy, Kendall, Young & Mead, 2009; Jones et al., 2007; O’Connell et al., 2001; Wiles et al., 1998).

Exercise has been shown to have a positive effect on boosting the confidence of individuals which is said to be beneficial in their ability to attend to their day to day life (Carin-Levy et al., 2009). The many challenges reported by the participants in caring for themselves due to their limited mobility were in the form of weakness, numbness, tingling and issues with balance. Linking stroke survivors with services designed to promote their level of confidence in attending to their self-care tasks would seem a necessary component of rehabilitation efforts by the healthcare team.

Physiotherapy has been shown to be appreciated by patients due to the belief that it will bring about functional improvement, assist in keeping patients moving, as well as generally keeping them busy (Pound, Bury, Gompertz & Ebrahim, 1994).
In speaking with the participants concerning their perception of how severe they consider their stroke to be, I felt a certain degree of concern that while most participants considered their stroke to be quite severe, often due to their limited mobility, they nevertheless had high hopes of regaining their physical function at a level similar to what it was prior to their stroke. Within the literature patients are said to anticipate high levels of functional ability within the first three months following their stroke (McKevitt, et al., 2004). The danger here may lie in a miscommunication between patients and therapists. The view held by patients regarding rehabilitation is that if they work hard enough, doing as instructed by health professionals, they can expect to get back to being as close to normal as possible (Wiles, et al., 1998). Therefore, achieving functional ability, as perceived by patients, is dependent on how much effort they expend.

Within this research study, relying on one’s self was a key finding among the participants with respect to overcoming the challenges stroke presented in their lives. If individuals feel that it is their personal efforts which will lead them to achieving a state of normalcy (Wiles, et al., 1998) then it is no wonder that stroke survivors may place so much emphasis on their inner strength to overcome what no doubt appears to be the most challenging of situations. In a study by Jones et al. (2008) to learn about the beliefs and strategies used by individuals to support the period of recovery following stroke, researchers were generally surprised at the number of participants who expressed hope and optimism in their ability to achieve their goals in light of the severe level of difficulties they experienced. Maintaining a state of optimism is thought to be an important factor in assisting individuals to face stressful events or situations where there is little perceived control on their part (Jones et al., 2008).
In a study which specifically looked at the self-care practices of the Black community, Becker et al. (2004) examined the self-care practices among African Americans suffering from chronic illness. Within this study, respondents cited the importance of focusing on their inner strength to assist them in effectively managing their illness. This strength was derived from their religious and cultural values. Central to the development of self-care approaches by the respondents were spirituality, social support and advice from family and friends as well as alternative healing traditions (Becker, et al., 2004). Similar values were expressed by the participants in this research study on stroke; particularly the value of the family and close friends for advice and emotional support.

Contrary to the study by Becker et al. (2004), alternative healing traditions were not expressed by many participants in this research study. Being of Caribbean heritage myself, and having an awareness of the various alternative healing approaches undertaken by this cultural group, I was surprised to learn that only one participant was seeking alternative forms of therapy to manage his risk factor for stroke. In treating his high cholesterol, this participant made it known that his mother was looking into herbal therapies he could take instead of pills to manage his condition. Drinking cerasee tea to ‘purge the blood’ and taking a herb ‘wash-out’ are common practices to maintaining good health in the Caribbean culture. The use of marijuana, as one participant reported, represented a part of his self-care practices in assisting him to deal with his illness. It is important to note that within the Jamaican culture, there are spiritual as well as medicinal properties equated with the use of marijuana.

Recovery Process

For the participants within this research study recovery was mainly brought about by the support of their families and the care they received from the healthcare team. This is in line with
the study by Becker et al., 2004, which found that recovery of African-Americans from chronic illness was mainly due to the social support they received from family or close friends. Within the literature, support has been found to have a reassuring effect on individuals coping with stroke (Rochette, et al., 2006).

Ways in which participants in the study felt supported by family members were: assisting them to stay on track with what needs to be done as part of their recovery process, ensuring that the advice provided by nurses during discharge planning was followed, gathering information about herbal therapies which could be used as part of their treatment regime, and assisting them to take part in activities which has the potential to build on their cognitive abilities.

For the participants in this research study, the family is depicted as a source of motivation. The family promotes a feeling of optimism on the part of the participants, as they look ahead to the future. The comments which were made by the participants about the support they received from members of their family, displayed a feeling of interdependence. Family members demonstrated a commitment to meeting the needs of each other, demonstrating the feeling of responsibility individuals feel for the wellbeing of one another.

Recovery for the participants was also brought about by the care they received from members of the health care team; this largely included the care of registered nurses, rehabilitation specialists as well as physicians. The major aspect of this care which participants valued was the fact that these health professionals got them moving, decreasing their risk of boredom throughout the day. This raises an important issue which requires attention on the part of the health care team, which is the problem of prolonged periods of inactivity experienced by stroke patients. Jones et al. (2008), comment on the negative aspects of stroke patients who exist in this manner while in hospital. The authors state that such experiences can lead to feelings of helplessness and
despair which could be detrimental to the progress of these individuals. I would venture to go
another step further to comment that stroke survivors be they in hospital or in the community,equire the same consideration to reduce feelings of helplessness which could impede their
progress on their road to recovery.

