The University of Nottingham

UNITED KINGDOM · CHINA · MALAYSIA

# Delivering post-stroke education in Ghana: a feasibility Randomised Controlled Trial (RCT) with nested qualitative interviews

**Philemon Adoliwine Amooba**

MSc, BSc, FGCN, SRN

Thesis submitted to the University of Nottingham for the degree of Doctor of Philosophy

September 2022

# Abstract

**Background**: Stroke remains a significant global health problem, particularly in Africa. In Ghana, stroke survivors and their family caregivers lack information and consequently experience poor stroke outcomes. However, no study evaluating the provision of post-stroke information currently exists.

**Aim**: The aim of this research was to evaluate the feasibility of conducting a Randomised Controlled Trial (RCT) of a post-stroke education intervention for stroke survivors and their family caregivers in Ghana.

**Methods**: The research was organised into three studies.

In the first study, a systematic review was conducted. A search for articles on post-stroke education interventions was carried out in nine major electronic databases. The review included RCTs of interventions with leaflets, booklets, audio-visual tapes and/or computer-mediated educational programmes with or without discussion and teaching sessions and reported outcomes on knowledge of stroke, anxiety, depression, self-efficacy, and caregiver's burden. The Joanna Briggs Institute critical appraisal tool was used to appraise included studies and extract relevant data.

A feasibility RCT was conducted in a teaching hospital in Ghana. Adult stroke survivors and their family caregivers were recruited as dyads and randomised to receive post-stroke education intervention plus usual care or only usual care. The intervention included issuing a stroke information booklet with face-to-face discussions with a healthcare professional and a two-week follow-up telephone call. The main outcome measures were descriptions of feasibility outcomes (recruitment, retention and delivery of the intervention). At three months follow-ups, signals of intervention effects were collected on knowledge of stroke, anxiety, depression, and caregiver burden.

Semi-structured interviews were conducted with stroke survivors and family caregivers from both arms of the trial at three months follow-ups. Nurses who provided the intervention and collected outcome measures were also interviewed. Participants were questioned on their experiences of stroke, caring for survivors, using post-stroke information, participation in the trial, and the content and delivery of the intervention. Interviews were transcribed and analysed thematically.

**Results**: Eight RCTs were included in the review and synthesised through a narrative summary. There was limited evidence regarding the effectiveness of post-stroke education. However, although most studies did not report statistically significant differences in knowledge of stroke, there were general improvements in stroke knowledge. The finding of this review with stakeholders' feedback were used to develop the stroke information booklet utilised in the feasibility trial.

A total of 50 dyads were recruited for the feasibility trial and randomly allocated to post-stroke education intervention (25 dyads) and usual care (25 dyads). Of these, 36 (72%) dyads completed the trial. Recruiting and retaining participants, delivering the intervention, and collecting outcome data responsive to change were feasible. Participants in both groups showed improvements in some outcomes. The intervention group had slightly increased stroke knowledge, but wide confidence intervals reflected the small sample. The intervention was acceptable to participants who valued the information and advice provided.

Interviews were conducted with 15 participants: six stroke survivors and six family caregivers, half of whom had received post-stroke education and half who had not, and three nurses delivered the intervention. Four main themes emerged from the stroke survivor and family caregiver interviews that illuminated unmet information needs. Participants needed to make sense of what had happened to them and to prepare for living with stroke over the long term. They also lacked understanding of issues associated with recovery, minimising the risks of further strokes and wanted more information about stroke. The nurses' interview revealed challenges with implementing post-stroke education but indicated the need to provide post-stroke education.

**Conclusions**: The feasibility trial suggests that conducting a definitive RCT is feasible. However, some aspects of the design would need changing before conducting a fully powered definitive trial. This research is essential as it was the first feasibility RCT of a post-stroke education intervention in Ghana and, therefore, valuable in developing evidence-based stroke care interventions in this country.

# Table of contents

Abstract ..... i

Table of contents ..... iii

List of tables ..... xii

List of figures ..... xiii

List of abbreviations ..... xiv

Acknowledgements ..... xv

**Chapter One - Background** ..... 1

1.1 Introduction ..... 2

1.2 Overview of stroke ..... 3

1.2.1 Definition of stroke ..... 3

1.2.2 Incidence and prevalence ..... 4

1.2.3 Types of stroke ..... 5

1.2.4 Risk factors for stroke ..... 6

1.2.5 Global burden of stroke ..... 8

1.2.6. Psychological impact of stroke ..... 9

1.2.7 Caregiver burden ..... 13

1.2.8 Management of stroke ..... 15

1.2.9 Provision of stroke information ..... 16

1.3 Stroke in sub-Saharan Africa ..... 23

1.3.1 Knowledge and awareness of stroke in sub-Saharan Africa ..... 25

1.3.2 Provision of stroke care in Africa ..... 27

1.4 Profile of Ghana ..... 31

1.4.1 Ghana's health service delivery ..... 32

1.4.2 Healthcare seeking practices of Ghanaians ..... 34

1.4.3 Healthcare policies on NCDs in Ghana ..... 36

1.4.4 Stroke and its management in Ghana ..... 37

1.5 The researcher's perspective ..... 40
1.6 Research aim, objectives, and plan of investigation ..... 41
1.7 Philosophical assumptions underpinning the research ..... 42
1.8 Plan of thesis ..... 44
**Chapter Two** - **Randomised controlled trials of post-stroke education interventions for stroke survivors and their family caregivers – A systematic review** ..... 45
2.1 Introduction ..... 46
2.2 Review question ..... 47
2.3 Aim and objectives of the review ..... 47
2.3.1 Objectives ..... 48
2.4 Review methods ..... 48
2.4.1 Review protocol ..... 48
2.4.2 Eligibility criteria ..... 48
2.4.2.1 Types of studies ..... 48
2.4.2.2 Types of participants ..... 50
2.4.2.3 Types of interventions ..... 50
2.4.2.4 Types of outcome measures ..... 50
2.4.3 The search strategy for identification of studies ..... 51
2.4.4 Selection of studies ..... 54
2.4.5 Assessment of methodological quality of included studies ..... 54
2.4.6 Data extraction and management ..... 55
2.4.7 Data synthesis and summary of findings ..... 56
2.4.8 Results of the review ..... 56
2.4.8.1 Study selection ..... 56
2.4.8.2 Assessment of methodological quality of included trials ..... 59
2.4.8.3 Characteristics of included studies ..... 62
2.4.8.4 Participants ..... 62

2.4.8.5 Nature of interventions ..... 63
2.4.8.6 Outcome measures ..... 65
2.5 Summary of review results ..... 69
2.6 Review conclusion and implications for the feasibility of RCT intervention ..... 72
**Chapter Three - Post-stroke education intervention in Ghana: a feasibility randomised controlled trial (RCT)** ..... 75
3.1 Introduction ..... 76
3.1.1 Research aim and objectives ..... 76
3.2 Research design considerations ..... 76
3.3 Quasi-experimental ..... 77
3.3.1 Cross-sectional design ..... 77
3.3.2 Pre-test post-test design (before and after design) ..... 78
3.4 Randomised Controlled Trial (RCT) ..... 78
3.5 Feasibility Randomised Controlled Trial (RCT) ..... 81
3.5.1 Study setting ..... 84
3.5.2 Research governance and ethical considerations ..... 85
3.5.2.1 Ethical considerations ..... 85
3.5.2.2 Study preparations ..... 87
3.5.3 Sampling ..... 89
3.5.3.1 Planned sample size ..... 89
3.5.3.2 Study population – eligibility criteria ..... 90
3.5.3.3 Inclusion criteria for stroke survivors ..... 90
3.5.3.4 Inclusion criteria for family caregivers ..... 90
3.5.3.5 Exclusion criteria for stroke survivors and family caregivers ..... 91
3.5.4 Recruitment procedure ..... 92
3.5.4.1 Identification and invitation to the study ..... 93
3.5.4.2 Informed consent ..... 93

3.5.4.3 Enrolment of study participants ..... 94
3.5.5 Participant procedures ..... 94
3. 5.5.1 Baseline Assessments ..... 94
3.5.5.2 Stroke survivor characteristics ..... 95
3.5.5.3 Stroke survivor baseline measures ..... 95
The Hospital Anxiety and Depression Scale (HADS) ..... 98
3.5.5.4 Family caregiver characteristics ..... 99
3.5.5.5 Family caregiver's baseline measures ..... 100
Caregiver burden ..... 100
3.5.6 Randomisation and blinding ..... 102
3.5.6.1 Usual care ..... 103
3.5.6.2 Intervention ..... 103
3.5.7 Outcome measures ..... 110
3.5.8 Other follow-up questions ..... 111
3.5.9 Data entry and data management ..... 112
3.5.10 Data analysis ..... 113
3.5.11 Trial management ..... 113
**Chapter Four - Post-stroke education in Ghana: feasibility randomised controlled trial results and discussion** ..... 114
4.1 Introduction ..... 115
4.2 Participant recruitment ..... 115
4.3 Participants' characteristics and baseline measures ..... 118
4.3.1 Stroke survivors' baseline assessment ..... 118
4.3.1.1 Stroke survivors' characteristics ..... 118
4.3.1.2 Baseline measures for stroke survivors ..... 121
4.3.2 Family caregivers' baseline assessment ..... 122
4.3.2.1 Family caregivers' sociodemographic characteristics ..... 122

4.3.2.2 Baseline measures for family caregivers ..... 124
4.4 Feasibility outcomes ..... 125
4.4.1 Retention and follow-up ..... 125
4.4.2 Data collection and completion ..... 126
4.4.3 Participant randomisation ..... 126
4.4.4 Delivery of the intervention ..... 126
4.5 Acceptability and suitability of the information booklet ..... 127
4.5.1 Stroke survivors' responses to the information booklet ..... 127
4.5.2 Family caregivers' responses to the stroke information booklet ..... 131
4.6 Outcome measures data ..... 134
4.6.1 Stroke survivor outcome measures data ..... 134
4.6.2 Family caregiver outcome measures data ..... 136
4.7 Discussion ..... 137
4.8 Summary ..... 142
**Chapter Five - Post-stroke education in Ghana: Qualitative interviews** ..... 144
5.1 Introduction ..... 145
5.2 Rationale for qualitative research 'nested' within RCTs ..... 145
5.3 Aim and objectives ..... 147
5.3.1 Stroke survivors ..... 147
5.3.2 Family caregivers ..... 147
5.3.3 Nurses ..... 147
5.4 Method ..... 148
5.4.1 Consideration of qualitative research method ..... 148
5.4.2 Interviews ..... 148
5.4.2.1 Approaches to individual interviews ..... 151
5.4.2.2 Interview topic guides ..... 152
5.4.2.3 Stroke survivors' topic guide ..... 153

5.4.2.4 Family caregiver topic guide ..... 154
5.4.2.5 Nurse topic guide ..... 154
5.4.2.6 Piloting of interview guides ..... 155
5.4.3 Sampling ..... 155
5.4.3.1 Sample size ..... 155
5.4.3.2 Sampling strategy ..... 156
5.4.3.3 Identification and selection of participants ..... 156
5.4.4 Study participants ..... 157
5.4.5 Interviewing procedures ..... 157
5.4.5.1 Stroke survivors and their family caregivers ..... 157
5.4.6.2 Nurses ..... 158
5.4.7 Data analysis ..... 158
5.4.7.1 Transcription ..... 158
5.4.7.2 Rigour/ Trustworthiness ..... 159
5.4.7.3 Thematic analysis ..... 161
5.4.7.4 Data management ..... 162
5.4.7.5 Being an 'insider' ..... 162
5.4.7.6 Presentation of themes ..... 164
5.4.8 Ethical considerations ..... 164
5.5 Summary of chapter ..... 165
**Chapter Six - Post-stroke education in Ghana: Qualitative findings and discussion** ..... 167
6.1 Introduction ..... 168
6.2 Interviews with stroke survivors ..... 168
6.2.1 Stroke survivors' characteristics ..... 168
6.2.2 Themes and sub-themes ..... 169
6.2.3 Theme 1: Making sense of what happened ..... 170

6.2.3.1 Stroke is a traumatic experience ..... 170
6.2.3.2 Lack of previous knowledge of stroke and the risk factors ..... 171
6.2.3.3 Delays in a formal diagnosis ..... 173
6.2.4 Theme 2: Living with stroke in the long-term ..... 175
6.2.4.1 Feelings of weakness and a reduction in mobility ..... 175
6.2.4.2 Reduced employment prospects ..... 177
6.2.4.3 Acceptance of the condition and recovery prospects ..... 178
6.2.4.4 The impact of superstition and the subsequent stigma ..... 180
6.2.5 Theme 3: Lacking understanding about recovery and avoiding the risk of further strokes ..... 180
6.2.5.1 Poor levels of current knowledge about stroke ..... 181
6.2.5.2 Failure to proactively seek information ..... 182
6.2.5.3 Current education provision not structured ..... 183
6.2.6 Theme 4: Desiring stroke information ..... 184
6.2.6.1 A desire to learn ..... 184
6.2.6.2 Viewing the trial as a source of information ..... 185
6.3 Interviews with family caregivers ..... 188
6.3.1 Family caregiver's characteristics ..... 188
6.3.2 Themes and sub-themes ..... 189
6.3.3 Theme 1: Making sense of what had happened ..... 190
6.3.4 Theme 2: Coping with the medium to the long-term impact of caring for stroke survivors ..... 191
6.3.4.1 The emotional impact of caring for stroke survivors ..... 191
6.3.4.2. Cost ..... 193
6.3.4.3 Juggling of responsibilities ..... 193
6.3.5 Theme 3: Current education provision not structured ..... 194
6.3.6 Theme 4: Desire for stroke information ..... 195
6.3.6.1 A desire to learn ..... 195

6.3.6.2 Viewing the trial as a source of information ..... 196
6.3.6.3 Viewing the trial as an opportunity to generate information for others .. 198
6.4 Interviews with nurses ..... 199
6.4.1 Characteristics of nurses interviewed ..... 199
6.4.2 Themes and sub-themes ..... 200
6.4.3 Theme 1: The difficulties involved in providing post-stroke education ..... 200
6.4.3.1 The demands of the physical care need of the individual ..... 200
6.4.3.2 Limited education for staff ..... 201
6.4.3.3 Lack of time for patient education ..... 202
6.4.4 Theme 2: The need for the intervention ..... 203
6.4.4.1 Recognition of ignorance about stroke ..... 203
6.4.4.2 Promoting consistent information ..... 204
6.4.4.3 Added benefits when combined with a follow-up visit ..... 205
6.4.4.4 It gives people information to take away with them ..... 205
6.4.5 Theme 3: Perceived limitations of the intervention ..... 206
6.5 Discussion ..... 207
6.6 Conclusion ..... 212
**Chapter Seven - General discussion and conclusion ..... 213**
7.1 Introduction ..... 214
7.2 Summary of the main research findings ..... 214
7.3 The feasibility of post-stroke education for stroke survivors and their family caregivers ..... 216
7.3.1 Study sample ..... 216
7.3.1.1 Recruitment ..... 216
7.3.1.2 Retention and attrition ..... 217
7.3.2 Delivery of the post-stroke education intervention ..... 218
7.4 The feasibility of using the study outcomes ..... 219

7.5 Strengths and limitations of the research ..... 220
7.5.1 Strengths of the study ..... 220
7.5.2 Limitations of the study ..... 221
7.6 Relevance to other studies ..... 223
7.7 Context and implications of the research ..... 228
7.7.1 Implications for practice ..... 228
7.7.2 Implications for future research ..... 231
7.8 Recommendation for future trial ..... 231
7.9 Conclusion ..... 232
**References ..... 233**
Appendix 1 – Database Search Strategy ..... 294
Search History (MEDLINE Database) ..... 294
Search History (CINAHL Database) ..... 296
Search History (Embase Database) ..... 300
Search History (PsychoINFO Database) ..... 303
Search History (ASSIA Database) ..... 304
Appendix 2 - Modified JBI MAStARI standardised data extraction form ..... 306
Appendix 3 - Summary of the reviewed randomised controlled trials ..... 307
Appendix 4 - Participant Information Sheet ..... 315
Appendix 5: Favourable ethics opinion from the UoN ..... 318
Appendix 6: Ethics approval letter ..... 319
Appendix 7: Research study poster ..... 320
Appendix 8: Consent Form ..... 321
Appendix 9: Stroke survivor background information ..... 323
Appendix 10: Knowledge of stroke questionnaire ..... 325
Appendix 11: Hospital Anxiety and Depression Scale (HADS) ..... 327
Appendix 12: Family Caregiver background information ..... 329

Appendix 13: Modified Caregiver Strain Index (MCSI) ..... 330
Appendix 14 - Stroke Information booklet ..... 332
Appendix 15: Interview guide for stroke survivors ..... 338
Appendix 16: Interview guide for family caregiver ..... 341
Appendix 17: Interview guide for nurses ..... 344

# List of tables

Table 2.1: Summary of inclusion and exclusion criteria ..... 51
Table 2.2: Keywords and synonyms using the PICO framework ..... 53
Table 2.3: JBI critical appraisal checklist for RCTs ..... 55
Table 2.4: Assessment of methodological quality of included studies ..... 61
Table 2.5: Summary of post-stroke education intervention ..... 64
Table 2.6: Summary of knowledge of stroke outcome ..... 66
Table 3.1: Contents of stroke survivor baseline assessments Contents of stroke survivor baseline assessments ..... 95
Table 3.2: Content of family caregiver baseline assessments ..... 100
Table 3.3: The features of usual care and post-stroke education intervention ..... 105
Table 3.4: Components of the post-stroke education intervention ..... 109
Table 3.5: Content of patient and family caregiver outcome measures ..... 111
Table 4.1: Sociodemographic and clinical characteristics of stroke survivors (N=50) ..... 120
Table 4.2: Baseline measures of stroke survivors (N=50) ..... 121
Table 4.3: Sociodemographic characteristics of family caregivers (N=50) ..... 123
Table 4.4: Family caregivers' baseline measures (N=50) ..... 124
Table 4.5: Stroke survivors' satisfaction with the content and presentation of the stroke information booklet (N = 11) ..... 128
Table 4.6: Positive features of the stroke information booklet (N=11) ..... 129
Table 4.7: Negative features of the stroke information booklet (N=11) ..... 129
Table 4.8: Stroke survivors' responses to how the stroke information booklet assisted them to cope with stroke ..... 129
Table 4.9: Stroke survivors who wanted additional stroke information (N = 11) ..... 130

Table 4.10: Family caregivers' satisfaction with the content and presentation of the stroke information booklet (n = 9) ..... 131
Table 4.11: Positive features of the stroke information booklet (N = 9) ..... 131
Table 4.12: Negative features of the stroke information booklet (N = 9) ..... 132
Table 4.13: Family caregivers' responses to how the written information assisted them to cope with caring for a stroke survivor ..... 132
Table 4.14: Family caregivers who wanted additional information about stroke (N = 9) ..... 133
Table 4.15: Stroke survivors' baseline and 3-month follow-up outcome measures scores ..... 135
Table 4.16: Family caregivers' baseline and 3-month follow-up outcome measures scores ..... 137
Table 6.1: Characteristics of stroke survivors interviewed ..... 169
Table 6.2: Themes and sub-themes for stroke survivors ..... 170
Table 6.3: Characteristics of family caregivers interviewed ..... 189
Table 6.4: Themes and sub-themes ..... 190
Table 6.5: Characteristics of nurses interviewed ..... 199
Table 6.6: themes and sub-themes ..... 200

# List of figures

Figure 2.1: PRISMA diagram showing the flow of systematic identification, screening, inclusion and exclusions of articles identified ..... 58
Figure 3.2: Consort diagram of the post-stroke education intervention trial ..... 83

# List of abbreviations

| | |
|---|---|
| AIDS: | Acquired Immunodeficiency Syndrome |
| CIA: | Central Intelligence Agency |
| CSI: | Caregiver Strain Index |
| GBD: | Global Burden of Diseases |
| GDP: | Gross Domestic Product |
| GHS: | Ghana Health Service |
| GOG: | Government of Ghana |
| GSS: | Ghana Statistical Service |
| HADS: | Hospital Anxiety and Depression Scale |
| HICs: | High Income Countries |
| HIV: | Human Immunodeficiency Virus |
| JBI: | Joanna Briggs Institute |
| KATH: | Komfo Anokye Teaching Hospital |
| KNUST: | Kwame Nkrumah University of Science and Technology, Kumasi – Ghana |
| KSQ: | Knowledge of Stroke Questionnaire |
| LMICs | Low- and Middle-Income Countries |
| MOH: | Ministry of Health |
| NCDs: | Non-Communicable Diseases |
| NHIS: | National Health Insurance Scheme |
| MRC: | Medical Research Council |
| RCT: | Randomised Controlled Trials |
| SR: | Systematic Reviews |
| TIA: | Transient Ischaemic Attack |
| UK: | United Kingdom |
| USA: | United States of America |
| WHO: | World Health Organisation |

# Acknowledgements

I would like to express my sincerest appreciation to all who helped me complete this PhD programme. Firstly, I would like to thank my supervisors, Professor Avril Drummond, Dr Linda East, Dr Philip Clissett and Dr Fiona Moffatt for their immerse guidance throughout this PhD. I am truly grateful for their constant support, encouragement, and advice throughout this whole process.

Secondly, I am highly indebted to the Commonwealth Scholarship Commission in the UK for funding this PhD study. Without their financial and moral support, this PhD programme would not have been possible. Prior to the scholarship award, Professor E. Tsiri Abenyega recommended my nomination to the then Vice-Chancellor of KNUST, Professor William Otoo Ellis. Additionally, Professor Peter Donkor, Professor Charles Ansah, and Dr Linda East provided references to support the scholarship application. I am indeed grateful to these individuals for trusting in me, as well as my employer, KNUST for granting me study leave to pursue this PhD.

Again, I would like to express my gratitude to all the participants who took part in the study. Without their cooperation and support, this research would not have been possible. Also, my sincere appreciation goes to the KATH stroke clinic and stroke unit staff, particularly Dr Fred Sarfo, Dr Vida Obese, Dr Sheila Adamu and Director Regina Jubin (DDNS) for their assistance with the study. Thank you to Mary Akugre, Wilhelmina Owusu and John Amissah for assisting to provide the intervention and the interviews as well as to Dr Andrea Venn of the UoN for the advice on statistics.

Finally, my deepest appreciation and love go to my amazing family: my late dad Abesigo, uncles Alanasa and Adiiro, and Hajia Rakia, who did not live to see this day. To my mum Rebecca, sister Alice, my amazing and indefatigable wife – Freda Asomlokiya, children – Frances Winimi, Carol Awinloya and Caleb Adeliwine and to Mike and Carol Clark, my friends in the UK, I thank you all for your continuous support. It has been four eventful years and I could not have done it without you all. Thank you all for your unflinching support and funding which helped me achieve everything I had wanted to do.

# Chapter One

# Background

## 1.1 Introduction

Stroke continues to present significant public health and socioeconomic challenges worldwide (Feigin et al., 2015). Every year, around 6.7 million stroke-related deaths occur, making it the second most common cause of premature death after coronary heart disease globally (World Health Organisation (WHO, 2016a)). Stroke is also one of the leading causes of disability, responsible for over 42 million cases of long-term disability worldwide (Global Health Estimates, 2015). More than two-thirds of the global burden of stroke occurs in Low- and Middle-Income Countries (LMICs), to which all countries in sub-Saharan Africa, including Ghana, belong (Feigin et al., 2016). The overwhelming negative impact of stroke in sub-Saharan Africa is partly due to the poor awareness of stroke, limited resources, and the lack of well-coordinated healthcare systems (Baatiema et al., 2017a; Urimubenshi et al., 2018).

Stroke prevention interventions are essential strategies to reduce the burden of stroke (Norrving et al., 2018). The Global Stroke Services Action Plan recommends education to promote stroke awareness as a core prevention strategy to deal with stroke in resource-poor countries (Lindsay et al., 2014). Education delivered as a primary prevention strategy aims to assist individuals in adopting measures to reduce the risk of getting a stroke. In contrast, secondary prevention education aims to provide stroke survivors with information to prevent further strokes and self-manage (Forster et al., 2012). Poorly informed stroke survivors are less likely to comply with preventive measures, less able to self-manage and are more likely to have poor outcomes (Department of Health, 2010). Additionally, most stroke survivors have a poor understanding of stroke and are unaware of the benefits of lifestyle changes and the importance of complying with preventive measures (Lowe et al., 2007).

The research reported in this thesis is to provide information to stroke survivors and their family caregivers about stroke and its secondary prevention. This study explored the provision of stroke information to improve knowledge about stroke among people living with stroke in Ghana. Following a systematic review of existing evidence, a three-phase approach was used to determine the feasibility of conducting a definitive trial of post-stroke education intervention in Ghana. The first phase was to design a stroke information booklet based on a systematic review of the literature. The second phase was to conduct a feasibility Randomised Controlled Trial (RCT) of delivering the

stroke information booklet with face-to-face discussion. Conducting a feasibility trial alone could not provide a comprehensive understanding of the contextual issues surrounding the intervention in Ghana. Thus, the third phase involved conducting nested qualitative interviews. Data was collected from stroke survivors, their caregivers and nurses who delivered the intervention to explore their perspectives on stroke, the need for the intervention and their experiences participating in the feasibility trial.

Within this context, the opening chapter of this thesis sets the scene by presenting the background of the research. First, it provides an overview of the definition, incidence and prevalence, the types of and risk factors for stroke, and describes the global burden and management of stroke. This is followed by a section on stroke, specifically in sub-Saharan Africa, describing the specific public health concerns related to stroke, which includes awareness and management of stroke in Africa. The profile of Ghana, the country within which this research was undertaken, is then presented with contextual information on key areas such as healthcare in the country, health-seeking practices of the people and existing healthcare policies detailed. Specific information on stroke and its management in Ghana is documented as the basis necessitating this study. The researcher's perspective on stroke care in Ghana with the philosophical assumptions underpinning the research are also discussed. Finally, the plan of the thesis is summarised in the latter parts of the chapter.

## 1.2 Overview of stroke

### 1.2.1 Definition of stroke

Stroke is a Non-Communicable Disease (NCD) of public health significance worldwide. It is a known medical emergency, and any delay in treatment can lead to death, poor prognosis, or long-term physical and neurological problems (Ryan and Harbison, 2011; Kernan et al., 2014). The WHO defines stroke as ''rapidly developing clinical signs of focal (or global) disturbance of cerebral function, with symptoms lasting 24 hours or longer or leading to death, with no apparent cause other than of vascular origin'' (Aho et al., 1980).

However, in recent times, the time-based WHO stroke definition has been challenged with the current advances in brain imaging technology. The American Heart/Stroke

Association indicates that the 24-hour limit for declaring a stroke is unreflective of current knowledge, stating that permanent brain injury can begin much sooner and before the onset of clinical symptoms (Sacco et al., 2013). There are also assertions that the 24-hour inclusion criterion is misleading and undermines the medical urgency required to respond to a transient ischaemic attack (TIA), which has similar clinical symptoms to a stroke, but mostly resolves within 24 hours (Donnan et al., 2008).

Consequently, the American Heart/Stroke Association proposed the tissue-based stroke definition to reflect brain damage as detected by Computerised Tomography (CT) scan or Magnetic Resonance Imaging (MRI) after stroke. This definition states that “stroke is an episode of acute neurological dysfunction presumed to be caused by ischemia or haemorrhage, persisting ≥24 hours or until death, but without sufficient evidence to be classified as one of the above” (Sacco et al., 2013). Notwithstanding the limitation inherent in the WHO definition of stroke, this definition remains valid and is commonly applied in many clinical and epidemiological studies (Aho et al., 1980).

### 1.2.2 Incidence and prevalence

Stroke occurs in all geographical locations worldwide, affecting people of all ages, races, and gender. Several reports show that stroke occurrences have increased, particularly in Africa (Global Burden of Diseases (GBD) 2016 Stroke Collaborators, 2019; Katan and Luft, 2018; Owolabi et al., 2018). In 2002, WHO estimated around 15.3 million stroke events globally, reportedly increasing to approximately 16 million in 2005 (Johnston et al., 2009; Strong et al., 2007). Furthermore, there was a projected rise in stroke to around 18 million in 2015 and 23 million by 2030 if pragmatic stroke preventive interventions are not introduced (Strong et al., 2007). The rise in stroke cases does reflect not only the prevalence of stroke in High-Income Countries (HICs), but also the much higher incidence in Low- and Middle-Income Countries (LMICs), specifically in sub-Saharan Africa (Ezejimofor et al., 2017; Owolabi et al., 2015).

The incidence of stroke is known to be declining in HICs, partly due to deliberate efforts to reduce the risk factors for stroke. However, the overall stroke incidence rate remains high due to the ageing population (Feigin et al., 2016). The American Heart Association 2016 update on Heart Diseases and Stroke indicates that about 795,000 people in the United States of America (USA) experience a new or recurrent stroke. On average, every 40 seconds, someone has a stroke in the USA (Mozaffarian et al.,

2016). In the United Kingdom (UK), the Royal College of Physicians (RCP) reports that there are more than 100,000 stroke cases each year and estimates that every five minutes, one stroke occurs in the UK (RCP, 2015). However, by comparison, unlike in LMICs, where many people experience stroke at a younger age (e.g., 15 years and above), most strokes occur in people aged 70 years and above in developed countries (Adeloye, 2014; Feigin et al., 2014; Wang et al., 2013).

### 1.2.3 Types of stroke

A stroke is classified according to its cause, and typically, this is due to blood disruption to the brain caused by two main mechanisms: ischaemia (blockage) and haemorrhage (bleeding) (George and Steinberg, 2015). It is crucial to establish the cause of a stroke through a CT brain scan to provide appropriate treatment for acute stroke (Sacco et al., 2013). Clinical epidemiological data suggest that misdiagnosis due to the lack of brain imaging is common, reflecting the lack of specialist skills to correctly interpret images to establish the correct diagnosis (Gurley and Edlow, 2019).

Research suggests that thromboses due to atherosclerotic lesions or embolus from proximal vessels or cardiac sources are the most common causes of ischaemia (Albers et al., 2004; Mergenthaler et al., 2003). Thromboses are static clots, whereas emboli are fragments of fat, air, clots, and fibrin in circulation (Garcia et al., 1998). Cerebral arteries, when occluded by these clots, deprive the affected vascular territory of the brain of blood supply (Thurman and Jauch, 2002). Consequently, brain cells (neurons) deprived of glucose, oxygen and other nutrients for cellular activities die (Markus et al. 2004).

On the other hand, a haemorrhagic stroke can occur from cerebral vessel leakage (bleeding). Usually, this bleeding occurs in subarachnoid and intracerebral spaces due to rupture or head trauma (Sturgeon et al., 2008). Occasionally, cause of the bleeding may be unclear but can be associated with a genetic predisposition, a congenital malformation of arteriovenous vessels or other disorders of blood vessels such as amyloid angiopathy (Sahni and Weinberger, 2007; Sturgeon et al., 2007).

Stroke epidemiological surveys indicate that the prevalence of ischaemic stroke subtypes is around 80% - 87% of all stroke cases, while the remaining 13% - 20% are haemorrhagic stroke subtypes (Gomes et al., 2013; Feigin et al., 2015). However, most stroke-related mortalities and disabilities are caused by haemorrhagic stroke

(Gomes et al., 2013). Further research indicates that ischaemic stroke recurrence is 2% within the first seven days of onset and 29% within the first five years after a stroke (Feigin et al., 2014). There are significant differences in ischaemic stroke case fatality rates between HICs and LMICs. Data from a recent epidemiological study shows that early case fatality in LMICs is 25% higher than in HICs, with disparities attributable primarily to better acute stroke treatment in the HICs (Feigin et al., 2015).

Although the prevalence of ischaemic stroke in Africa and other LMICs exceeds that of haemorrhagic stroke, the proportion of haemorrhagic strokes is higher than in most HICs (O'Donnell et al., 2010; Feigin et al., 2015). For example, a study reported that while the prevalence of haemorrhagic stroke in Africa was 34%, HICs recorded only 9% of haemorrhagic strokes (Owolabi et al., 2015). In Ghana, however, there is mixed evidence of which stroke subtype is prevalent. While some studies have reported a higher prevalence of ischaemic stroke (Sarfo et al., 2014; Donkor et al., 2014a; Sarfo et al., 2017), others suggest that haemorrhagic strokes are more common than ischaemic strokes (Wiredu and Nyame, 2001; Sarfo et al., 2015; Sarfo et al., 2016).

### 1.2.4 Risk factors for stroke

Globally, efforts to control and prevent stroke have been stalled by the lack of recognition of the main risk factors for stroke. The need to correctly recognise and control the risk factors are important strategies for preventing stroke. While reported risk factors for stroke vary, they are broadly classified into modifiable and non-modifiable risk factors (Goldstein et al., 2011; Norrving, 2014). Modifiable risk factors are linked with unhealthy lifestyles and disease conditions that can be controlled (modified) by behavioural change or drug treatment (Markus, 2008; Furie et al., 2011). The INTER-STROKE studies show a wide range of important modifiable risk factors, indicating that ten major risk factors contribute to about 90% of all stroke cases worldwide (O'Donnell et al., 2010; O'Donnell et al., 2016). These include hypertension, smoking, obesity, physical inactivity, psychological factors, diabetes mellitus and excess alcohol intake. Other researchers argue that five main risk factors are of significance, namely hypertension, diabetes, lack of physical exercise, atrial fibrillation, and smoking; these collectively contribute to about two-thirds of the global stroke cases (WHO, 2006; Donnan et al., 2008; Mackay and Mensah, 2004).

Hypertension is the most significant risk factor, responsible for about 60% - 70% of all stroke cases globally (Feigin et al., 2009; O'Donnell et al., 2016). It is estimated that a 2.6 odds ratio predisposes individuals with hypertension to stroke (Hankey, 2011). However, few individuals are aware of their hypertensive state, and many remain undiagnosed (Ale and Braimoh, 2017; Ataklte et al., 2015). This is more common among the populations living in sub-Saharan Africa, where studies show low awareness of hypertension (Bosu, 2010; WHO, 2014). Controlling these modifiable risk factors has been reported to reduce the incidence of stroke significantly (Di Legge et al., 2012). For example, reducing hypertension and smoking cessation help lessen the risk of stroke by as much as 30% - 40% (Kawachi et al., 1993; Turnbull, 2003; Lawes et al., 2004). While there is no clear indication in the literature for any risk factor as a leading cause of haemorrhagic stroke, several clinical and epidemiological studies have concluded that hypertension and high cholesterol levels are the common risk factors for stroke (Mensah, 2008; Collaboration APCS, 2005; Tirschwell et al., 2004; Bots et al., 2002; Woo et al., 2002).

Research has also shown the impact of non-modifiable risk factors such as age, gender, race, and ethnic differences on the incidence of stroke (Sturgeon et al., 2008; 2007). Age is an important factor contributing to stroke; the risk of stroke doubles every ten years above age 55 (Norrving et al., 2018). Whilst most stroke cases occur in populations under 60 in sub-Saharan Africa; stroke affects many older people aged 70-75 in developed countries (Connor et al., 2007; Owolabi et al., 2018). Although stroke occurs in all age groups, there are reports of gender differences in incidence (Petrea et al., 2009). Under 40 years of age, men are more at risk than women. However, women are twice as at risk as their male counterparts between the ages of 45 and 54 years, mainly when they are post-menopause or pregnant (Lloyd-Jones et al., 2009). Overall, the incidence of stroke in men is about 30% higher than in women (Appelros et al., 2009).

Ethnicity has also been reported as a determinant of stroke. For example, in the USA, African-Americans are recorded to have a higher incidence of stroke than any other ethnic group or race, possibly due to their genetic makeup (Woo et al., 1999; Lloyd-Jones et al., 2009). Similarly, African Caribbean in the UK are at greater risk of stroke than other ethnic groups (Markus, 2008). Therefore, it is important that the public,

including stroke survivors and their family caregivers, are made aware of these risk factors by providing of information to help reduce the burden of stroke.

### 1.2.5 Global burden of stroke

Stroke is a significant public health and socioeconomic concern worldwide (Owolabi et al., 2018). It impacts the individual's physical and psychosocial functioning and health-related quality of life, as well as risk factors for monitoring and management, and also places a significant economic burden on families and communities across the globe (Saka et al., 2009; Cadilhac et al., 2009). Stroke can cause physical and neurological problems within 24 hours, with stroke progression and paralysis being common post-stroke sequelae (Indredavik et al., 2008; Govan et al., 2007). Such sequelae may result in moderate to severe forms of disability that affects the daily lives of stroke survivors and can lead to prolonged hospitalisation or institutionalisation (Smeltzer et al., 2008; Phipps et al., 2003).

Data on the global burden of stroke disease shows a significant increase in stroke-related mortality by 26% from 1990 to 2010 (Mensah et al., 2015). WHO recorded about 6.7 million deaths from stroke in 2012 and 25.7 million stroke survivors with various forms of disabilities over the same period (WHO, 2016b). However, it is essential to note that the current global stroke burden is inequitably distributed as more of this burden is disproportionately found in populations living in LMICs compared to HICs (Mensah et al., 2015). Around 80% of the worldwide stroke burden occurs in LMICs, particularly in sub-Saharan Africa (Truelsen, 2010; Owolabi et al., 2015). Although HICs have witnessed a substantial decrease in stroke incidence of about 42% over the last four decades, LMICs recorded over 100% increase over the same period (Feigin et al., 2009). This inequitable stroke burden is further evident when comparing the contrasting rates of stroke survival in these two regions: that is, 84% for HICs against 16% for LMICs within the first three years after a stroke (Owolabi et al., 2015).