Support for the participants during their recovery process was also derived from their
religious beliefs. Within the Black community, the church has held a historical role as being a
place where individuals have felt safe during the hardest of times (Giber, Appel, Davidhizar &
Davis, 2008). The church is seen as a source of social support as well as an extension of the
family. The church family is viewed as being an important source of support in many situations
including times of illness (Holt & McClure, 2006). In an article describing the health outcomes
of African Americans as they relate to the church (Giber, et al., 2008) spirituality assisted in
optimizing the health status among African Americans by providing them with education related
to health.

In a study exploring the connection between religion and health in the African American
community (Holt & McClure, 2006), participants spoke of dealing with health issues by ‘giving it
up to’ or ‘giving it over to’ God, or ‘putting it in God’s hands’. These comments were similar to
that reported by a participant in this research study on stroke concerning ‘leaving it to God’.
Although this statement may appear fatalistic or passive on the surface, Holt and McClure (2006)
state that attitudes such as these may act by providing great comfort to the individual.

In a systematic review conducted by Lamb et al. (2008) on the psychosocial spiritual
experience of elderly individuals recovering from stroke, connection to others, such as family and
friends, as well as spiritual connectedness were important to most individuals recovering from
stroke.
Since recovery for the participants in the study was most often spoken about in terms of a return to their pre-stroke life, participants often stressed their desire to achieve improvement in their physical functioning rather than concentrating on adapting to their circumstance. This was contrary to the study by Burton, 2000 where the focus of recovery on the part of patients was on adaptation and the development of coping skills, rather than simply improvement in physical function alone. While studies suggest that it is more important for individuals who have had a stroke to adapt to and accept their new situation rather than recover specific abilities (Burton, 2000; Bendz, 2003), results of this research study shows a link between the self-concept of stroke survivors within the African-Caribbean community to their functional abilities. This was illustrated in the quote by Participant L.S. wherein he commented on continuing to play rugby following his stroke. The reason for this, as he stated, is that the Caribbean culture knows very little about stroke and sees illness as the end of mobility.

Participants in the study were committed to recovering their functional and cognitive abilities by continuing to undertake activities which had formed part of their formal rehabilitation program. This represents the personal responsibility participants equate with their recovery process as well as once again exemplifies the personal determination of participants to overcome the challenges stroke presents in their lives.

Cultural Aspects of Care

A major aspect of this research study was to discover the cultural aspects of care participants felt were important in their experience with the health care team, primarily concerning the care they received from registered nurses during the early recovery period. When asked to describe the ways in which nurses can assist the African-Caribbean community in their recovery from stroke, responses by the participants fell into one main category which was the
provision of education. Information participants report absolutely wanting included education on stroke as well as diet. The event of a stroke for the participants was spoken of as a catastrophic event, for which they were unprepared and which was out of their control. In promoting feelings of control to manage one’s illness, a necessary step would appear to be the provision of education to increase the competency of individuals to undertake such a task.

For participants who did receive information regarding stroke care, it was given to them in the form of written information, rather than being verbally discussed with them. As one participant pointed out, following his stroke he was just given paperwork and told to read this. The same participant did not possess any knowledge on stroke prior to his illness. One can see that this is not an effective method of providing information on stroke. The danger here lies in the fact that individuals may fail to develop an awareness of the importance of taking measures which will decrease their risk of stroke. This was most evident in the comment made by Participant L.S. who stated that even after his second stroke, he remains unclear as to the warning signs of stroke and does not think that he will ever know what they are unless he asks. This was the same individual who returned to playing rugby following his first stroke.

The dissatisfaction of participants in this study in the health care team not meeting their information needs, is supported by other research which has indicated that the information needs of stroke survivors and their families are not fully being met (Garrett & Cowdell, 2005; Hanger & Wilkinson, 2001; Rodgers, Bond & Curless, 2001; Wiles et al., 1998). The principle of providing individualized information to patients has been supported by the research undertaken by Wiles et al. (1998); wherein information which addressed the concerns of individual patients was found to be more beneficial to patients and carried with it the potential to improve their quality of life. In an effort to meet the information needs of the participants in the study, in
addition to recognizing that stroke is a medical emergency requiring prompt intervention, I discussed the warning signs of stroke with each individual interviewed.

In a review carried out by the Cochrane Group on information provision following stroke for patients and their caregivers (Smith, Forster & Young, 2009), evidence was found to support the routine provision of information for stroke patients and their families; however, the best way to provide this information remained unclear. The results of their study nevertheless suggest that strategies in the provision of information which actively involve patients and their caregivers, and included follow-up care to clarify and reinforce information presented, should be used in routine practice.

The information needs identified by the participants in this research study, is closely linked to those within the literature. Information pertaining to stroke which they desired included: warning signs of a stroke, risk factors, as well as how to decrease the possibility of a reoccurrence.

Recognizing that there are aspects of the Caribbean diet which is unhealthy, as commented on by some of the participants, there was a strong desire by participants to receive information pertaining to ways of modifying their diet to promote a healthy lifestyle. The most significant aspect of the Caribbean diet which the participants were concerned with was the intake of salt.