Stroke significantly impacts economic development and healthcare systems (Demaerschalk et al., 2010). The healthcare provided for people with stroke is expensive and prolonged and also involves monitoring and secondary prevention through hypertension, diabetes and other risk factors management and screening, medical treatment through hospitalisation, and the need for follow-up care. According

to a study conducted in the United States of America, the overall cost of stroke to the economy in 2008 was $65.5 billion, and the majority was for direct healthcare costs (Demaerschalk et al., 2010). In the UK, stroke is the fourth leading cause of mortality and disability, costing the government approximately £26 billion yearly for stroke care services (Stroke Association, 2018).

The indirect costs of stroke include lost productivity due to significant morbidity or premature mortality (Saka et al., 2009; Cadilhac et al., 2009; Di Carlo, 2009). Stroke disrupts the future of individuals and families by negatively impacting their health during their peak mid-life years, undermining national development by depriving nations of valuable human resources at a time of life when affected individuals are likely to be most productive (Forouzanfar et al., 2015; Mensah et al., 2015). Besides the physical burden, individuals with stroke and their family caregivers also face psychological problems such as anxiety, depression, uncertainty, and a feeling of loss of control, which lead to severe personality disorders (Stein et al., 2018; Salter et al., 2008).

## 1.2.6. Psychological impact of stroke

Stroke survivors face problems such as paralysis, loss of speech, cognitive disorders, and infections, which lead to prolonged hospitalisation or even a permanent disability (Hotter et al., 2018). To be confronted with such problems and other complications, no matter how small, has a direct impact on the well-being of stroke survivors. When confronted with a stroke, stroke survivors are likely to be concerned about how stroke and its treatment will affect their life, work, and relationships with others. These concerns can stimulate stroke survivors to ask questions about treatment and care and seek assistance from healthcare providers. However, inadequate interventions to address these concerns by healthcare providers can result in psychological problems, such as anxiety, depression, fear, misconception, and other emotional disturbances (Hotter et al., 2018; Rodgers et al., 2001).

**Anxiety and depression among stroke survivors and caregivers**

Anxiety and depression are common psychological problems affecting stroke survivors (Godwin et al., 2013). They cause distressing symptoms for stroke survivors and their caregivers; and negatively impact their quality of life (Hackett et al., 2014; Choi-Kwon et al., 2005). Anxiety is a vague and distressing feeling of discomfort or

fear that affects stroke survivors and their family caregivers. A systematic review and meta-analysis of observational studies involving 22,262 participants reported an 18.7% rate of anxiety symptoms following a stroke (Knapp et al., 2020). Anxiety is a common emotional reaction to situations and threats perceived as uncontrollable or unavoidable with a heightened awareness of imminent danger and an automatic response (Chun et al., 2018).

Anxiety after a stroke can occur for many possible reasons. One of the most common causes of anxiety is the sudden onset of stroke with neurological deficits. Another reason is being dependent for a prolonged period. People may be consumed by fear of uncertainty, social isolation, lack of control, and worrying about prognosis (Chun et al., 2018). People with stroke experience increased anxiety due to sudden onset, neurological problems, complications, pain or discomfort, and inability to return to regular life and work. In addition, post-stroke anxiety can be caused by multiple worries, for example, finances, health, and an inability to stop worrying (American Psychiatric Association, 2013). According to a survey, many people have expressed disproportionate fear and apprehension after a stroke. These feelings are significant in people unaware of the consequences a stroke (Fang et al., 2017).

Anxiety can activate the sympathetic nervous system as well as the hypothalamic-pituitary-adrenal axis. This activation produces a variety of physiological responses, including increased oxygen consumption, decreased immune response, and autonomic tone (Frazier et al., 2002). Many studies have shown that anxiety affects autonomic nervous system regulation, the activity of the hypothalamic-pituitary-adrenal axis and myocardial effusion, which in turn cause increased blood pressure, heart rate, and cardiac output in stroke survivors (Thomas et al., 2008, Tsigos and Chrousos, 2002). Previous research has suggested a strong link between psychological factors and the development of hypertension, as well as the impact of psychological factors on the incidence and progression of a stroke or in morbidity and mortality among stroke patients (Morris et al., 2017; Hamer et al., 2008; Franco et al., 2003; Robinson et al., 2004). Post-stroke anxiety tends to last longer when associated with post-stroke depression (Campbell Burton et al., 2013).

Depression is a loss of interest or pleasure for two weeks or longer, which may be accompanied by fatigue or loss of energy, worthlessness or inappropriate guilt,

diminished concentration, and indecisiveness (Kim, 2016). A meta-analysis of 61 cohorts of 25,488 patients estimated that 31% developed depression at some point, especially up to five years following stroke (Hackett et al., 2014). The prevalence of major depression generally decreases over time. For instance, a study identified post-stroke depression in 50% of patients during the acute stage, which had reduced to 12% at a one-year follow-up (Robinson et al., 2010). Similarly, another study found that 30% of study participants were depressed three months after a stroke; after one year, more than half of these patients were no longer depressed (Astrom et al., 1993). A recent study of 478 patients with acute stroke found that approximately 57% had depression (Montgomery-Asberg Depression Scale >8). This percentage rapidly decreased over time (Kim et al., 2016).

Although various factors have been linked to post-stroke depression, the findings have been inconsistent. A recent systematic review of 23 studies with 18,374 participants found that age and gender were not consistently associated with post-stroke depression (Kutlubaev et al., 2014). There was also no consistent link between the hemisphere of stroke, lesion location, or pathological subtype and depression. A history of depression before stroke was linked to post-stroke depression in four studies, while cognitive impairment was associated with depression in two of four studies.

There is evidence that severe stroke and early or late physical disability are the most consistent risk factors for post-stroke depression. In a recent study, changes in Montgomery-Asberg Depression Scale scores were well-correlated with improvements in neurological impairment (Kim et al., 2014). Patients' acute depressive symptoms are related to physical dysfunction, whereas chronic post-stroke depression has an additional psychosocial component (Gainotti et al., 2002; Aben et al., 2002). The close relationship between post-stroke depression and neurological deficits suggests that post-stroke depression may be a psychological, reactive depressive symptom associated with sudden functional deficits (Kim et al., 2016; Kim et al., 2000). When functional deficits persist for a prolonged period, subsequent familial and social issues may exacerbate post-stroke depression (Robinson and Jorge, 2016). Post-stroke depression may also be influenced by the patient's personality traits and environmental factors, such as social support, economic matters, and job stability, among others (Robinson and Jorge, 2016).

Although there has been considerable research from high-income countries into the psychological problems after a stroke, few studies have investigated these problems in low- and middle-income countries, despite high levels of reported stroke-related morbidity (Towfighi et al., 2017). In sub-Saharan Africa, research in Nigeria discovered that negative emotions (including anxiety, fear and depression) were present in stroke patients who presented to the hospital (Owolabi, 2008; Ojagbemi et al., 2017). Similarly, a case-control study in rural Tanzania also discovered that, in their cohort of stroke survivors had high levels of depression (53.0%), which is high compared to data from developed countries (Jones et al., 2011). Additionally, this study found that anxiety levels (21.6%) were consistent with previous findings (Wilkinson et al., 1997). Stroke survivors and carers had significantly higher anxiety levels than control participants without stroke, whereas levels of depression were similar across all the groups. Increased carer anxiety and depression were associated with reduced self-reported levels of cognitive function in stroke survivors (Jones et al., 2011). A recent meta-analysis estimates that almost 1 in 3 individuals with stroke in Africa have depression (Ojagbemi et al., 2017a). However, this review may have underreported post-stroke depression, which is frequently under-recognised in Africa, where resources are relatively limited, and mental health issues are underappreciated (Moran et al., 2013). Additionally, this review included studies with small samples and very different types of healthcare settings for stroke survivors.

**Anxiety and depression cause poor stroke outcomes**

Underlying psychological problems, particularly anxiety and depression, can independently increase the risk of recurrent stroke and exacerbate stroke symptoms. It can also impact functional recovery in activities of daily living, physical function, cognitive recovery, and problem-solving in both the short and long term, which can compromise rehabilitation outcomes and negatively impact the quality of life after stroke (Campell Burton et al., 2013; Fang et al., 2017). Post-stroke anxiety has been linked to poor self-control, decreased immune response, immobility and fatigue, negatively impacting recovery (Fang et al., 2017).

Such psychological problems risk compromising the rehabilitation process, resulting in poor health-related quality of life, considerable health expenditure, and ongoing mortality and morbidity (Szekely et al., 2007, Mayou et al., 2000). Anxiety disorder,

common after stroke, has been linked to an increased risk of stroke recurrence (Tully et al., 2008, Hemingway et al., 2001, Roest et al., 2010). Anxiety and depression in stroke patients have been shown to impact the functional outcome (Lewis et al., 2001). Anxiety and depression symptoms should be recognised and treated as soon as possible to prevent more severe effects on neurological outcomes in stroke patients (Gainotti et al., 2001). Recently, anxiety and depression screening questionnaires such as the Generalised Anxiety Disorder (GAD), Hospital Anxiety and Depression Scale (HADS), Beck Anxiety Inventory, Hamilton Anxiety and Depression Scale, and the General Health Questionnaire-30 were developed and validated. These are easy to administer and take less than five minutes for patients to complete (Rumsfeld and Ho, 2005, Spitzer et al., 2006). Once significant symptoms of anxiety and depression are identified, establishing appropriate interventions to relieve symptoms is essential.

### 1.2.7 Caregiver burden

Caregivers play an important role in assisting ill people, whether acutely or chronically ill. As stroke survivors experience long-term impairments in physical, psychosocial, and cognitive function, they rely mainly on caregivers for practical and emotional support concerning activities with daily living (Johnston et al., 2009; Thompson and Walker, 2011). Stroke-related impairments in patients may cause loss of independence in self-care activities and mobility, increasing the responsibility and burden on the caregiver, family, and community (Wu, 2009). Caregivers are expected to transfer stroke survivors several times a day, which causes fatigue, sleep disturbance, weight loss and indigestion, all of which increase the risk of mortality (Mcpherson et al., 2011; Haley et al., 2010). Caregivers may experience emotional and psychological trauma because of a lack of interaction and witnessing a loved one's suffering (Perkins et al., 2012). Caregivers of patients with neurological disorders are more vulnerable to social isolation, emotional burden, and decreased quality of life (Thommessen et al., 2002; Martinez-Martin et al., 2003; Bhatia et al., 2003). Thus, caring for patients with stroke presents an increased burden to the caregivers, which manifests as increased rates of anxiety and depression among them.

Several studies on stroke caregivers have identified the burden and impact on their physical and psychological well-being, including high levels of psychological distress and depression; increased rates of physiological illness and personal, family, and

social problems (Anderson et al., 1995; Carnwath et al., 1987). It is reported that the primary caregivers of stroke patients have an equal to or higher incidence of mental illness than stroke patients and bear a high burden simultaneously (Dankner et al., 2016; Kruithof et al., 2016). The prevalence of depressive symptoms was 40.2%, and that of anxiety symptoms was 21.4% in the main caregivers of stroke patients (Loh et al., 2017). Many studies have found that the incidence of mental illness among the main caregivers of stroke patients is equal to or greater than that of the stroke patients themselves (Wu et al., 2012; Dankner et al., 2016).

Studies have shown that the mental states of caregivers have an impact on their social function, economy, body health, and quality of life and are also linked to the psychological state and prognosis of stroke patients (Atteih et al., 2015; Gbiri et al., 2015; Savini et al., 2015; Joo et al., 2017). As a result, stroke caregivers who are vulnerable to depression should be mainly targeted and given comprehensive assessment, which is beneficial for caregivers' mental health as well as stroke patients' rehabilitation, and ultimately improves the quality of life of the patient and family (Li et al., 2016; Young et al., 2014).

Besides the physical and emotional burden on caregivers, financial challenges also arise due to reduced income caused by the stroke survivor's inability to return to their previous occupation due to limited activity and participation. At the same time, long-term use of drugs, economic pressures of rehabilitation and concerns about the health status of patients also have a considerable impact on the quality of life of the caregivers (Caro et al., 2017).

Despite the paucity of research on caregiver burden in sub-Saharan Africa, those conducted have revealed some experiences of caring for stroke patients in a resource-poor context. A study in Uganda on the burden and experiences of primary caregivers found that caregivers experience life changes due to the sudden assumption of new responsibilities (Gertrude et al., 2019). In addition, caregivers reported issues mainly due to financial difficulties, emotional distress, high caregiving demands and a lack of rehabilitation support services in their community. In a related study in South Africa (Masuku et al., 2018), caregivers reported feeling frustrated and finding it difficult to communicate because they lacked effective communication strategies. The participants' experiences reflected their context-specific experiences, including

feminisation of caregiving, barriers to healthcare, the influence of low health literacy and contextual perspectives on stroke and aphasia. However, these studies have some limitations. Notably, these studies are single-centre studies, and the participants were recruited from one area where the participants may not have been representative of stroke caregivers in the general population. Thus, the findings have to be treated with some caution.

### 1.2.8 Management of stroke

Individuals must contact emergency medical services or report to the hospital as soon as they recognise stroke symptoms to receive treatment (Rudd et al., 2016). Several assessment tools are used to identify stroke symptoms; the most widely used tools are the Cincinnati Prehospital Stroke Scale and the Los Angeles Prehospital Stroke Screen (Kidwell et al., 2000; Kothari et al., 1999). However, the Face, Arm, Speech, and Time (FAST) test tool is increasingly sensitive and widely used to establish stroke symptoms (Watkins et al., 2013; Fothergill et al., 2013). The National Collaborating Centre for Chronic Conditions (NCC-CC, 2008) and NICE (2008; 2016) recommend using the FAST tool to quickly screen for stroke in the prehospital and hospital settings. Appropriate use of this tool helps to quickly identify the common signs of stroke, including Facial palsy, Arm weakness, and Slurred speech, and then underlines it is - Time to act by calling emergency services (Harbison et al., 2003; Kidwell et al., 2000; Llanes et al., 2003). In addition to a physical assessment, clinical investigations are equally essential to establish a stroke (Sahni and Weinberger, 2007). For example, a CT brain scan or MRI differentiates ischaemic stroke from haemorrhagic stroke (Pendlebury and Rothwell, 2008).

Once a stroke is diagnosed, time is of the essence in its treatment since delays in treatment can result in worsening and longstanding physical and neurological impairments (Jauch et al., 2013; Acker et al., 2007). For example, a clot-busting drug (thrombolysis) given within 3 hours after an acute ischaemic stroke can prevent or even reverse brain damage (Powers et al., 2018). According to Summers et al. (2009), acute stroke treatment should be initiated within 3 to 72 hours after a stroke. This should start with a prehospital assessment before transferring to a hospital or stroke unit for definitive treatment. Time-dependent treatment is appropriate for only a small proportion of patients following a stroke; time-dependent treatments are expensive

and not affordable in low resource economies; dedicated stroke unit care is effective for all (Stroke Unit Trialists' Collaboration, 2013). A dedicated stroke unit that provides specialised stroke care is reported to be the best model for stroke patients because it is associated with better stroke outcomes (Adams et al., 2007; European Stroke Initiative, 2003).

Several trials have found that stroke unit care had better outcomes than the alternate form of care. According to a Cochrane review, stroke patients managed in dedicated units had better stroke outcomes in reducing hospitalisation, dependence, and deaths (Stroke Unit Trialists' Collaboration, 2013). Stroke units are standard in Western Europe and North America, typically including acute stroke and rehabilitation units with several components (Stroke Unit Trialists' Collaboration, 2013; Indredavik, 2009). A critical component of a stroke unit is a multidisciplinary team (comprising doctors, nurses, physiotherapists, occupational, speech and language therapists, and social workers) that coordinates their activities through regular meetings (Langhorne and Pollock, 2002). Patients are introduced and assessed at these meetings to identify their problems before setting short and long-term recovery goals. The patient and family are usually involved in the decision-making process regarding their care by receiving continual education about stroke and how to live with it (Langhorne and Pollock, 2002).

### 1.2.9 Provision of stroke information

After acute treatment, providing information about stroke to assist people in self-management, feeling more in control, and developing positive attitudes towards the disease becomes an essential component of care (Parke et al., 2015; Du and Li, 2016). Stroke survivors and their families can benefit from post-stroke education by being more aware of their situation and participating more effectively in their healthcare and life decisions (Martins, 2009). Combined with the appropriate support, post-stroke education provides people with the necessary knowledge and strategies to help prevent or reduce the risk for a recurrent stroke, improve outcomes and enhance self-care management of long-term complications (Maasland et al., 2011). Information may be beneficial in reducing patients' and caregivers' depression and improving their hospitalisation experience (Bailey, 2010). According to a Cochrane review (Forster et al., 2012), providing relevant information to stroke survivors and their family caregivers

improved their stroke knowledge, increased information satisfaction, and lowered depression among stroke survivors. Conversely, while providing information to stroke survivors and their caregivers was beneficial, the most effective method remained unclear because they had varied and unique educational needs. Therefore, health providers were encouraged to develop educational interventions that meet people's educational needs and personal situations.

A wide range of information is produced nationally and locally on leaflets, booklets, videos and audiotapes available to inform people about stroke and appropriate stroke care services in western countries such as the UK (Forster et al., 2012). Despite the emphasis on providing post-stroke information, research reveals that stroke survivors' understanding of stroke, its effects, and available support are still lacking. A systematic review identified multiple and diverse unmet educational needs of stroke survivors and their family caregivers (Hafsteinsdottir et al., 2011). Furthermore, over half of community-dwelling adults with a stroke for at least five years wanted more information (McKevitt et al., 2011). Caregivers of stroke survivors in another study in the UK indicated that while leaflets were available, they were not always relevant to their situation (Mackenzie et al., 2007). Even in countries where information is widely available and accessible, stroke survivors perceive deficiencies in their education.

**Post-stroke education**

The presence of anxiety and depression after stroke leads to poor outcomes. Health care providers must identify ways to respond to and manage the psychological problems that stroke survivors and their families experience. They must also assist them in self-managing and decision-making about their healthcare and lives (Du and Li, 2016). In this regard, in the UK and other western countries, there is increasing emphasis on providing health information to assist stroke survivors and their families in the disease trajectory (Foster et al., 2012). For instance, the Department of Health in the UK has encouraged healthcare professionals to put information at the centre of people's health, improve access to quality information and empower the public to make better healthcare decisions (DoH, 2004). The UK government has developed and launched the information prescriptions service. More importantly, patients have a legal right to adequate information before receiving healthcare services and participating in healthcare decision-making, as specified and regulated in the policy and legislation document (DoH, 2009).

Post-stroke education is considered an interactive process of providing information and explanations about stroke disease trajectory, treatment and concerns of patients and caregivers of long-term issues. This education also involves providing appropriate reassurance and psychosocial support to stroke survivors. The main aim of post-stroke education is to keep stroke survivors and their caregivers informed about stroke and to enable them to take more responsibility for their health and respond better and more quickly to health problems (Heinemann et al., 2015). After a stroke, patients' information needs are likely to be higher, and they rely on health care providers to explain their current condition and how they can cope with life. There is no universal agreement regarding what works best or how its effects can be measured. However, most researchers consider that timely post-stroke education tailored to the information needs of patients may be an important intervention to lessen the fear of the unknown and make patients have better control over their situation.

**Information needs among stroke survivors and family caregivers**

An American Researcher proposed the concept of information need, defined as people's 'awareness or recognition of not knowing or existence of uncertainty ((Taylor, 1962; Ford, 1980). As a result, people "require some form of knowledge for resolution" and have "a desire to locate and obtain information to satisfy their requirements" (Chen and Hernon, 1982; Du and Li, 2016). Therefore, the idea that patients should receive sufficient information is not new. Although the USA pioneered the initiative to provide health information to patients, other countries, such as Australia, Canada, New Zealand, and the United Kingdom are implementing similar initiatives (Forster et al., 2012). These efforts improved patients' awareness and access to health information (Shepperd et al., 1999).

The provision of information is a complex intervention in stroke care (Eames et al., 2013). It is designed to help patients obtain information that will enable them to actively participate in their treatment (Forster et al., 2012). Research suggests that stroke patients should be informed about all aspects of their disease and treatment (Heinemann et al., 2015; Rodgers et al., 2001). Although the information is necessary for all stages of the patient journey, patients' information needs or areas of concern vary at different stages of stroke and may change over time (Hanger et al., 1998).

According to Hanger *et al*. (1998), patients frequently have unanswered questions during their disease process and treatment.

Before a stroke, Information provision to the public mainly focuses on lowering risk, increasing early recognition, and reducing treatment delays. As a result, the information focuses on: stroke risk factors, affected organ or body part, warning signs or symptoms, emergency nature of stroke, physiological processes, functional consequences, medication or medical interventions used to control risk factors, and actions required to respond to a potential stroke and treatment strategies (Sug Yoon et al., 2001).

During the acute period of stroke, patients may visit a health facility for early medical treatment when they recognise that they are having a stroke. Stroke survivors may seek expert information and explanations from healthcare professionals at this time in order to understand their diagnosis and treatment options and accept treatment. Patients who do not have clear and detailed information may decline medications or doctor referrals (Hjelmblink et al., 2010). Patients may require detailed information after admission to the hospital and during their stay in an acute care setting. Patients need to understand stroke, the meaning of symptoms, the nature of their current disease condition, and the impact of the disease on them. Patients should also be aware of the treatment they are receiving, the results of any examinations they have had, such as scans or X-rays, and the meaning of the diagnosis. Patients need to understand the treatment that will alleviate their symptoms, treatment options, the effectiveness and potential side effects of these treatments, possible treatment outcomes, and future recovery. Patients may also seek advice on the purpose or importance of walking or moving while in hospital and how to eliminate bad habits, such as smoking (Garrett and Cowdell, 2005).

At discharge, patients may still want more information about their condition when the acute stage has passed. Patients may inquire about the course of their illness or disease process and evaluate their symptoms and treatment outcomes. Patients may, however, become concerned about long-term issues at this stage (Garrett and Cowdell, 2005). As a result, patients may desire information about their prognosis and possible life situation post-discharge, as well as information on continuing treatment

after discharge, follow-up schedules, and prevention of stroke recurrence. Patients may also need information about their goals or needs for continued daily care and rehabilitation services. Patients may require assistance managing their limitations due to physical and psychological impairments. Patients may need guidance on how to cope at home and overcome difficulties with issues in their daily life, such as driving or resuming sexual activity, availability of local voluntary support groups or organisations and contact details of health professionals (Almborg et al., 2008).

Keeping people who have had a stroke informed is essential to their well-being (The Royal College of Physicians National Stroke Guidelines, 2016). Stroke patients' information needs persist and change over time during all stages of the stroke journey. However, the information provided by health professionals often fails to address all these concerns or uncertainties fully, and the needs of patients are not adequately met (Gallacher et al., 2013; Coulter et al., 1999). Inadequate education and lack of information for patients and their families may increase distress, anxiety, and dissatisfaction, negatively affecting their care decision-making and quality of life (Mossman et al., 1999). Therefore, health professionals should identify the patients' information needs during the different stages of stroke and provide high-quality and individualised information to the patients (Kerr et al., 2010).

**Theories of health education**

The most widely applied theories in health education used to influence patients' behaviour are the Health Belief Model and Adult Learning (Sharma and Romas, 2008; Knowles, Holton and Swanson, 2005). The Health Belief Model was previously used in stroke to explore patient beliefs regarding risk-related behaviour change (Sullivan et al., 2009). In the Health Belief Model, people are taught how certain behaviours put them at risk of a particular illness and the serious consequences of the illness. Teaching patients about stroke can increase their understanding of the risk factors and the disease trajectory that can influence their behaviour in managing and preventing recurrent stroke (Sharma and Romas, 2008). This overlaps with the self-efficacy theory, which refers to people's confidence in their ability to take control of their lives and perform a particular behaviour (Bailey, 2010; Wong et al., 2010). The fundamental assumption of the self-efficacy theory is that the more confident people

are, the more likely they are to initiate behavioural change and maintain that behaviour (Bandura, 1986; Bandura, 1997). Self-efficacy is considered the link between knowledge and action. Enhancing post-stroke education may give patients the knowledge and skills to cope with stroke and decrease their anxiety and depression. Self-efficacy theory has been used to underpin the educational intervention for orthopaedic patients (Pellino et al., 1998; Yeh et al., 2005; Heye et al., 2002).

Most health education studies are based on adult education or learning theories. These theories emphasise that education can assist patients in meeting their needs to care for themselves. As a result, patients can learn to perform certain behaviours that improve their well-being (Eames et al., 2013; Walsh and Shaw, 2000). Education aims to remove irrational beliefs, influence behaviours, and support patient empowerment by providing or receiving accurate information and advice on how the patient can best engage in his or her health and care (Dixon-Woods, 2001). These educational theories rely on cognitive reappraisal, which impacts emotion and well-being (Heikkinen et al., 2008; Callaghan and Li, 2002).

It is essential to provide appropriate information to patients after a stroke. However, the amount of information that a patient is comfortable with or can assimilate varies greatly (Bernier et al., 2003). This variation is not only between individuals but even in the same individual at different times, depending on the specific context. Post-stroke education should be tailored to the individual's needs at a particular time to provide a proper balance between enough and too much information (Heinemann et al., 2015). There is controversy around providing information regarding the risk and complications of a stroke. Some studies have assumed that some patients do not always need to know disease-related information, especially if the information constitutes bad news. However, elsewhere, it is observed that explicit information that successfully increased knowledge about the risk of anaesthesia did not increase anxiety in a group of patients awaiting cardiac surgery (Case et al., 2005; Garden et al., 1996).

**Methods for providing information to stroke survivors**

Patients have received information in a variety of ways and formats, including verbal information from healthcare professionals, written materials such as patient information leaflets or booklets, magazines and newspapers, medical books and

professional journals, and audio-visual materials, such as television, radio or video/audio tapes, and electronic format, for example, web-based internet resources or first-hand information from expert patients. Studies have shown that each approach has strengths and weaknesses (Du et al., 2016). Fitzpatrick and Hyde (2005) interviewed twelve experienced nurses in Ireland to learn more about how preoperative education is practised in clinical contexts. The findings indicated that the quality of preoperative education was significantly determined by the nurse caring for the patient. The availability and accessibility of teaching materials influenced the nurse's delivery method. If educational resources are unavailable, the oral explanation would be the only way for nurses to deliver information to their patients.

On the other hand, oral explanations can be forgotten or misunderstood, particularly by stroke survivors with impaired cognition and memory. Adult patients, on average, forget approximately half of what they were told within five minutes of leaving the consultation (Kenny et al., 1998). People may only retain about 20% of what they hear, but this can increase to 50% if there is an additional visual or written input (Kenny et al., 1998). Thus, relying on giving verbal information alone may not always be practical. The use of media such as leaflets and videos can help to deliver information in a potentially more efficient and interesting way (van Zuuren et al., 2006; Roth-Isigkeit et al., 2002). A systematic review of randomised controlled trials concluded that using video and printed information on the general process and risks of anaesthesia for preoperative education positively impacts anxiety and knowledge (Lee et al., 2003).

It is argued that written information offers many advantages over other teaching media as it is reusable, readable at any time, and easy to reproduce and distribute. For developing research-based disease-specific written information can reinforce and assist with verbal communication (Walsh and Shaw, 2000, Lewis and Newton, 2006). Patient information leaflets have a long history in healthcare as an essential source of health information for patients. They are the most cost-effective and time-efficient means of communicating health messages (Semple and McGowan, 2002). Traditionally, they were a way of providing information to a passive recipient, but more recently, they are part of empowering patients (Dixon-Woods, 2001). Written information should be concise and presented in simple language avoiding jargon or complex medical terms. According to a study, a one-page information handout would

be a low-cost and efficient way of measurably reducing the anxiety and fears that many patients have about anaesthesia and surgery (Fitzgerald and Elder, 2008).

Several studies have established a positive effect of written information provided preoperatively and have demonstrated surgical patients' better understanding of their illness and management (Ivarsson et al., 2005a; Ferrús-Torres et al., 2011). One positive effect is that written information helps patients recall and that patients find written information easier to discuss with family and friends. Information leaflets are strongly recommended in emergency care settings to improve patient satisfaction (Arnold et al., 2009). However, Johansson et al. (2005), in their systematic review of 11 trials involving 1044 adult orthopaedic patients, found that leaflets alone will not benefit preoperative patients unless together with oral information. Without oral explanation, patients find the written materials complex to understand and difficult to remember. Providing written materials, in combination with oral information to patients, maybe one of the more effective methods of patient education (Stern and Lockwood, 2005, Hodgkinson et al., 2000).

## 1.3 Stroke in sub-Saharan Africa

Public health in Africa has traditionally focused on communicable diseases. Malaria, tuberculosis, and Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome (HIV/AIDS), collectively referred to as infectious diseases, are predominant causes of premature deaths and disability in Africa (Bhutta et al., 2014). In 2010, over 91% and 95% of the world's deaths related to malaria and tuberculosis occurred in Africa (Lozano et al., 2012). The occurrence of more than two-thirds of the global burden of HIV/AIDs in sub-Saharan Africa further strengthens the image of infectious disease as a significant health burden in Africa (Bhutta et al., 2014; Holmes et al., 2017).

However, despite the continuing challenges of infectious diseases, non-communicable diseases (NCDs) such as stroke, hypertension, cancers, and diabetes, are now significant causes of morbidity and mortality. These NCDs are projected to overtake infectious diseases as causes of premature mortality by 2030 (Nyirenda, 2016; Mathers and Loncar, 2006). This phenomenon, described as 'epidemiological transition', is driven by sociodemographic factors and lifestyle changes contributing to

the growing trend of NCDs in Africa (Roth et al., 2015). People in Africa now face the double burden of a high prevalence of communicable and NCDs (Atiim et al., 2016; Ekpenyong et al., 2012). In this context, competition for scarce healthcare resources means that stroke continues to rise in Africa due to limited strategies for prevention and care services (Keates et al., 2017).

Africa has the highest incidence, prevalence, and case-fatality of stroke, almost seven times higher than developed countries (Ezejimofor et al., 2017; Khedr et al., 2014; Walker et al., 2011). In a recent review, there were 483 000 new stroke cases among people aged 15 years and above from ten African countries in 2009 (Adeloye, 2014). In the same year, 1.89 million stroke survivors were estimated among people aged 15 years and older, with a prevalence rate of 317.3/100,000. The number of new stroke cases increased in 2013 to 534,000, and the number of stroke survivors increased to 2.09 million, indicating an increase of 10.8% and 9.6% of new stroke cases and stroke survivors, respectively, probably due to population growth and ageing between 2009 and 2013. However, this may be an underestimation of the burden of stroke in Africa due to poor quality research, missed diagnoses, and record keeping (Connor et al., 2007; Walker et al., 2010).

Other research has also shown that in many African countries, the burden of stroke is higher than in high-income countries. The Global Burden of Disease study reported in 2002 that three sub-Saharan African countries (Liberia, Angola, and Sierra Leone) had recorded some of the highest death rates worldwide due to stroke (WHO, 2004; WHO, 2002). These high fatality rates were primarily related to poor stroke care services, including a lack of systems to quickly recognise a stroke and inadequate attending healthcare professionals (Akinyemi and Adeniji, 2018). Stroke incidence is continually rising because of low awareness, poor diagnosis and poor treatment for hypertension (Owolabi et al., 2015; Boateng et al., 2017). It is estimated that over 90% of stroke-related disorders are associated with hypertension (Mensah, 2008).

With the growing stroke burden in Africa coupled with the projected increases in risk factors such as hypertension and diabetes, more people are likely to experience a stroke (Namale et al., 2018). Indeed, it is estimated that one in six adults will experience a stroke in their lifetime (Kaste and Norrving, 2010). Given this, a significant public health concern is whether the existing health systems in Africa are

sufficiently prepared to tackle this problem. In the absence of well-coordinated stroke care systems, providing information to people to educate them about the misconceptions and prevention and coping strategies could at least improve resilience among stroke survivors in Africa.

### 1.3.1 Knowledge and awareness of stroke in sub-Saharan Africa

In Africa, stroke is commonly believed as a spiritual disease. This belief manifests in words used to describe stroke in many dialects. In Nigeria, for example, a stroke is referred to in various local dialects as: “a hug from the spirit” in Ibo, “a slap from the ghost” in Ibibio, and “paralysis by the spirit” in Hausa (Ekeh, 2017). Many people living in Africa believe that stroke has a supernatural cause. In a study in Tanzania, rural dwellers believed stroke was caused by witchcraft, while urban dwellers also believed stroke occurred due to attacks from demons and witchcraft (Mshana et al., 2008). This belief is not only held by laypeople but also among some healthcare workers. In Nigeria, 14% of all healthcare workers, 61% non-clinicians, believed stroke was a spiritual disease caused by evil spirits and witchcraft (Akinyemi et al., 2009). The sudden onset of body weakness makes people to attribute supernatural causes to stroke. Often, people with such beliefs will resort to spiritual or traditional treatment rather than treatment in hospitals (Jenkins et al., 2018).

Anecdotal reports from northern Nigeria suggest that a commonly claimed cure for stroke amongst the Hausas was to tie a ram to the paralysed side of the body as treatment. As a result, relatives or patients may ask for discharge from the hospital against medical advice to enable them to seek traditional treatment (Ekeh, 2017). As many as 13%-14% of respondents in studies carried out in Ghana and Nigeria reportedly preferred spiritual treatment to hospital treatment (Donkor et al., 2014; Akinyemi et al., 2009). For these reasons, the role of traditional healing practices and practitioners in providing health care for stroke and other NCDs in Africa cannot be ignored by healthcare researchers and providers. Interestingly, traditional or herbal medicine has increasingly become an alternative treatment in many countries (Feigin, 2007). Traditional and faith healers are common alternative or complementary treatments for diabetes (Abo et al., 2008; Rutebemberwa et al., 2013), hypertension (Risenga et al., 2007), and stroke (Hundt et al., 2004).

Regarding those in the population who accepted that stroke is a medical condition, there is the problem of poor knowledge. Kaddumukasa et al. (2015) showed a lack of stroke awareness in their study on knowledge of stroke in Uganda. Around 76% of the respondents failed to recognise stroke as a brain condition that required emergency medical treatment. Likewise, about three-quarters of Nakibuuka et al.'s (2014) research respondents did not recognise that the brain was the organ affected in stroke. Furthermore, the heart was incorrectly identified by 54% of respondents as the injured organ after a stroke (Ayanniyi et al., 2006).

Similarly, there is poor identification of the risk factors for stroke among many people in Africa. Around 37% of participants in Donkor et al.'s (2014) study identified lack of exercise as the most common risk factor, while only 13% identified diabetes as a risk factor for stroke. In the same study, 23% of respondents accurately specified one well-known risk factor for stroke, 21% enumerated two recognised risk factors, 14% correctly stated three established risk factors and only 10% rightly listed four or more established risk factors (Donkor et al., 2014). In Uganda, 36.6% of participants reported that the leading risk factors for stroke were stress and 28.9% hypertension. None of the participants in a study identified cigarette smoking as a risk factor for stroke (Kaddumukasa et al., 2015). In a Nigerian study, hypertension was identified by 78.2% of participants as the most common stroke risk factor, followed by stress (59.9%) and old age (58.3%) (Ayanniyi et al., 2006). However, in another study, only 39.8% of participants identified at least one well-known modifiable or potentially modifiable risk factor, while hypertension was recognised by only 34.7% of the respondents. Other risk factors that respondents identified were diabetes (7.3%), alcohol intake (4.5%), cigarette smoking (3.8%), being overweight and obese (1.9%) and heart disease (0.6%) (Wahab et al., 2015). Two other studies conducted in Nigeria showed better knowledge of the risk factors in which 69.4% (Komolafe et al., 2015) and 88.6% (Akinyemi et a., 2009) identified hypertension as the most common stroke risk factor. The participants of these two studies are noteworthy; the first was carried out among students at a secondary school, whereas the second study was conducted among healthcare workers. These studies show the immense significance of information provision and educational levels.

Regarding stroke symptoms, numbness on one side of the body was reported by 44% of respondents as the most common symptom, while unspecified pain was the least

cited (11%) in a study in Nigeria (Akinyemi et al., 2009). However, in another Nigerian study, weakness (51.9%) was frequently stated as a stroke symptom (Komolafe et al., 2015). Additionally, a study carried out among hospital workers in Nigeria reported better knowledge of one-sided body weakness (61.9%) commonly identified as a stroke symptom (Akinyemi et al., 2009). Additional investigation in Ghana reported that over 70% of respondents thought that healthy lifestyle changes can reduce the risk of stroke, that it is a preventable disease, or requires emergency treatment (Donkor et al., 2014). Most (83.0%) of respondents in another Nigerian study considered stroke preventable, although only 37.1% were aware of stroke recurrence (Wahab et al., 2015). Overall, the general awareness of stroke is poor in Africa. However, in countries like the UK, many people can recognise stroke symptoms due to widespread media campaigns on stroke (Dombrowski et al., 2013).

### 1.3.2 Provision of stroke care in Africa

In many African countries, the stroke burden disproportionately affects relatively young people (mostly under 60 years old) at the peak of economic productivity (Feigin et al., 2015). The profound impact of stroke in Africa can be due to the lack of access to optimal healthcare, difficulty in implementing evidence-based practices and a lack of established systems for stroke care (Urimubenshi et al., 2018; Ezejimofor et al., 2016). One of the problems noted with access to stroke care in Africa is the poor health-seeking practices of the people. More than 80% of the population in Africa live in rural areas and lack access to western types of hospitals, but have easy access to traditional healers, churches, and other spiritual installations (Ekeh, 2017). As a result, spiritual or traditional herbal treatment for stroke is common (Cossi et al., 2012; Jenkins et al., 2018). In South Africa, almost 10-30% of patients search for traditional treatment before biomedical treatment, and around 40-80% identify traditional or faith-based treatment to complement biomedical treatment because of socio-cultural beliefs (Hundt et al., 2004; Thorogood et al., 2004).

Secondly, as many countries are low-and-middle-income-earning, sub-Saharan Africa is a resource-poor area. Unfortunately, in the annual budget of these countries, healthcare is not prioritised. The availability of and access to the western type of healthcare provision is scarce, particularly in rural areas, as most hospitals with stroke units are found in better-resourced urban areas (Brainin et al., 2007; Akinyemi and

Adeniji, 2018). Even in urban areas, services are often hampered by a lack of essential equipment and stroke specialists (Langhorne et al., 2012). Therefore, there is advocacy for increased support to expand healthcare delivery, including stroke care services (Ocampo, 2013).

Additionally, there is the problem of affordability of stroke care. A systematic review recorded $8424 as the highest mean stroke treatment cost in Nigeria, while the lowest was $416 in Senegal (Kaur et al., 2014). Research in Togo also estimated the cost of stroke care at €936 for expenses accrued within 17 days after stroke, which is more than 100% of the average mean annual medical expenses for an average Togolese (Guinhouya et al., 2010). In most countries in Africa, the existence of health insurance that covers the cost of treatment is limited. As a result, healthcare expenses are largely borne out of pocket. Stroke survivors and their families are often expected to bear the cost of stroke treatment themselves, placing such care beyond the reach of most families.

The primary objective of acute stroke treatment is to minimise brain damage and improve outcomes. Time is critical, making it crucial for stroke survivors to get to the hospital quickly for treatment. However, in Africa, stroke survivors do not arrive at the healthcare facility early for treatment (Ekeh and Isamade, 2014; Napon et al., 2017). In a study by Sene-Diouf et al. (2007), many patients in Senegal arrived late (after 6 hours of stroke onset) at the medical centre. Only one patient was admitted before the sixth hour, and no patient was admitted before the third hour, even though 70% of the participants lived in the capital city, Dakar, where the medical centre was located. Delayed treatment was associated with the remoteness of the health centre. A related study in Nigeria examined the time stroke survivors arrived at a medical centre and reported that 13 (10.2%) arrived at the hospital within 3 hours after stroke, and 52 (40.6%) arrived after 3 hours but within 24 hours. Another 41 (32.0%) arrived after 24 hours but within a week, while the remaining 22 patients (17.2%) arrived after more than a week. Late arrival for treatment is common in developing countries, although delayed acute stroke treatment can contribute significantly to stroke-related mortality (Ekeh et al., 2017).

Late presentation for stroke treatment can partly be related to poor knowledge about stroke and the inability of people to quickly recognise stroke symptoms, as discussed in section 1.3.1. Additionally, transportation to medical centres remains a major barrier to accessing optimal stroke care in Africa. Most hospitals in sub-Saharan Africa have few or no ambulance services, with patients reaching the hospital by private transport arrangement. This includes using personal cars, cabs/taxis, buses, tricycles, or motorbikes. A lack of ambulance services, even in more advanced Morocco, accounted for a 120-minute delay as against the recommended delay of 65 minutes (Chtaou et al., 2016). Furthermore, as seen in Senegal, pre-hospital care for patients with stroke is unknown (Sene-Diouf et al., 2007).

Another barrier to optimal stroke care is the lack of stroke specialists. There are few neurologists in Africa, meaning that non-neurologists and general practitioners treat many stroke survivors, reducing the chances of a good outcome. The WHO recommends at least one neurologist for 100,000 people, but in Africa, the “best” case is one neurologist for 500,000 (Ivory Coast and Senegal) (Diop and Gouider, 2014). In Ethiopia, it is one for 5 million. While most countries have at least one neurologist, Cape Verde Islands, Gambia, Equatorial Guinea, Guinea-Bissau, Liberia, Sao Tome and Principe have none (Bower et al., 2014; Diop and Gouider, 2014). Furthermore, a well-coordinated multidisciplinary stroke team is almost non-existent because of the dearth of paramedical staff, physiotherapists, occupational therapists, and trained stroke nurses (Ogun et al., 2005). The lack of stroke units in Africa cannot be overemphasised; very few countries have dedicated stroke units (Chtaou et al., 2016; Abd-Allah and Moustafa, 2014).

Aside from the few stroke units, limited equipment for stroke care affects optimal care delivery. Except for South Africa, many countries in sub-Saharan Africa do not have CT, and in the few that have, the scanners are insufficient and sparsely distributed (Abu Bakar et al., 2005; Akinyimi and Adeniji, 2018). Additionally, the cost of CT scan services makes them unaffordable to most patients even where scanners are available (Kolapo et al., 2006; Zenebe et al., 2005). Inevitably, this affects treatment with thrombolysis which is already a scarce and inaccessible treatment in many African countries (Ossou-Nguiet et al., 2016; Baatiema et al., 2017a). Furthermore, the challenges with access to rehabilitation services and poor compliance with secondary

prevention measures pose a problem for long-term stroke management. For instance, in The Gambia, there is limited access to physiotherapy for approximately 47% of stroke inpatients (Garbusinski et al., 2005). While stroke survivors in Africa may experience the same rehabilitation needs as their counterparts in HICs, those in Africa receive more limited rehabilitation (Rhoda et al., 2015).

Apart from the limited access to rehabilitation, poor compliance with secondary stroke prevention due to a lack of knowledge compounded by inadequate education and support can compromised long-term stroke care (Mendis et al., 2005; Thorogood et al., 2004). The WHO recommends lifestyle modifications and aspirin as the most cost-effective preventive measures for stroke, but compliance is generally poor (Stroke Therapy Clinical Guideline, 2000; Lemogoum et al., 2005). A research study in The Gambia found that out of the 71% of patients discharged on aspirin, only 7% were still taking aspirin 12 months later (Garbusinski et al., 2005). Stroke survivors often have a marginal understanding of stroke and are unaware of the benefits of lifestyle changes nor the significance of adhering to secondary prevention treatment (Lowe et al., 2007).

Overall, the situations mentioned above suggest that the experience of stroke survivors in Africa is generally poor. Qualitative research also confirms this, suggesting that stroke survivors in rural Rwanda, for example, lack social support and suffer negative attitudes from their family and community (Urimubenshi and Rhoda, 2011). Another study on the experience of stroke among the lower socioeconomic class in South Africa revealed that stroke survivors are socially isolated, leading to feelings of hopelessness (Maleka et al., 2012). Stroke survivors and their family caregivers in Ghana, where this study was conducted, are subjected to similar circumstances.

Despite the challenges of delivering adequate healthcare, it is hypothesised here that simple, low-cost interventions such as providing information to stroke survivors and their family caregivers could enhance their self-management and assist them in coping better with these experiences.

## 1.4 Profile of Ghana

This section focuses specifically on Ghana and provides important background information about the context of this research. It will describe the delivery of health care services, health-seeking practices, healthcare policies and the influence of these factors on the care of stroke survivors and their family caregivers.

Ghana, previously known as the Gold Coast, was the first country in sub-Saharan Africa to gain independence from its British colonisers in 1957 (Gocking, 2005). Geographically, Ghana is in West Africa with tropical weather conditions. It has land boundaries with three former French colonies (Burkina Faso, Togo, and Cote D'Ivoire) and meets the Atlantic Ocean to the south (Abukari et al., 2015; Miller et al., 2009). Politically, Ghana currently has 16 administrative regions carved out from 10 previously existing regions. These regions are divided into 216 metropolitan/municipal/district assemblies, responsible for planning and enforcing local environmental, sanitation and health laws within their jurisdiction (GHS, 2016).

Ghana's population in 2015 was around 27,758,108, representing an 11.17% increase in population growth compared to 2010 when the last population and housing census was conducted (WHO, 2016b). The population demographics are 51% female and 49% male, 38% below the age of 15 years and 5.3% over 60 (Ghana Statistical Service, 2012; WHO, 2015). The majority, 70% of the population, reside in urban and peri-urban areas, with about 37% residing in the two most densely populated regions - Ashanti (19.4%) (the study area) and Greater Accra (16.3%) (the nation's capital city). The Ghana Statistical Service (2013) survey shows that around 74% of Ghanaians, aged eleven years or older are literate in English, French or a Ghanaian language, with some gender-based differences (about 80% males as compared to 68% females) and locality (84% in urban areas compared to 63% in rural areas) (Ghana Statistical Service, 2008; WHO, 2015). Life expectancy in 2014 was 61.3 years for both genders, significantly improving from 46 in 1960 (World Bank, 2016).

Ghana is a multi-ethnic and multi-faith country, with many Ghanaians being Christians (71.2%), Muslims (Islam) (17.6%), and Traditional worshipers (5.3%) (Ghana Statistical Service, 2013). As a result, religious beliefs and spiritual attitudes to diseases influence people's health-seeking practices, including their need for care

provision (Binka et al., 2018) and ways of coping with illness (Maliski et al., 2010; Phelps et al., 2009).

Economically, Ghana has been a lower-middle-income country since 2011 and currently has a Gross Domestic Product (GDP) of US$ 134 billion and a per capita income of US$ 4,700 (WHO, 2016b; Cooke et al., 2016). The World Bank (2016) ranks Ghana as the 15$^{th}$ richest among 48 countries in sub-Saharan Africa, with a Gross National Income (GNI) per capita of $1,590 (compared to $44,300 in the USA). The economy of Ghana is mainly dependent on agriculture, which contributes about 42% of GDP (GOG, 2012; WHO, 2009). Ghana is known for its high-quality cocoa beans and is the world's second-largest producer and exporter. Notwithstanding being endowed with crude oil, gold and other natural resources, Ghana remains a developing country and is highly dependent on international donors for funding in many sectors, including healthcare (Adua et al., 2014; CIA, 2019). The country's healthcare financing priority is preventing and treating communicable diseases (GHS, 2016).

### 1.4.1 Ghana's health service delivery

Like many African countries, Ghana has a multi-healthcare system comprising biomedical care, ethnomedical care, and faith healing systems (de-Graft Aikins, 2014). Biomedical care is the western type of healthcare provided by the formal healthcare delivery system that is either public or private (Drislane et al., 2014). The ethnomedical care system consists of herbal and traditional medicine, which can be either regulated and provided by trained persons or unregulated and provided by traditional herbalists (Aziato and Antwi, 2016; Agyei-Baffour et al., 2017). The faith-healing system comprises non-pharmacological treatment delivered by spiritualists and pastors (de-Graft Aikins et al., 2005).

The Ministry of Health (MOH) oversees the country's health service delivery system with the overall responsibility for formulating and monitoring healthcare policies, mobilising funding, and implementing all formal healthcare services through its agencies. The Ghana Health Service (GHS) is the largest agency, providing nearly 60% of healthcare services (GHS, 2014; WHO, 2009). Other agencies, including teaching/tertiary hospitals, the Christian Health Association of Ghana (CHAG), quasi-

government hospitals (military, police, and university hospitals) and private clinics/maternity homes/hospitals, provide the remaining 40%.

Ghana is a signatory to the Alma Ata declaration on primary health care and operates a three-tier health delivery structure, with the primary level being the first point of contact within the formal health care delivery system (Hall and Taylor, 2003; WHO, 2016b). Healthcare services are provided at Community-based Health Planning and Services facilities (CHPS compounds) by community health officers and community volunteers. The CHPS compound policy was introduced to improve access to healthcare services for the rural population as part of the primary healthcare strategies (GHS, 2014). Within the primary level are sub-district level facilities, where healthcare services are provided at clinics and health centres. These facilities serve as referral facilities for the CHPS compound, with midwives, general nurses and physician assistants providing healthcare services. Higher up the structure are the secondary healthcare facilities, where general medical practitioners and specialists are in charge of providing healthcare services in hospitals that serve as referral facilities for the primary level facilities (GHS, 2016). Teaching/tertiary hospitals provide tertiary services and are the referral facilities for secondary healthcare facilities. Unfortunately, the healthcare system has constantly been confronted with problems of access, quality and quantity of workforce, inadequate funding, and disproportionate distributions of healthcare personnel in urban centres, compounded with sparsely staffed rural areas.

Regarding healthcare infrastructure, Ghana has five teaching/tertiary hospitals: Korle Bu Teaching Hospital in Accra (Ghana's capital city), Komfo Anokye Teaching Hospital in Kumasi (the study setting), Cape Coast Teaching Hospital, and the Tamale Teaching Hospital. In addition to the four mentioned is a Military Hospital in Accra that provides specialist care. Though not entirely akin to hospitals in developed countries, the tertiary/teaching hospitals provide specialist care with relatively well-equipped infrastructure for diagnosing and treating NCDs, including stroke.

Ghana has a social health insurance policy known as the National Health Insurance Scheme (NHIS) that helps offset the cost of medical expenses for subscribers. Healthcare in Ghana was not publicly funded until 2004, when the NHIS was implemented to replace out-of-pocket payments to improve financial access to healthcare (Mensah et al., 2010; NHIS, 2017). Except for the poor and the vulnerable

(aged ≤18 and ≥60 years and pregnant women) whose subscription is free, the scheme is financed with yearly premiums from subscribers and NHIS levies on goods (NHIA, 2013). Annual premiums are determined based on whether members are in formal or informal employment.

Through the introduction of the NHIS, many have widely acknowledged the financial relief on individual healthcare expenditure. While the implementation of the scheme has significantly improved access to healthcare (Browne et al., 2016; Sarpong et al., 2010), it is currently being threatened by systemic mismanagement, the high cost of premiums and low subscriptions (Kotoh and Van der Geest, 2016; Schieber et al., 2012; Ganle et al., 2014). As a result, it is still common to pay out-of-pocket for healthcare, especially for treating chronic diseases. Despite the existence of the NHIS, there are still significant disparities in access to health care and the distribution of healthcare resources (Atuoye et al., 2016).

Communicable diseases remain highly prevalent, while the escalating incidence of NCDs, such as stroke, has also become a growing concern for public health and policy (de-Graft Aikins, 2007). However, like in other African countries, the healthcare facilities in Ghana (especially the primary and secondary healthcare facilities) are under-resourced to diagnose, treat, and monitor people with CVDs, including stroke (de-Graft Aikins et al., 2014; Kengne and Mayosi, 2014). In addition, contextual issues influence the poor health-seeking practices of the people that hinder the provision of optimal stroke care (Jenkins et al., 2014).

### 1.4.2 Healthcare-seeking practices of Ghanaians

As previously stated, healthcare in Ghana is provided through biomedical, ethnomedical, and faith-healing systems. Broadly, healthcare provision in Ghana can be described as pluralistic. The formal healthcare system provides biomedical care. Many Ghanaians prefer biomedical care to alternative care because biomedical care is thought to be ideal for self-care practice (de-Graft Aikins, 2003; de-Graft Aikins, 2005). However, the psychosocial impact of chronic diseases, the high costs of biomedical management and the desire for a ‘cure’ for chronic disease discourage people from continuing with biomedicine alone (Teye, 2013; Kolling et al., 2010).

As a result, chronically ill Ghanaians often use alternative medicine, which includes ethnomedicine (mainly traditional medicine) and faith healing. The WHO (2008, 2011)

reported that more than 80% of the populations in low-income countries use traditional medicine for primary health care. About 60% of children with malaria-related high fever In Ghana are treated with herbal medicines at home (WHO, 2003). Traditional medicine continues to be widely used by many people because it is readily accessible, inexpensive, and culturally accepted (Galabuzi et al., 2009). However, traditional medicine is avoided when its usage becomes life-threatening or contraindicated for an individual who needs biomedical care (Price et al., 2011). In addition, undetermined dosages of medicinal products, vague information on the mechanism of action of medications, and adverse reactions are important issues that confront the use of traditional medicine in Ghana (de-Graft Aikins, 2003).

As discussed earlier, selecting biomedicine or traditional medicine depends partly on knowledge and beliefs about the causes of diseases. de-Graft Aikins (2003) described four knowledge modalities in making sense of chronic illness and treatment practices in Ghana – common sense, scientised, religious, and emotional knowledge. According to de-Graft Aikins (2004), common sense meanings are embedded within the socio-cultural explanations of health and illness with the social observation and interaction of the individual. Scientised meanings refer to aspects of common-sense knowledge resulting from experience with biomedical personnel, media, literature, or from other individuals diagnosed with the same condition. Religious knowledge constitutes traditional religious and Christian beliefs, while emotional knowledge is based on the personal experiences of the disease. Individuals are more likely to attribute a disease to a spiritual cause (sorcery/witchcraft) when there is no clear association between their scientised knowledge and the characteristics of the disease. So, traditional medicine will be used mainly in these circumstances since biomedicine cannot attend to the spiritual cause of chronic diseases.

Traditional healers often promise cures to their patrons, a claim not made concerning chronic disease management in biomedical care (Kolling et al., 2010). Consequently, with the expectation of being cured, many people choose traditional medicine for diseases for which biomedicine has no cure. In comparison with biomedicine, traditional medicine is more accessible and affordable. The WHO (2013) reported that in many African countries, biomedical services are limited, with the ratio of medical doctors to a population standing at 1:40,000 while the ratio of traditional healers to the population stands at 1:500.

Driven by the desire for a cure, chronically ill people in Ghana often engage in cure-seeking practices. These practices include shopping between biomedicine, ethnomedicine and faith-healing. In a study assessing the decision-making experiences of patients with end-stage kidney disease, many interviewees did not understand the chronic nature of their disease, and they wanted a cure for it (Boateng et al., 2018). The inability to access biomedical treatment or conservative therapy in their search for a cure made many chronically ill kidney patients resort to alternative forms of treatment. They simultaneously used non-replacement renal therapy and traditional or faith-based healing approaches (Boateng et al., 2018).

This phenomenon, referred to as 'healer shopping', occurs when a patient seeks treatment from a second or third healer for an episode of illness without being referred by the first healer (de-Graft Aikins, 2005; Kroeger, 1983). This practice is common in Ghana and many other African countries. People who practice healer shopping use traditional medicine even though their first contact was with biomedicine (Awah, 2006). Many explanations have been provided for concurrently using traditional medicine and biomedicine, but the most common reasons are poverty and the search for a cure. A survey in Nigeria showed that 69.4% of 278 respondents reported using both biomedicine and traditional medicine simultaneously within one month (Adibe, 2009). The respondents reported they used traditional medicine for both communicable and NCDs. Anecdotal evidence suggests that the prevalence of traditional medicine usage is high in Ghana, although there is no specific data published in the country.

### 1.4.3 Healthcare policies on NCDs in Ghana

In most African countries, healthcare policymakers have prioritised the management of communicable diseases over that of NCDs. Thus, there is a dearth of clearly formulated policies for preventing and managing NCDs (Cobden et al., 2010; Mbanya et al., 2006). This is partially related to the concentration of donor funders on communicable diseases, including malaria, tuberculosis, and HIV/AIDS, though this focus has lately been challenged (de-Graft Aikins, 2007). Even though Ghana's disease profile shows high levels of communicable diseases such as malaria and HIV/AIDS, the country is believed to be undergoing an epidemiologic transition characterised by the growing prevalence of NCDs (WHO, 2009).

In dealing with the epidemiologic transition in Ghana, specific strategies have been developed by the MOH to direct efforts from a curative approach to a more public health approach in response to the increasing burden of NCDs (Agyei-Mensah and de-Graft Aikins, 2010). The initial strategy was to establish a Non-Communicable Diseases Control Programme (NCDCP) in 1992 (Ministry of Health, 2012). This was the starting point for developing and implementing several other strategies to tackle the growing burden of NCDs. A Regenerative Health and Nutrition Programme (RHNP) to improve the prevention and management of NCDs was introduced in 2006 (Tagoe and Dake, 2011). This programme created and promoted the adoption of healthy lifestyles such as healthy eating, regular exercise, drinking potable water, and getting adequate rest. The programme was integrated into the 5-year Programme of Work (5yPOW) of the MOH for 2007 – 2011 (Ministry of Health, 2007; Tagoe and Dake, 2011). However, the lack of a structured evaluation of this policy after it was incorporated into the 5yPOW of the MOH prevented its sustenance. A major criticism of this programme was that it runs parallel to other programmes targeting NCDs in the country, making the prevention and control of NCDs inefficient (Bosu, 2012; Bosu, 2013).

The Ministry of Health (2011) later formulated a national policy for the prevention and control of chronic NCDs. This included five key components: primary prevention, early detection and clinical care, health system strengthening, NCD financing options, and monitoring and evaluation. This policy document, however, was short of well-defined targets and outcomes and would have been difficult to evaluate. A five-year strategy for managing, preventing and controlling chronic NCDs was then developed, spanning 2012 and 2016 (Ministry of Health, 2012). Two more components, rehabilitation and palliative care, and social support systems and partnerships, were added to the five. This document included well-defined targets, but the strategy has not yet been evaluated.

### 1.4.4 Stroke and its management in Ghana

Like many African countries, Ghana lacks reliable data from community-based surveillance to estimate the incidence, prevalence, and burden of stroke (Mensah, 2008). However, the few hospital-based mortality and case fatality reports show that stroke-related mortality and morbidity in Ghana are higher than in developed countries

such as the USA and the UK (WHO Global InfoBase, 2004). A colonial-era cardiovascular disease burden report attributed 2% of deaths to stroke in the then Gold Coast (now Ghana) (Edington, 1954). In a later stroke-related mortality study at the Korle-Bu Teaching Hospital in Accra, deaths linked with stroke were 1,086 (11%) of 9,760 post-mortems from 1994-1998 (Wiredu and Nyame, 2001). In a recent age-standardised mortality survey, the WHO estimates a death rate of 118.4 per 100,000 in Ghana caused by stroke. This is more than three times the USA's 30.4 per 100,000 and far higher than the UK's 45.0 per 100,000 (WHO Global InfoBase, 2004). Furthermore, the WHO survey revealed that stroke accounted for 6.1% of total deaths in Ghana in 2004. However, these estimated stroke-related deaths may be under-reported, as most deaths occurring outside hospitals are not recorded in Ghana. Notwithstanding, stroke emerged as the second leading cause of premature adult deaths in Ghana, outnumbering malaria-related deaths in 2012 (WHO, 2015). Several recent case fatality studies report an escalating stroke burden with high mortality of about 41% - 43% (Sarfo et al., 2014; Sarfo et al., 2015; Sarfo et al., 2016). Contrary to developed countries, most recorded stroke deaths occurred in Ghana's hospitals within 24 hours of admission, partially due to lack of awareness, poor assessment, diagnosis, and treatment (Baatiema et al., 2017b).

At the Komfo Anokye Teaching Hospital (KATH), Ghana's second-largest teaching/tertiary medical facility (the site where this study was conducted), stroke was responsible for 9.1% of all medical adult admissions and 13.2% of deaths between 2006 and 2007 (Agyemang et al., 2012). Additionally, a survey to establish a 30-year stroke admissions pattern and mortality rate in KATH (1983-2013) reported an average of 28 days of admission and a 41% mortality rate (Sarfo et al., 2015). With the ongoing epidemiological transition linked with ageing, urbanisation and increasing risk factors for stroke, such as hypertension and diabetes, the potential burden of stroke in Ghana will be significant, and the demand for stroke care services will inevitably increase (Owolabi et al., 2018; Baatiema et al., 2017).

Ghana, however, lacks the necessary resources in terms of infrastructure and well-coordinated multidisciplinary teams to tackle the increasing stroke rates (Gould et al., 2011). Baatiema et al. (2017) reported that Ghana had only one stroke unit with no thrombolytic therapy, seven functional CT machines, and three functional MRI scanners found in the two most populated cities (Accra and Kumasi), serving over 30

million Ghanaians. Specialist stroke care in Ghana is still fledgling. There are only two leading teaching/tertiary hospitals, KATH and Korle-Bu, with stroke units and review clinics (Johnson et al., 2017; Sarfo et al., 2016). The KATH stroke unit has a six-bed capacity and serves an estimated population of 15 million (Sarfo et al., 2016; Sarfo et al., 2018). Regarding personnel, Baattiema et al. (2017) reported that there were only four neurologists and no occupational or speech pathologists to support acute stroke care in the country in 2016. Inadequate knowledge of healthcare workers regarding stroke care has contributed to poor communication, complications and healer-shopping over the past years (Johnson et al., 2017; Gould et al., 2011). The situation reflects limited resources and a low priority for stroke care provision in Ghana.

In addition to the resource constraints, access to optimal stroke care in Ghana is confronted with several other factors attributable to stroke survivors and their families. Many stroke survivors present late for medical treatment, several hours after the recommended 3 to 72 hours after stroke (Baatiema et al., 2017b). This is commonly due to poor stroke awareness, influencing the patient and family's decision to go for traditional or faith treatment rather than medical treatment (Baatiema et al., 2017b). For instance, when the individual perceives a stroke as retribution from the gods, herbal or traditional medicine becomes the first treatment choice (Donkor et al., 2014). Such practices have often driven families and patients to abandon or delay medical care for traditional or faith-based treatment (de-Graft Aikins et al., 2005). As a result, some people may request discharge against medical advice to allow them to continue with traditional or spiritual treatment (Ekeh, 2017).

People's heightened interest in traditional treatment is also due to the practice of advertising through the media. Many traditional medicine practitioners promise stroke cure (Baatiema et al., 2017b). As a result, many people, after being diagnosed with a stroke, often insist on discharge. Refusal to respond to the demands for early discharge results in non-compliance with treatment, the sudden disappearance of patients from the hospital, or patients abandoned by family members. In some circumstances, family members or patients deny the diagnosis and try to dissociate their condition from stroke due to perceived spiritual beliefs (Sanuade, 2018; Sanuade et al., 2018). For this reason, some people do not accept medical treatment in such a situation, and care provision becomes difficult.

To prevent further stroke, strategies targeting the provision of information to improve stroke awareness among people living with stroke in Ghana are highly relevant. However, post-stroke education that provides information to people with stroke to understand their illness and support them in self-manage is not readily accessible. While there is evidence that the delivery of post-stroke education can support stroke survivors and their families by improving their knowledge of stroke and support services, its applicability and acceptability in Ghana are not certain. In Ghana and other sub-Saharan African countries, there is limited information on the availability of leaflets, booklets and videos or audiotapes for people with stroke (Donkor et al., 2014). Currently, in Ghana's hospitals, providing information after stroke is not routine, leaving people with stroke inadequately prepared to self-manage.

In summary, anecdotal evidence suggests that the incidence of stroke is increasing in Ghana, although there are no accurate national data to confirm this. The lack of a stroke register also limits the information available on the trajectory of the disease. Existing stroke care services are inadequate to meet the increasing demand, and neither are there clear policies to address the growing challenges of stroke. An effort has been made to provide stroke care services, but in many ways, this has only further highlighted the inadequacy of stroke care in the country.

## 1.5 The researcher's perspective

The researcher is a registered nurse in Ghana and works as a clinician and a lecturer. His encounter with specialist stroke care started in the UK during his master's degree in 2011. It continued with the operationalisation of the KATH stroke unit in 2013, where he was involved in stroke care. His role as a clinician drew his attention to the information needs of people with stroke at the stroke unit. Most stroke survivors treated at this unit were discharged home, and their family caregivers assumed care roles with little or no guidance regarding information from healthcare professionals. The researcher realised that stroke survivors and their family caregivers were inadequately prepared to self-manage stroke. One of the problems identified was the limited understanding of stroke that triggered anxiety and depression among people with stroke. As previously discussed, people living with stroke in Ghana have limited knowledge of the condition and how to self-manage (Baatiema et al., 2017b). However, hospital admission may be short, and the lack of community health and social care

services in Ghana means that after hospital discharge, families become the primary providers of care and support to stroke survivors (Johnson et al., 2017).

Providing information to stroke survivors and their families was important if secondary complications were reduced and self-management of stroke improved. Thus, the researcher wanted to know if a post-stroke education intervention could help improve the knowledge of stroke among stroke survivors and their family caregivers and could assist them in developing preventive and coping strategies. In the UK and other western countries, it is known that providing information to people with stroke has helped improve their knowledge and reduced anxiety and depression. However, it is not known if this applies to Ghana and other developing countries.

With the researcher's background, he believed he would be in a position to facilitate access to information for people with stroke, to understand their experiences and the contextual issues surrounding stroke in Ghana.

## 1.6 Research aim, objectives, and plan of investigation

This research aimed to evaluate the feasibility of conducting an RCT of a post-stroke education intervention for stroke survivors and their family caregivers in Ghana.

The objectives of this research were to:

1. Identify the existing evidence and strategies for post-stroke education interventions.
2. Evaluate the feasibility of conducting a definitive trial to assess the effectiveness of post-stroke education intervention in Ghana.
3. Explore the experiences and information needs of stroke survivors, family caregivers and nurses who participated in the feasibility trial to refine the design for a definitive trial.

The UK Medical Research Council (MRC) recommends that developing complex interventions such as post-stroke education starts with a systematic review to identify and assess existing evidence (Craig et al., 2008; Skivington et al., 2021). This should identify strategies that will enhance the delivery of the intervention. The guideline also recommends that implementing complex interventions is likely to be enhanced if users

are involved at all phases of the intervention development and evaluation process, advocating those qualitative methods can inform this process. It suggests that a full-evaluation study should be preceded by an appropriate piloting or feasibility phase to ensure that the intervention and research procedures are feasible.

Subsequently, this research was carried out in three phases based on the MRC recommendations (Craig et al., 2008). These were:

1. **Systematic review:** The review identified relevant evidence, assessed the quality of evidence, and informed the design of a stroke information booklet used in the intervention.
2. **Feasibility RCT:** This tested the delivery of the intervention and the appropriateness of research procedures, including recruitment, randomisation, outcome measures and the acceptability of the post-stroke education intervention.
3. **Qualitative interviews:** These explored the experiences and information needs of stroke survivors, family caregivers and nurses to understand and refine the intervention if needed.

These phases are presented sequentially in this thesis.

## 1.7 Philosophical assumptions underpinning the research

It is important to examine the philosophical perspectives that underpin this research, as they have informed the study design selection, data collection and analysis methods, and interpretation of the results. This section explores the ontological and epistemological beliefs underpinning this study and describes the assumptions that were adopted for the research.

Ontology refers to studying of nature or being and how researchers perceive the worldview (Jackson, 2013). It relates to “what is” – that is, it questions the existence of reality, whether reality is dependent or independent of our senses. In healthcare research, the principal ontological question relates to whether phenomena are ‘real’ and considered to exist independent of our ideas, or whether they are ‘ideal’ and deemed not to exist independently and comprise in their entirety of our ideas

(Giacomini, 2010). These contrasting ontological assumptions are referred to as ‘realism’ and ‘idealism’ (Breen and Darlaston-Jones, 2010).

Epistemology refers to the study of nature and forms of knowledge (Grix, 2002). Epistemology focuses on how we know reality, acquire knowledge, and justify what we know (Scotland, 2012). In other words, epistemology questions how reality can be studied about ontology. From a realist ontology, reality can be studied through objective methods, and quantitative research provides a robust methodological approach to this position (Nicholls, 2011). In idealism, reality is studied through subjective methods commonly used in qualitative research (Mahoney and Goertx, 2006). Therefore, the epistemological assumption of a researcher largely reflects the “view of what we can know about the world and how we can know it” (Marsh and Furlong, 2002). Therefore, researchers are encouraged to situate their research within a paradigm consistent with their philosophical beliefs (Morgan, 2007; Mackenzie and Knipe, 2006).

In healthcare research, philosophical assumptions are predominantly based on pragmatic factors rather than ideological (O’Cathain et al., 2007). From the pragmatist’s viewpoint, the diversity of ‘truths’ is comprehensible through different forms of inquiry and a plurality of methods (McCready, 2010). This assumption has been recognised as the most suitable epistemology for a mixed-methods approach (Tashakkori and Teddlie, 2003) which allows researchers to draw from both quantitative and qualitative research approaches to answer a particular research question (Creswell, 2013).

Pragmatists hold the view that the research question should determine the choice of the research design and not the method or paradigm (Muncey, 2009). This research approach enables the use of any method that will facilitate the understanding and solution to the problem. It has been stated that mixed-methods research can help answer research questions that cannot be answered by either qualitative or quantitative methods alone and can provide a greater range of tools to meet the aims and objectives of the study (Creswell and Plano Clark, 2011). Mixing both methods draws upon their strengths and resolves their weaknesses, providing a more comprehensive picture of the issue under consideration rather than the study (Doyle

et al., 2009; Ihantola and Kihn, 2011). The pragmatic approach to this current research was influenced by the belief that the research was not driven solely by theory or by data, but a process which allows the researcher to move between inductive and deductive through a process of inquiry (Morgan, 2007).

Pragmatism holds high regard for the reality and influence of the inner world of human experience in action. It views knowledge as both being constructed and based on the experience of the world we live in (Johnson and Onwuegbuzie, 2004). Pragmatism does acknowledge that researchers are constrained in their ability to obtain certain knowledge of reality. The available research tools and assumptions limit them; and accept that knowledge is fallible (Holt, 2009; Maxwell, 2012). Researchers adopting pragmatism generally argue that knowledge is constructed, and reality situated within the context in which it was generated (Hooper and Wood, 2002). Therefore, conclusions are interpreted with caution and viewed as “current reality”. Meaning and knowledge are viewed as being tentative and subject to modification over time, and the knowledge acquired is a provisional truth (Johnson and Onwuegbuzie, 2004). The philosophical precepts of pragmatism are consistent with the aim and objectives of this research study and are inherent within this thesis.

## 1.8 Plan of thesis

In addition to this opening chapter, this thesis has six more chapters. Chapter Two presents a systematic review on post-stroke education interventions. Chapter Three describes the feasibility RCT research methods. Chapter Four presents the feasibility trial results and discusses the principal findings. Chapter Five describes the research methods employed for the qualitative phase of the study, while Chapter Six presents and discusses the findings of the qualitative interviews. In the final chapter (Chapter Seven), the key research findings are summarised and discussed, evaluating the strengths and limitations of the study. In concluding this thesis, the implications for the practice of post-stroke education and areas that need further investigation are considered, and recommendations are presented.

# Chapter Two

## Randomised controlled trials of post-stroke education interventions for stroke survivors and their family caregivers – A systematic review

## 2.1 Introduction

The previous chapter highlighted the escalating prevalence of stroke and the challenges confronting stroke survivors and their family caregivers, particularly in Ghana. A well-coordinated healthcare system in Ghana is currently absent, and stroke awareness is low among patients and their informal caregivers. This inherently suggested a need to provide stroke information to equip stroke survivors and their family caregivers with self-management and prevention strategies. Thus, it became necessary to research the delivery of post-stroke education in the Ghanaian setting.

The first objective of this research was to identify existing evidence and strategies for post-stroke education interventions. An appropriate starting point for doing this was to conduct a systematic review. Findings of Systematic Reviews (SRs) of high-quality RCTs are regarded as the 'gold standard' for evidence-based practice (Polit and Beck, 2012). SRs are known to provide the most robust evidence of the efficacy and effectiveness of healthcare interventions (Evans, 2003). The MRC (2008) guidelines for developing and evaluating complex interventions recommend that research begin with SR, except when a high-quality review has been conducted lately. SRs are often described as "the most reliable form of evidence to guide clinical practice" (Clarke, 2011) since they include thorough assessment, evaluation and collation of all evidence that meets the criteria for the review.

SRs improve rigour and reduce the risk of bias, by inviting collaboration and consensus by involving more than one reviewer at each stage of the review process. The essential principle that differentiates a SR from a narrative or descriptive review is the combination of a systematic search and the attempt to locate, appraise, and summarise evidence from available high-quality studies pertinent to a specific review question using an explicit, logical, and scientific methodology (Higgins and Green, 2011). Accordingly, the findings from well-conducted SRs should form reliable tools to guide healthcare decisions and practice. The aim of conducting a SR is not only to establish whether an intervention is effective regarding a particular outcome but also to determine the quality of the evidence. If the existing evidence is deemed at high risk of bias or needs to be updated, this would support the rationale for conducting further studies (Eggar et al., 2008).

Even though it is not quite up to date, there is currently a SR on the effects of post-stroke education intervention (Forster et al., 2012). The Cochrane review assessed the effects of information provision on stroke knowledge and other key stroke-related outcomes among stroke survivors and carers. This review reported higher stroke knowledge, information satisfaction and lower depression scores among stroke survivors and carers in the intervention group. However, there was no significant effect on the anxiety or depression cases among patients, carers' mood or satisfaction, or death. The authors concluded that, although the effects of information provision were statistically significant, the interventions had a small clinical effect on depression, suggesting the need for more extensive trials to assess the effects of post-stroke education. The inclusion criteria for this review were broad, with the review examining stroke education, support, and training. The review included studies other than post-stroke education materials that did not adequately estimate the effects of the provision of information. In addition, several years have passed since the publication of Forster et al.'s review. The emergence of new studies with varied outcomes indicate that a further review is warranted to ensure that the latest evidence is considered.

A SR process requires developing an explicit and reproducible comprehensive search strategy to identify relevant studies, select eligible studies, assess the methodological quality of studies for inclusion, and critically appraise and synthesise the findings of included studies (JBI, 2016). This process facilitates greater confidence that the results include all the relevant and available evidence.

## 2.2 Review question

The review question was 'what are the strategies for and the effects of post-stroke education on the stroke survivor and family caregiver's knowledge of stroke and other stroke-related outcomes?

## 2.3 Aim and objectives of the review

The aim of this review was to examine and synthesise evidence on the effects of post-stroke education interventions for stroke survivors and their family caregivers.