What was interesting to note in this study is that participants although aware of the link between salt intake and hypertension; did not possess the same knowledge related to the link between hypertension and stroke.

Measures to control hypertension, thus reducing one’s risk of stroke, have been well documented within the literature (Campbell, Burgess, Taylor, Wilson, Cleroux, Fodor, Leiter &
For hypertensive patients the effects of reducing dietary salt intake is most pronounced after the age of forty-four (Leenen et al., 1999). A decrease of 100 mmol of daily sodium intake can result in a decrease of 6.3 mm Hg in systolic blood pressure and 2.2 mm Hg in diastolic blood pressure (Leenen et al., 1999, p.S29).

Considering that hypertension is a common and treatable illness, while uncontrolled hypertension has serious consequences, researchers consider measures to control hypertension to be of high priority within the Canadian health care system (Campbell, et al., 1999).

While a priority, efforts to change the cultural diet of Caribbean people may not be the easiest of tasks, as was demonstrated in a comment made by one of the participants concerning the difficulty Caribbean people have in making changes affecting their diet. This sentiment is echoed in the study conducted by Brown et al. (2007) to gain an understanding of how the health beliefs of African-Caribbean people influence the way in which they manage their diabetes. Individuals within their study felt that health professionals did not take their dietary preferences into account when giving advice on how to control their diabetes. For this reason individuals found it difficult to incorporate dietary advice about treating their diabetes and doubted the information given to them by health professionals. The doubt participants had in the value of dietary advice given to them by health professionals, stemmed from it being at odds with their beliefs about natural foods being wholesome and good for them. Sadly, participants in the study felt that it would take three generations before African-Caribbean people would change their traditional eating habits.

Faced with an illness such as stroke, as experienced by the participants within this research study, lifestyle changes related to diet may not be such an impossible task for
participants to undertake. This is best illustrated in the statement made by T.M., related to quitting smoking following his stroke, ‘Once you’re faced with death it’s much easier to quit cold turkey than to go through any other process.’ Perhaps a factor related to the ease with which African-Caribbean people will adopt changes to their diet, may lay in the severity of their illness as well as the ability of health professionals to work within the traditional diet of the cultural group they serve.
Chapter 6

Implications, Limitations and Summary

The implications of the research study for nursing practice, nursing education and future research will be presented in this chapter. In addition, avenues for future research as well as the limitations and strengths of the study will be highlighted followed by a conclusion.

Nursing Practice

The findings of this research study identify some key areas related to health promotion and education on disease prevention which should be targeted to the African-Caribbean community.

The provision of stroke information to African-Caribbean people should be considered a priority for nurses caring for this patient population. This was exemplified in the fact that participants did not know the warning signs of a stroke prior to the event, they did not know that their underlying medical condition put them at risk of a stroke, as well as having limited knowledge of the subject even after having become ill. The information needs identified for this population includes: education pertaining to risk factors for stroke, recognition of the warning signs of stroke as a medical emergency, information related to the importance of medication, in addition to lifestyle modifications; particularly dietary changes with respect to reducing salt intake to assist in the control of hypertension.

Additional points which should be highlighted, in education on stroke provided to African-Caribbean people, is the young age at which stroke affects individuals of this race. In a U.S. population based study of stroke (Kissela et al., 2004), stroke risks in Blacks were
shown to be higher at all ages but excessively so in the younger age category of 35 to 54 years of age. The rationale for including this information is to raise awareness among members of the population of their increased risk of stroke at a young age, compared to the general population. This may assist in motivating change, leading to lifestyle modifications which may reduce their risk of stroke. When advocating lifestyle changes, it needs to be an ongoing process even if patients are receiving medication to address their overall cardiovascular risk (Campbell et al., 1999).

A key point to keep in mind with respect to the provision of information on stroke is to present information which is individualized. Research indicates that individualized information for patients following stroke, is more effective than generalized (Wiles et al., 1998). This speaks to the intensely personal experience stroke is, as suggested in Burton’s (2000) study.

If our goal is to present information on stroke in ways which benefit the African-Caribbean community, it is worthwhile to consider how to best achieve this by once again turning to the literature. Community based programs are shown to typically work best if the information presented is targeted to those most at risk as well as being tailored to the relevant ethnic and cultural groups being addressed (Feigin & Rodgers, 2004). In the study by Pratt et al., (2003) looking at stroke knowledge and barriers to stroke prevention among African Americans, the researchers felt that in order for health programs to be effective and persuading to those at risk, the information presented must address the cultural characteristics of the target audience.

Nursing Education

Participants in the study commented on the care they received from nurses while they were in the hospital. For the majority, their experience with nurses were positive, conveying an overall feeling that they felt cared for and supported by nurses. The needs that remain unmet by
participants were the cultural understanding that nurses have of African-Caribbean people.

Within this research study the psychological impact of stroke on patients included feelings of intense fear, uncertainty, regret, loss of body control and overall emotional distress. The role of nurses is to be able to respond to these feelings expressed by patients, in order to alleviate suffering. Taking the time to learn about the culture of patients will allow nurses to offer individualized nursing care. Knowledge of the stroke patient’s experiences throughout the recovery process is beneficial for nurses in evaluating, planning and providing nursing care during recovery (Hafsteinsdottir & Grypdonck, 1997).

Stroke is an intensely personal experience, as suggested in Burton’s (2000) study, which would mean that in order for the nursing care of stroke patients to be most effective, it is necessary to consider the individuality of each patient. Recognizing and responding to the role culture plays in shaping the perception patients have of their illness, cannot be ignored. This is not to say that everyone from a particular cultural group experiencing the same illness will be seeking the same level of care; however, it does alert a nurse to important aspects to consider and topics to be explored which have been found to be sources of interest to that particular cultural group.

Research indicates that nurses seek to understand how people’s cultural beliefs of health and illness affect their experience, yet there is sparse literature about how to elicit cultural beliefs or incorporate them into healthcare practice (Meetoo & Meetoo, 2005). It is my hope that the use of the explanatory model of illness framework will represent an avenue by which nurses can elicit the illness perception of cultural groups they care for.
Future Research

Findings identified in this research study point to a number of areas meriting further research. Many of the participants felt that their stroke resulted from the stress they were experiencing within their personal lives rather than their underlying illness. Additional research could be conducted to explore how stress is perceived within the African-Caribbean community as well as coping mechanisms employed. Some participants described a feeling of detachment from their bodies, a phenomenon that could be explored with participants in greater detail. Several participants thought that they might need to change their traditional diet, following having identified aspects of the African-Caribbean diet which are unhealthy. Further research could explore factors that facilitate and impede dietary changes in this group. Last, a number of participants expressed an aversion to taking medications; further research might examine if those of African-Caribbean culture are different in this respect from other groups.

Participants were generally uninformed about stroke and recovery and thought that members of the Caribbean community knew little about this topic. Participatory action research through storytelling might be a particularly useful method for further research exploring stroke and stroke recovery among members of the African-Caribbean community.

Limitations and Strength of the Study

There are several limitations of this research study. Due to the small sample size, the key findings of the study were limited in scope; however the data gathered did capture all the elements of the event in question, a goal for researchers conducting qualitative studies (Sandelowski, 2000). The small sample size also prevented saturation of the data from being achieved. Perhaps with the inclusion of more participants, additional key findings may have emerged from the data. Attempts to increase the sample size could have been achieved by
extending the recruitment period, extending the time diagnosed since stroke, as well as the inclusion of individuals from additional sites.

While the main focus of this research study was to provide a description of the illness perception of African-Caribbean people, with no comparison group, it is difficult to say what the similarities and differences may have been in terms of how stroke is perceived.

With the majority of participants in the study being men, the perception of women with stroke is not adequately portrayed. Within the literature stroke is said to affect women and men in different ways (Hilton, 2002).

The major strength of this research study was that the cultural background of the researcher was similar to the participants in the study. Differing cultural backgrounds of clients and practitioners are said to possibly hinder disclosure to people of other cultures (Meetoo & Meetoo, 2005). With both the researcher and participants being of Caribbean heritage, this may have assisted in establishing rapport and contributed to the ease participants felt in providing rich descriptions of their illness experiences.

Conclusion

This study sheds light on the illness perceptions of African-Caribbean people recovering from stroke. It contributes to the body of research which exists on racial and ethnic disparities in stroke (Gorelick, 1998; Pratt et al., 2003; Feigin & Rodgers, 2004; Kissela et al., 2004; Bravata et al., 2005 & Ovbiagele & Levine, 2006). In addition, it contributes to what limited studies exist on the influence of culture on the manner in which chronic illness is viewed within the African-Caribbean community (Eaves, 2000; Scott 2001; Becker et al., 2004 & Brown et al., 2007). It has responded to the need identified for research which will bring to light the personal experience of
people recovering from stroke (Hafsteinsdottir & Grypdonck, 1996; Pilkington, 1999; Burton, 2000; Dowswell et al., 2000 & O’connell, et al., 2001).

The use of the explanatory model of illness framework provides an avenue whereby nurses can communicate with patients to gain their perspective on how stroke is experienced within the African Caribbean population.

Being aware of the cultural meanings that individuals attach to their illness allows us as health professionals to provide patient centered care, a necessary part of today’s healthcare arena.
References


APPENDIX A

Overview of the Study

Explanatory Models of Recovery from Stroke
Within the African-Caribbean Community in Canada

Summary of Proposed Study

The Topic
Stroke is the most common serious neurological condition worldwide. It is financially taxing on the Canadian Healthcare System and on the lives of the stroke survivor and their families. This is due to the physical, cognitive and psychosocial consequences of the disease. Racial differences are reported to exist, with members of the Black population having a higher incidence than Caucasians in being afflicted by the illness. Worldwide, stroke is considered to be an important cause of mortality and morbidity in Blacks. As a result of the tremendous burden stroke poses to the economy and the health status of patients, education pertaining to the needs of stroke survivors is of paramount importance. However, no serious attempt at reducing the economic burden of stroke can be made without specifically targeting the groups at the highest risk. Understanding the illness experience from the patient’s perspective is an essential component to the development of appropriate strategies to facilitate recovery. The purpose of this study is to describe how Caribbean stroke survivors, who live in Canada, understand their illness and manage their care during the early recovery period.