### 2.3.1 Objectives

The specific objectives were to identify:

1. The effects of post-stroke education on stroke survivors and family caregivers' knowledge of stroke, anxiety, depression, satisfaction, and caregivers' burden.
2. Post-stroke educational intervention strategies used to provide stroke information to patients and/or family caregivers.

## 2.4 Review methods

Systematic reviews are carried out using an agreed protocol to ensure methodological reliability and reproducibility. Therefore, conducting systematic reviews following an internationally agreed and recognised procedure is the best practice. The Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) were used to guide the conduct of the systematic review process. The following sections follow the headings of the PRISMA checklist (Moher et al., 2015).

### 2.4.1 Review protocol

The conduct of systematic reviews must first be pre-determined by a carefully planned and developed protocol (Moher et al., 2009; Centre for Reviews and Dissemination, 2009). The Cochrane reviews and the Joanna Briggs Institute (JBI) suggest that the protocol should be explicit and follow the steps of a systematic review process (Higgins and Green, 2011; Tawfik et al., 2019). Also, the review protocol should contain detailed outlines of materials and methods and the objective of the review that guides the conduct of the study (Greenhalgh, 1997). The protocol also sets out explicit criteria to minimise bias and errors in the selection and analysis of evidence (Magarey, 2001; Petticrew, 2003).

### 2.4.2 Eligibility criteria

#### 2.4.2.1 Types of studies

Systematic reviews of healthcare interventions have generally focused on evidence from RCTs. For instance, the Cochrane Collaboration has, until recently, absolutely focused on reviews of RCTs (Higgins and Green, 2011). RCTs are considered the highest grade of evidence as they are recognised as the most resistant to biases, especially selection bias, and the associated confounding effects (Polit and Beck,

2014; Evans, 2003). Selection bias occurs when there are fundamental differences between the intervention and control groups in important factors affecting treatment response (Centre for Reviews and Dissemination, 2009). These factors may be known or unknown.

However, there has been criticism of the restricted emphasis on RCTs. From a 'critical realist perspective', Clegg (2005) argued that such systematic reviews take an overly narrow definition of 'evidence' and that focusing on 'what works' within such a framework may not reveal how interventions are implemented or how they operate within 'real-world' settings. Additionally, Williams and Garner (2002) argued that a pure evidence-based approach is too simplistic and fails to tackle the nuances of interpersonal relationships in clinical care. Therefore, these authors suggest that other approaches to systematic reviewing should be considered, meaning that human processes cannot be attributed to simple causalities. Several healthcare interventions may not readily lend themselves to an RCT design where conducting such a trial may be unethical or impractical. These authors argue that other methods and approaches should be considered as there is scope for more than one methodological perspective. The rationale for a particular approach will depend on the aims and objectives of the review.

Realist reviewing is a relatively new approach to reviewing and seeks to explain and unpack how complex interventions might work rather than evaluate whether the interventions work (Pawson et al., 2005; Shepperd et al., 2009). Such approaches might be applicable in situations where the objective is to map how different aspects of the intervention interact or to identify how it works for specific individuals or groups (Petticrew et al., 2013). An objective of the current review was to appraise the evidence for the effectiveness of post-stroke education interventions in improving the knowledge of stroke and other outcomes. Another objective was to identify various post-stroke education intervention strategies that have been delivered and what have been shown to work effectively. Therefore, it was important to include only study designs that could address the question of efficacy and effectiveness of the intervention. As such, the ideal review would include all evidence from high-quality RCTs.

This is consistent with the rationale for the current review, which was to inform the development of the content of a stroke information booklet for the subsequent feasibility RCT. Therefore, only RCTs were included in the review as this rigorous research design can be used to determine effectiveness. The decision not to include observational and qualitative studies was made because these studies do not provide high-grade evidence for the efficacy or effect of interventions.

#### 2.4.2.2 Types of participants

The review included studies that recruited adult patients aged ≥18 years, clinically diagnosed with stroke or Transient Ischaemic Attack (TIA), admitted, or discharged from stroke units or hospital wards, with or without their family caregivers. Family caregivers were identified as people who assisted stroke patients/survivors in the day-to-day activities at home; caregivers were adults aged ≥18 years.

#### 2.4.2.3 Types of interventions

Interventions were included if they used any form of post-stroke education using leaflets, booklets, videos, audiotapes and/or computer-mediated educational programmes, with or without discussions and teaching sessions on stroke and its management in stroke units or hospital ward settings. Standard or usual care was defined as routine stroke care that did not include structured stroke information provision or any of the post-stroke education forms listed above. In the case of usual care, post-stroke education is usually given in an ad-hoc manner and is not structured. Studies were excluded if they provided training and support.

#### 2.4.2.4 Types of outcome measures

An initial reading of the literature suggested that providing stroke information impacted the knowledge and mood of stroke survivors and family caregivers (Forster et al., 2013). Therefore, studies were included if they assessed outcome measures that included knowledge of stroke, anxiety, depression, satisfaction, self-efficacy, and caregiver burden. In addition, studies were included if they assessed any of the above with other outcomes such as quality of life and functional and rehabilitation goals. Studies were, however, excluded if they assessed only measures of functional rehabilitation goals and knowledge besides stroke, such as medication as outcomes.

This is because the review aimed to evaluate post-stroke education interventions that assessed knowledge of stroke with other keystroke outcomes such as anxiety and depression. Table 2.1 provides a summary of the inclusion and exclusion criteria of the review.

### Table 2.1: Summary of inclusion and exclusion criteria

| | **Inclusion** | **Exclusion** |
|---|---|---|
| **Type of studies** | RCTs conducted on the effectiveness of post-stroke education in stroke units or hospital wards | Non-RCT designs were used to evaluate the effectiveness of post-stroke education. |
| **Type of participants** | Adult patients (aged ≥18 years) diagnosed with stroke /TIA and/or their family caregivers admitted to or discharged from stroke units or hospital wards. | |
| **Type of intervention** | Any form of post-stroke educational interventions with leaflets, booklets, videos, audiotapes and/or computer-mediated educational programmes, with or without discussion and teaching sessions in a stroke unit or a hospital ward. | Provided training and support |
| **Outcome measure** | Knowledge of stroke, self-efficacy, anxiety, depression, satisfaction, and caregiver's burden | Measuring only functional rehabilitation goals and knowledge besides stroke, such as medication as outcomes |

## 2.4.3 The search strategy for identification of studies

A comprehensive search strategy for relevant articles was carried out in three stages. First, an initial search was carried out through the bibliographies of MEDLINE and CINAHL electronic databases to identify keywords, Medical Subject Headings (MeSH) and indexing terms used in titles and abstracts of potentially relevant articles (JBI, 2009). The second stage utilised these identified search terms to conduct a thorough search across nine major electronic databases from their inception to June 2017 and then updated in January 2019 (Goldsmith et al., 2007). The following electronic databases were searched: AMED; ASSIA; CINAHL; Cochrane Library; EMBASE; MEDLINE; PsycINFO; The Cochrane Central Register of Controlled Trials from the Cochrane Library, and Web of Science. The third stage involved scanning completed

references identified through the search of the electronic databases. As Hawker et al. (2002) advocated, unpublished articles were searched for by scanning abstracts of electronic thesis and conference papers.

The keywords and search terms in Table 2.2 below were used to develop the search strategy using the Participant, Intervention, Comparator and Outcome (PICO) framework guide (Crowther and Cook, 2007). Search terms and their synonyms that describe the disorder (stroke), the participant (stroke patients/survivors and family caregivers/carers), intervention (education) and outcomes were generated. The search terms were modified according to the individual databases and were linked by the Boolean operator 'AND' or 'OR' to arrive at the final number of articles titles and abstracts which were scanned. With the assistance of an experienced librarian, appropriate search terms were developed to explore the various databases. The search was limited to all relevant published studies in the English language and was not limited to the year of publication during the search period. The individual searches for studies in the various electronic databases are attached in Appendix 1. The search strategy included all settings, and all identified citations were screened for eligibility. In addition, the reference lists of included articles were searched for further studies that evaluated the effects of post-stroke education for stroke survivors and/or their family caregivers.

## Table 2.2: Keywords and synonyms using the PICO framework

| Key component | Search term |
|---|---|
| **Disorder (stroke)** | Acute stroke, Stroke,<br>Brain isch?emia<br>Intracranial haemorrhage<br>Cerebral haemorrhage<br>Cerebral isch?emia<br>Cerebrovascular disorders<br>Cerebrovascular diseases<br>Cerebrovascular accidents<br>Cerebrovascular events<br>Transient ischemic attack |
| **Population** | Patients, Stroke patients<br>Stroke survivors<br>Carers, Caregivers<br>Informal carers, Informal caregivers<br>Family carers, Family caregivers |
| **Intervention (education)** | Education, Health education<br>Patient education<br>Caregivers' education, Carer's education<br>Stroke education, Information provision<br>Information dissemination<br>Stroke information<br>Educational needs, educational program*<br>Educational intervention |
| **Outcome measures** | Knowledge, stroke knowledge<br>Anxiety, Depression<br>Self-efficacy<br>Satisfaction<br>Caregiver burden |

### 2.4.4 Selection of studies

A three-stage screening process was adopted to select studies for the review. One reviewer (the researcher, PA) appraised the titles and excluded those unrelated to the review question in the first stage. In the second stage, abstracts of all retained articles were read individually and in duplicate by two reviewers (PA and AB). Using two reviewers was to ensure that potentially relevant records were not overlooked and to reduce bias (AB was a colleague research student with relevant knowledge and publications on systematic reviews). A hard copy of the complete publication for every article that was potentially relevant was obtained. The same two reviewers then assessed these independently and in duplicate. However, a third reviewer (LE, the researcher's academic supervisor) was consulted once when there was a disagreement on the study selection.

### 2.4.5 Assessment of methodological quality of included studies

Generally, the quality and reliability of systematic reviews depend on the validity of the included primary data (Crowther and Cook, 2007). Therefore, studies with low validity in systematic reviews may render the findings unreliable (Liberti et al., 2009). Therefore, assessing the methodological quality of potentially relevant studies helps select research designs of high validity for inclusion in a review (Moher et al., 2007). Additionally, a critical appraisal helps exclude studies with systematic bias and errors and assists in interpreting the systematic review findings (JBI, 2010). This assessment process may be subjected to the reviewer's bias. As a result, at least two independent reviewers should assess and agree on the quality of a study before a conclusion (Mulrow and Oxman, 1997; Meade and Richardson, 1997).

The methodological quality of articles for this review was assessed independently by two reviewers (PA and AB) using the Joanna Briggs Institute (JBI) critical appraisal checklist for RCTs (Table 2.3) (JBI, 2016). The assessment covered randomisation, allocation concealment, groups' baseline characteristics and measurements, blinding of participants, treatment givers and assessors, treatment groups, follow-up, analysis, outcomes, outcome measurement, statistical analysis, and the overall trial design. Each of these factors was categorised as yes, no, or unclear. Studies with a total score

of 8/13, calculated by counting the number of 'yes' responses, were considered high-quality articles and were included.

### Table 2.3: JBI critical appraisal checklist for RCTs

| Item No. | Topic | Checklist item |
|---|---|---|
| **1** | Randomisation | Was true randomisation used for the assignment of participants to treatment groups? |
| **2** | Allocation concealment | Was allocation to treatment groups concealed? |
| **3.** | Groups baseline | Were treatment groups similar at the baseline? |
| **4.** | Blinding participants | Were participants blind to treatment assignment? |
| **5.** | Blinding treatment givers | Were those delivering treatment blind to treatment assignment? |
| **6.** | Blinding assessors | Were outcome assessors blind to treatment assignment? |
| **7.** | Treatment groups | Were treatment groups treated identically other than the intervention of interest? |
| **8.** | Follow-up | Was follow-up complete, and if not, were strategies to address incomplete follow-up utilised? |
| **9.** | Analysis | Were participants analysed in the groups to which they were randomised? |
| **10.** | Outcomes | Were outcomes measured in the same way for treatment groups? |
| **11.** | Outcome measurement | Were outcomes measured in a reliable way? |
| **12.** | Statistical analysis | Was the appropriate statistical analysis used? |
| **13.** | Trial design | Was the trial design appropriate, and were any deviations from the standard RCT design (individual randomisation, parallel groups) accounted for in the conduct and analysis of the trial? |

## 2.4.6 Data extraction and management

It can be challenging to extract relevant data from eligible studies for a systematic review, and errors can occur if this process is not accurately carried out (Petitti, 1994). In extracting objective relevant data about study characteristics and conclusions, standardised data extraction tools were developed to minimise bias and errors as well as to improve the reliability of systematic review findings (Pearson et al., 2005). The review question determines the development or modification of the data extraction tool. However, the basic information to be extracted included the study design and setting, participants' characteristics, sample size, interventions, outcome measures, results, and conclusion (CRD, 2009; Evans, 1999). A minimum of two independent reviewers

are needed for the data extraction stage to reduce errors and reviewer subjectivity in the interpretation of findings (Higgins and Green, 2008).

Data extracted for this review was summarised using the modified JBI MAStARI standardised data extraction form (Appendix 2). PA extracted relevant information about the study method, study participants, the intervention (post-stroke education), outcome measures, study findings, and the conclusion. At the same time, LE and the supervision team cross-checked the information to certify the information extracted.

## 2.4.7 Data synthesis and summary of findings

The data were synthesised systematically within a narrative synthesis, including textual descriptions and tabulations of the findings. The narrative synthesis explored the relationship and findings within and between the included studies, using the guidelines from the Centre for Reviews and Dissemination (2009). A narrative summary of findings was carried out since meta-analysis was not appropriate as the individual trials differed considerably in intervention types and outcome measures (Popay et al., 2006).

## 2.4.8 Results of the review

### 2.4.8.1 Study selection

Figure 2.1 illustrates an extensive literature search of nine electronic databases, identifying 2,092 citations. After examining the titles and removing duplicates, 1721 articles remained. Further examination of the titles and abstracts in the light of the inclusion criteria resulted in selecting 26 publications as potentially eligible. Hence, the full texts of these articles were retrieved. A detailed evaluation of these full texts resulted in the further exclusion of 18 studies for the following reasons: outcome measures focused only on functional and rehabilitation goals (n=6) and provided training and support (n=11). The two reviewers agreed on 89% of all included studies. However, there was a disagreement between the two reviewers on one study, which was resolved by a third reviewer (LE) to exclude it. This is because the outcome was based only on participants' knowledge of their medication.

A total of 8 articles met the inclusion criteria and were methodologically assessed for inclusion. An additional search of reference lists of relevant articles, thesis index and other grey information did not result in any further findings. Refer to Figure 2.1 for the PRISMA flow chart for the study selection process.

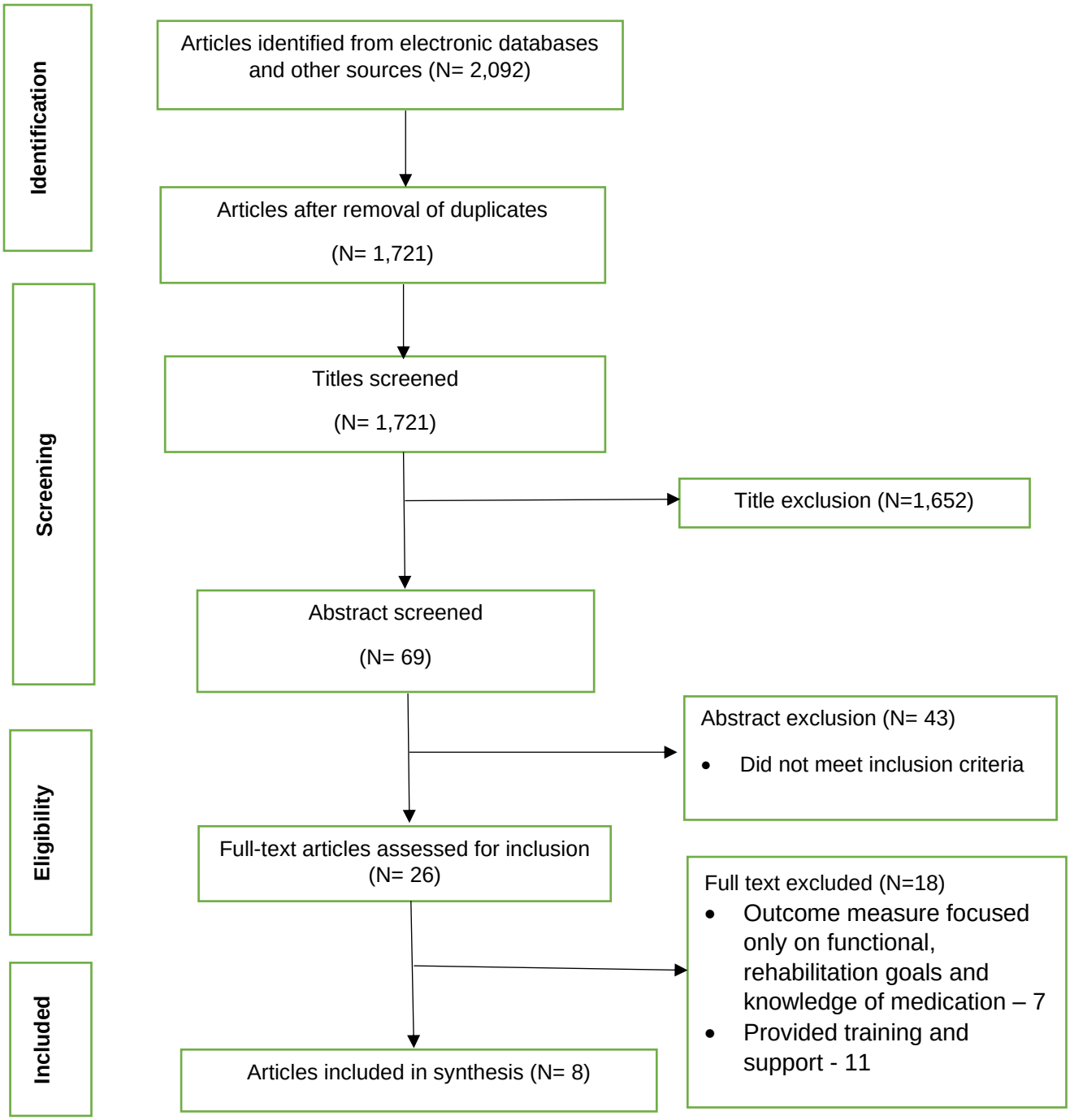



**Figure 2.1: PRISMA diagram showing the flow of systematic identification, screening, inclusion and exclusions of articles identified**

All eight studies included were RCTs, and the results were analysed by narrative summary. Data were synthesised in terms of methodological quality assessment, characteristics of studies, nature of interventions, and outcomes.

### 2.4.8.2 Assessment of methodological quality of included trials

All eight trials were appraised using the Joanna Briggs Institute critical appraisal checklist for RCTs (Table 2.3) (JBI, 2016). Two reviewers (PA and AB) independently rated the included studies, and the scores are shown in Table 2.4. There was 100% agreement on the quality scores of the included trials. Four of the eight trials (50%) were scored 11/13 (high) (Eames et al., 2013; Hoffmann et al., 2007; Smith et al., 2004; Mant et al., 1998). All the other four trials also obtained high-quality scores of 9/13 and 10/13 (Maasland et al., 2007; Franze´n-Dahlin et al., 2008; Lowe et al., 2007; Rodgers et al., 1999). A particular strength of all the trials was a clear trial design that was appropriate to the standard of RCT design (question 13 of the JBI checklist). Nonetheless, the weakness was the inability to blind participants and treatment providers due to the nature of the intervention. This has the potential to raise performance bias among participants in self-reported outcomes. Overall, the trials were of sound methodological quality.

Participants, in general, were randomly allocated to treatment groups. In five of the eight trials, randomisation was computer-generated without the researchers' knowledge (Eames et al., 2013; Hoffmann et al., 2007; Maasland et al., 2007; Rodgers et al., 1999; Mant et al., 1998). In one trial, randomisation was carried out by the researcher by giving out sealed opaque envelopes that assigned participants to treatment groups (Lowe et al., 2007). Allocation of participants by randomisation reduces the risk of selection bias, thereby increasing the methodological robustness of RCTs. However, although it was reported that participants were randomly allocated in two trials, it was not clear how the randomisation process was done (Franze´n-Dahlin et al., 2008; Smith et al., 2004), and this has the potential to raise selection bias.

Participants' baseline characteristics were broadly similar. However, one trial did not report this (Maasland et al., 2007). Five of the eight trials reported that the outcome assessors were blinded (Eames et al., 2013; Hoffmann et al., 2007; Smith et al., 2004; Rodgers et al., 1999; Mant et al., 1998). While in two trials, the status of the outcome assessors was unclear (Franze´n-Dahlin et al., 2008; Lowe et al., 2007), and in one trial, it was not stated whether the outcome assessor was blinded or not (Maasland et

al., 2007). The unblinding of outcome assessors can raise detection bias which may threaten the methodological robustness of the trial. All the trials accounted for the loss and completed follow-up participants. Overall, all the trial treatment groups were treated identically, outcome measures were assessed in the same way with valid, reliable scales, and participants analysed in the groups they were randomised with the appropriate statistical test.

## Table 2.4: Assessment of methodological quality of included studies

| Studies | Randomisation | Allocation concealment | Groups' baseline | Blinding participants | Blinding treatment givers | Blinding assessors | Treatment groups | Follow-up | Analysis | Outcomes | Outcome measures | Statistical analysis | Trial design | Overall quality |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **Eames et al. (2013)** | Yes | Yes | Yes | Unclear | Unclear | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | 11/13 |
| **Franze´n-Dahlin et al. (2008)** | Yes | Yes | Yes | Unclear | Unclear | Unclear | Yes | Yes | Yes | Yes | Yes | Yes | Yes | 10/13 |
| **Hoffmann et al. (2007)** | Yes | Yes | Yes | Unclear | Unclear | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | 11/13 |
| **Lowe et al. (2007)** | Yes | Yes | Yes | Unclear | Unclear | Unclear | Yes | Yes | Yes | Yes | Yes | Yes | Yes | 10/13 |
| **Maasland et al. (2007)** | Yes | Yes | Not stated | Unclear | Not stated | Not stated | Yes | Yes | Yes | Yes | Yes | Yes | Yes | 9/13 |
| **Mant et al. (1998)** | Yes | Yes | Yes | Unclear | Unclear | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | 11/13 |
| **Rodgers et al. (1999)** | Yes | Unclear | Yes | Not stated | Not stated | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | 10/13 |
| **Smith et al. (2004)** | Yes | Yes | Yes | Not stated | Unclear | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | 11/13 |

### 2.4.8.3 Characteristics of included studies

All the included studies adopted the Consolidated Standards of Reporting Trials (CONSORT) format of reporting trials (Kane et al., 2007, Schulz et al., 2010). All eight studies were carried out in three European countries and Australia. Two studies were conducted in Australia (Eames et al., 2013; Hoffmann et al., 2007), one in Sweden (Franze´n-Dahlin et al., 2008), and four in the United Kingdom (Lowe et al., 2007; Smith et al., 2004; Rodgers et al., 1999; Mant et al., 1998) and one in the Netherlands (Maasland et al., 2007). Participants were recruited from hospitals with organised stroke care services. As a standard practice, stroke information materials were given to patients and their family caregivers or displayed on notice boards. Participants in all the studies were assigned to a stroke education programme comprising structured written information with or without verbal information, plus the standard practice or the standard practice only. All the studies evaluated the effects of education on knowledge of stroke, anxiety, depression, and other stroke-related outcomes.

### 2.4.8.4 Participants

A total of 924 stroke/Transient Ischemic Attack (TIA) patients and 586 caregivers/spouses were enrolled in the eight studies. Two studies enrolled stroke /TIA patients (Lowe et al., 2007; Hoffmann et al., 2007), and one only enrolled TIA (Maasland et al., 2007). Four studies enrolled both stroke/TIA patients and their family caregivers (Eames et al., 2013; Smith et al., 2004; Rodgers et al., 1999), and one study only enrolled spouses of stroke patients (Franze´n-Dahlin et al., 2008). The sample size of the studies ranged from 65 to 204, with a majority of the participants having a stroke /TIA. Participants were recruited as inpatients or after their discharge from the hospital.

The inclusion criteria employed in all the eight studies were as follows: Adult patients and/or family caregivers ≥18 years, diagnosed with a stroke or TIA, adequate cognition and communication, hearing and vision to participate in an interview and discussion, and being able to complete the assessment forms or questionnaires.

### 2.4.8.5 Nature of interventions

The second objective of this review was to describe strategies used to deliver of post-stroke educational interventions. Thus, in this section, the nature of interventions delivered is described. The section also highlights the type of education intervention tested, how the intervention was delivered, duration, intensity and how the intervention differs from usual care provided.

A full description of the interventions tested is summarised in Table 2.5. Broadly, the nature of interventions was similar. Three of the eight interventions were delivered to individual participants (one-to-one teaching) with tailored content based on information needs assessment by healthcare professionals (Eames et al., 2013; Hoffmann et al., 2007; Maasland et al., 2007). While three interventions, although, were delivered to individual participants but did not state whether the content was tailored or not (Lowe et al., 2007; Smith et al., 2004; Mant et al., 1998). Another two of the eight interventions were provided to participants in groups which meant interaction among group members (Franze´n-Dahlin et al., 2008; Rodgers et al., 1999).

Six of the eight trials had the content of the intervention written - two were compiled as booklets (Eames et al., 2013; Smith et al., 2004), and another two were compiled as files or folders (Lowe et al., 2007; Mant et al., 1998), and two were computer-mediated booklets (Hoffmann et al., 2007; Maasland et al., 2007). However, in another two trials, it was not clear whether written information was given in addition to a lecture or an educational session (Rodgers et al., 1999; Franze´n-Dahlin et al., 2008). In five of the eight trials, participants in the intervention group received written information alongside a face-to-face explanation of the content (Eames et al., 2013; Hoffmann et al., 2007; Maasland et al., 2007; Lowe et al., 2007; Smith et al., 2004). The face-to-face interaction lasted between 15 minutes to 1 hour for a session. Generally, the education content included: how stroke occurs, effects and management of stroke, including drug treatment and rehabilitation, and risk factors for stroke, while the usual care was generically written information from Stroke Associations given on a routine, sometimes on-demand or ad-hoc basis.

## Table 2.5: Summary of post-stroke education intervention

| Study | Content of education intervention | Intervention delivery (Individual or group) | Mode of delivery |
|---|---|---|---|
| Eames et al. (2013) | Individuals chose from 34 topics on stroke education after information needs assessment | Individually tailored | Tailored written stroke information booklet and individual face-to-face discussions with follow-up telephone calls. |
| Franze´n-Dahlin et al. (2008) | Symptoms and the occurrence of stroke, risk factors, treatment, prevention, personality changes and social aspects | Group | 20 to 30 minutes lecture to groups of 10 spouses |
| Hoffmann et al. (2007) | How stroke occurs, risk factors, understanding and managing the effects, reducing stroke risk, treatment and rehabilitation, and managing after discharge. | Individually tailored | Computer-generated information booklet given to individual participants with explanations after information need assessment |
| Lowe et al. (2007) | CareFile contained telephone numbers for stroke-related services, local agencies, general stroke information and information on secondary stroke prevention personal to the patient. | Individual | The content of the CareFile was discussed with the patient for 15-20 minutes, and the patient was allowed to ask questions and take CareFile home for reference or consult the General Practitioner (GP) in the advert of an arisen question |
| Maasland et al. (2007) | General introduction of diagnosis, prescribed medication and four risk factors for stroke or some general information on frequent vascular risk factor | Individually tailored | A 20 – 25 minutes individualised computer-mediated education programme with slide shows, background voice and a personal address by one of the researchers. The information was displayed on the screen and printed. |
| Mant et al. (1998) | A collection of eight Stroke Association leaflets that describes what stroke is, its causes, effects, problems and how to deal with stroke | Individual | Information pack sent to patients and carers via a post on or before discharge |
| Rodgers et al. (1999) | The nature of stroke, treatment, and recovery of stroke. The role of the multidisciplinary team members in stroke recovery. | Group | The information was delivered in one 1-hour small-group educational session for inpatients and their informal carers and followed up with six 1-hour educational sessions after discharge from the hospital. |
| Smith et al. (2004) | Information about stroke causation and its consequences, stroke recovery, financial benefits, relevant services and a specific section for carers. | Individual | A 20-minute meeting for discussion of the manual with a multidisciplinary stroke team every two weeks |

### 2.4.8.6 Outcome measures

Broadly, the outcomes that were assessed in the reviewed studies included knowledge of stroke, anxiety and depression, satisfaction with information, self-efficacy, caregiver burden, and quality of life. These are summarised in Appendix 3. These outcomes were evaluated during follow-ups that ranged from 1 week to 12 months. Some of the outcomes were self-reported by the participants. They were evaluated using validated standardised scales such as the Hospital Anxiety and Depression Scale (HADS), and others used Likert-scaled questionnaires.

**Knowledge of stroke**

All eight trials evaluated patient or caregiver knowledge or both at least one week to 12 months of follow-up (Eames et al., 2013; Lowe et al., 2007; Maasland et al., 2007; Hoffmann et al., 2007; Smith et al., 2004; Mant et al., 1998). All used five different questionnaires explicitly developed for the study, as shown in Table 2.6. Three of the eight trials reported a statistically significant difference in knowledge of stroke (Lowe et al., 2007; Franze´n-Dahlin et al., 2008; Rodgers et al., 1999). Even though the remaining five trials did not report a statistically significant difference, there was generally an increase in knowledge of stroke scores among participants in the intervention group (Eames et al., 2013; Maasland et al., 2007; Hoffmann et al., 2007; Smith et al., 2004; Mant et al., 1998). Overall, the finding on knowledge of stroke was inconsistent as three of the eight studies recorded an increase in the knowledge of stroke while the remaining five did not.

## Table 2.6: Summary of knowledge of stroke outcome

| Study | Measure used | Follow-up | Measure assessed | Significant |
|---|---|---|---|---|
| Eames et al. (2013) | 25-item Knowledge of Stroke Questionnaire (KSQ)) | 3 months | Stroke knowledge | Not significant |
| Franze´n-Dahlin et al. (2008) | 13-item questionnaire | 6 and 12 months | Knowledge of stroke | **Significant** |
| Hoffmann et al. (2007) | 25-item Knowledge of Stroke Questionnaire (KSQ)) | 3 months | Stroke knowledge | Not significant |
| Lowe et al. (2007) | Questionnaire | 3 and 6 months | Knowledge of stroke | **Significant** |
| Maasland et al. (2007) | 14 questionnaire validated tool | 1 week and 12 weeks | Knowledge of stroke | Not significant |
| Mant et al. (1998); | 57-knowledge questionnaire | 6 months | Knowledge of stroke | Not significant |
| Rodgers et al. (1999) | 26-item Knowledge of Stroke Scale | 6 months | Knowledge of stroke | **Significant** |
| Smith et al. (2004) | Questionnaire | 3 and 6 months | Knowledge of stroke | Not significant |

### Anxiety and depression

Five of the eight studies assessed anxiety and/or depression as outcome measures using the Hospital Anxiety and Depression Scale (HADS) with case scores ≥11 at three- and six-month follow-ups (Eames et al., 2013; Hoffmann et al., 2007; Smith et al., 2004; Mant et al., 1998; Rodgers et al., 1999). Three of the five studies recorded no significant difference in anxiety and depression (Eames et al., 2013; Mant et al., 1998; Rodgers et al., 1999), while two studies reported significant differences in only anxiety (Hoffmann et al., 2007; Smith et al., 2004).

### Participant satisfaction with information

Participant satisfaction with information was measured differently with inconsistent findings in four studies (Eames et al., 2013; Lowe et al., 2007; Franze´n-Dahlin et al., 2008; Mant et al., 1998). In Eames et al. (2013) study, satisfaction was measured under four sections: medical information, practical information, service and benefits,

and prevention information at 3 months outcomes. All these were measured by self-reporting and assessed using a 10-point Likert scale, where 1=’not at all.’ and 10=’extremely…’. The study reported a significant difference between groups, with the intervention group being satisfied with the information on medical, practical, services and benefits, and prevention. In a study by Lowe et al. (2007), satisfaction with the information given was measured with the KSQ, with no significant differences between groups regarding satisfaction with the information received. Additionally, in Franze´n-Dahlin et al.’s (2008) study using an 11-item questionnaire, satisfaction with the intervention was assessed at 6- and 12-month follow-ups and reported no significant difference (P=0. 911) between treatment groups. The study by Mant et al. (1998) reported no significant difference in satisfaction with information received at 6 months follow-up using a questionnaire.

**Self-efficacy**

Two studies evaluated participants’ self-efficacy as a secondary outcome measure during a 3-month follow-up (Eames et al., 2013; Hoffmann et al., 2007). One study assessed self-efficacy regarding coping with stroke, access to practical and emotional help, managing stress, access to stroke information, and talking with a doctor and other healthcare professionals (Eames et al., 2013). The authors reported a significant difference with access to stroke information but no significant difference for the other measures of self-efficacy.

In the other study, self-efficacy was measured with the ‘self-efficacy to perform self-management behaviour scale’ (Hoffmann et al., 2007). This study found no significant difference between groups. However, in this study, self-efficacy was assessed regarding getting information about stroke, obtaining help from the family, community, and friends, communicating with a doctor, controlling/managing depression, and managing the disease in general with its symptoms.

**Quality of life**

The participants’ quality of life was assessed in five studies (Eames et al., 2013; Franze´n-Dahlin et al., 2008; Hoffmann et al., 2007; Rodgers et al., 1999: Mant et al., 1998). Eames et al.’s (2013) study, assessed patients’ quality of life using the Stroke

and Aphasia Quality of Life Scale – 39 Generic (SAQOL-39g). There was no significant difference in the quality of life. Similarly, finding no significant difference in the quality of life, Mant et al.'s (1998) study used the 36-item Short-Form Health Survey Instrument (SF-36). Also, in Rodgers et al.'s (1999) study, the SF-36 was used to assess the perceived health status of participants. There was no significant difference in the patients' and caregivers' SF-36 scores, but there was a significant difference in a separate analysis of patients and caregivers (p=00.4)

The other two studies assessed the quality of life as perceived health status with different assessment tools (Hoffmann et al., 2007; Franze´n-Dahlin et al., 2008). In Franze´n-Dahlin et al.'s (2008) study, the perceived health state of participants was assessed using the Visual Analogue Scale (VAS). The study recorded no significant difference at 6 and 12 months. In another study by Hoffmann et al. (2007), perceived health status was measured using the COOP chart. The COOP chart was used to measure the physical fitness, feelings, daily activities, pain, change in health, overall health, social support, and quality of life. There was no significant difference regarding perceived health status.

**Compliance with secondary prevention**

Two studies assessed compliance with secondary prevention as a primary or secondary outcome measure using either an apparatus or self-reporting instruments (Lowe et al., 2007; Maasland et al., 2007). However, there was no significant difference in the blood pressure reading at follow-up assessments in both trials. Also, there was no significant difference in compliance with risk factors prevention such as cholesterol level, weight, cigarette and alcohol consumption, and physical activity measured in the Maasland et al's. (2007) study. The authors reported that patients' compliance with risk factor prevention was higher in the intervention group than in the control group.

**Caregiver burden**

Two studies evaluated the caregiver burden as an outcome measure at 3- and 6-month follow-ups using the caregiver strain index (Eames et al., 2013; Mant et al., 1998). Both studies reported no statistically significant difference between intervention

and control groups. However, caregivers in the intervention group of one trial scored better on the SF-36, particularly for one dimension (mental health) (Mant et al., 1998).

### Other outcome measures

One study also assessed other outcome measures; psychological health was reported not significant (Franze´n-Dahlin et al., 2008). In the same study, there was no significant difference between groups at 6 and 12 months when the perceived social support, economic status, sense of coherence and functional ability were assessed. Also, Maasland et al.'s (2007) study reported no significant difference between groups of functional ability using the modified Rankin score. Additionally, Smith et al.'s (2004) study recorded no statistically significant difference between groups after assessing participants' physical and social function.

Lowe et al. (2007) study also reported no statistically significant difference between groups in utilisation of CareFile. Participation and mood of the participants were assessed at 3- and 6-months follow-up. In Rodgers et al.'s (1999) study, participants' satisfaction with services, carers' emotions, disability and handicap were assessed and were reported as not statistically significant. Similarly, Mant et al.'s (1998) study, reported no significant difference in handicap and patient's behaviour.

## 2.5 Summary of review results

The first objective of this review was to examine the existing evidence on the effects of post-stroke education intervention. There is limited evidence that post-stroke education interventions can lead to positive outcomes for stroke survivors and their family caregivers compared to usual care. A review of RCTs published between 1998 and 2013 was conducted to analyse the existing evidence. A total of eight RCTs were identified and were designed with a range of topic areas, duration, and frequency to compare with usual care. Among the various forms of post-stroke education interventions, no attempts have been made to evaluate the effectiveness of oral explanation using written information in resource-poor countries.

The trials included in the review produced conflicting findings about the effectiveness of post-stroke education for stroke survivors and their family caregivers. Some trials

demonstrated the effects of post-stroke education on improving stroke knowledge (Lowe et al., 2007; Franze´n-Dahlin et al., 2008; Rodgers et al., 1999) and anxiety of people with stroke (Hoffmann et al., 2007; Smith et al., 2004). In contrast, others found no evidence that participants' knowledge of stroke increased or that there was any effect on anxiety, depression and caregivers' burden (Eames et al., 2013; Mant et al., 1998; Maasland et al., 2007; Hoffmann et al., 2007; Smith et al., 2004; Rodgers et al., 1999). There were also conflicting reports on participants' satisfaction with the information provided. One of the five studies that measured satisfaction with information as an outcome found that stroke survivors and their caregivers were satisfied with being informed (Eames et al., 2013). Evidence of the effect of post-stroke education is inconclusive. As a result, there is a need for further research on the provision of information on stroke, especially in Africa, where such evidence is limited.