The Method
A qualitative descriptive exploratory design will be used to study the experience of recovery from stroke among African-Caribbean stroke survivors. An application for approval has been submitted to Queens University Ethics Board and approval will be sought from Stroke Recovery Canada, support groups for stroke survivors as well as two teaching hospitals in the Greater Toronto Area. Participants will be recruited from the out-patient stroke clinics of the hospitals. The nurse clinicians at the clinics will be asked to approach potential participants who are of Caribbean heritage. If the individual is
agreeable, the nurse clinician will provide contact information to the researcher, who will arrange to meet with the stroke survivor at a mutually agreeable time and place. Semi-structured interviews, lasting approximately 45 minutes, will be scheduled by the researcher with each participant and if requested by the participant, a family member may be present at the interview. Informed consent will be obtained in writing from the participants. During the interview, the researcher will gauge the tiredness of the participants, making allowance for a second meeting if required. Interview transcripts will be entered into a program for qualitative data analysis and data will be analyzed to look for common themes and meanings of the participants’ experience.

The Researchers
Denise Wilson, a graduate student in the Master of Science program, School of Nursing at Queen’s University is the principal investigator. Dr. Marianne Lamb, Graduate Coordinator, School of Nursing at Queen’s University will be responsible for supervising the student’s overall research.

Study Approvals
Approval will be obtained for this study from the Queen’s University Ethics Board before interviewing commences. In addition, approval will be sought from each of the participating health facilities, prior to any interviewing. Confidentiality of the data will be maintained and no names of the participants will be used in any presentation or publication.

If any additional information is required, please do not hesitate to contact:

Denise Wilson
Queens University
7dcw@queensu.ca
416-558-7828
APPENDIX B

Consent Form

INFORMATION/CONSENT FORM

TITLE OF PROJECT:
Explanatory Models of Recovery from Stroke
Within the African-Caribbean Community in Canada

OVERVIEW OF THE STUDY:
You are being invited to participate in a research study conducted by Denise Wilson, a graduate student in nursing at Queens University. Dr. Marianne Lamb, Graduate Coordinator, School of Nursing at Queens University will be responsible for supervising the student’s research. The aim of the study is to describe the beliefs and perspectives of individuals of African-Caribbean heritage who have had a stroke. In the study we also want to learn about how these individuals are managing in caring for themselves after their stroke. Denise Wilson, the researcher, will read through this consent form with you, describe the study in detail and answer any questions you may have. The study has been approved by the Queen’s University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board.

DETAILS OF THE STUDY:
The purpose of this study is to find out how people of the African-Caribbean Community understand their illness and how they are managing after their stroke. The researcher will contact you to arrange a private interview that lasts approximately 45 minutes, and that will be held at a location of your choice. You are welcome to have a family member present at the interview session.
During the interview, the researcher will ask a series of questions about your illness experience. If you become tired during the interview process, we will stop the interview and reschedule a convenient time to continue our discussion.
The researcher may contact you a second time to clarify any information or request an additional meeting. Your name will not be used in the study. No information that discloses your identify will be released or published without your specific consent to the disclosure. With your permission, conversations will be recorded. All information pertaining to the study will be kept in a locked drawer, and only shared with members of the research team. Recordings will be kept for five years and then destroyed.

There are no known harms associated with your participation in this research. While you may not benefit directly from participating in this study, results obtained from the study may lead to improvements in educational programs or professional care of individuals of African-Caribbean heritage who experience stroke.

Your participation in this study is voluntary and you may withdraw from the study at any time. If you choose not to participate, you will continue to have access to quality care.

**PARTICIPATION STATEMENT AND SIGNATURE SECTION:**

I have read and understand the consent form for this study. I have had the purposes and procedures of this study explained to me. I have been given sufficient time to consider the above information and to seek advice if I chose to do so. I have had the opportunity to ask questions which have been answered to my satisfaction. I am voluntarily signing this form. I will receive a copy of this consent form for my information.

If at any time I have further questions, problems or adverse events, I can contact

Denise C. Wilson at 416-558-7828

OR

Dr. Marianne Lamb at 613-533-6000 ext 74764

If I have questions regarding my rights as a research subject I can contact

Dr. Albert Clark, Chair, Queen’s University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board at 613-533-6081.
By signing this consent form, I am indicating that I agree to participate in this study.

____________________________________________________________________
Signature of Participant                                    Date

____________________________________________________________________
Signature of Witness                                      Date

**STATEMENT OF INVESTIGATOR**
I, or one of my colleagues, have carefully explained to the subject the nature of the above research study. I certify that, to the best of my knowledge, the subject understands clearly the nature of the study and demands, benefits, and risks involved to participants in this study.

____________________________________________________________________
Signature of Principal Investigator                           Date
Title: Explanatory Models of Recovery From Stroke Within the African-Caribbean Community in Canada.