The second objective of the review was to identify strategies for the delivery of post-stroke education intervention. The review identified various stroke education strategies, such as providing information using a leaflet with or without face-to-face discussion with stroke survivors and family caregivers, which could be replicated, even in resource-limited settings such as Ghana (Eames et al., 2013). This strategy could help inform people about stroke without dedicated chronic care centres and associations that provide education and support to stroke survivors and their families. The content of the interventions was broadly similar, and key components include "what is stroke, effects and management of stroke, including drug treatment and rehabilitation, and risk factors for stroke".

There are several reasons why the results of this review cannot be generalised to a broader context. Firstly, all the studies were conducted exclusively in Europe and Australia, where the culture, delivery of stroke care services, and geographical factors are very different to African countries. To date, no evaluation of post-stroke education has been carried out among stroke survivors and their caregivers in Africa, including in Ghana (Forster et al., 2012). Evidence generated from these existing studies cannot be directly transferred to the Ghanaian context of healthcare delivery without a more critical and context-specific investigation, as cultural and social factors may influence people's responses to such interventions.

Secondly, the finding of this review was inconclusive, partly due to the use of different scales to measure outcomes. Some outcome measures lack formal evaluation of psychometric properties (Eames et al., 2013). Additionally, using a uniform questionnaire might have made it difficult to accurately assess stroke knowledge as not all participants will have been exposed to the same content (Eames et al., 2013; Hoffmann et al., 2007). As a routine practice in stroke units and hospitals where these studies were conducted, stroke survivors and their caregivers were exposed to stroke information materials on admission or at chronic care facilities. This might explain why there was generally improved background knowledge of stroke in the intervention group but not of statistically significant difference. This makes it difficult to generalise these findings to environments where stroke survivors and their caregivers are not routinely exposed to stroke information (as is usually the case in sub-Saharan Africa).

Additionally, the interventions administered in one of the eight reviewed studies were delivered by a multidisciplinary team. This may not be readily tenable in a Ghanaian context where a multidisciplinary team is lacking (Smith et al., 2004). Likewise, other interventions which require participants to attend discussion meetings six times over six months may not be feasible, acceptable, and applicable in settings like Ghana, where participants travel long distances, more than 30 km, to access stroke care services (Franze´n-Dahlin et al., 2008; Rodgers et al., 1999). However, the critical thing noted is that the interventions did not focus much on technology such as Digital Video Discs (DVDs) and videotapes. These may not always be available in resource-poor countries like Ghana, where availability may be challenging.

A strength of this review is that an extensive search strategy was employed to locate all relevant information on post-stroke education. Although this was believed to be comprehensive enough to identify all relevant studies, it is possible that some studies were not found during the search process. There is also a possibility of publication bias as the search strategy did not cover unpublished studies and other grey literature. Additionally, all the searches were conducted in English, so studies without an English abstract were not identified. Therefore, this review has an English Language bias, a limitation.

An important finding from this review is that different questionnaires were used to measure the outcome of knowledge of stroke and other related outcomes among stroke survivors and family caregivers. This was an essential factor in the decision not to complete a meta-analysis in this review and is also an important consideration for further research in this area. Eligibility for inclusion in the post-stroke education interventions was based on the cognition and ability of the stroke survivor to communicate. Therefore, patients with more severe cognitive impairment or aphasia were excluded. These populations are commonly excluded from studies of educational interventions. Identifying effective educational resources for and methods to conduct research into these populations is a current research gap (Eames et al., 2013).

Although the mean sample size of the included studies was 116, only three included a power calculation (Eames et al., 2013; Hoffmann et al., 2007; Smith et al., 2004). Some trials had inadequate sample sizes, raising the possibility of a type II error (Lowe et al., 2007; Mant et al., 1998). It is therefore not clear whether the significance and non-significance of these findings were based on adequate or inadequate power. There was also high-performance bias within the included studies, which was expected due to the inability to blind treatment providers and participants. However, most studies blinded the outcome accessors to minimise detection bias (Eames et al., 2013; Hoffmann et al., 2007; Smith et al., 2004; Mant et al., 1998; Rodgers et al., 1999). This review further highlights the need for adequate powered RCTs in this area.

## 2.6 Review conclusion and implications for the feasibility of RCT intervention

While providing information to stroke survivors and their family caregivers is emphasised in Europe and other high-income countries, there is no such emphasis in Ghana (a low-middle income country). Information on stroke is widely available through the media, chronic-care facilities, and Stroke Associations in Europe (Dombrowski et al., 2013; Flynn et al., 2014). This review has highlighted several strategies and contents of stroke education: written information booklets, face-to-face discussions and verbal reinforcements. However, to the best of the researcher's knowledge, the current practice of post-stroke education in Ghana and other African

countries is unknown, and there is no evidence to support such a practice. As a result, further research in a resource-poor context is justified by the findings of this review.

Evidence-based practice can improve clinical decision-making and the quality of patient care and treatment by integrating the best research evidence with clinical expertise, patient preferences and resource considerations (DiCenso et al., 2005; Akobeng, 2005a; MacPhee and Pratt, 2005). Decisions based on scientific clinical research, patient and family preferences and clinical expertise instead of purely experiential knowledge and intuition are considered to increase effectiveness, minimise the possibility of error and standardise practice (Rashotte and Carnevale, 2004; Parahoo, 2006). Even though clinical expertise, patient preferences and specific contexts and situations have been incorporated in the definition of evidence-based practice, it appears that best research evidence remains the core element of evidence-based practice (Mantzoukas, 2008). In defining the validity of evidence, RCTs and systematic reviews of RCTs are the cornerstone or the gold standard for the evidence-based practice movement (Walker, 2003, Rycroft-Malone, 2006, Berwick, 2005, Franks, 2004).

The systematic review presented in this chapter has highlighted implications for future research. There is limited evidence, especially in developing countries presented in the literature, and there is a need for context-appropriate, well-designed RCTs to assess the effectiveness of providing stroke information. The provision of information is routine in many stroke care services in the UK, and it may be ethically challenging to withdraw the provision of education to establish a control group. Notwithstanding this challenge, RCTs may be feasible to evaluate post-stroke education intervention in a setting like Ghana, where the provision of information is not routine. This is especially the case when gathering evidence for healthcare professionals to provide information. It is also vitally important that further research focus on the appropriate information content and outcomes that are relevant and meaningful to Ghana's context. Whilst increasing stroke knowledge is an important outcome, the ability to improve psychological outcomes such as reducing anxiety and depression as well as self-management are argued to be meaningful. Therefore, from the review, the proposed intervention in the feasibility RCT incorporated content on what is stroke, management and self-care strategies for stroke survivors and their family caregivers. The provision

of training and other support was beyond the scope of the intervention as it would require the services of other multidisciplinary team members, such as occupational and physiotherapists, who are not readily available.

One of the considerations for conducting this review was to assess whether any intervention seemed particularly promising for use in Ghana. The review identified an educational strategy in Eames et al.'s (2013) trial that utilised written information leaflet and face-to-face discussions with stroke patients and their family caregivers. Eames et al's. (2013) strategy was underpinned by The Health Belief Model and the Adult Learning theory which aims to influence behaviour. As this study involved adults, it was essential to adopt this strategy for the feasibility trial. Other strengths of Eames et al's (2013) study included its randomised controlled design. The intervention design was informed by a series of previous studies with the intended population and the inclusion of both patients and carers, which enhances the applicability to health professionals working in stroke care. Furthermore, patients and carers were recruited as participants as the intervention was designed to meet their needs. Overall, the components of this strategy involved low technology that could be adapted and tested for application in resource-limited settings such as Ghana.

Given the conflicting results from the previous trials included in the review and the inappropriateness of direct application of the existing evidence to a Ghanaian context, there is a definite need for conducting well-designed trials at Ghanaian hospitals. This will provide an evidence base of whether or not newly developed post-stroke education interventions are effective in improving the knowledge, anxiety, depression and other stroke outcomes among stroke survivors and their family caregivers in Ghana. The next chapter will explore the feasibility of conducting a post-stroke education intervention in Ghana using the stroke information booklet designed from the findings of this review and with feedback from Patient and Public Involvement (PPI).

# Chapter Three

# Post-stroke education intervention in Ghana: a feasibility randomised controlled trial (RCT)

# 3.1 Introduction

The previous chapter reviewed the evidence underpinning the provision of post-stroke education and highlighted the need to conduct research in a context other than in developed countries. This chapter describes the methods of the quantitative phase of the research. It begins with the research aim and objectives and explores the research designs considered. The rationale for choosing a feasibility RCT design is presented, followed by a detailed account of the methods and procedures for recruitment, data collection, and data analysis.

## 3.1.1 Research aim and objectives

The aim of the research was to evaluate the feasibility of conducting an RCT on post-stroke education intervention delivery in Ghana.

The specific objectives were to:

1. Determine the potential for recruitment and 3-month retention of stroke survivors and their family caregivers;
2. Determine the completeness of data capture in study measures;
3. Assess the willingness of eligible participants to be randomised;
4. Explore the acceptability and practicality of the post-stroke education intervention and study processes;
5. Assess outcome measures in relation to suitability, completion rates and missing data;
6. Determine the potential intervention effect of knowledge of stroke, anxiety and depression, and caregiver burden.

# 3.2 Research design considerations

When designing a research study to determine whether a particular intervention is associated with a particular outcome of interest, two main research designs have to be considered: observational and experimental. In an observational study, the researcher observes a treatment's or intervention's effects without trying to assign treatments to the participants; examples are cohort studies, case-control studies, and cross-sectional studies (Song and Chung, 2010). By comparison, in an experimental study, the researcher introduces an intervention to the participants and observes the

effect of the treatment (Thiese, 2014). This study concerned the delivery of a post-stroke education intervention, and a range of experimental study designs was assessed for suitability.

## 3.3 Quasi-experimental

A quasi-experimental design is an interventional study whereby participants are not randomly assigned to groups. These designs are often used when randomisation is not possible or feasible (Haynes et al., 2012). However, the allocation to treatment conditions or groups (intervention versus no intervention) can be carried out either by systematic allocation or convenience. The allocation can also include self-selection in which participants choose the treatment themselves or by administrator selection in which policymakers, researchers, and clinicians, among others, assign treatment conditions to participants (Shadish et al., 2002). Like experimental studies, quasi-experimental designs involve comparing changes in one group that receives an intervention with a group that does not (comparison control group). Therefore, the comparison group should be as similar as possible to the intervention group in terms of baseline characteristics. The purpose of the comparison group is to capture outcomes that may occur if the intervention had not been implemented (White and Sabarwal, 2014). For their suitability, this study, examined two quasi-experimental study designs – cross-sectional design and the pre-test post- test.

### 3.3.1 Cross-sectional design

A cross-sectional study design can investigate the association between the intervention and the outcomes of interest (Setia, 2016). In a cross-sectional study, exposure and participant outcome measures are assessed simultaneously, although recruitment may occur over time (Sedgwick, 2014). It would be possible to assess participants' outcomes of interest at a single time and compare those who received post-stroke education intervention with those who did not. However, it would not be possible to determine whether the observed difference between the groups' outcomes was a result of the post-stroke education intervention itself or was due to unmeasured confounding variables between the groups. Cross-sectional studies can describe the prevailing characteristics in a given population but not determine what is 'cause' and what is 'effect' (Coggon et al., 2009). Consequently, using a cross-sectional design for

this study was not suitable as it would not be possible to determine whether post-stroke education had any effect compared to no post-stroke education.

### 3.3.2 Pre-test post-test design (before and after design)

A pre-test post-test study measures the effect of an outcome of interest before and after a particular intervention is implemented (Thiese, 2014). In a before and after design, there may be one group (single arm) measured before and after the intervention, or multiple groups (arms), with a comparison between groups. A control group usually receives no intervention in the multiple pre-test post-test study. The researcher often identifies this control group as having similar characteristics to the intervention group. The participants' measurements are obtained before the introduction of the intervention and after the intervention from both groups to allow comparisons between the changes in the scores in each group, and observed differences are assumed to be due to the intervention (Ladak et al., 2013; Jalaludin et al., 2012).

The current study could have been designed so that participants' baseline measurements would have been assessed before the introduction of the post-stroke education intervention and after the education was given. In this way, it would have been possible to compare the measurements before and after the introduction of post-stroke education intervention, and it could be presumed that any observed differences between the groups were due to the post-stroke education intervention (Eccles et al., 2003). However, there would also be potential for other explanations for any observed differences, for instance, socio-demographic differences between the groups, which could likely result in selection bias (Wludyka, 2011). Additionally, there are likely to be unknown factors which could affect outcomes; thus, there are always limitations to this type of research design (Grimes and Schulz, 2002). The lack of randomisation in quasi-experiment design increases the risk of selection and performance biases.

## 3.4 Randomised Controlled Trial (RCT)

In a Randomised Controlled Trial (RCT), two or more different treatment groups are compared to assess the efficacy and effectiveness of interventions (Chow et al., 2017). RCTs are acknowledged as the most rigorous scientific research design for evaluating the efficacy and effectiveness of interventions (Concato et al., 2000). Within healthcare,

efficacy can be defined as the ability of a treatment, intervention, or therapy to produce the intended beneficial effect under ideal situations (Dorland, 2007). In contrast, effectiveness refers to how successful intervention is when delivered ‘under real-world conditions’ (Glasgow et al., 2003).

In an RCT, participants are prospectively randomised to one of two or more groups: the intervention or control group. The randomisation process provides an equal opportunity for participants to be assigned to any given group without prediction or influence from study personnel (Kahan et al., 2015). Random allocation of participants to groups ensures a balanced distribution of known confounding factors (such as age, gender, education, and the prognosis of the disease) and unknown confounders (such as undiagnosed comorbidities), which can prevent bias and minimise the effects of these confounding variables (Akobeng, 2005; Houle, 2015). A fair distribution of these variables ensures that a similarity in the baseline characteristics of the groups is achieved before the intervention. This increases the probability that any observed differences between the groups can be reasonably attributed to the intervention under investigation and not to any confounding factors (Sullivan, 2011; Attia, 2005).

RCTs are well-established in drug trials, where it is mandatory to demonstrate the safety and efficacy of medication before they are prescribed (Bothwell et al., 2016). However, RCTs of interventions in nursing practice are less common (Egerod et al., 2005). For instance, RCTs evaluating nursing practices, such as educational interventions, are limited compared to RCTs in medicine and pharmacological interventions (Vedelo and Lomborg, 2011). This may be because several nursing interventions are carried out based on experience, tradition, and intuition rather than supported by robust scientific evidence (Pravikoff et al., 2005). In the case of post-stroke education in Ghana, stroke survivors and their family caregivers are provided with information based on the nurses’ opinions, previous knowledge, and experience, and not on any evidence-based practice guidelines. Therefore, to contribute to a high hierarchy of evidence for the provision of post-stroke information in developing countries, there is the need to evaluate the impact of the delivery of post-stroke education intervention using a rigorous research design, such as an RCT.

However, conducting an RCT of complex interventions such as post-stroke education can be challenging due to some inherent difficulties associated with carrying out the method. For instance, in clinical trials, participants, investigators, healthcare providers, and outcome assessors are often 'blinded' or 'masked' to protect against bias (Friedman et al., 2010; Norrie, 2011). The purpose of blinding is to prevent performance and detection bias from participants' or healthcare providers' knowledge of the treatment allocations (Schulz et al., 2002). Lack of blinding can lead to exaggerated estimates of treatment effects (Attia, 2008; Forder et al., 2005). Blinding may be easily achieved in drug trials as a placebo drug which resembles the experimental drug is offered to the participants in the control group. By doing this, individuals involved in the research, including the investigators, would not know whether the placebo or experimental drug had been given.

On the other hand, when delivering a non-drug trial, it is not always possible to blind the participants or those providing the treatment, as it may be challenging to design a placebo. As a result, this may increase bias and affect the method's robustness. Using a placebo is untenable in a post-stroke education trial. There may be difficulties in standardising the treatment, as educational interventions are often, and indeed should be, adapted and tailored to the individual needs of stroke survivors (Eames et al., 2013). Despite such difficulties, where an RCT is feasible, possible, and ethical, it is still considered the most robust method to evaluate the effectiveness of an educational intervention. As the systematic review identifies, many researchers have managed to carry out RCTs in this area.

An objective of this study was to establish whether outcomes are better for stroke survivors and their family caregivers who received post-stroke education intervention than those who did not. The most robust way to evaluate this is to prospectively randomise stroke survivors and their family caregivers to receive written stroke information as part of the care in the hospital and compare them with those who did not. The systematic review reported in Chapter Two included RCTs used to evaluate the effects of post-stroke educational interventions. However, this intervention is relatively new and perhaps the first to be developed in Ghana. Additionally, there are limited data from developing countries, including Ghana, on stroke survivors' willingness to engage in post-stroke education. Therefore, before committing

resources to a definitive trial, it is sensible first to explore whether such a trial would be feasible in the 'real world' of the Ghanaian context. It is also strongly recommended by the UK MRC which is the main guiding framework for this study.

## 3.5 Feasibility Randomised Controlled Trial (RCT)

A feasibility study is a type of research carried out before the main study to answer the question: "Can this study be done?" (National Institute of Health Research, 2015). In other words, a feasibility study enables the researcher to understand better the processes involved in developing the main study practicable in the real-world context (Bugge et al., 2013). The findings of a feasibility study can determine whether an intervention is 'doable' in a particular setting (Bowen et al., 2009). The MRC guidelines for developing and evaluating complex interventions recommend conducting of feasibility studies as part of the initial steps to developing interventions (Craig et al., 2008; Skivington et al., 2021).

Traditionally, RCTs are expensive to conduct because they are highly time-consuming for researchers and participants (Thiese, 2014). It is therefore important that they are appropriately designed and conducted to maximise the efficient use of time and resources and to minimise the unnecessary burden on participants and researchers. Feasibility studies may either be randomised or not (Arain et al., 2010). However, in feasibility RCTs, it is usually important to establish whether randomisation is feasible and acceptable to both researchers and participants.

Randomised trials are not common in stroke care research in Ghana; thus, the feasibility and acceptability of randomisation was one of the important considerations for this research. As a result of the limited number of randomised trials on post-stroke education intervention in Ghana, it was important to determine whether randomisation would be possible. There were several reasons why this may not be the case, such as staff not being familiar with the research method and stroke survivors and their family caregivers having concerns with being randomised. Other reasons are the lack of suitable outcome measures on which to base the sample size calculation and the contamination of the intervention and control group (Shanyinde et al., 2011). A feasibility RCT can assess the availability of data, the usefulness and limitations of a

database and the time needed to collect and analyse data (Arain et al., 2010; NIHR, 2018). Overall, feasibility RCTs help determine the optimum components of a definitive RCT (Eldridge et al., 2016). Regarding the above uncertainties, a feasibility RCT was justified to inform the design and conduct of a definitive trial of post-stroke education intervention in Ghana.

In this feasibility RCT, eligible stroke survivors and their family caregivers were recruited as dyads and randomised to a two-arm trial to test randomisation and other feasibility outcomes as determined from the systematic review. The dyads were assigned to a group after baseline assessment. Those assigned to the intervention group received a stroke information booklet and a face-to-face verbal discussion of the booklet's content for approximately 20-25 minutes in addition to usual care and a two-week follow-up telephone call. Those assigned to the control group received usual care, but not the stroke information booklet, and had no discussion or telephone call at two weeks. Three months after randomisation, a follow-up was made with both groups to assess outcomes. This feasibility trial was single-blind, so only the outcome assessor was blinded to the treatment groups (the researcher and the two nurses who provided the education intervention were aware of group allocation). A consort diagram of participants' flow in the trial is presented in Figure 3.1.

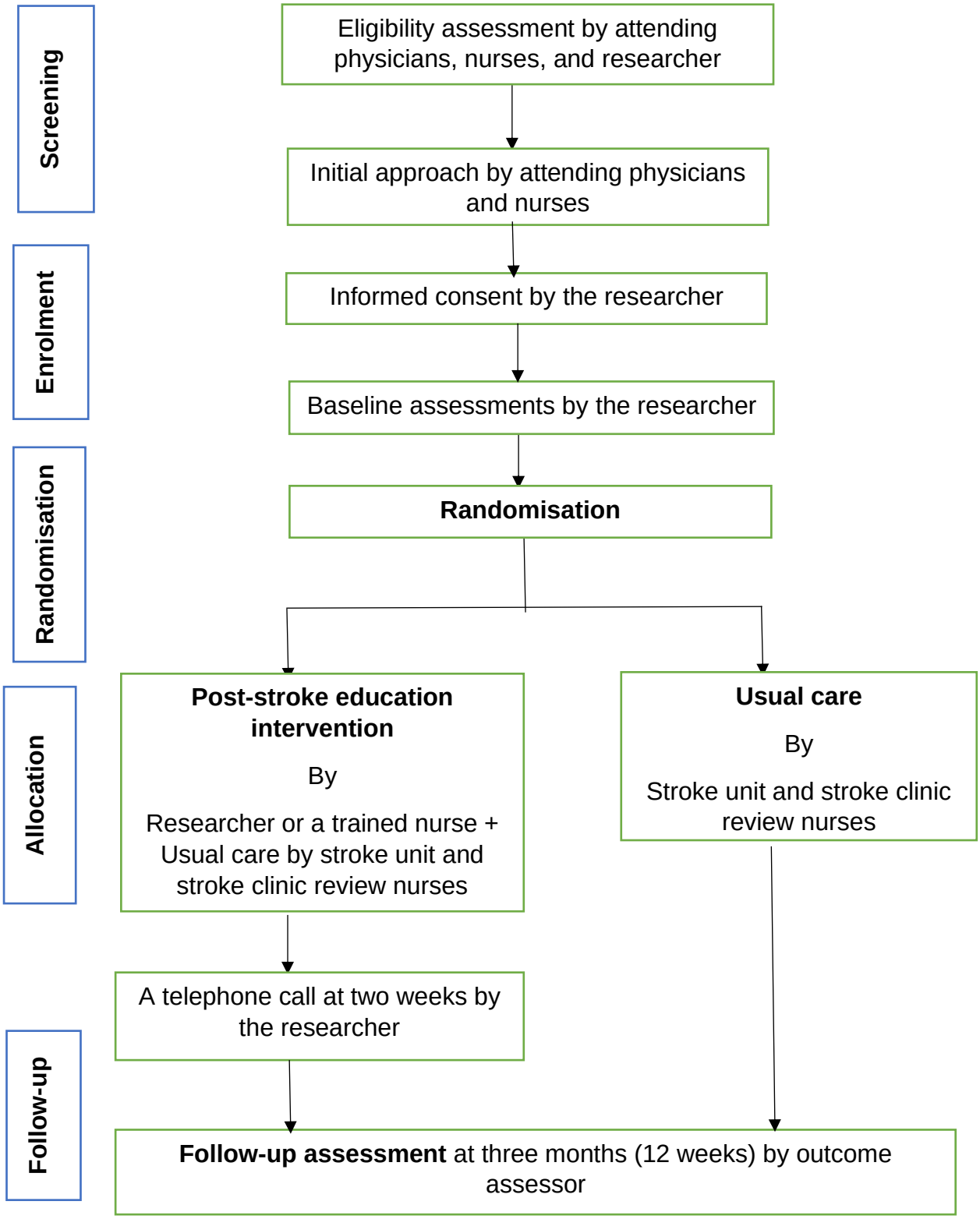



**Figure 3.2: Consort diagram of the post-stroke education intervention trial**

### 3.5.1 Study setting

The study was a single-centre trial at the Komfo Anokye Teaching Hospital (KATH) in Kumasi between November 2017 and July 2018. As with previous studies presented in the systematic review (Eames et al., 2013; Hoffmann et al., 2007), this study was conducted in a hospital with a stroke unit and review clinic, although not as well-developed and equipped as in high-income countries.

KATH is the second largest of five teaching hospitals in Ghana and is a tertiary healthcare facility. KATH is one of the two leading tertiary hospitals in the country with a stroke unit and stroke review clinic for acute stroke management and monitoring of stroke survivors for secondary stroke prevention (Sarfo et al., 2016). Individuals diagnosed with or suspected of having a stroke are referred from different locations within the country and beyond to KATH for specialist stroke management. Stroke survivors are usually admitted into the stroke unit through the Accident and Emergency (A&E) Centre of the hospital or referred to the stroke clinic for outpatient specialist consultation. However, not all stroke survivors reporting to the hospital are accommodated in the stroke unit due to inadequate bed space (six beds). Stroke survivors discharged from either the stroke unit or general medical wards are scheduled for medical reviews every Tuesday at the stroke review clinic (Sarfo et al., 2016). The intention to include the stroke review clinic as a setting for recruitment was to increase the accessibility to stroke survivors because of the limited number of patients admitted to and discharged from the small stroke unit.

Another reason for choosing KATH was that it is the only hospital with a stroke unit and stroke review clinic within the Ashanti region. In Ghana, there is no stroke register or other recognised association through which stroke survivors could be identified and recruited for this study. Thus, the best opportunity to contact prospective participants was either through the KATH stroke unit or the review clinic. Stroke survivors could have been contacted at the other hospital with a stroke unit and review clinic. However, this was not practicable as the two hospitals are far apart. Moreover, KATH was a familiar environment for the researcher, facilitating access to staff and participants.

### 3.5.2 Research governance and ethical considerations

In healthcare research, research governance guides researchers to conduct research according to regulations, principles, and good clinical practice standards (Shaw et al., 2005). This study was carried out following the UK research governance framework, Research Ethics Committee (REC) guidance, and Good Clinical Practice (GCP) (Health Research Authority, 2014, European Medicines Agency, 2002). The research governance framework requires all research involving human participants be ethically designed and conducted while respecting human dignity.

An important step in the research governance recommendations is identifying and engaging with gatekeepers before contacting participants. It is recognised that gatekeepers' roles in safeguarding patients can (rightly) pose hurdles to researchers (Steinhauser et al., 2006). Therefore, researchers must negotiate continuously with gatekeepers and participants to ensure they agree and consent to the research (Sindre et al., 2015). In facilitating access to the stroke unit and stroke review clinic to carry out this study, the researcher initiated and maintained discussions with the physician in charge and the nurses. These discussions focused on the aim and objectives of the study, its methodology and anticipated contribution to stroke care in the hospital. After the physician and nurse manager supported the research, the researcher sent a formal request letter with the study protocol to the Head of the Directorate of Medicine for formal permission. Administrative permission was given on the condition that the ethical committee's approval for the study was obtained before recruitment. The study was then registered with the Research and Development Unit (RDU) of KATH following the submission of the study protocol for ethics review according to the local research governance policy.

#### 3.5.2.1 Ethical considerations

Research involving human participation raises ethical issues that must be considered before recruitment (Bracken-Roche et al., 2017). Stroke survivors and their family caregivers are often exposed to abuse or harm because of their disability, emotional distress and social problems (Wolfenden and Grace, 2015). Therefore, they are regarded as vulnerable individuals and require special care, support or protection, especially regarding research. During the study, the researcher was conscious of

avoiding risk of harm or abuse to participants. Three ethical issues were considered in-depth: the question of equipoise, the principle of beneficence and non-maleficence, and the ethical approval process.

**The question of equipoise:** Equipoise was introduced over 30 years ago as a remedy for RCT problems where participants could be exposed to treatment considered inferior by chance through random allocation (Hey et al., 2017). The principle of equipoise, therefore, assumes that there is no evidence that one treatment (either the control or intervention group) is better than or superior to the other at the time of designing an RCT (Cook and Sheets, 2011). Thus, when there is genuine uncertainty or disagreement over the clinical effectiveness of the intervention arm in the trial, there is a true state of equipoise (Freedman, 1987). Equipoise means that stroke survivors participating in the trial would not be concerned about being disadvantaged, and the physician would not be worried about violating a duty of care (Weijer et al., 2015).

At the outset of this study, it was unclear whether the provision of stroke information to stroke survivors and their family caregivers was 'superior' to the usual care and was not part of routine care. As a result, no stroke survivor and the family caregiver were denied the treatment they usually receive through the random assignment. The usual care nurses and other staff provided was given to all participants in both arms. Since previous studies included in the systematic review produced inconclusive statistical evidence of the superiority of post-stroke education intervention compared to usual care among stroke survivors and their family caregivers, it was concluded that equipoise did exist. Conducting this study would have been unnecessary and unethical if the researcher was already certain that providing structured stroke information benefits stroke survivors and their family caregivers (Hey et al., 2017; London, 2017).

**The principle of beneficence and non-maleficence:** Beneficence involves weighing the benefits of an intervention or treatment against the risks, while non-maleficence means preventing the causation of harm (Polit and Beck, 2012). With these principles in mind, researchers are often advised to consciously develop strategies to minimise harm or abuse to research participants. The study did not use invasive procedures, so the risk of physical harm resulting participating in the study was most unlikely. However, there was the possibility of emotional distress, as participants had to

respond to some questions that may have provoked their sensitivities. Participants were also encouraged to disclose any abuse and coercion to the researcher or the ethics committee with their contact numbers on the participant information sheet (Appendix 4). Considering the risk-to-benefit ratio, the conduct of the research was ethical, as its outcomes were to inform the design of a definitive trial. Carrying out this definitive trial would have the potential to generate evidence to guide policy and best practice recommendations for providing of stroke information to stroke survivors and their family caregivers in Ghana. To ensure that the study did not unduly burden the participants, simple and easy-to-complete questionnaires were selected for the study. In addition, any unusual changes in a participant's condition noticed during the data collection were referred to the attending physician or the nurse-in-charge for further examination.

**Ethical approval process:** The University of Nottingham (UoN) sponsored the research. Therefore, the researcher, as an international research student collecting data abroad, was obliged to subject the study protocol to the ethics review committee of the University for consideration. This was to ensure that the study was structured in compliance with the research governance policy and ethical principles of the University and that it was also covered by the public liability and research insurance policies of the University. The study was reviewed by the Research Ethics Committee (REC) of the Faculty of Medicine and Health Sciences at the UoN for ethical opinion. After receiving a favourable ethics opinion (Appendix 5) from the UoN, the study protocol with the research registration certificate from KATH was submitted to the Committee on Human Research Publication and Ethics (CHRPE) of the School of Medical Sciences (SMS) at the Kwame Nkrumah University of Science and Technology (KNUST), Kumasi – Ghana for an unconditional ethical approval (Appendix 6). No participants were recruited until ethical approval was obtained from the CHRPE, SMS.

### 3.5.2.2 Study preparations

Preparations for data collection began after obtaining ethical approval. The preparations were; site preparation, creation of a research master file, data management and training of identified staff to deliver the post-stroke education intervention.

**Site preparation:** As the researcher was familiar with the study site, it was helpful to engage the physician in charge, who is an experienced stroke researcher and the nurses in charge of the stroke unit and the stroke review clinic. With their support, two furnished offices were identified and assigned to the study on days of recruitment and follow-up interviews. Prospective participants were invited to complete the study procedures, including recruitment, data collection, and delivery of the intervention in these offices. As part of the site preparations, posters (Appendix 7) designed to advertise the study were prominently displayed on notice boards at the stroke unit and the stroke review clinic to create awareness and inform prospective participants and staff about the study.

**Research master file:** A research master file was created, which contained all the study documents, including the letter of administrative permission, the approved participant information sheet, the approved informed consent form, the approved poster for advertisement, ethics approval letter and screening logs. All questionnaires, stroke information booklets, participant information sheets, informed consent forms, and other source documents were printed and packed in readiness for the conduct of the study.

**Data management:** An electronic database was created using access software to input and store data. Data collected with the questionnaires and other source documents were inputted into this database that the researcher was securely handled. Subsequently, the data was 'transported' to the Statistical Package for the Social Sciences (SPSS) software for data cleaning and analysis.

**Training of nurses to deliver the post-stroke education intervention**

Nurses' responsibility is to provide information and coordinate care activities for stroke survivors and their families (Summers et al., 2009). Nurses at KATH provide information to stroke survivors and their family caregivers as part of routine care. However, this is done in an ad-hoc manner and not structured or supported by written information, as proposed for this study. Therefore, three nurses were identified from the stroke unit team who were available, willing to be part of the study and were most appropriate to the role. The researcher gave all three nurses basic training on research and stroke. The basic training was a 3-hour session delivered in person and covered

research governance, the research protocol and background on stroke. After the basic training, the researcher trained two nurses on the intervention delivery and the third nurse to administer the questionnaire. She assisted in collecting the outcome measures as a blind assessor at follow-up.

The intervention delivery training was a 4-hour session covering what is stroke, risk factors, problems experienced after a stroke, and recovery after a stroke with a stroke information booklet developed by the researcher prior to the study. The booklet was developed from the finding of the systematic reviews and with feedback from healthcare professionals, stroke survivors and family caregivers, which is presented in more detail under section 3.5.6.2. This was followed by two practice post-stroke education sessions among the two nurses, which were video recorded for the nurses to reflect on their skills and for the researcher to provide feedback. The nurses then undertook at least two practice sessions with three volunteer stroke survivors and their family caregivers to make them conversant with the intervention. The researcher in person observed the sessions with the volunteer stroke survivors and family caregivers. The researcher provided ongoing supervision during the setup of the intervention. Competency was monitored by the researcher through supervision throughout the study period. This ensured that all participants assigned to the intervention group received the same intervention.

## 3.5.3 Sampling

### 3.5.3.1 Planned sample size

A formal prospective sample size calculation was not required as this was a feasibility trial (Billingham et al., 2013; Arain et al., 2010). The aim of this study was not to determine whether post-stroke education intervention had comparable effects in terms of stroke survivors' and family caregivers' outcomes with usual care; therefore, there was no requirement to calculate the sample size to power the study. Instead, the feasibility RCT focused on whether it could be possible to conduct a definitive trial and to design parameters for such a trial.

Sample size calculation in part is determined by the amount of variance in the outcome of interest in the population (Thabane et al., 2010). It is commonly considered that a

minimum of 50 participants is sufficient to determine this variability. Although there is disagreement over the ideal number for sample size estimates, the target for this feasibility study was to recruit 100 individuals (50 dyads). Based on data from the KATH biostatistics unit (from the previous year), 40 and 50 stroke survivors usually attend scheduled medical reviews at the stroke review clinic every Tuesday, accompanied by their family caregivers. It was therefore believed that recruiting between 3 and 4 stroke survivors and their family caregivers per week over 12 weeks could achieve the target sample size (50 stroke survivors and 50 family caregivers).

### 3.5.3.2 Study population – eligibility criteria

Stroke survivors accompanied by identified family caregivers who were admitted to the stroke unit or attended scheduled medical reviews at the stroke review clinic were screened for eligibility to participate in the trial.

### 3.5.3.3 Inclusion criteria for stroke survivors

Individuals were included in the study if they met the following inclusion criteria:

1. Were aged ⩾18 years as the intervention was developed for adults rather than children;
2. Had a confirmed diagnosis of stroke (ischaemia or haemorrhagic) for ≥1 month;
3. Were able to provide informed consent to be part of the study;
4. Had an identified adult family caregiver who lived with them and/or assisted them with the day-to-day activities of living, including hospital follow-up visits;
5. Were admitted to the KATH stroke unit and nearing discharge and/or attending the stroke review clinic;
6. Were declared medically stable to take part in the study by the attending physician or nurses.
7. Had no severe communication problems.

### 3.5.3.4 Inclusion criteria for family caregivers

Family caregivers were included in the study if they met all the following inclusion criteria, i.e., if they:

1. Were aged ≥18 years;
2. Lived with the stroke survivor and/or assisted with the day-to-day care activities;

3. Were willing to accompany the stroke survivor for hospital follow-up visits;
4. Were able to provide consent to be part of the study.

#### 3.5.3.5 Exclusion criteria for stroke survivors and family caregivers

The stroke survivor and the family caregiver were recruited as a pair (dyad). So, if one of them was excluded, the other was also excluded. Stroke survivors and their family caregivers were excluded from the study if the:

1. Stroke survivor or the family caregiver was unable to understand and communicate in English or the local Ghanaian language (Twi);
2. Stroke survivor and the family caregiver could not be contacted by telephone;
3. Stroke survivor or the family caregiver was not available for follow-up;
4. Stroke survivor transferred out of the stroke unit to the general medical ward;
5. A family caregiver did not accompany the stroke survivor to the stroke clinic.

The aim of this study was to evaluate the feasibility of conducting post-stroke education intervention for stroke survivors and their family caregivers. As a result, individuals with a confirmed stroke diagnosis established for one month or more were included as it was practicable to recruit them. However, recruiting under one-month was not realistic due to acute severe stroke illness. Moreover, the stroke survivors were declared unwell and medically unstable to participate in the study by the attending physician or nurses as they would not have been well enough to participate.

Family caregivers were included because they play important roles and offer physical and emotional support to enable stroke survivors to continue living in their environment with an acceptable quality of life (Clissett et al., 2013; Luker et al., 2017). In Ghana, family caregivers are the main providers of care and support following discharge from hospital as there are no social care services (Johnston et al., 2017). Therefore, including family caregivers in this study was appropriate so that the intervention's effect on the caregivers' capacity to support stroke survivors could also be evaluated.