Investigator: Denise C. Wilson, R.N., BScN, CNCC(c)

Co-Investigators: Dr. Marianne Lamb
Graduate Coordinator, School of Nursing
Queen’s University

Introduction
You are being asked to take part in a research study. Please read this explanation about the study and its risks and benefits before you decide if you would like to take part. You should take as much time as you need to make your decision. You should ask the study doctor or study staff to explain anything that you do not understand and make sure that all of your questions have been answered before signing this consent form. Before you make your decision, feel free to talk about this study with anyone you wish. Participation in this study is voluntary.
Background and Purpose

You have been asked to take part in this research study because you are of African-Caribbean heritage and have recently suffered a stroke. While we know that stroke affects many individuals within the Canadian population, little data exists regarding the effects of stroke on members of the Black community. Worldwide, stroke is a major health problem among Blacks.

The purpose of this study is to describe how African-Caribbean stroke survivors, who live in Canada, understand their illness and manage their care during the early recovery period. Results obtained from the study may lead to improvements in educational programs or professional care of individuals of African-Caribbean heritage who experience stroke.

About 10 – 15 people will take part in the study from the Toronto Western Hospital Secondary Stroke Prevention Clinic at the University Health Network.

Study Visits and Procedures

The researcher will contact you to arrange a private interview that lasts approximately 45 minutes, and that will be held at a location of your choice. You are welcome to have a family member or friend present at the interview session. During the interview, the researcher will ask a series of questions about your illness experience. If you become tired during the interview process, we will stop the interview and reschedule a convenient time to continue our discussion.

The researcher may contact you a second time to clarify any information or request an additional meeting. Your name will not be used in the study. No information that discloses your identify will be released or published without your specific consent to the disclosure. With your permission, conversations will be recorded.

Risks Related to Being in the Study

Some questions are very personal having to do with your ability to perform tasks of everyday living. It is important that you know that you do not have to answer
any question you do not wish to answer, and that you can stop at any time. It also may be embarrassing for you, if the answers to the interview questions became known publicly. For this reason the research team will do everything possible to maintain the confidentiality of all interviews.

**Benefits to Being in the Study**
While you may not benefit directly from participating in this study, results obtained from the study may lead to improvements in educational programs or professional care of individuals of African-Caribbean heritage who experience stroke.

**Voluntary Participation**
Your participation in this study is voluntary. You may decide not to be in this study, or to be in the study now and then change your mind later. You may leave the study at any time without affecting your care. You may refuse to answer any question you do not want to answer, or not answer an interview question by saying “pass”.

We will give you new information that is learned during the study that might affect your decision to stay in the study.

**Confidentiality**
If you agree to join this study, the study team will look at your personal health information and collect only the information they need for the study. All information obtained during the study will be held in strict confidence.

Tapes will be stored in a locked drawer in a secure location by the principal investigator. At the end of the study, the audio-recorded tapes of the interviews
will be kept for 5 years in a secure location at Queen’s University, School of Nursing. There will be no written material that identifies participants.

Representatives of the University Health Network Research Ethics Board may look at the study records and at your personal health information to check that the information collected for the study is correct and to make sure the study followed proper laws and guidelines.

All information collected during this study, including your personal health information, will be kept confidential and will not be shared with anyone outside the study unless required by law. You will not be named in any reports, publications, or presentations that may come from this study.

**Expenses Associated with Participating in the Study**

You will not incur any expenses as a result of taking part in this study.

**Questions About the Study**

If you have any questions, concerns or would like to speak to the study team for any reason, please call: Denise C. Wilson, principal investigator at 416-603-5818.

If you have any questions about your rights as a research participant or have concerns about this study, call Ronald Heslegrave, Ph. D., Chair of the University Health Network Research Ethics Board (REB) or the Research Ethics office number at 416-946-4438. The REB is a group of people who oversee the ethical conduct of research studies. These people are not part of the study team. Everything that you discuss will be kept confidential.
Consent
This study has been explained to me and any questions I had have been answered. I know that I may leave the study at any time. I agree to take part in this study.

_________________________   ___________________   ________

Print Study Participant’s Name   Signature   Date
(You will be given a signed copy of this consent form)

My signature means that I have explained the study to the participant named above. I have answered all questions.

_________________________   ___________________   ________

Print Name of Person Obtaining Consent   Signature   Date

Was the participant assisted during the consent process? □ YES □ NO

If YES, please check the relevant box and complete the signature space below:

☐ The person signing below acted as a translator for the participant during the consent process and attests that the study as set out in this form was accurately translated and has had any questions answered..

_________________________   ___________________   ________

Print Name of Translator   Signature   Date

_________________________   ___________________
Relationship to Participant    Language
☐ The consent form was read to the participant. The person signing below attests that the study as set out in this form was accurately explained to, and has had any questions answered.

_____________________________  _________________________  ____
Print Name of Witness  Signature  Date

Relationship to Participant
### Socio-demographic Data Collection Form

<table>
<thead>
<tr>
<th>Participant Number</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Place of Birth</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Age in years</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Gender</th>
</tr>
</thead>
<tbody>
<tr>
<td>male</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Length of Time in Canada</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Living Arrangements</th>
</tr>
</thead>
<tbody>
<tr>
<td>Private home</td>
</tr>
<tr>
<td>Retirement home</td>
</tr>
<tr>
<td>Long-term Care</td>
</tr>
<tr>
<td>Other</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Number of People living with you</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Marital Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Single (never married)</td>
</tr>
<tr>
<td>Married/Common Law</td>
</tr>
<tr>
<td>Divorced/Separated</td>
</tr>
<tr>
<td>Widow/Widower</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Years of schooling</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Employment Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Retired</td>
</tr>
<tr>
<td>Unemployed</td>
</tr>
<tr>
<td>Employed: leave of absence/illness leave</td>
</tr>
<tr>
<td>Part-time</td>
</tr>
<tr>
<td>Full-time</td>
</tr>
</tbody>
</table>
APPENDIX E

Semi-Structured Interview Schedule

Opening Introduction:
I would like to thank you for agreeing to take part in this research study. Stroke is an illness affecting many individuals within the Canadian population. While there has been published reports on the experience of those affected by the illness, very little research exists on the experience of those within the African-Caribbean community.

Our conversation today is for the purpose of finding out what it was like for you to have a stroke and how you’ve been managing during the past few months of recovery. Are there any questions or concerns you have before we begin?

What do you call your problem?
What do you think caused your problem?
Why do you think it started when it did?
What does your sickness do to you? How does it work?
How severe is your sickness?
How long do you think you will have it?
What have you done so far to treat your illness?
What treatments do you think you should receive?
What are the most important results you hope to receive from the treatment?
What are the chief problems your sickness has caused for you?
What worries or concerns do you have about your illness?
(above questions adapted from Kleinman, 1978, p.256).

What is your day-to-day routine like, in taking care of yourself?
What was helpful for you during the first few months of your stroke?
How can nurses assist someone of your culture to recover from stroke?
Appendix F
Queen's Research Ethics Approval

QUEEN'S UNIVERSITY HEALTH SCIENCES & AFFILIATED TEACHING
HOSPITALS RESEARCH ETHICS BOARD

December 10, 2008

Ms. Denise Wilson
School of Nursing
Cataract Building
92 Barrie Street
Queen's University

Dear Ms. Wilson,

Study Title: Explanatory Models of Recovery from Stroke Within the African-Caribbean Community in Canada
Co-Investigators: Dr. Marianne Lamb

I am writing to acknowledge receipt of your recent ethics submission and the ethics approval letter from Trillium Health Centre. We have examined the protocol and consent form for your project (as stated above) and consider it to be ethically acceptable. I am providing ethics approval to begin recruitment of subjects for your study. This approval is contingent upon receipt of approval from Toronto Western Hospital. This approval is valid for one year from the date of the Chair's signature below. This approval will be reported to the Research Ethics Board. Please attend carefully to the following list of ethics requirements you must fulfill over the course of your study:

➢ Reporting of Amendments: If there are any changes to your study (e.g. consent, protocol, study procedures, etc.), you must submit an amendment to the Research Ethics Board for approval. (see http://www.queensu.ca/vpr/reb.htm).

➢ Reporting of Serious Adverse Events: Any unexpected serious adverse event occurring locally must be reported within 2 working days or earlier if required by the study sponsor. All other serious adverse events must be reported within 15 days after becoming aware of the information.

➢ Reporting of Complaints: Any complaints made by participants or persons acting on behalf of participants must be reported to the Research Ethics Board within 7 days of becoming aware of the complaint. Note: All documents supplied to participants must have the contact information for the Research Ethics Board.

➢ Annual Renewal: Prior to the expiration of your approval (which is one year from the date of the Chair's signature below), you will be reminded to submit your renewal form along with any new changes or amendments you wish to make to your study. If there have been no major changes to your protocol, your approval may be renewed for another year.

Yours sincerely,

[Signature]
Chair, Research Ethics Board

[Signature]
Date

94
December 4, 2008

Ms. Denise Wilson
34 Reginald Street
Hamilton, Ontario
L8P 3Y1

Dear Ms. Wilson,

RE: Explanatory Models of Recovery from Stroke Within the African-Caribbean Community in Canada (ID#392)

Ethics Approval Expiry Date: November 20, 2009

This letter is to inform you that the above-named research study has been granted approval by the Research Review Team (RRT) with a full-quorum of voting members on November 20, 2008 for a period of one year. The following documents have been approved until the expiry date noted above:

➢ Summary for proposed study, version received November 4, 2008
➢ Research Proposal on Stroke, version dated October 27, 2008
➢ Information/Consent Form, version received November 4, 2008

Please ensure to submit the original copy of the Health Systems Review signature page from the Application Form.

Please note that ongoing projects must be renewed prior to the expiry date.

During the course of the research, any significant deviations from the approved protocol (that is, any deviation which would lead to an increase in risk or a decrease in benefit to participants) and/or any unanticipated developments within the research should be brought to the attention of the Research Review Team.