Prospective participants who understood and communicated in English or the local language (Twi) were included as the study documents were written in English, the official language used in Ghana. Participants who did not read and understand English had the study documents read and verbally translated into Twi. Twi is the native

language of the people of Kumasi and is widely spoken in Ghana (Ager, 2018). However, it is generally not written or read by many people. The nurses and doctors who are the participants' usual care team use Twi to explain complex medical terminologies to patients and their families who understand and speak Twi but not English. The criteria were therefore designed to exclude individuals who could not understand and communicate in English or Twi because there were no available resources to hire the services of interpreters. In addition, the inherent difficulty in arranging and liaising with interpreters was likely to interfere with the scheduling of follow-up visits. Furthermore, if non-English or Twi-speaking individuals were included, transcribers would have been needed for both the intervention and the data collection. Using a transcriber was likely to change the intervention, which may have likely affected the reliability and transferability of the finding (Kvale, 2007). The inclusion criteria also ensured that only prospective participants who were available for follow-ups to complete outcome measures were considered. Stroke patients travel long distance to the stroke clinic and are only available on clinic days (Every Tuesday). As a result, individuals who could be reached by telephone were included to facilitate follow-up arrangements and to respond to questions of participants in the intervention group at two weeks of telephone calls.

Stroke survivors were excluded from the study if they had problems with the use and understanding of the language as determined by the attending physicians or nurses. Since the intervention design involved verbal interaction with participants, it was challenging to include participants who had problems with the use and understanding of the language. The exclusion criteria are common in stroke information provision studies (Forster et al., 2012). Also, individuals who did not consent to be part of the study were not enrolled in keeping with Good Clinical Practice (Health Research Authority, 2014).

### 3.5.4 Recruitment procedure

As presented in section 3.5.2, before data collection, the researcher engaged with the consulting physicians and nurses at the stroke unit and stroke review clinic to solicit their support for the study. Posters of the study entitled "post-stroke education in Ghana" were displayed on key notice boards at the stroke unit and the stroke review clinic to invite prospective study participants (Appendix 7). Some of these posters were

also displayed in key staff areas, such as the consulting physicians' table and the nurses' assessment table. Additionally, verbal reminders from nurses about the study were given at the clinic on every review day.

### 3.5.4.1 Identification and invitation to the study

The recruitment for the trial started by identifying prospective participants at the stroke unit and the stroke review clinic. The attending physicians and the nurses identified potential participants and introduced them to the study. The attending staff screened potential participants to determine their eligibility to participate in the trial. All eligible participants who wished to be part or wanted information about the study were referred to the researcher to obtain this and then, if appropriate, obtain informed consent.

### 3.5.4.2 Informed consent

Informed consent is a process that allows prospective study participants with decision-making capacity to voluntarily decide on participation in a research study (The Council for International Organisation for Medical Sciences, 2016). The decision is usually "informed" based on the researcher's disclosure and the participant's understanding of the aims, methods, procedures, risks, benefits, and any adverse events associated with the study. The researcher must ensure that potential participants are genuinely informed about the research, before they consent to participate (Hall et al., 2012; Newton and Appiah-Poku, 2007; World Medical Association, 2013).

The Participant Information Sheet (PIS) (Appendix 4) was used to provide the informed consent. The PIS was written in English and verbally translated into Twi for participants who could not read and understand the English language. The researcher explained the aim of the study, study procedures, potential risks, and benefits. Eligible participants were also made aware that their participation was voluntary. They could withdraw from the study without explaining for their decision, which would not affect their care in the hospital.

Furthermore, eligible participants were assured that all the information collected for the research would be securely stored and kept confidentially for at least seven years according to the University of Nottingham research policies. All documents such as

consent forms and the participants' background information sheet containing identifiable participants' information were securely stored separately and only accessible to the researcher and the supervision team. Participants' identification numbers were used on the study questionnaires instead of the participants' names to maintain anonymity. The identity of participants was not disclosed at any time during the research process. Only those in the research team had access to personal data. No personal information or medical notes of eligible participants were examined until they had given written consent.

Participants were invited to ask questions about the study before they decided on participation. Those who decided to participate were given consent forms (Appendix 8) to sign or thumb-print and dated before enrolment. Consent was for data collection and applied to the entire duration of the study, including the follow-up assessment and qualitative interviews. Participants were given a copy of the signed consent forms that the researcher witnessed while the original was retained in the study file. A second copy was filed in the stroke survivor's hospital folder.

#### 3.5.4.3 Enrolment of study participants

A trial screening and enrolment log was maintained throughout the study. The nurses routinely maintained a register of all stroke survivors admitted to the stroke unit or those who attended the stroke review clinic. At the same time, the researcher logged every individual enrolled in the study. All participants who enrolled in the study were administered the study procedures.

### 3.5.5 Participant procedures

This section describes the study procedures, including the instruments used in data collection (assessment of measures), randomisation and blinding, the delivery of the post-stroke education intervention and data analysis.

#### 3. 5.5.1 Baseline Assessments

After enrolment, baseline data were collected before participants were randomised. The baseline data were participants' characteristics and baseline measures. Data collected on participants' characteristics included the stroke survivor and family caregiver demographic information, and the stroke survivor's medical details, while the

baseline measures completed were the Knowledge of Stroke Questionnaire (KSQ) (Hoffmann et al., 2007), and Hospital Anxiety and Depression Scale (HADS) (Zigmond and Snaith, 1983). In addition, family caregivers were assessed on the Modified Caregiver Strain Index (MCSI) (Sullivan, 2008). The background and medical information were collected to provide descriptive information on participants' characteristics that could be relevant to the findings of the study. The information was gathered by self-reporting and review of stroke survivor's medical notes (hard copy hospital folder). Table 3.1 provides a summary of the baseline assessments.

### Table 3.1: Contents of stroke survivor baseline assessments

| Area of assessment | Questionnaire | Method of collection |
|---|---|---|
| **Stroke survivor characteristics** | Background information<br><br>Clinical information | Face-to-face interview or self-completed<br><br>Review of medical records |
| **Knowledge of stroke** | 25-item Knowledge of Stroke Questionnaire (KSQ) | Self-reported |
| **Anxiety and Depression** | Hospital Anxiety and Depression Scale (HADS) | Self-reported |

#### 3.5.5.2 Stroke survivor characteristics

The stroke survivor characteristics were gathered using the background information questionnaire (Appendix 9), which contained a list of questions on participants' socio-demographic information. Clinical information was also recorded. A face-to-face approach was used to collect the background information from participants who could not self-complete the questionnaire, while the clinical information was collected from medical records.

#### 3.5.5.3 Stroke survivor baseline measures

Based on the study's objectives, both clinical and non-clinical stroke-related measures were collected using questionnaires derived from recognised, reliable, and validated instruments. These measures have been widely used to evaluate the effectiveness of post-stroke education intervention among stroke survivors and their family caregivers (Eames et al., 2013; Franze´n-Dahlin et al., 2008; Hoffmann et al., 2007; Lowe et al.,

2007; Rodgers et al., 1999). The measures were collected both at baseline and three months follow-ups.

**Knowledge of stroke**

The intervention provided information to stroke survivors and their family caregivers. It is recognised that, in western societies, providing stroke information improves the understanding of stroke, giving stroke survivors some control in self-management (Stroke Foundation, 2015). Thus, the baseline assessment of stroke knowledge was essential to evaluate existing knowledge in stroke survivors.

There are several questionnaires developed to assess stroke knowledge. Hou et al. (2017) review found 59 stroke knowledge tests. Of the 59, only one Knowledge of Stroke Questionnaire (KSQ) was validated and was selected for this study. This KSQ (Appendix 10) was developed by Hoffmann et al. (2007) and was found reliable in Eames et al. (2013) study. The KSQ had a good test-retest reliability and was used in other post-stroke education intervention studies (Eames et al., 2013; Hoffmann et al., 2007).

The KSQ was chosen because it was easy to administer and understand. Completing the KSQ takes about 5 minutes, and it can be self-administered by stroke survivors and caregivers who can read and write (Hoffmann, 2007). The questionnaire was read and verbally translated into Twi for participants who could not read or understand English. The list of questions was consistent with the content of the stroke information booklet used for the intervention and captured questions that assessed the stroke survivor's general knowledge of stroke. Moreover, the questions were easy to understand, as there was no medical jargon.

The KSQ consists of 25 questions with responses in a format that is true/false/do not know. The questions focused on what is a stroke, risk factors for stroke, and the signs and symptoms after stroke. Participants were required to tick the responses that best answered the questions above. Each correct response was scored one (1), and an incorrect response was scored zero (0). A total of 13 and more correct responses indicated an average to very good knowledge of stroke. On the other hand, a total score of less than 13 indicated poor knowledge of stroke.

**Anxiety and depression**

This study was designed to assess the feasibility of conducting a trial to evaluate the impact of a post-stroke education intervention. Consequently, the presence of anxiety and depression among stroke survivors and their family caregivers was considered as an important measure for assessing the impact of post-stroke education.

Many screening instruments are used to measure the presence of anxiety and/or depression. These instruments are broadly classified as self-rated and clinician-rated scales. Generally, the self-rated scales are preferred to the clinician-rated scales as they are inexpensive and easy to complete by non-clinicians (Cusin et al., 2010; Zimmerman et al., 2008). The researcher examined three widely used screening instruments for their suitability in terms of timing and convenience to administer. These included the Hamilton Rating Scale for Depression (Ham-D), Beck Depression Inventory (BDI) and the Hospital Anxiety and Depression Scale (HADS) (Hamilton, 1960; Beck et al., 1961; Zigmond and Snaith, 1983).

- **Hamilton Rating Scale for Depression (Ham-D)**

The Ham-D is one of the earliest scales designed to measure the performance of antidepressants in depressed patients (Hamilton, 1960). It is a clinician-rated scale and is considered the 'gold standard' for measuring the severity of depression among psychiatric patients for over 40 years (Williams, 2001). However, a review found that the overall internal reliability of the scale was adequate, but many of the items were poor contributors to measuring the severity of depression (Bagby et al., 2004). Another limitation was that Ham-D had few item responses for anxiety, making it difficult to measure anxiety accurately (Cusin et al., 2010). This means another scale, the Hamilton Anxiety Rating Scale (Ham-A) was needed to screen for anxiety (Hamilton, 1956). However, Ham-A was criticised for its apparent inaccuracy in discriminating between anxiety and depression (Maier et al., 1988). It also takes 27 – 35 minutes to complete the Ham-D and Ham-A scales (Sharp, 2015; Thompson, 2015). The lengthy time and the need for an experienced and trained interviewer limited the use of these scales in non-psychiatric patients (Sharp, 2015). Given the limited time for this study, it was practically impossible to engage participants for such a long time

to assess only anxiety and depression while waiting to assess other measures. Therefore, Ham-D was discounted due to practical reasons.

- ***Beck Depression Inventory (BDI)***

The BDI was developed in the 1960s to assess the severity of depression in psychiatric patients (Beck et al., 1961), and was subsequently revised to measure depression in non-psychiatric patients (Steer et al., 1986). It is a self-rated scale which contains a 21-item questionnaire that assesses symptoms and attitudes often exhibited by depressed patients and rarely shown by non-depressed psychiatric patients (Beck et al., 1986). The BDI questionnaire takes about 5-10 minutes (Lerdal et al., 2014). The BDI was criticised for being lengthy and required a great demand for individuals, especially those with depression, to complete (Sauer et al., 2013). Another limitation is that it is only used to assess post-stroke depression, and so another scale for measuring anxiety was needed. Although the Beck Anxiety Inventory (BAI) scale could be used, the suitability of the instrument in discriminating between anxiety and depression was problematic (Muntingh et al., 2011). Therefore, considering the time and the need to use two separate scales to measure anxiety and depression, the Hospital Anxiety and Depression Scale was chosen over the BDI and Ham-D for this study.

## The Hospital Anxiety and Depression Scale (HADS)

The HADS was used to screen stroke survivors and their family caregivers for the presence of anxiety and depression in this study. It is widely used for measuring anxiety and depressive symptoms in non-psychiatric patients (Brennan et al., 2010; Tyrer and Methuen, 2006). An advantage of the HADS over other scales is that it evaluates both anxiety and depression with a quick and straightforward questionnaire (Hansson et al., 2009).

The HADS (Appendix 11) is a 14-item self-reporting scale that was first used and validated among outpatients during formal psychiatric interviews (Zigmond and Snaith, 1983). It has two separate subscales for anxiety and depression that has seven questions each. Each question has four responses ranging from 0-3. Although the anxiety and depression questions are interspersed within the questionnaire, these

elements must be scored separately. In total, each subscale produces scores that range from 0 to 21. For quantification, cut-off scores are available; scores less than 8 indicate no case of anxiety and/or depression, 8 -10 indicate mild case, 11 – 14 moderate and 15-21 severe (Stern, 2014; Vuletić et al., 2012). Generally, higher or lower scores indicate greater or lower degrees of anxiety and depression, respectively (Brennan et al., 2010). For this study, a case of anxiety and depression scored 11 or more.

The HADS is a reliable and valid instrument use in both research and clinical practice (Crawford et al., 2001). It is widely used in general medical settings, including stroke units and rehabilitation centres (Stern, 2014; Bailey, 2008; Sanne et al., 2003). The internal consistency, as indicated by Spearman's correlation, of HAD's anxiety subscale items has been reported as ranging from 0.76 to 0.41 ($p<0.01$ for all items) and for the depression subscale, 0.60 to 0.30 (all lower than $p<0.02$) (Zigmond and Snaith, 1983). The questionnaire is validated in many languages, countries and settings, including general practice and community settings in Africa (Bocéréan and Dupret, 2014; Bjelland et al., 2002; Abiodun, 1994). In sub-Saharan Africa, it is found reliable with high sensitivity and specificity among HIV/AIDS patients in Nigeria, with population characteristics like Ghana (Sale et al., 2014). The HADS instrument was previously used in post-stroke education intervention studies to detect anxiety and depressive states in patients and their caregivers (Eames et al., 2013; Hoffmann et al., 2007; Aben et al., 2002). Compared with the Ham-D and the BDI, the HADS is simple and easy to use to complete (Stern, 2014). Completing the HADS takes about 2-5 minutes. The HADS was selected for this study considering the brevity, simplicity, and presumed ability to measure anxiety and depression within 5 minutes.

#### 3.5.5.4 Family caregiver characteristics

The family caregiver characteristics were collected using the family caregiver information questionnaire (Appendix 12). This questionnaire contained a list of questions on the caregiver's details and socio-demographic information that include the date of interview, participant's identification number, name, address, gender, date of birth, marital status, caregiver's relationship with the patient, education level, religion, occupation, living situation and whether the caregiver has received a written

information on stroke or not. The caregiver's identification number was the same as the stroke survivor's number. This information was gathered through a face-to-face interview and a self-completed questionnaire (Table 3.2). This information was collected to identify those who have participated in the study and the possible recruitment procedures to follow for a definitive study.

### Table 3.2: Content of family caregiver baseline assessments

| Area of assessment | Questionnaire | Method of collection |
|---|---|---|
| **Caregiver characteristics** | Background information | Face-to-face interview or self-report |
| **Knowledge of stroke** | 25-item Knowledge of Stroke Questionnaire (KSQ) | Self-reported |
| **Anxiety and Depression** | Hospital Anxiety and Depression Scale (HADS) | Self-reported |
| **Caregiver burden** | Modified Caregiver Strain Index (MCSI) | Self-reported |

### 3.5.5.5 Family caregiver's baseline measures

As identified in the systematic review, the family caregiver's baseline measures were knowledge of stroke, anxiety and depression, and caregiver burden. Apart from the caregiver burden, the other baseline measures are presented in section 3.5.5.4.

### Caregiver burden

Several caregiver burden screening instruments were used to measure the impact of caring for stroke survivors. A review by Rigby et al. (2009) included nine screening instruments to measure caregiver burden, and four were widely used. These are the Caregiver Strain Index (CSI), Relatives Stress Scale (RSS), Caregiver Burden Scale, and Sense of Competence Questionnaire. The CSI was more widely used and recommended for clinical practice and research since it is more practicable for assessing caregiver burden in stroke than the other lengthy and more complicated instruments. Additionally, the CSI was commonly used in cross-sectional surveys and intervention trials to measure caregiver strain (Donnelly et al., 2004; Ferrell et al., 1995; Wade et al., 2003). Lately, the CSI was modified to make it more adaptable and easier for users.

The Modified Caregiver Strain Index (MCSI) was used in the current study to assess family caregivers' burden (Appendix 13). The MCSI is a self-reporting instrument that was developed as a modification of the Caregiver Strain Index (CSI) in 2003 (Sullivan, 2008). The MCSI consists of 13 statements requiring caregivers' responses to assist people with chronic disabilities in the following aspects: financial, physical, psychological, social, and personal (Onega, 2018). The response to each of the 13 statements is numerically scored as; yes, regularly = 2; yes, sometimes = 1; and no = 0 (Thornton and Travis, 2003). The caregiver ticks the column best describing his/her situation. The scores in each column are tallied and multiplied by the corresponding value (2, 1, or 0) to obtain a subtotal score for that column. A total score is obtained by adding the subtotal scores of each column. The total score ranges from 0 to 26, 0 indicating no caregiver strain and 26 indicating extreme strain (Sullivan, 2008; Onega, 2018). Higher total scores, therefore, indicate greater caregiver burden and vice versa.

The MCSI was selected over CSI as it is more reliable. The CSI has a strong internal consistency (Cronbach's α=0.86), clinical validity, and a significant correlation with other caregiver burden scales (van Exel et al., 2004; Robinson, 1983). However, the MCSI has an internal reliability coefficient that is slightly higher (=.90) than the coefficient originally reported for the CSI in 1983 (=.86). Two-week retest data for one-third of the caregiving sample (n=53) was assessed, and this resulted in a test-retest reliability coefficient of 0.88 (Thornton and Travis, 2003).

Other reasons for choosing the MCSI were that it is a useful instrument for detecting strain in family caregivers and is easy to administer. It is also convenient, brief, self-administered, and easy to score (Thornton and Travis, 2003). The strength of the MCSI is that it clarifies and updates many of the items on the CSI. However, the MCSI is limited by the lack of a corresponding subjective rating of caregiving impact. Furthermore, the MCSI has no breakdown of scores regarding low, moderate, or high caregiver strain, so professional judgment is needed to evaluate the total score of the level of caregiver strain (Onega, 2018).

### 3.5.6 Randomisation and blinding

To ensure that the baseline characteristics were evenly distributed among the two groups, participants were randomised to one of two arms of the trial, post-stroke education intervention plus usual care (intervention group) or usual care only (control group) after baseline assessments. The random allocation sequence was computer-generated using a Stata programme by an independent statistician from the Kintampo Health Research Centre (KHRC) computer centre. To achieve equal distribution of participants to the two groups, consecutive numbers were first assigned to prospective participants and ranked from the smallest to the largest numbers. These ranked numbers were divided into two halves before they were randomly assigned to either usual or intervention groups using a Stata command. This was to ensure an equal chance of selecting a participant into the two groups.

The allocation sequence was known only to the statistician and was concealed from the researcher. Upon recruiting a participant, a telephone call or text message was sent to the statistician for a random group allocation that was assigned to the participant (stroke survivor/caregiver dyad) immediately after baseline assessment. Neither the researcher nor anyone involved in participant recruitment or outcome assessment had access to the randomisation list. This was done to minimise selection and allocation bias.

The trial was single-blind as it was impossible to blind stroke survivors and family caregivers in the intervention and usual care groups. The two nurses assisted in providing the intervention for the researcher. However, the outcome assessor was blinded. Additionally, healthcare workers who provided usual care were blind to the assigned groups. Participants were advised not to disclose their group to the staff after allocation. In order to minimise contamination between the two treatment groups of the trial, the booklet for the intervention was put in the participant's handbag or envelope to hide it from staff and other participants. The participants were also advised not to share the booklet and any information discussed during the face-to-face encounter with other participants or staff to prevent contamination.

### 3.5.6.1 Usual care

Stroke survivors admitted to the KATH stroke unit received medical and nursing care until they were discharged home. However, the stroke unit did not have skilled stroke specialists or specialist equipment, and there were no established stroke pathways or clinical guidelines for usual stroke care. There were also difficulties accessing Computerised Tomography (CT) scans to confirm stroke diagnosis due to the cost or non-functioning of the only scanner in the hospital (Batiemaa et al., 2017). In circumstances where the acute ischaemic stroke was established, no thrombolysis treatment was available. Nevertheless, provisional stroke diagnoses were made based on the presenting symptoms and sometimes confirmed with a CT brain scan. Depending on the stroke severity, the physiotherapists or the assistants carried out bedside therapy, or patients were referred to the physiotherapy unit. There was no organised in-patient rehabilitation ward as part of the stroke unit.

Providing post-stroke information was limited and was delivered by nurses, physiotherapists, and other healthcare personnel in a responsive and ad-hoc manner rather than proactively and systematically. Contrary to developed countries, no stroke information leaflets were displayed anywhere in the unit, and written information materials were not provided. It was unusual for any stroke information to be shared with stroke survivors and caregivers on admission.

After discharge home, stroke survivors were scheduled for medical review visits at the stroke review clinic to monitor and prevent stroke by managing risk factors such as hypertension and diabetes (Sarfo et al., 2016). At the clinic, a nurse took the vital signs, including the blood pressure and blood sugar levels before the physician saw the individual. Similarly, there were no stroke information leaflets displayed anywhere in the clinic and stroke information was not routinely shared with stroke survivors and their caregivers.

### 3.5.6.2 Intervention

Following randomisation, participants assigned to the intervention group received the usual care plus the post-stroke education intervention. The intervention was delivered either by the researcher or one of the two nurses trained for this purpose. The

intervention consisted of a stroke information booklet (see Appendix 14) and a face-to-face verbal discussion session with stroke survivors and their family caregivers at the outpatient department or the stroke unit. The content of the booklet was discussed for approximately 20 - 25 minutes. The booklet was read aloud and verbally translated into Twi for those who could not read or understand English. Participants were encouraged to ask questions and to read or be assisted to read the booklet after they were given the booklet to take home.

Since the provision of the stroke information was meant to empower adult participants to take control of their situation, the intervention was underpinned and guided by the principles of adult learning theory (Knowles, 1990; Knowles et al., 2005). The adult learning theory is described as a collection and utilisation of several concepts and theories through which adults acquire knowledge and skills (Rogers and Horrocks, 2010). These principles include the consideration of a person's: need to know, self-concept, prior experiences, readiness to learn, orientation to learning and motivation to learn (Knowles et al., 2005). The adult learning principles consider how adults are engaged and motivated to learn to bring about a long-term change in attitude, knowledge, and behaviour (Smith, 2002). Adult education has been recognised as the desirable process by which adults acquire knowledge and skills bringing about change in attitude and behaviour (Knowles et al., 2005).

Adult learning theory uses approaches to learning that are collaborative and problem-based. The theory emphasises equality between teachers and students (Dunn, 2002, Zoller and Harrison, 2007). The booklet's design and intervention's structure, content and mode of delivery enhanced proper discussion between the educator (the researcher or trained nurses) and the participants (stroke survivor and family caregiver). The structure of the intervention allowed the active participation of the patients and their caregivers in the discussion. Participants were allowed freely to ask questions for clarification and make contributions based on their previous knowledge and experience. This approach facilitates knowledge acquisition and retention as the participants actively participate in the discussion (Forster et al., 2012). Based on this theory, the post-stroke education intervention is intended to improve the knowledge of stroke survivors and family caregivers about stroke and its management. This, in turn, will help reduce anxiety, depression, and family caregiver burden.

A follow-up telephone call was placed separately to stroke survivors and caregivers two weeks after the intervention. This was to encourage them to read the booklet or give it out to someone to read for them and ask whether they had any further questions. The telephone call was also intended to find out how they were recovering and answer any new questions. Those who had not read the booklet at the time of the call were encouraged to do so. They were asked to give a call to the researcher whose number was on the booklet if they had any further questions. The usual care and post-stroke education interventions are summarised in Table 3.3.

## Table 3.3: The features of usual care and post-stroke education intervention

| Element | Usual care | Post-stroke education |
|---|---|---|
| **General description** | Unstructured verbal information may have been given | Booklet-based advice, explanation, and discussion |
| **Key content** | Not determined. Done in an ad-hoc manner | What is stroke and its causes<br>How to live a healthy life after stroke and how family caregivers can support stroke survivors |
| **Use of written materials** | None | The stroke information booklet was written with simple texts and diagrams handy for quick reference |
| **Mode of delivery** | Different nursing staff and allied health professionals | Nurses trained to use the information booklet |

### Development of the stroke information booklet

Like other complex interventions, developing a written information booklet for post-stroke education, should be guided by evidence. The UK MRC provides a framework that comprehensively guides the development and evaluation of complex interventions in healthcare (Craig et al., 2008; Skivington et al., 2021). Complex interventions comprise multiple components and may act independently or interdependently (Bennett and Closs, 2011; Campbell et al., 2000). The MRC framework advocates that

important steps such as finding evidence to inform the design of the intervention should constitute the initial stage of the development of the intervention. This study used the MRC framework to develop the intervention (stroke information booklet).

The booklet contained information about stroke and its management for people living with stroke. This was based on the finding of the review, previous research on the informational needs of stroke patients and family caregivers and delivering post-stroke education as well as feedback from stakeholders, including patients and the public, to make the content context-appropriate (Eames et al., 2013; Hafsteinsdóttir et al., 2011; Hoffmann et al., 2007). After consultation with patients and the public, the content was refined to focus on the definition of stroke, causes of stroke, risk factors for stroke, problems experienced after stroke, recovery after stroke, what to do at home and what family caregivers can do to support people living with stroke.

The Health Belief Model underpin the intervention's development (Sharma and Romas, 2008). This model has been applied to investigate beliefs on risk-related behavioural change among stroke patients (Sullivan et al., 2009). The model assumes that to achieve behaviour change, a person must believe that he or she is at risk of a particular illness (perceived susceptibility); that the consequence of that illness is serious (perceived severity); that making the behaviour change can produce a positive outcome (perceived benefit) and that the perceived benefit of behaviour change outweighs any perceived barriers to behaviour change (Sharma and Romas, 2008). Another component of the model is the person's self-efficacy (confidence in their ability) to perform a behaviour (Sharma and Romas, 2008).

Based on The Health Belief Model, when providing information about stroke, there is the need to describe risk factors such as hypertension, diabetes, obesity, high cholesterol, heart diseases, excessive alcohol consumption and smoking. The post-stroke information described these risk factors, and participants were made aware that these conditions or situations make one susceptible to stroke. Once a stroke occurs, the individual experiences both physical and psychological problems which are the consequences stroke. To prevent a second stroke, participants were made aware that they needed to adapt behaviour certain lifestyles, such as eating a healthy diet to lose weight, taking regular medications to control hypertension and diabetes or any

underlying cause, reducing alcohol consumption and smoking. Giving participants practical advice on addressing these risk factors and reassuring them will enhance their confidence to perform certain healthy activities to help prevent stroke.

**Patient and Public Involvement (PPI)**

To develop a context-appropriate information booklet, stakeholders, including patients and the public, were consulted during the development phase of the booklet. The initial draft of the booklet was given to two postgraduate students and two stroke nurses in Nottingham to review and comment on the booklet's content, readability, understandability, components, and design. They were asked to give feedback within a week. After considering their comments, the drafted booklet was given to two nursing lecturers, doctors (2) and nurses (2) at the stroke unit, all in Ghana, to read and focus on the content, readability, understandability, and design. They were also asked to complete this in one week. The drafted booklet was finally given to two stroke survivors and their family caregivers in Ghana to read at home. They were asked to comment on the booklet's readability, content, understandability, and design. They had one week to read and discuss with family members and, after that, give feedback to the researcher. The feedback was provided to the researcher through a face-to-face discussion, email, and telephone calls.

The postgraduate students and stroke nurses in Nottingham reported giving verbal and written feedback. Discussion about the feedback took place in a quiet setting with each of them. All healthcare workers, stroke survivors and family caregivers in Ghana gave feedback through email and telephone chats.

**Comments from PPI**

The two postgraduate students expressed satisfaction with the booklet and felt the content was appropriate. However, one suggested that the booklet's title, "About stroke" be changed to "Stroke information booklet". The two nurses working at the stroke unit in Nottingham found the booklet useful and clear. They were happy with the contents and components of the booklet as it reflected the needs of patients they had encountered.

In Ghana, the two lecturers teaching nursing found the booklet was readable and understandable and did not make any further comments. The two doctors and two nurses working at the KATH stroke unit were all happy with the booklet. However, they made several specific comments and suggestions, for example, avoiding the use of technical words such as ‘haemorrhage’, and this was replaced with the simple word ‘*bleeding’*.

Finally, the two stroke survivors and their family caregivers liked the pictures and diagrams and reported that they understood the contents. There were no specific changes which they advised needed to be made. The booklet was finalised, incorporating the suggestions of the people consulted. Generally, everyone who reviewed the final version of the booklet commented that it was readable, simple, understandable, and well-presented before it was administered to participants.

An important concept for creating written information materials to enhance their clarity is provided by Ivnik and Jett (2008). They suggested that to create written materials that were relevant to the patients, the following issues need to be considered; Who needs to be involved (collaboration), Why is the pamphlet needed (purpose), What messages need to be conveyed (content) and how will the publication look (design). After identifying the educational needs of patients in literature and interactions with some stroke survivors and their family caregivers at the stroke unit and clinic, an initial draft of the information booklet was created. The researcher then collaborated with the above people to finalise the booklet considering why the booklet was needed, the content and the design. The booklet was designed as an eight-page pamphlet composed of two A4 sheets folded into two and stapled at the middle of the spine to open easily (see Appendix 14). The education was delivered as outlined in Table 3.4.

## Table 3.4: Components of the post-stroke education intervention

| Component | Task |
|---|---|
| **Introduction** | Welcome the participants (stroke survivor and family caregiver) and make them comfortable on chairs<br>Explain the rationale of the education<br>Handover the booklet and allow time for them to read it<br>Ask them what they know about stroke and clarify any myth about stroke before you start to discuss each section of the booklet with participants |
| **What is stroke** | Define and explain what stroke is, types of stroke, causes of stroke and how stroke occurs |
| **Risk factors** | Explain common personal risk factors such as hypertension, diabetes, and obesity<br>Classify risk factors into conditions, behaviour, family history and other characteristics |
| **Problems experienced after a stroke** | Explain to participants common physical and psychological problems that may be experienced after a stroke<br>Name common complications such as weakness of arms and legs |
| **Recovery after stroke** | Explain to participants the process of recovering from a stroke<br>The need for treatment and rehabilitation to restore lost functions<br>Explain to participants activities they should do at home to promote recovery<br>Explain to caregivers' activities they should do to support stroke survivors |
| **Secondary Prevention** | Explain to participants activities to do to modify their lifestyle (Healthy living habits)<br>Control medical conditions such as hypertension and diabetes<br>Explain to participants the signs and symptoms of stroke, and when noticed, they should report to the hospital immediately |
| **Other information** | Importance of medical reviews and check-ups<br>Need for follow-up medical care post-discharge<br>Medication management, Rehabilitation<br>Allow participants to clarify any issue discussed<br>Encourage participants to re-read the booklets and send a missed call to the researcher for any clarifications<br>Inform participants of follow-up telephone calls at two weeks |
| **Conclusion** | Thank participants for their attention |

### 3.5.7 Outcome measures

The aim for this study was to determine the feasibility of conducting a definitive trial to evaluate the effectiveness of post-stroke education intervention in Ghana. The feasibility assessment was based on the measurement of recruitment, retention, data completion, stroke survivor and caregiver satisfaction and the acceptability of the intervention. The major aspects of feasibility addressed were whether the eligibility criteria were realistic; whether prospective participants were willing to be randomised; the attrition rate; the content and acceptability of the post-stroke education intervention as designed and the most suitable primary outcome measure(s) for a definitive study.

The participant's secondary outcome measures were assessed using the same assessment tools in section 3.5.5. Both stroke survivors and their family caregivers were assessed on follow-up on their knowledge of stroke using the knowledge of Stroke Questionnaire (KSQ) (Hoffmann et al., 2007), anxiety and depression using the HADS (Zigmond and Snaith, 1983). In addition, family caregivers were assessed on the caregiver burden using the Modified Caregiver Strain Index (MCSI) (Sullivan, 2007).

A follow-up was conducted to collect outcome measures three months after baseline assessments. The systematic review that informed this study had trials assessing outcome measures at one week, 12 weeks, three months, six months, and 12 months to determine whether the observed outcomes were sustained. Since this was a feasibility study, however, the follow-up was limited to three months as the main aim was to ascertain the feasibility of the research processes. In a definitive trial, a longer follow-up period would be indicated. A nurse blind to the treatment allocation of participants conducted the follow-up assessments. This was implemented during the routine medical appointments at the stroke review clinic or in the participants' homes.

Although the outcome assessor was blinded to the group allocation of participants, it was possible that during the outcome assessment, participants could have revealed directly or indirectly their group allocation. Thus, at the end of each follow-up visit, the assessor was asked to report whether there had been "un-blind" and, if not, to make the best guess as to whether the participants were in the control or intervention group.

This aspect formed part of the assessment of feasibility. If outcome assessors could identify the group allocation of the majority of participants, then a masked outcome assessment may not have been possible in a definitive RCT. A summary of the content of outcome measures is outlined in Table 3.5.

### Table 3.5: Content of patient and family caregiver outcome measures

| Participant | Area of assessment | Questionnaire | Method of collection |
|---|---|---|---|
| **Stroke survivor and family caregiver** | Knowledge of stroke | 25-item Knowledge of Stroke Questionnaire (KSQ) | Self-reported |
| **Stroke survivor and family caregiver** | Anxiety and Depression | Hospital Anxiety and Depression Scale (HADS) | Self-reported |
| **Stroke survivor and family caregiver** | Satisfaction | 10-item Likert questionnaire | Self-reported |
| **Family caregiver** | Caregiver burden | Modified Caregiver Strain Index (MCSI) | Self-reported |

## 3.5.8 Other follow-up questions

In addition to the outcome measures outlined above, the follow-up questionnaires also had questions on whether the participants in the intervention group read the booklet. Participants who did not read the booklet were asked to indicate why they did not, and if there were additional topics about stroke, they would like to receive information about. Participants were then asked if they had any questions about stroke, and those who responded 'yes' were further asked their preferred method of receiving the information.

Participants' satisfaction with the content and presentation of the written information was assessed to determine the acceptability of the intervention using a Likert scale. Likert scales are popular psychometric item scoring schemes to quantify people's opinions on different issues (Bishop and Herron, 2015). Likert scales have been criticised for eliciting response bias, which respondents display independent of the content of the questions (Dolnicar et al., 2011). However, Carifio and Perla (2007; 2008) argue that all true scales must necessarily include multiple questions on a given topic whose summative score reflects the scale or measurement and contend that a

minimum of six items is necessary to create a reliable scale that measures some construct. Therefore, participants assigned to the intervention group who read the booklet responded to a 10-point Likert scale where 1= 'not satisfied…' and 10= 'extremely satisfied' with the content and presentation of the stroke information booklet (Hoffmann et al., 2007). This Likert scale was used in previous post-stroke education interventions to examine the participants' satisfaction with the content and presentation of written information received (Eames et al., 2013). The Likert scale is simple and easy to complete and also examines how satisfied participants are with the written information received.

Participants who read the booklets were further asked to underline or tick the positive and negative features of the information booklet and explain in their own words how the information had assisted them in coping with stroke. The follow-up questions were carried out to assess the acceptability of the intervention.

### 3.5.9 Data entry and data management

Steps were taken throughout the study to minimise missing data by maintaining contact with participants during the study period. If any returned questionnaires were incomplete, the researcher contacted the participants by telephone or waited for them to come for review to collect the missing information where possible. This minimised the missing data and maximised the full completion of individual outcome measures. It is recognised that a personalised approach increases response rates (Sahlqvist et al., 2011). After completion, each questionnaire was then checked for missing responses.

All identifiable data of participants were held on secured access and excel databases on the researcher's personal computer and an assigned university computer, with both passwords protected. The identifiable data were kept separate from the outcome data. All non-identifiable data were stored in a secured SPSS (Statistical Package for the Social Sciences) file, version 24, on the University of Nottingham computer and the researcher's personal computer under a password. Hard copies of completed questionnaires were stored in locked cabinets in the postgraduate research students' office, allowing access to only the academic supervisors and the researcher. After data collection was completed, the researcher carried out data cleaning before analysis.

This involved checking that the data entered were consistent with the original questionnaire booklet and other data entered.

### 3.5.10 Data analysis

The quantitative data for each stroke survivor/family caregiver dyad were entered into a Microsoft Access spreadsheet with allocation codes kept separately and linked only by the trial ID. The data were exported to Excel and then imported to SPSS from Microsoft Excel for data cleaning before analysis. Participant characteristics, recruitment, retention and completion rates were described using descriptive statistics. Results for categorical data were presented in frequencies and percentages. The normality of continuous data was visually checked on a histogram for normal distribution or otherwise. Results of normally distributed continuous data were reported in means and standard deviations (Ghasemi and Zahediasl, 2012). The trial data were analysed using descriptive statistics with no intention to carry any statistical test because the study did not aim to draw inferences from the data. The participants' outcome data were summarised with descriptive statistics and presented as means and standard deviations.

The between-group difference was calculated by subtracting the mean score of the intervention group from the mean score of the usual care group. The intention for calculating this was to present a broad indication of the possible trends and treatment effects that could be found in a future definitive trial rather than to provide a definitive result in this feasibility trial. Thus, p-values are not presented, as the study was not designed to estimate the effect of the intervention.

### 3.5.11 Trial management

The study was managed by the researcher and his academic supervisors, who met monthly via skype or telephone calls during the data collection period. The researcher was responsible for the day-to-day administration of the study at the study site and reporting the activities of the study to the academic supervisors through emails and during monthly supervision meetings. Overall, the researcher was responsible for the recruitment and random sequence allocation of study participants, provision of post-stroke education intervention, data entry and analysis. A statistician, independent of the study, was responsible for generating and keeping the randomisation list.