Sincerely,

Nicole Pageau, RN, BA
Quality Manager, Regional Stroke Program
Chair – Research Review Team
APPENDIX H
University Health Network Research Ethics Approval

Notification of REB Initial Approval

Date: March 6th, 2009
To: Denise Wilson
      Toronto Western Hospital, 399 Bathurst St.
      Toronto, Canada M5T 2S8
Re: 08-1076-BE
      Explanatory Models of Recovery From Stroke Within the African-Caribbean Community in Canada

REB Review Type: Expedited
REB Initial Approval Date: March 6th, 2009
REB Expiry Date: March 6th, 2010

Documents Approved:
- Protocol - Research Proposal
  Version date: October 27th, 2008
- Consent Form
  Version date: March 4th, 2009
- Semi-Structured Interview Schedule
  Received on: December 10th, 2008
- Data Collection Form
  Received on: December 10th, 2008

The above named study has been reviewed and approved by the University Health Network Research Ethics Board.
If, during the course of the research, there are any serious adverse events, confidentiality concerns, changes in the approved project, or any new information that must be considered with respect to the project, these should be brought to the immediate attention of the REB. In the event of a privacy breach, you are responsible for reporting the breach to the UHN REB and the UHN Corporate Privacy Office (in accordance with Ontario health privacy legislation - Personal Health Information Protection Act, 2004). Additionally, the UHN REB requires reports of inappropriate/unauthorized use of the information.

Please be aware that it is UHN policy that research-related activities involving an external party require a research agreement. An 'external party' refers to a corporation other than UHN or an individual who is not UHN personnel. Should a research agreement be required in this case, the study may not begin at UHN until the agreement has been signed by all parties. Should the negotiation process raise concerns, the REB reserves the right to reconsider its approval.

If the study is expected to continue beyond the expiry date, you are responsible for ensuring the study receives re-approval. The REB must be notified of the completion or termination of this study and a final report provided. As the Principal Investigator, you are responsible for the ethical conduct of this study.

There's always an answer. We'll find it.
The UHN Research Ethics Board operates in compliance with the Tri-Council Policy Statement, ICH/GCP Guidelines, the Ontario Personal Health Information Protection Act (2004), and Part C, Division 5 of the Food and Drug Regulations of Health Canada.

Sincerely,

[Signature]

Ronald Hesler, Ph.D.
Chair, University Health Network Research Ethics Board
APPENDIX I
Study Amendment (February 26, 2009)

February 26, 2009

Ms. Denise C. Wilson
34 Reginald Street
Hamilton, ON  L8P 3Y1

Re:  “Exploratory Models of Recovery from Stroke Within the African-Caribbean Community in Canada” NURS-237-08

Dear Ms. Wilson,

I am writing to acknowledge receipt of your letter dated February 23, 2009 which requested approval for an amendment to your study. I have reviewed this request:

- Addition of Stroke Recovery Canada, a support group for stroke patients in the Greater Toronto Area from which to recruit participants

and hereby give my approval. Receipt of this amendment will be reported to the Research Ethics Board.

Yours sincerely,

[Signature]

Albert Clark, Ph.D.
Chair
Research Ethics Board
May 25, 2009

Ms. Denise Wilson
34 Reginald Street
Hamilton, ON  L8P 3Y1

Re: “Explanatory Models of Recovery From Stroke Within the African-Caribbean Community in Canada” NURS-237-08

Dear Ms. Wilson,

I am writing to acknowledge receipt of your letter dated May 22, 2009 which requested approval for the following amendments to the above-named study:

- Change in inclusion criteria – extended to 2 years post-stroke as opposed to 6 months post-stroke
- Addition of two organizations for recruitment purposes
  - Credit Valley Hospital, Mississauga
  - Next Step to Active Living, Mississauga

I have reviewed these amendments and hereby give my approval. Receipt of these amendments will be reported to the Health Sciences Research Ethics Board.

Yours sincerely,

Albert Clark, Ph.D.
Chair
Research Ethics Board
APPENDIX K

Summary of the Researcher’s Background and Experience

Due to my role as both the principal investigator in this research study as well as the facilitator in the interview process, it is important that I discuss my background and experience to minimize any influence this may have on the study. The purpose of undertaking this exercise is to recognize how my background and experience may relate to my thoughts and views on the topic of stroke in the African-Caribbean community.

My background includes having worked for the past eight years as a staff nurse in the field of critical care nursing, undertaken formal training in adult education, as well as having spent the past two years reviewing academic literature pertaining to the topic of stroke in the Black community. For these reasons I consider myself as having the knowledge required to undertake this research study.

Within my profession I have had the opportunity to work with many individuals who have suffered a stroke as well as their family members. Due to my extensive experience working with stroke patients, I feel competent in my ability to communicate with this patient population and assess their needs pertaining to nursing care. During my career I have often felt that the topic of culture did not receive adequate attention in the nursing care of patients. I consider one’s culture to be an important aspect of their view on health and illness.

Being of the same cultural background as those of the participants in the study; offers me a fair degree of insight into their values and beliefs, the manner in which they may deal with challenging situations, as well as their views related to ill health. While I possess additional insight, that another researcher from a different cultural background may not have, it is imperative that I view the participants as individuals in their own right, with their own distinctive ways of looking at the world and the perception they have of their illness.