# Chapter Four

# Post-stroke education in Ghana: feasibility randomised controlled trial results and discussion

## 4.1 Introduction

The previous chapter outlined the methodology of the feasibility RCT. This chapter presents the findings of this phase of the study. It describes the feasibility outcomes that include participant recruitment and characteristics, baseline measures, retention and follow-up, data collection and completion, participant randomisation, delivery of the intervention and its acceptability. The participant outcome measures data are then presented. This is followed by a discussion of the feasibility results highlighting aspects of the study that worked well and those that were problematic.

## 4.2 Participant recruitment

The first objective of the feasibility trial was to determine the potential for recruitment and retention of stroke survivors and their family caregivers. As a result, the recruitment for the trial started with screening for eligibility to enlist 50 stroke survivor/family caregiver dyads (i.e.,100 individuals). Recruitment commenced on 21 November 2017 at the stroke review clinic and continued every Tuesday of each week until 30 March 2018, when the last dyad was recruited. Within the same period, there was ongoing recruitment at the stroke unit.

### Recruitment at the stroke review clinic

Figure 4.1 shows the consort diagram of the overall recruitment figures and the flowchart of participants through the trial. At the stroke review clinic, 120 stroke survivors and their family caregivers were assessed for eligibility. Of the 120, 72 (60%) were excluded for not meeting the inclusion criteria or declined participation. The main reason for exclusion was family caregivers not accompanying stroke survivors to the clinic (n= 20). Other reasons were that stroke survivors were not able to understand and communicate in English or Twi (n=10); the accompanying family caregiver was below 18 years (n= 9); stroke survivors were not available for follow-up (n=11), and the accompanying relative not living with the stroke survivor (n=10). Twelve stroke survivors and their family caregivers declined participation. Due to ethical considerations, asking for reasons for declining was not possible. However, reasons volunteered included not wanting to invest time in the trial and feeling fatigued due to prolonged waiting time at the clinic. Therefore, 48 (40%) dyads (a total of 96 participants) were recruited from the stroke clinic for the trial.

## Recruitment at the stroke unit

During the recruitment period, 70 stroke survivors were admitted to the stroke unit and assessed with their family caregivers for eligibility to participate in the trial. Of the 70, 20 (29%) did not survive. Of the remaining 50, only two dyads were recruited, and 48 were excluded. The principal reason for exclusion was difficulty in communication (n=23). This was either due to a nasogastric tube in situ (n=15) or stroke impairment (n=8). Other reasons for exclusion were that ten stroke survivors indicated their unavailability for follow-up. Four stroke survivors were not available for recruitment as they were transferred out of the stroke unit to the general medical wards. The attending physicians judged eight stroke survivors as medically unstable to participate in the trial, while three stroke survivors had no identifiable family caregiver. Recruitment from the stroke unit was generally slow due to a slow turnover of patients in the unit. This was a result of a combination of limited bed space (6 beds) and prolonged patients' hospitalisation (approximately 6–8 weeks). For these reasons, most recruitments were carried out at the stroke review clinic.

Overall, 190 stroke survivors and their family caregivers were assessed for eligibility at the stroke review clinic (n=120) and stroke unit (n=70). Recruitment ended when the target of 50 dyads (a total of 100 individuals) was reached. At the stroke review clinic, 48 dyads were recruited, and two were recruited from the stroke unit. All 50 dyads who met the inclusion criteria provided written consent before enrolling in the trial.

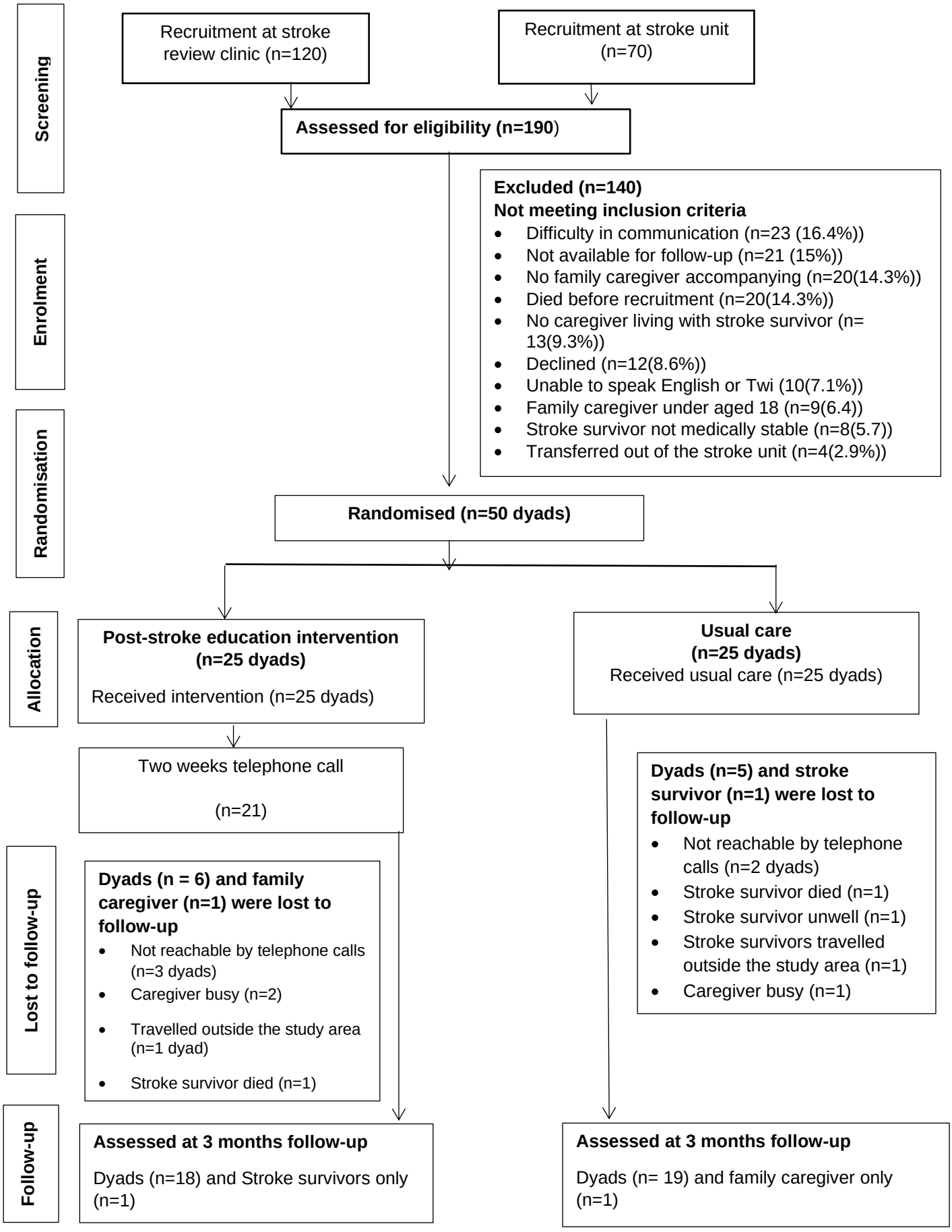



**Figure 4.1 Consort diagram of the progress through the trial**

## 4.3 Participants' characteristics and baseline measures

Baseline data were collected from all 50 dyads before they were randomly assigned to a group (25 dyads each to the post-stroke education intervention group and the usual care (control) group. The baseline data collected were the stroke survivors' and family caregivers' sociodemographic characteristics and baseline measures, as well as the clinical characteristics of stroke survivors.

### 4.3.1 Stroke survivors' baseline assessment

#### 4.3.1.1 Stroke survivors' characteristics

Table 4.1 provides a summary comparison of the two groups of stroke survivors' sociodemographic and clinical characteristics.

At baseline, the mean age of stroke survivors in the two groups was similar (57.48 years in the post-stroke education intervention group and 58.44 for the usual care group), with slightly more men (27/50) in the trial than women (23/50). For educational status, more stroke survivors were formally educated at the secondary and tertiary levels in the usual care group (17/25) compared to the intervention group (13/25). All stroke survivors lived with a family member(s). However, there were more stroke survivors (6/25) who lived with their nuclear family (spouse and children only) in the intervention group compared to those who lived with the extended family (19/25) in the usual care group. Overall, more stroke survivors were diagnosed with ischaemic stroke (n=39/50) than haemorrhagic stroke (n=11/50) enrolled in the trial. However, more ischaemic stroke survivors were allocated to the intervention (n= 21/25) as there was more haemorrhagic stroke (7/25) in the usual care group. There was no difference in the prevalence of previous strokes in both groups: the current stroke was the first for most stroke survivors (45/50) in the trial. However, at the time of enrolment, more individuals had a stroke in the past 12 months in the intervention group (15/25) compared to the usual care group (10/25).

Both groups were similar at baseline in terms of occupation and co-morbidities. However, there were more stroke survivors (24/50) with hypertension compared with other co-morbidities. Also, both groups were similar in terms of whether they had

previously received written stroke information at the hospital, with most (46/50) indicating they had not previously received written information after a stroke.

In summary, both groups had broadly similar sociodemographic and clinical characteristics regarding age, gender, marital status, religion, occupation, living situation, co-morbidities and whether they had previously received written stroke information. However, there were some differences in length of time since stroke, type of stroke diagnosed and level of formal education. Stroke survivors in the intervention group were more likely to be diagnosed with stroke for 12 months or less at the time of recruitment than those in the usual care group. In addition, stroke survivors in the intervention group were more likely to be diagnosed with ischaemic stroke compared to haemorrhagic stroke than in the usual care group. Stroke survivors in the usual care group were more likely to be educated at the secondary or tertiary levels than those in the post-stroke education intervention group.

## Table 4.1: Sociodemographic and clinical characteristics of stroke survivors (N=50)

| Variables | Post-Stroke education (N=25) | Usual care (N=25) | Total (N=50) |
|---|---|---|---|
| **Age in years** | | | |
| **Mean (SD)** | 57.48 (12.0) | 58.44 (11.58) | |
| **Gender** | | | |
| **Male** | 14 (56.0%) | 13 (52.0%) | 27 (54.0%) |
| **Female** | 11 (44.0%) | 12 (48.0%) | 23 (46.0%) |
| **Marital status** | | | |
| **Single** | 0 (0.0%) | 1 (4.0%) | 1 (2.0%) |
| **Married** | 18 (72%) | 20 (80%) | 38 (76.0%) |
| **Divorced/separated** | 1 (4.0%) | 1 (4.0%) | 2 (4.0%) |
| **Widowed/widower** | 6 (24.0%) | 3 (12.0%) | 9 (18.0%) |
| **Religion** | | | |
| **Christian** | 24 (96.0%) | 23 (92.0%) | 47 (94.0%) |
| **Islam** | 1 (4.0%) | 2 (8.0%) | 3 (6.0%) |
| **Education** | | | |
| **No formal education** | 1 (4.0%) | 2 (8.0%) | 3 (6.0%) |
| **Basic Education** | 11 (44.0%) | 6 (24.0%) | 17 (34.0%) |
| **Secondary/Tertiary** | 13 (52.0%) | 17 (68.0%) | 30 (60.0%) |
| **Employment status** | | | |
| **Employed** | 17 (68.0%) | 19 (76.0%) | 36 (72%) |
| **Unemployed** | 0 (0.0%) | 1 (4.0%) | 1 (2.0%) |
| **Retired** | 5 (20.0%) | 5 (20.0%) | 10 (20.0%) |
| **Others** | 3 (12.0%) | 0 (0.0%) | 3 (6.0%) |
| **Living with** | | | |
| **Spouse only** | 6 (24.0%) | 3 (12.0%) | 9 (18.0%) |
| **Spouse and children** | 6 (24.0%) | 3 (12.0%) | 9 (18.0%) |
| **Family/relative** | 13 (52.0%) | 19 (76.0%) | 32 (64.0%) |
| **Type of stroke** | | | |
| **Ischaemic** | 21 (84.0%) | 18 (72.0%) | 39 (78.0%) |
| **Haemorrhagic** | 4 (16.0%) | 7 (28.0%) | 11 (22.0%) |
| **Stroke duration in months** | | | |
| **0 - < 6** | 10 (40.0%) | 7 (28.0%) | 17 (34.0%) |
| **6 –< 12** | 5 (20.0%) | 3 (12.0%) | 8 (16.0%) |
| **12 –< 18** | 0 (0.0%) | 3 (12.0%) | 3 (6.0%) |
| **18 –< 24** | 0 (0.0%) | 3 (12.0%) | 3 (6.0%) |
| **More than 24** | 10 (40.0%) | 9 (36.0%) | 19 (38.0%) |
| **Previous stroke** | | | |
| **Yes** | 2 (8.0%) | 3 (12.0%) | 5 (10.0%) |
| **No** | 23 (92.0%) | 22 (88.0%) | 45 (90.0%) |
| **Co-morbidities** | | | |
| **None** | 6 (24.0%) | 4 (16.0%) | 10 (20.0%) |
| **Hypertension only** | 11 (44.0%) | 13 (52.0%) | 24 (48.0%) |
| **Hypertension/Diabetes** | 7 (28.0%) | 7 (28.0%) | 14 (28.0%) |
| **Other** | 1 (4.0%) | 1 (4.0%) | 2 (4.0%) |
| **Previously received written stroke information at the hospital** | | | |
| **Yes** | 2 (8.0%) | 2 (8.0%) | 4 (8.0%) |
| **No** | 23 (92.0%) | 23 (92.0%) | 46 (92.0%) |

### 4.3.1.2 Baseline measures for stroke survivors

Table 4.2 below shows the comparison of the measures that were assessed at baseline for the 50 stroke survivors.

For the knowledge of stroke measures, higher scores indicate better stroke knowledge. In contrast, for the Hospital Anxiety and Depression Scale (HADS), higher scores indicate worse levels of anxiety and depression, with cases at ≥11 (Hoffmann et al., 2007; Stern, 2014). The data for the knowledge of stroke and HADS measures were plotted on a histogram and visually checked for normal distribution (Kirkwood and Sterne, 2003; Ghasemi and Zahedias, 2012). Although the sample was small, there were no outliers that affected the normal distribution of the data; therefore, the measures were presented using means and standard deviations, which were appropriate for normally distributed data (Field, 2013).

The baseline measure for knowledge of stroke was similar for stroke survivors in both groups. At baseline, stroke survivors in both groups had similar mean scores for the HADS (7 or less), which was within the normal range (Stern, 2014). This indicated that anxiety and depression were not an issue for stroke survivors.

**Table 4.2: Baseline measures of stroke survivors (N=50)**

| Measure | Post-Stroke education (N=25) | Usual care (N=25) |
|---|---|---|
| **Knowledge of stroke (0-25)**** | | |
| **Mean (SD)** | 15.16 (3.09) | 14.56 (3.78) |
| **Hospital Anxiety and Depression Scale (HADS) Mean (SD)** | | |
| **HADS anxiety subscale* (0-21)** | 5.20 (4.08) | 5.48 (4.34) |
| **HADS depression subscale* (0-21)** | 6.64 (3.64) | 7.44 (3.48) |

***higher scores indicate better knowledge of stroke*

**higher scores indicate worse levels of anxiety and depression*

*(SD) – Standard Deviation*

## 4.3.2 Family caregivers' baseline assessment

### 4.3.2.1 Family caregivers' sociodemographic characteristics

Table 4.3 shows the comparison of family caregivers' sociodemographic characteristics.

At baseline, the mean age of family caregivers was higher in the intervention group compared to the usual care group (47.8 years in the intervention group and 41.9 years in the usual care group). Overall, family caregivers were younger compared to stroke survivors. More males were family caregivers in the intervention group (12/25) compared to the usual care group (8/25). In contrast, more females were caregivers in the usual care group (17/25) than in the intervention group (13/25). Family caregivers in the intervention group (22/25) were more likely to be employed compared to the usual care group (19/25). More family caregivers (12/25) were caring for their spouses in the intervention group compared to the usual care group (6/25), while more caregivers (13/25) were caring for their parents in the usual care group compared to the intervention group (8/25). At the time of enrolment, more caregivers in the intervention group (15/25) had cared for their relative stroke survivor for the past 12 months than in the usual care group (10/25).

There was no difference in both groups in terms of marital status, religion, education, and whether caregivers had previously received written stroke information at the hospital. Overall, most caregivers (45/50) indicated that they had not previously received written stroke information at the hospital since their relative had a stroke.

## Table 4.3: Sociodemographic characteristics of family caregivers (N=50)

| Variables | Post-Stroke education (N=25) | Usual care (N=25) | Total (N=50) |
|---|---|---|---|
| **Mean (SD) age in years** | 47.8 (12.69) | 41.9 (13.48) | |
| **Gender** | | | |
| **Male** | 12 (48%) | 8 (32%) | 20 (40%) |
| **Female** | 13 (52%) | 17 (68%) | 30 (60%) |
| **Marital status** | | | |
| **Single** | 6 (24.0%) | 6 (24.0) | 12 (24.0%) |
| **Married** | 18 (72%) | 18 (72.0%) | 36 (72.0%) |
| **Divorced/separated** | 0 (0.0%) | 1 (4.0%) | 1 (2.0%) |
| **Widowed/widower** | 1 (4.0%) | 0 (0.0%) | 1 (2.0%) |
| **Religion** | | | |
| **Christian** | 23 (92.0%) | 23 (92.0%) | 46 (92.0%) |
| **Islam** | 2 (8.0%) | 2 (8.0%) | 4 (8.0%) |
| **Education** | | | |
| **No formal education** | 2 (8.0%) | 3 (12.0%) | 5 (10.0%) |
| **Basic Education** | 7 (28.0%) | 4 (16.0%) | 11 (22.0%) |
| **Secondary/Tertiary** | 16 (64.0%) | 18 (72.0%) | 34 (68.0%) |
| **Occupation** | | | |
| **Employed** | 22 (88.0% | 19 (76.0%) | 41 (82.0%) |
| **Unemployed** | 1 (4.0%) | 1 (4.0%) | 2 (4.0%) |
| **Retired** | 2 (8.0%) | 0 (0.0%) | 2 (4.0%) |
| **Others** | 0 (0.0%) | 5 (20.0%) | 5 (10.0%) |
| **Caregiver relationship with the patient** | | | |
| **Spouse** | 12 (48.0%) | 6 (24.0%) | 18 (36.0%) |
| **Parent** | 8 (32.0%) | 13 (52.0%) | 21 (42.0%) |
| **Child** | 2 (8.0%) | 0 (0.0%) | 2 (4.0%) |
| **Sibling** | 3 (12.0%) | 6 (24.0%) | 9 (18.0%) |
| **Duration of caregiving in Months** | | | |
| **0 - < 6** | 10 (40.0%) | 7 (28.0%) | 17 (34.0%) |
| **6 –< 12** | 5 (20.0%) | 3 (12.0%) | 8 (16.0%) |
| **12 –< 18** | 0 (0.0%) | 3 (12.0%) | 3 (6.0%) |
| **18 –< 24** | 0 (0.0%) | 3 (12.0%) | 3 (6.0%) |
| **More than 24** | 10 (40.0%) | 9 (36.0%) | 19 (38.0%) |
| **Previously received written stroke information at the hospital** | | | |
| **Yes** | 2 (8.0%) | 3 (12.0%) | 5 (10.0%) |
| **No** | 23 (92.0%) | 22 (88.0%) | 45 (90.0%) |

### 4.3.2.2 Baseline measures for family caregivers

Table 4.4 compares the family caregivers' baseline measures in the two groups.

The baseline measures for the family caregivers were similar in both groups except for the depression subscale score, which was slightly higher in the intervention group (mean = 6.80) compared to the usual care group (mean= 4.84). Overall, the HADS mean scores for both groups were within the normal levels for anxiety and depression (Stern, 2014). The data were normally distributed; thus, the measures were presented in means and standard deviations. For the caregiver burden, higher scores indicate higher demand for care, which means a high burden of care for the caregiver. The mean score for the caregiver burden was similar in both groups and was within moderate levels of the burden of care for the stroke survivor (Onega, 2018).

**Table 4.4: Family caregivers' baseline measures (N=50)**

| Measure | Post-Stroke education (N=25) | Usual care (N=25) |
|---|---|---|
| **Knowledge of stroke (0 - 25)**** | | |
| **Mean (SD)** | 16.12(3.18) | 16.76 (3.05) |
| **Hospital Anxiety and Depression Scale (HADS) Mean (SD)** | | |
| **HADS Anxiety subscale* (0-21)** | 8.08 (5.61) | 7.92(5.42) |
| **HADS Depression subscale* (0-21)** | 6.80 (5.24) | 4.84 (4.64) |
| **Caregiver burden (0 - 13)[a]** | | |
| **Mean (SD)** | 14.04 (5.81) | 14.12 (5.02) |

***Higher scores indicate better knowledge of stroke*

**Higher scores indicate worse levels of anxiety and depression*

[a]*Higher scores indicate higher demand for care*

*(SD) – Standard Deviation*

## 4.4 Feasibility outcomes

### 4.4.1 Retention and follow-up

Stroke survivors and their family caregivers were followed-up at three months after baseline assessment from 20 February to 28 June 2018. As indicated in Figure 4.1, of the 50 dyads (100 participants) randomised to either the intervention or usual care group, follow-up assessment data were collected from 76/100 (76%) stroke survivors and family caregivers; 18/25 (72%) dyads had received the intervention and 19/25 (76%) usual care. Follow-up assessments were also collected from one stroke survivor without the family caregiver (intervention group) and one family caregiver without the stroke survivor (usual care group).

A total of 24/100 (24%) stroke survivors and family caregivers were lost to follow-up from both groups: 6/25 dyads, one family caregiver from the intervention group and 5/25 dyads and one stroke survivor from the usual care group. The reasons for being lost to follow-up, although varied, were not different between the two groups. For the intervention group, one stroke survivor died before follow-up, and the caregiver could not be followed-up because of the emotional trauma; one stroke survivor and family caregiver travelled outside the area where they lived and could not be reached for follow-up. One caregiver declined, making it difficult to access the stroke survivor since the caregiver was the gatekeeper. One family caregiver was busy and could not be reached, so only the stroke survivor was followed-up. Several telephone calls were made to three stroke survivors and their family caregivers, but these calls were not answered.

In the usual care group, one stroke survivor died, the caregiver could not be followed-up, and two stroke survivors and their caregivers could not be reached by telephone. One stroke survivor was unwell, but the caregiver was followed-up. One stroke survivor and the caregiver travelled outside the study area, while one caregiver was busy, and the stroke survivor could not be followed-up. The scores of the outcome data for the remaining participants who completed the study are presented in section 4.6.

### 4.4.2 Data collection and completion

Participant baseline characteristics and outcome measures were collected using questionnaires. The researcher or a nurse blinded to participants allocation to groups successfully administered and collected these questionnaires to reduce bias. Both groups completed the questionnaires with no apparent difficulties.

Each participant was encouraged to complete the entire questionnaire at baseline and follow-up. The questionnaire was handed over to the researcher, who checked that all fields were filled out before they were collected, and this ensured that missing data were collected. There were no missing data on baseline assessment. Four stroke survivors' questionnaires had missing data for follow-up, and they were contacted by telephone to provide the missing data. No participant raised the study burden as a concern.

### 4.4.3 Participant randomisation

The randomisation processes for the trial worked smoothly with an unpredictable assignment to the groups. However, there were imbalances with a disproportion in age and gender allocations between the family caregiver groups, probably attributable to the sample size but which could have occurred by chance. Random allocation was performed using a Stata Statistics programme, and this approach is known to minimise selection and allocations bias (Akobeng, 2005).

No participant raised concerns about randomisation. No one refused recruitment when they knew they would be randomised, suggesting this was acceptable and feasible for a definitive trial.

### 4.4.4 Delivery of the intervention

Assessment of the delivery of the intervention explored whether the post-stroke education intervention was delivered according to the research protocol and whether it was feasible and acceptable for participants. The assessment included the delivery of the intervention, barriers, facilitators for adherence to the intervention and the experience of the intervention. This is presented in detail in the qualitative component of this study in chapters 5 and 6. Overall, the intervention was delivered as intended.

The intervention was delivered in a manner consistent with the approved protocol. All 25 stroke survivors and their family caregivers in the intervention group received a stroke information booklet and a face-to-face discussion. They could ask questions and demonstrate some understanding of what was presented to them. So, the intervention was delivered as intended. However, only 11/25 (44%) of stroke survivors and 9/25 (36%) family caregivers read the information booklet at home.

Some participants were unable to read the booklet because they could not read or find someone to read the content to them, while others had misplaced it. Among those who read the booklet, only one raised an issue about the presentation of the information. There was, therefore, a dichotomy between people expressing a wish to have information and reading it. See section 4.5 for the details of participants' responses to the booklet.

### Adherence to the interventions

Some survivors and their caregivers did not read the book, but data was not collected on this in detail. Although using the booklet seemed to improve the knowledge of some individuals about stroke, it is difficult to comment on this aspect of the study with confidence. The bigger question is whether reading the material and improving knowledge resulted in any behaviour changes and that were beyond the scope of this feasibility trial.

## 4.5 Acceptability and suitability of the information booklet

Participants in the intervention group responded to questions about the written information booklet. This was to help assess the acceptability and suitability of the information booklet to guide a future trial.

### 4.5.1 Stroke survivors' responses to the information booklet

Of the 19/25 stroke survivors followed up in the intervention group, 11/19 (57.89%) read the information booklet after the first meeting with the researcher. Eight of nineteen (42.11%) stroke survivors could not read the booklet. The main reason for their inability to read the booklet was due to stroke-related impairment, which was not

identified in the hospital (n=4). Other reasons were that they could not read in English (n=2), while others had misplaced or forgotten about the booklet (n=2).

All the stroke survivors (n=11) who read the booklet were satisfied with its content and presentation as indicated on a Likert scale (Table 4.5). On the Likert scale, higher numbers from 1 to 10 indicated high satisfaction, and lower numbers indicated low or no satisfaction (Hoffmann et al., 2007).

### Table 4.5: Stroke survivors' satisfaction with the content and presentation of the stroke information booklet (N = 11)

| *Likert Scale | 1 LOW | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 HIGH |
|---|---|---|---|---|---|---|---|---|---|---|
| **Satisfaction with Content** | | | | | | 1 /11 (9.09%) | | 5/11 (45.45%) | | 5/11 (45.45%) |
| **Satisfaction with Presentation** | | | | | | 1/11 (9.09%) | 1/11 (9.09%) | 2/11 (18.18%) | 3/11 (27.27%) | 4/11 (36.36%) |

*Likert scale – from 1 – 10 where 1 is not satisfied and 10 extremely satisfied

Tables 4.6 and 4.7 show stroke survivors' positive and negative features about the stroke information booklet. Eight of the 11 (42.11%) stroke survivors who read the booklet described positive features that made it user-friendly (see Table 4.6). Four stroke survivors stated that the booklet's content was easy to understand. One stroke survivor stated that the words used in the booklet were simple; the booklet provided examples to illustrate important points (n=1), and the font size made the booklet's content easy to read (n=1).

However, three stated that the booklet had a poor layout. Specifically, its content was overcrowded, the font was too small, and the diagram/pictures were difficult to understand. The remaining eight stroke survivors did not find any negative features about the booklet, suggesting they were satisfied with it.

### Table 4.6: Positive features of the stroke information booklet (N=11)

| Feature | Stroke survivors' responses |
|---|---|
| **Easy to understand** | 5/11 (45.45%) |
| **Used simple words** | 4/11 (36.36%) |
| **Easy-to-read font** | 2/11 (18.18%) |
| **Provided examples** | 1/11 (9.09%) |
| **Helpful pictures** | 1/11 (9.09%) |

### Table 4.7: Negative features of the stroke information booklet (N=11)

| Feature | Stroke survivors' responses |
|---|---|
| **Poor layout/overcrowded** | 1/11 (9.09%) |
| **Font too small** | 1/11 (9.09%) |
| **Diagrams/pictures difficult to understand** | 1/11 (9.09%) |
| **None** | 8/11 (72.72%) |

After reading the booklet, all eleven stroke survivors felt that the written information had assisted them in several ways; broadly, it improved their understanding of stroke and equipped them with the knowledge to adapt to healthy lifestyles post-stroke (see Table 4.8).

### Table 4.8: Stroke survivors' responses to how the stroke information booklet assisted them in coping with stroke

| Categories | Stroke survivor's response |
|---|---|
| **Improved understanding of stroke** | • "By helping me to know what to do at a point in time"<br>• "I learnt a lot about diets, exercise and causes of stroke"<br>• "I now know the "genesis" of the disease (stroke) and how it can occur"<br>• "It gave me a general knowledge of stroke"<br>• "It reminded me of how serious I have to take the treatment"<br>• "It also alerts me that failure to comply with the treatment can worsen my illness"<br>• "I learnt about dietary and exercise" |
| **Adopting healthy lifestyles** | • "Change behaviour (lifestyle)"<br>• "Doing exercise regularly"<br>• "Improved my eating habit and helped me to exercise" |

Table 4.9 indicates additional topics stroke survivors wanted to receive information. Most (n=7) wanted information on one or more specific topics on stroke. However, four stroke survivors indicated they did not want any information on the topics listed in Table 4.9 beyond those presented in the stroke information booklet.

## Table 4.9: Stroke survivors who wanted additional stroke information (N = 11)

| Additional information on stroke | Number stroke survivors |
|---|---|
| **What to expect at home?** | 6 (54.54%) |
| **Equipment and aids necessary after stroke** | 6 (54.54%) |
| **Recovery after a stroke** | 4 (45.45%) |
| **Warning signs of stroke** | 3 (36.36%) |
| **Effects of stroke** | 3 (36.36%) |
| **What is stroke (medical)?** | 2 (18.18%) |
| **Treatment available after a stroke** | 2 (18.18%) |
| **Where to obtain further support/information** | 2 (18.18%) |
| **Medications prescribed after a stroke (for treatment or prevention)** | 2 (18.18%) |
| **Reducing your risk of stroke/preventing further stroke** | 2 (18.18%) |
| **Support groups** | 2 (18.18%) |
| **How stroke is diagnosed** | 1 (9.09%) |
| **Information about exercises/activities to do after a stroke** | 1 (9.09%) |
| **Information about a healthier lifestyle (e.g., losing weight, healthy eating, giving up smoking)** | 1 (9.09%) |

At the end of the follow-up questions, stroke survivors were asked whether they had any questions about stroke and the preferred method of receiving stroke information. Five stroke survivors indicated ‘yes’ they had questions about stroke. In terms of their preferred method for receiving information, three of the five indicated that they would like to talk with the healthcare professional caring for them, and two would like a video.

## 4.5.2 Family caregivers' responses to the stroke information booklet

Nine of the 19/25 (76%) family caregivers who were followed up in the intervention group, indicated that they read the booklet. Two family caregivers indicated that they could not read the booklet due to their inability to read in English, and one had misplaced and forgotten about it.

Overall, family caregivers were satisfied with the content and presentation of the booklet as indicated on a Likert scale (Table 4.10).

### Table 4.10: Family caregivers' satisfaction with the content and presentation of the stroke information booklet (n = 9)

| *Likert Scale | 1 LOW | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 HIGH |
|---|---|---|---|---|---|---|---|---|---|---|
| **Satisfaction with Content** | | | | | 1/9 (11.11 %) | | 1/9 (11.11 %) | 3/9 (33.33 %) | 1/9 (11.11 %) | 3/9 (33.33 %) |
| **Satisfaction with Presentation** | | | | | | 1/9 (11.11 %) | 1/9 (11.11 %) | 5/9 (55.56 %) | 1/9 (11.11 %) | 1/9 (11.11 %) |

*Likert scale – from 1 – 10 where 1 is not satisfied and 10 extremely satisfied

Regarding the positive features of the information booklet, all nine family caregivers indicated various aspects of the booklet that they liked, as outlined in Table 4.11.

### Table 4.11: Positive features of the stroke information booklet (N = 9)

| Feature | Family caregivers' responses |
|---|---|
| **Easy to understand** | 2/9 (22.22%) |
| **Helpful pictures** | 2/9 (22.22%) |
| **Used simple words** | 1/9 (11.11%) |
| **Provided examples** | 0/9 |
| **Easy-to-read font** | 0/9 |
| **All the above** | 4/9 (44.44%) |

For the negative features, each family caregiver stated that the diagrams/pictures were difficult to understand, poor colours and lengthy writing. However, six caregivers stated they thought there were no negative features (see Table 4.12).

### Table 4.12: Negative features of the stroke information booklet (N = 9)

| Feature | Stroke survivors' responses |
|---|---|
| **Poor layout/overcrowded** | 1 (11.11%) |
| **Font too small** | 1 (11.11%) |
| **Diagrams/pictures difficult to understand** | 1 (11.11%) |
| **None** | 6 (66.66%) |

Regarding how the booklet provided information that improved understanding of stroke and strategies to improve care, the caregiver statements are in Table 4.13.

### Table 4.13: Family caregivers' responses to how the written information assisted them **in coping** with caring for a stroke survivor

| Categories | Family caregiver's response |
|---|---|
| **Improved the understanding of knowledge of stroke** | • "It gave me more insight as to how to care for a stroke patient"<br>• "It took off my perception of stroke being a spiritual disease"<br>• "It made me know the dos and don'ts of stroke"<br>• "It has helped me to know about stroke"<br>• "It's a guide to successful management of stroke"<br>• "It gave me more information about stroke"<br>• "It helped me know how the sickness is like and how to manage it"<br>• "It has assisted me in the caregiving process and how to serve medications"<br>• "It also alerts me that failure to go about the treatment will be disastrous" |
| **Benefits to the family caregiver** | • "It has helped change my lifestyle after reading about the risk factors for stroke" |

Of the 9 family caregivers who read the information booklet, 8 wanted information on topics described in Table 4.14.

### Table 4.14: Family caregivers who wanted additional information about stroke (N = 9)

| Additional topics on stroke | Number of family caregivers |
|---|---|
| **Effects of stroke** | 5 (55.55%) |
| **Treatment available after a stroke** | 4 (44.44%) |
| **Causes of stroke** | 4 (44.44%) |
| **Recovery after a stroke** | 3 (33.33%) |
| **Equipment and aids necessary after stroke** | 3 (33.33%) |
| **Information about a healthier lifestyle (e.g., losing weight, healthy eating, giving up smoking)** | 3 (33.33%) |
| **How stroke is diagnosed** | 2 (22.22%) |
| **What to expect at home?** | 2 (22.22%) |
| **Reducing your risk of stroke/preventing further stroke** | 2 (22.22%) |
| **What is stroke (medical)?** | 1 (11.11%) |
| **Medications prescribed after a stroke (for treatment or prevention)** | 1 (11.11%) |
| **Support groups** | 1 (11.11%) |
| **Information about exercises/activities to do after a stroke** | 1 (11.11%) |
| **Warning signs of stroke** | 1 (11.11%) |

Five caregivers had questions about stroke and wanted to receive information to address such questions through the following preferred methods; written information (n=1), talks with a healthcare professional (n=2), face-to-face with a doctor (n=1), telephone talk with a doctor (n=1) and talks from a stroke group (n=1).

## 4.6 Outcome measures data

This section presents the stroke survivor and the family caregiver outcome measures. All data were plotted and visually checked for normality. The data on each outcome measure was normally distributed for the stroke survivors and the family caregiver scores. There were no outliers that skewed the distribution despite the small sample. Therefore, the outcome measures are presented using means and standard deviations, as appropriate for normally distributed data (Field, 2013).

### 4.6.1 Stroke survivor outcome measures data

Table 4.15 shows the means and the standard deviations of the outcome measures for the two groups.

Overall, the outcome measures for both groups were broadly similar; there was generally an increase in the outcome measure score from the baseline score. For the knowledge of stroke outcome measure, there was a small increase from the baseline score in both groups, meaning stroke survivors had a small increase in the knowledge of stroke. The increase in stroke knowledge was slightly more in the usual care group compared to the intervention group.

Although both groups had a small increase in the HADS score, the HADS score for anxiety in the usual care group increased more than any other measure from the baseline scores. This showed that while stroke survivors in both groups expressed some mild anxiety symptoms during the follow-up, the anxiety score was higher in the usual care group than in the intervention group. The HADS outcome score remained within the normal range for anxiety and depression in both groups except for the usual care group. The score for HADS-A showed the mild presence of anxiety among stroke survivors at the three months follow-up.

## Table 4.15: Stroke survivors' baseline and 3-month follow-up outcome measures scores

| Measure | Baseline sores Mean (SD) | | Outcome scores Mean (SD) | | Unadjusted Mean Difference (95% CI) | Adjusted Mean Difference (95% CI) |
|---|---|---|---|---|---|---|
| | PSE (N=25) | Usual care (N=25) | PSE (N=19) | Usual care (N=19) | | |
| **KS**** | 15.16 (3.09) | 14.56 (3.78) | 16.32 (2.52) | 15.95 (3.03) | 0.37 (-1.46, 2.20) | -0.18 (-1.62, 1.87) |
| **HADS – A*** | 5.20 (4.08) | 5.48 (4.34) | 7.84 (4.19) | 8.05 (4.65) | -0.21 (-3.12, 2.70) | 0.50 (-3.22, 2.21) |
| **HADS – D*** | 6.64(3.64) | 7.44 (3.48) | 7.47 (2.22) | 7.16 (3.37) | 0.32 (-1.57, 2.20) | -0.40 (-1.24, 2.04) |

***Higher scores indicate better knowledge of stroke*

**Higher scores indicate worse levels of anxiety and depression*

*(SD) – Standard Deviation*

*PSE – Post-stroke education*

*KS – Knowledge of Stroke*

*HADS – A – Hospital Anxiety and Depression Scale – Anxiety Subscale*

*HADS – D – Hospital Anxiety and Depression Scale – Depression Subscale*

The results of the between-group differences, as shown in Table 4.15, indicate that the direction of change is towards the post-stroke education intervention except for the HADS anxiety, where the difference was in a direction that favours the usual care group. All the confidence intervals were wide due to the small sample size. Since the baseline score was slightly different, it was necessary to adjust the between-group difference for baseline differences using linear regression. When carrying out a linear regression, in addition to checking that the data are normally distributed, it is also important to check that variance of the residual values (the difference between the observed and predicted values in the model) is approximately equal in both groups (Kirkwood and Sterne, 2003). This was performed using SPSS; the results were not significant, probably due to the small sample size. The differences were adjusted for baseline scores since the differences from all other variables (such as level of education and gender) were not significant and would not have influenced the outcome measure. The adjusted results show that the direction of change was in favour of the usual care, except for HADS anxiety, which was in favour of the post-stroke education

intervention. However, these results must be interpreted with caution given the small sample size and the wide confidence intervals.

### 4.6.2 Family caregiver outcome measures data

Table 4.16 shows the means and the standard deviations for the outcome measures data of the family caregivers. The data in the table shows little difference between the two groups, although overall, there was a slight increase in the outcome measure scores from the baseline scores. However, the slight increase in the HADS score indicated the presence of mild anxiety and depression symptoms in both groups; although caregivers in the usual care group had a slightly lower mean depression score, it was within the normal range. For the caregiver burden, the difference from the baseline score to the outcome score was small.

The between-group mean differences showed that, except for knowledge of stroke changes that were in favour of the usual care group, the changes in HADS and the caregiver burden were in the direction of the intervention group. However, the adjusted mean difference for baseline scores using linear regression analysis shows that the direction of change in the knowledge of stroke and the caregiver burden mean differences were in favour of the intervention, while the HADS were in favour of the usual care group.

### Table 4.16: Family caregivers' baseline and 3-month follow-up outcome measures scores

| Measure | Baseline scores Mean (SD) | | Outcome scores Mean (SD) | | Unadjusted Mean Difference (95% CI) | Adjusted Mean Difference (95% CI) |
|---|---|---|---|---|---|---|
| | PSE (N=25) | Usual care (N=25) | PSE (N=18) | Usual care (N=20) | | |
| **KS**** | 16.12 (3.18) | 16.76 (3.05) | 16.83 (2.71) | 17.20 (2.97) | -0.37 (-2.24, 1.51) | 0.02 (-1.79, 1.76) |
| **HADS – A*** | 8.08 (5.61) | 7.92 (5.42) | 10.33(4.52) | 8.75 (4.92) | 1.58 (-1.54, 4.70) | -0.93 (-1.79, 3.64) |
| **HADS – D*** | 6.80 (5.24) | 4.84 (4.64) | 8.78 (3.64) | 6.85 (3.57) | 1.93 (-4.47, 4.30) | -1.18 (-1.17, 3.58) |
| **C B[a]** | 14.04 (5.81) | 14.12 (5.02) | 14.89 (5.14) | 14.35 (6.16) | 0.54 (-3.22, 4.30) | 0.06 (-3.17, 3.05) |

*** Higher scores indicate better knowledge of stroke*

**Higher scores indicate worse levels of anxiety and depression*

[a]*Higher scores indicate higher demand for care*

*(SD) – Standard Deviation*

*PSE – Post-stroke education*

*KS – Knowledge of Stroke*

*CB – Caregiver Burden*

*HADS – A – Hospital Anxiety and Depression Scale – Anxiety Subscale*

*HADS – D – Hospital Anxiety and Depression Scale – Depression Subscale*

## 4.7 Discussion

The aim of this research was to determine the feasibility of conducting a definitive RCT of post-stroke education intervention in Ghana. In this feasibility trial, the intervention was successfully delivered by the researcher and two nurses trained for the purpose. Some aspects of the trial worked well, and others would need changes in a definitive trial.

The recruitment target for this trial was calculated based on the attendance of scheduled stroke survivors in the stroke unit. Although this target was reached within the recruitment period, some issues need to be addressed in a future definitive trial; the recruitment process and follow-up of participants. Approximately, 26% of all those screened were eligible, and all (100%) provided consent. The eligibility rate for this

trial is lower than a previous trial conducted in the UK, which recorded a higher eligibility rate of 39% (Lowe et al., 2007). This reflects the differences in the eligibility criteria. One of these eligibility criteria, including dyads, meant that when one participant did not meet the inclusion criteria, the other partner was automatically excluded. In using this criterion, more than 50% of the stroke survivors did not meet this eligibility criterion as most family caregivers were absent during recruitment, others declined participation, and some were below the age of 18 years. Including dyads in studies has been problematic (Eames et al., 2013). Therefore, the eligibility criteria must be reconsidered in a future definitive trial.

In addition, recruitment in the current study faced challenges in identifying participants and limited bed space in the stroke unit. In Ghana, there is no stroke register or stroke advocacy group where the details of stroke survivors can be obtained. As a result, the only option was to identify and approach stroke survivors at the review clinic or stroke unit. This allowed potential participants only a short time to decide on their participation, so stroke survivors were lost to enrolment. Additionally, the once-weekly schedule of the clinic made it busy and the waiting time for consulting a physician was prolonged. As a result, some stroke survivors and their family caregivers viewed the research to as prolonging the waiting time and did not want to invest time in doing this. In a definitive trial, stroke survivors could be identified at the stroke clinic and recruitment arranged outside the medical review days to reduce stress and allow time for decision-making to participate in the trial.

Randomised controlled trials are the most rigorous type of scientific evaluation; however, the reliability and validity of the evidence from a trial rely on an appropriate procedure of random allocation (Kendall, 2003). Allocation in this study was determined by randomisation to ensure an equal chance of selecting participants into each group. No participant raised concerns about randomisation, and no one refused to be recruited when they knew they were to be randomised, suggesting that randomisation was acceptable and feasible.

Although the information booklet was kept in the participants' handbags, and they were asked not to pass it on, the possibility of contamination between the two groups cannot be excluded. The resources were not available to cluster randomised, so participants allocated to the intervention group could, in theory, be cared for in the clinic or unit

alongside each other. Even if the participants in the usual care group could have been prevented from seeing the booklet, it was impossible to avoid those in the post-stroke education group sharing the knowledge they had learned from the intervention by talking with those in the usual care group. So, the risk of information leakage from the intervention group to the control group leading to contamination of the trial arms can only be minimised but not be avoided. However, the effect of contamination is likely to result in an underestimation rather than an overestimation of differences between the two groups at follow-up; that is, the point estimate of an intervention's effectiveness can be reduced due to contamination between the two trial arms (Winkens et al., 1997; Torgerson, 2001; Keogh-Brown et al., 2007).

Retention throughout the trial to the 3-month follow-up was deemed successful, with 24 participants lost to follow-up. Participants' responses to follow-up were very positive. Research personnel were responsive and friendly, characteristics which have been shown to foster participant motivation and retention in a previous study (Dias et al., 2005).

The outcome measures appeared sensitive to change, and the overall differences were balanced and favourable for the intervention group compared to the usual care group for the stroke survivors. On the other hand, the overall difference favoured the usual care group for family caregivers. However, there is a degree of uncertainty in the findings due to the baseline differences in the level of education between groups (which were not adjusted for). Overall, although based on small sample size and not discounting the possibility of chance, the favourable direction of trends across the data indicates the potential benefit of this treatment in stroke survivors.

For the stroke survivors, the favourable finding in the intervention group is the slight increase in knowledge of stroke. While it is possible that these trends were due to chance, the intervention involved providing written information and face-to-face discussion about stroke with participants. The discussion may have allowed participants to ask questions and know more about stroke. Additionally, allowing the participants to take the information booklet home for reference could have helped them retain the information. Moreover, some of the participants were able to read the booklet and understood the content. This was a strategy used in Australia to examine the provision of written stroke information with verbal reinforcement (Eames et al.,

2013). Providing written information to stroke survivors has increased the stroke awareness (Collins et al., 2002). It is possible that because the researcher and the nurses trained for the intervention and provided the post-stroke education, they were particularly motivated to “go the extra mile” to explain the booklet’s content to participants, which facilitated their understanding of stroke.

Although anxiety and depression levels were within the normal scores, the stroke survivors in both groups had increased HADS scores from baseline, which was unexpected. While it is possible that these trends were due to chance, the intervention involved providing stroke information to supporting participants. Instead of reducing anxiety and depression, it may have increased them. It is also possible that, because stroke is considered a spiritual disease among many Ghanaians, informing people that they had a stroke triggered anxiety among stroke survivors and their family caregivers. Furthermore, raising the awareness of stroke may upset people with stroke and even cause questions about whether they had a stroke (Baatiema et al., 2017c). It would be necessary to explore the effects of post-stroke education on the anxiety and depression of participants in a bigger study.

The findings favoured the usual care group for the family caregivers, which was intriguing and required further discussion. The knowledge of stroke was slightly higher in the usual care group from baseline to outcome. On the other hand, the HADS score was higher in the post-stroke education group which was not expected. This could be attributed to the level of education of the participants where those in the usual care group had more tertiary education than the intervention group. Attaining higher education might have encouraged some participants to look for information about stroke from other sources such as the internet and other media. This is consistent with a study in Nigeria where the students at a secondary school had higher knowledge of stroke (Komolafe et al., 2015). It would, therefore, be important to stratify education in the definitive trial.

Overall, the outcome measures indicated a change from baseline to three months in the sample, showing that the measures were sensitive to change in this population. Additionally, there were some differences between the groups, which indicated that if such a difference exists, these measures have the potential to show this in a future definitive trial. However, the increase in HADS scores suggests that participants had

a mild emotional outcome, suggesting that participants in the intervention group were a little anxious and depressed after being exposed to the intervention. This issue merits further investigation, and it may be that the intervention should build in support to address this in a trial. It may suggest that the intervention has the potential to be effective as recognising the reality of the situation would likely cause such a result. However, some participants found it difficult to understand a few words used due to translational issues. Some words did not exist and were therefore difficult to translate. This would need to be examined as it may be possible to reword or explain these terms in the future.

The principal strength of this study is that it was the first RCT of post-stroke education intervention in Ghana. As such, there were no directly relevant studies to compare the results. Nevertheless, the trends were broadly consistent with the findings from the systematic review (see Chapter Two), post-stroke education interventions to inform stroke survivors and family caregivers about stroke can improve knowledge of stroke. An additional strength is that this RCT was conducted within a stroke care setting in Ghana. Such RCTs are extremely rare in developing countries, and randomisation procedures and processes are largely untested in such settings (Forster et al., 2012). Thus, the findings are relevant to post-stroke education but also have wider implications for trials within stroke care in developing countries, indicating that the methodology is largely feasible and there is potential for RCTs to be developed and used further in these contexts.

The principal limitation of this study is that it was conducted at a single stroke care site involving the researcher and two nurses delivering the intervention. The researcher was familiar with the hospital where this research was carried out, which may have positively impacted the staff's willingness to participate and engage with the research. Therefore, it cannot be assumed that the research could easily be conducted in other settings as it is unknown how many of the successes and barriers were peculiar to KATH. However, it would be seen that the main findings, for example, in relation to willingness of participants to be randomised and remain in the study and the sensitivity of the outcome measures for use in this population group, should apply more broadly to multiple sites.

A further limitation is that the small sample size led to slight differences in baseline measures that affected the outcome. As a result, there is a greater degree of uncertainty in the estimates of the treatment effect. Although the trends in the stroke survivors' outcomes appear to favour the post-stroke intervention group, the sample size is extremely small, and the possibility of chance differences cannot be discounted. Thus, a further powered study is required to ascertain whether post-stroke education intervention is effective.

In conclusion, a further powered trial would largely be feasible but would be subjected to the following three issues being addressed:

1. Identifying a sufficient number of people with stroke at the hospital and arranging for recruitment outside the review clinic days would be necessary. This would be essential to allow time for volunteers to decide on participation, and it may increase the eligibility rate.

2. As this study has shown, participants want stroke information from healthcare professionals who care for them in formats that include discussions, video, pictures, and audio recordings in their native languages. Translating the information booklet and providing videos on stroke in Twi would be necessary to enhance the intervention in a definitive trial.

3. It would be necessary to identify a suitable primary outcome measure for use in the definitive trial. Although the quality of participant measures appeared sensitive to change, the main goal of the post-stroke education intervention was focused on providing information. It is therefore imperative that the primary outcome measure should reflect the main purpose of the intervention. Based on these results, it would seem that a measure is somewhere in the knowledge of stroke.

## 4.8 Summary

This chapter presented the results and discussed the feasibility RCT. A total of 50 dyads were recruited and randomised, 25 each in the post-stroke education intervention group and the usual care group. The baseline measures were broadly similar in the two groups. At follow-up, a total of 37 dyads outcome data were collected,

which generally showed a small increase in all the outcome scores from the baseline scores.

With regard to the feasibility of conducting a definitive trial, it was concluded that it would be better to recruit from the stroke review clinic rather than the stroke unit. It was also found that participants were willing to be randomised, which is an important finding. Overall, the stroke information booklet was regarded as positive but could be refined further to include coloured pictures and good illustrations to help explain certain situations instead of words translated to Twi. Some participants also wanted the information in video or audiotape form, which could be explored further. Generally, the intervention was delivered according to protocol, suggesting that this could be used in a definitive trial.

# Chapter Five

# Post-stroke education in Ghana: Qualitative interviews

## 5.1 Introduction

The previous two chapters presented the feasibility RCT, which highlighted the use of quantitative methods to assess the feasibility of conducting a definitive trial of post-stroke education intervention in Ghana. However, the RCT design was limited in exploring the experiences surrounding the delivery of the feasibility trial. Thus, the qualitative method was used to explore participants' experiences after stroke and participating in the feasibility trial. This chapter presents the method used to conduct this qualitative study. It begins with the rationale for nesting a qualitative research study within a feasibility RCT and the justification for selecting qualitative interviews for this research. The chapter also describes the recruitment process, interview procedure and data analysis employed in the study.

## 5.2 Rationale for qualitative research 'nested' within RCTs

There were numerous reasons for conducting the qualitative phase of this study, including evaluating the acceptability of the intervention and gaining insight into the bigger picture of the experience of recovering from a stroke in a Ghanaian context. The existing literature on the experiences of living with stroke in developing countries, particularly in Ghana, is limited. A meta-synthesis by Salter et al. (2008) found only the personal experiences of stroke survivors living in the UK, USA, and Sweden. This finding reflects the inadequate presentation of stroke survivors' experiences in resource-poor countries with inadequate care provision. Previous research has not incorporated the needs of stroke survivors and family caregivers in resource-poor countries. Thus, to develop a relevant post-stroke education intervention, it is necessary to understand the individual's best response and coping with stroke in their natural environment. A study by Urimubenshi and Rhoda (2011) demonstrates that the needs and preferences identified by stroke survivors vary based on environment and socio-cultural beliefs. Therefore, understanding the experiences of survivors and their families and how they cope can inform the development of interventions to improve the outcomes of stroke even within a resource-poor context.

Another reason for the qualitative study is that healthcare professionals have the tendency to always offer information and care based on what they anticipate patients

and their family caregivers need to know, rather than the latter's perceived or actual information needs (Dean et al., 2008; Hui et al., 2008). A study by Ang et al. (2013) compared the views of caregivers of stroke survivors with those of neurologists and nurses about the educational needs of caregivers in an acute care environment and reported areas of disagreement. While healthcare professionals felt caregivers needed to know about medication, caregivers did not report medication as an information need. Instead, caregivers preferred hands-on experience and hearing from healthcare professionals to receiving printed materials. Therefore, the qualitative phase of this study seeks to determine the actual information needs of stroke survivors and their family caregivers rather than just anticipating what they might be. This can help develop an optimised post-stroke education intervention for a definitive trial.

Furthermore, this qualitative research aimed to enable the researcher to understand the practicality of delivering post-stroke education in Ghana from the perspectives of the nurses who administered the intervention. The MRC framework recommends using mixed-methods research to develop and evaluate complex interventions, including post-stroke education (Craig et al., 2013; Skivington et al., 2021). Using qualitative research within or alongside RCTs, either as stand-alone research or as part of a mixed methods process evaluation, will offer an insightful explanation of the delivery of post-stroke education intervention (Reelick et al., 2013; Moore et al., 2015). The qualitative research used with this feasibility RCT, in preparation for a definitive RCT, will enable a better understanding of the contextual issues in Ghana. This will be used to: refine the intervention content and its delivery, help the researcher to be sensitive to the participants involved and save money by steering the research towards an intervention that is more likely to be successful in a definitive trial (Cooper et al., 2014; Drabble et al., 2014; O'Cathain et al., 2015).

This qualitative research was 'nested' within the feasibility RCT and was thus an element of a larger study. The research design was not specific to a particular qualitative tradition such as ethnography, grounded theory, or phenomenology but used generic qualitative methods to collect and analyse data.

## 5.3 Aim and objectives

The aim of the qualitative research was to explore the experiences of stroke survivors and caregivers in taking part in the feasibility trial, as well as the nurses' perspectives on stroke care and post-stroke education in Ghana.

The following were the specific objectives for the qualitative research:

### 5.3.1 Stroke survivors

The specific objectives for stroke survivors were to;

1. Explore the experiences of living with a stroke
2. Identify the areas where stroke survivors need information
3. Assess views and thoughts on the content and the delivery of the post-stroke education intervention they received as part of the feasibility trial (for only those in the intervention group).

### 5.3.2 Family caregivers

The specific objectives for the family caregivers were to;

1. Explore the experiences of caring for a family member living with a stroke
2. Identify areas related to caring for stroke survivors where they need information
3. Assess their views on the content and the delivery of the post-stroke education intervention received as part of the feasibility trial (for only those in the intervention group).

### 5.3.3 Nurses

The specific objectives for interviewing the nurses were to;

1. Establish how nurses provide 'usual' stroke care, including providing information to stroke survivors and family caregivers
2. Assess the nurses' views on the content of the post-stroke education intervention as delivered in the feasibility trial
3. Examine facilitators and barriers to delivering the post-stroke education intervention in KATH.

## 5.4 Method

### 5.4.1 Consideration of qualitative research method

Several factors were considered when selecting a suitable qualitative method for the study. The most important was choosing a method to facilitate data collection and analysis based on the research objectives. Practical issues such as the study setting and available resources were also considered. As a result, interviews were chosen as the most suitable method for data collection.

### 5.4.2 Interviews

Interviews are widely used for data collection in qualitative healthcare research studies. This is because they are flexible and allow the researcher to gather in-depth information about the participants' experiences, perceptions and beliefs concerning a particular phenomenon (Austin and Sutton, 2014). Interviews can be used at any stage of the research process, either as the only qualitative approach or combined with other data collection methods in mixed-methods research (Peters and Halcomb, 2015). Interviews involve a conversation between the researcher and one or more individuals aimed at producing knowledge. The purpose of interviews is to obtain descriptions of the interviewee's lifeworld in order to interpret the significance of the events described (Kvale and Brinkmann, 2008). Additionally, interviews allow a more detailed and in-depth exploration of a phenomenon than a standard survey, enabling insights into how individuals understand and narrate aspects of a problem from their perspectives (Anderson, 2010). Several possible interview techniques were considered for the study:

**Group interview or focus group**: this is recommended as a convenient method for gathering consensus opinions of a phenomenon from a group of respondents in a single interview (Barbour, 2007). It involves an interaction between the researcher and a group of individuals, generally, 6-10 selected because they share similar characteristics (homogenous) to discuss a particular issue (i.e., focus) or topic raised and directed by the researcher (Hydén and Bülow, 2003; Barbour and Kitzinger, 2001). By design, focus group discussions allow different individuals' beliefs, thoughts, and experiences on a particular issue to be examined from contrasting and shared opinions (Bristowe et al., 2015).

At the same time, collecting information from several respondents in a focus group interview can often generate further discussions that may bring out new ideas and information within the group, as individuals share their views and ideas. This can lead the research into new and unexpected directions as novel ideas are generated (Acocella, 2012). However, conclusions about individuals' views and expressed thoughts should be interpreted with caution as individuals may speak and communicate differently during group meetings, changing their representation and position. While interviews with focus groups may empower participants to express their ideas and views more than they might think they can in individual interviews, there is a disadvantage in this, as respondents' attitudes may be more extreme within group discussions, resulting in an impact of 'polarisation' effect (Sussman et al., 1991). The result of sharing these individual experiences within a group is that participants may be affected by the opinions of other participants. If their viewpoint differs from the majority of the group, they may not be prepared to express it. In addition, in focus group discussions where one or more group members dominate, the other group members are less likely to contribute equally (Goering and Streiner, 2013). Therefore, the group may appear to have reached a consensus that may not accurately represent the views or opinions of all the group members.

Although focus group interview was a potentially useful method to gather data on collective experiences and information needs about stroke, it would have been overwhelmingly difficult to organise focus group interviews for this study because of logistical and socio-cultural constraints. Bringing individuals with different scheduled medical review dates together at the hospital or an agreed location for a group discussion would have been challenging as individuals live long distances apart. In addition, it would have been a challenge to organise focus group discussions in the busy stroke review clinic and stroke unit, where there was no suitable meeting space to accommodate more than four people. Moreover, getting individuals to discuss their health issues in a group openly would have been exceedingly difficult as Ghanaians tend not to openly discuss their health problems, especially potentially debilitating conditions such as stroke. Reticence is such that family members may even try to conceal such health problems of their relatives. Therefore, focus group discussions were ruled out as impracticable for the study.

**Individual interviews:** In many qualitative healthcare research studies, the individual interview is the most widely used data collection technique (Britten, 2006, Green and Thorogood, 2014). Whilst a focus group interview can gather collective experiences from multiple participants; an individual interview can explore further the individual's experiences and thoughts. Individual interviews are intended to gather thorough accounts of an individual's perceptions, beliefs, experiences and understanding of a particular phenomenon. Individual interviews involve a personal and confidential encounter between the researcher and the participant, enabling the researcher to use open-ended questions while probing to allow the respondents to react in their own words, rather than limiting them to choose between fixed answers (Mack et al., 2005). It could be argued that a sensitively led qualitative interview enables the participant to identify the relevant issues related to the focus of the study (Green and Thorogood, 2014). Using an individual interview approach allows the researcher to gather information on various issues related to a specific research question.

The emphasis of interviews can be the meaning constructed by the respondents based on their perspectives and understanding of the events they experienced in their life (Al-Busaidi, 2008). This, therefore, requires researchers to be flexible in their questions during interviews, drawing upon their expertise and knowledge to prompt further interesting issues that unfold during the interview (Jackson et al., 2007).

However, because of the contrived nature of the interview, it is likely to affect what individuals say, as both the researcher and participant seek to present themselves in a particular way during the interview (Silverman, 2006). Given that the purpose of an interview is to elicit respondents' experiences, it can be argued whether the interview responses are to be considered as direct access to experiences or as actively constructed narrative of events (Gubrium and Holstein, 2009; Riessman, 2011; Silverman 2011). Because the data collected can be represented in different ways developing from different epistemological positions (e.g., positivism, constructionism) (Breakwell, 2006), it was important that the position taken by the researcher was justified and explained in section 1.7 (Silverman, 2015).

Individual interviews with stroke survivors, family caregivers, and nurses allowed the exploration and probing of the experiences and thoughts about stroke and information

needs than in focus group interviews. This is because focus group discussions were not feasible for participants as they were not prepared to discuss their health issues openly. As a result, individual interviews were selected for this qualitative research.

#### 5.4.2.1 Approaches to individual interviews

Determining the approach to interview most suitable for this research was crucial. Three approaches to interviews are widely used in qualitative healthcare research studies. These include structured, narrative (unstructured), and semi-structured interviews (Stuckey, 2014). In structured interviews, the interviewer follows a specific set of questions in a predetermined order with a limited number of response categories for the interviewee to respond (Denzin and Lincoln, 2008). It would be suitable to use structured interviews if the participant is required to provide an answer to each ordered question, often of a shorter nature. A structured interview is also helpful if the researcher understands a great deal about the topic and generates the answers in an open-ended question-like survey format (Stuckey, 2014). Structured interviews, however, were not suitable for this study because the purpose of the study was to encourage participants to discuss their own experiences. A structured interview would not have allowed the researcher to explore views and thoughts further and would also have prevented the participants from being asked further to explore issues they raised.

Alternatively, narrative interviews (unstructured) do not follow a predetermined set of questions. However, they are based on the unfolding narrations or actions following an initial response from the perspective of a participant's lived experience to one or two questions from the researcher (Britten, 2006; Stuckey, 2014). This approach is helpful where the aim is to enable the individual to recount the lived experience narratively with the intention that after the initial question, the discussion will flow freely. However, unstructured interviews were not suitable for this research as the study seeks to explore specific areas of experience. Without a pre-prepared guide, there was a potential risk of missing significant areas.

In this study, therefore, semi-structured interviews were selected for data collection. Semi-structured interviews are the most used type of interview in qualitative research, and many studies illustrate the use of this method in the context of stroke (Cobbey et al., 2013; Moriche et al., 2010; Salter et al., 2008). The researcher sets out the outline for the topic to be discussed in semi-structured interviews, but the interviewee's

response determines the direction of the interview (Stuckey, 2014). The semi-structured interview guide offers the interviewer a clear focus and can provide reliable, comparable qualitative data. Furthermore, the open-ended nature of questions backed by extra prompts during interviews enables the researcher and the participant the freedom to deviate from the outline when issues of interest arise in the discussion (Britten, 2006). For this research, individual (one-to-one) semi-structured interviews were most suitable because the pre-specified topic guide ensured that all relevant areas of interest such as participants' experiences, thoughts and views about stroke, information needs, and participation of the feasibility trial were covered. However, this did not restrict the researcher or participant, who were free to explore unexpected issues of relevance that unfolded during the discussion.

#### 5.4.2.2 Interview topic guides

### Development of the interview topic guides

Interview topic guides were developed based on a review of the literature on education needs, post-stroke education interventions among people living with stroke and the research aim. Three separate interview guides were developed: one for the stroke survivors, another for the family caregivers, and the third for the nurses (Appendices 15, 16 & 17). Areas of specific interest were the experiences, thoughts and views about stroke and care for stroke survivors, the need for stroke information, and experiences of participating in the feasibility trial and the participants' views and thoughts about the intervention. Each section within the topic guides had several cues to prompt the interviewer, if necessary, to add more context and depth to the interview. This partially deductive approach was proposed to allow the researcher to be more sensitive to subtleties within the data (Tuckett, 2005), whilst providing adaptability to allow exploration of unanticipated themes and the amendment or additions to be made to the topic guide in response to new issues arising as the study progressed.

The interview guides were designed to explore a range of issues from the feasibility trial in terms of the desire for some specific information after a stroke. The interviews focused on exploring individuals' experiences and thoughts after stroke and caring for a stroke survivor. The topic guides began by asking the participant for background information (e.g., "please briefly tell me about yourself and family?", "please describe how your sickness started?", "please describe to me how stroke patients are cared for

in this hospital"). Asking questions that the interviewee feels comfortable with and that can be answered easily enables the participants to settle into the interview before proceeding with more challenging questions (Britten, 2006). The topic guides were initially developed so the interviews would last at least 20 minutes. However, this duration was extended to 30 to 40 minutes after the pilot interviews. The researcher believed this was a reasonable amount of time to capture detailed information without overburdening the interviewees.

#### 5.4.2.3 Stroke survivors' topic guide

The topic guide for stroke survivors (Appendix 15) began with basic descriptive questions to establish the interview style and build rapport before shifting to the main topics of the interview (Miller and Crabtree, 1999). Thus, stroke survivors were first asked 'How are you doing' and 'kindly tell me briefly about yourself and the people with whom you reside'; following these initial questions to help establish rapport and to relax the stroke survivor in the interview, questions were asked about their experiences, views, and thoughts about having a stroke and the information they needed to self-manage.

The topic guides covered a range of areas of stroke-related questions, including:

1. Stroke survivor's background and experience with stroke;
2. Post-stroke information;
3. Patient's participation in the trial;
4. Booklet, content, and delivery (for the intervention group only).

People with stroke were asked about their understanding of stroke and how it had impacted their lives. Asking participants to describe their opinions and thoughts about a condition effectively gets them to think freely. It prevents restricting their responses to what they assume the condition is and its impact on them (Miller and Crabtree 1999). The purpose of these questions was to gather information on stroke survivors' experiences, thoughts, and needs to refine the information booklet. It was essential to explore what the stroke survivors experienced, what information they needed to self-manage and their motivation for joining the feasibility trial.

#### 5.4.2.4 Family caregiver topic guide

The family caregivers were asked the same questions for the first time as those asked the stroke survivors to help establish rapport and settle them for the interview. Subsequent questions were asked about their experiences, views, and thoughts of caring for a stroke survivor, the information they received and the information they need to support their care for the stroke survivor, and their motivation for joining the study. Family caregivers in the intervention group were also asked if they would have liked anything included in the information booklet. See Appendix 16 for the interview guide for family caregivers.

The topic guide for the family caregivers discussed the following topics:

1. Background and experience in caring for the stroke survivor;
2. Post-stroke information;
3. Participation in the trial;
4. Booklet, content, and delivery (for the intervention group only).

#### 5.4.2.5 Nurse topic guide

The nurses were asked about their professional background and roles in the care of stroke survivors. Questions asked included their views and thoughts on providing post-stroke education as part of routine nursing care.

The interview topic guide covered the following topics:

1. Professional background;
2. Experience in stroke care, participating in the trial and delivering the post-stroke intervention;
3. Facilitators and barriers to the successful delivery of post-stroke education in routine activities.

The final interview topic guide for the nurses is seen in Appendix 17.

#### 5.4.2.6 Piloting of interview guides

Pilot interviews with a stroke survivor, family caregiver and a nurse were conducted. This was to facilitate an appropriate and easy understanding of the topic guides by both the interviewer and the respondents. The pilot interviews provided valuable feedback on the relevance and ease of understanding of the topic areas within the interview guides.

After the pilot interviews, minor revisions were made to the interview topic guide. The revisions included adding extra cues about support for stroke care information, and advice on recovery and rehabilitation for stroke survivors. Revisions made for the family caregivers included adding more cues about caring for a stroke survivor. There was no revision made to the nurses' interview guide.

The data collected from the pilot interviews with the stroke survivor and the family caregiver were not included in the data analysis. This was because the duration of the interviews was short, and there was not enough data captured by the estimation of the researcher. The nurse's pilot interview data was not added to the data analysis because the nurse interviewed was not among those selected to assist in the intervention and, therefore, was not part of the study.

### 5.4.3 Sampling

#### 5.4.3.1 Sample size

In qualitative research, sample sizes are not determined by any statistical calculations but are generally determined by the research aim and other factors, such as the depth and duration of each interview and the practicality of conducting the interviews (Britten, 2006). Baker and Edwards (2012) found in a review undertaken with qualitative research experts and early career researchers that the optimum number of interviewees to be included in a particular study depends mainly on the research aims and objectives. Other factors that need to be considered are the time and resources available to conduct the research. Individual semi-structured interviews usually take place once with an individual and typically last from 30 minutes to several hours (DiCicco-Bloom and Crabtree, 2006).

Based on the research objectives and the fact that this was a component of a larger study, a sample size of 15 participants was proposed for the interviews. These were six stroke survivors/family caregiver dyads (three dyads each from the two arms of the trial) and three nurses who helped provide the post-stroke education intervention. In part, the proposed sample was limited due to practical considerations regarding how much time was available to conduct and analyse the interviews. Similar small sample sizes have been reported in other studies that have successfully informed the development of interventions that have been used in RCT (Murphy et al., 2008; Jerson et al., 2013).

#### 5.4.3.2 Sampling strategy

A purposive sampling technique was initially considered. However, it was not practicable to purposively select participants because of the small population from which the sample was selected. As a result, the researcher used convenience sampling. Convenience sampling is a type of nonprobability sampling where members of the target population that meet specific practical criteria, such as easy accessibility, geographical proximity, availability at a given time or the willingness to participate in the study, are selected (Etikan et al., 2016).

For this interview, a convenience sampling approach was to ensure that interviewees who were willing and prepared to share their experiences and thoughts were invited from both arms of the trial, both genders (male and female) and different age groups (Green and Thorogood, 2004). Participants were invited to join the qualitative study after completion of follow-up in the feasibility trial.

#### 5.4.3.3 Identification and selection of participants

Stroke survivors and their family caregivers were initially identified and recruited for the feasibility trial and were informed about the qualitative interview. A detailed presentation of the study's identification and selection of participants is presented in Chapter Four, section 3.5.4. After the three months follow-up, the researcher reminded the stroke survivors and their family caregivers about the interview and invited those who were prepared to share their experiences to participate. The participants were selected from each feasibility trial arm (intervention and control groups). As discussed

above, the three nurses were selected as they helped administer the post-stroke education intervention in the feasibility trial.

### 5.4.4 Study participants

All the trial participants who had completed follow-up were approached and invited to participate in the interview. However, those who were not available for the face-to-face interview, were unwilling to share their experiences and had no time for the interview were excluded. Those who agreed were interviewed immediately after the outcome assessment. However, alternative times and places were scheduled with those who preferred this.

All participants consented to be interviewed as part of the qualitative research when they were initially recruited into the trial. Therefore, when respondents were identified for the interview, they were reminded about the initial consent and asked to consent to the interview only verbally. The nurses provided written consent since they were recruited at the first instance for the qualitative study. At the be

ginning of each interview, consent was obtained to audio record the conversation.

### 5.4.5 Interviewing procedures

#### 5.4.5.1 Stroke survivors and their family caregivers

The interviews were conducted in English or Twi for participants who could not freely express themselves in English. It was impossible to offer telephone and video call interviews since these options were not practicable at the setting due to poor network connectivity. However, participants had the choice of location and a convenient time. All stroke survivors and their family caregivers were interviewed privately on an individual (one-to-one) basis on the same day but at separate times.

Before start each interview, the researcher repeated the purpose of the study and allowed participant to ask questions. The researcher explained to participants that the interview was strictly confidential and information regarding personal details was anonymised. Thus, any opinions that they shared would not be attributed to them. It was explained that the interviews would be recorded, and the information collected would be transcribed verbatim. Participants were also informed that anonymised direct quotations might be taken from the interview and used in the study reports. The

interview topic guide was used to guide the conversation described above. This included asking follow-up questions to explore particular issues of interest if they arose in the discussion. For instance, a participant talked about how neighbours reacted to her condition (stroke). In order to understand more of the issues, the researcher deviated from the topic guide and asked follow-up questions for clarification.

A digital audiotape recorder was used to audio record all interviews after obtaining verbal consent from participants. There was no time limit for interviews, but most interviews lasted between 30 and 45 minutes.

#### 5.4.6.2 Nurses

The three nurses' interviews were completed face-to-face in English using the topic guide. Interviews with nurses were arranged after the last participant follow-up in the trial and at a suitable time. The researcher conducted all three interviews in a quiet meeting room at KATH and was audio recorded after written consent was obtained. Each interview lasted between 30 to 40 minutes.

### 5.4.7 Data analysis

#### 5.4.7.1 Transcription

Except for the three nurses and four family caregivers' interviews in English, all interviews were completed in Twi. Following the interviews, the seven interviews conducted in English were transcribed verbatim by the researcher after repeatedly listening to the voice recordings to check and confirm accuracy of the transcripts. This practice is typical before data analysis to improve the reliability and the accuracy of the transcribed data since inaccuracies can affect the reliability of the analysis and findings (Stuckey, 2014). Bailey (2008) indicated that transcription "involves close observation of data through repeated careful listening, and this is an important first step in the data analysis" (pg. 129). The interview recordings were, therefore, repeatedly listened to in full, then listened to again in conjunction with reading the written transcripts to gain a clear overview of the specific emphasis and meanings that the interviewees attributed in their interviews.

The interviews carried out in Twi were transcribed and translated into English by a Twi expert (lecturer in linguistics) who was also fluent in English. Translation between

languages may hinder the interpretation of the meaning of participants' experiences and result in the loss of meaning of participants' actual words, which decreases the overall rigour of the qualitative study (van Nes et al., 2010). Back-translation translates the target language (English) back to the source language (Twi) to assess the equivalence of the two language versions. It is the most common and rigorous procedure to validate the conceptual equivalence of the translation (Lopez et al., 2008). Nevertheless, some critiqued the back-translation approach for its basis in positivism, such that 'research is language free and that the same meaning in the source language can be found in the target languages' (Larkin et al., 2007, p.469). Others argue that its focus on linguistic equivalence rather than conceptual equivalence can be problematic (Jagosh and Boudreau, 2009). Squires (2008) argues that back-translation does not necessarily enhance the trustworthiness of reported findings more than an independently critical review by a competent bilingual individual.

Time and financial constraints prevented the back-translation. However, it was essential to engage the services of a bilingual competent individual to transcribe and translate the interviews completed in Twi to enhance the accuracy of the reported findings (Squires, 2008). This had the advantage of translation consistency and improved conceptual congruency. Maintaining conceptual equivalence of participant views was the most important consideration in the translation process, as the quality of translation can considerably affect data analysis and findings (Squires, 2009). After the transcription, the researcher reviewed and checked each transcript for accuracy against the audio recording. The researcher corrected any identified inaccuracies. All the identifiable details of participants were removed from the transcripts, and pseudonyms were assigned to ensure anonymity. The anonymised transcripts were uploaded into a project folder in QSR NVivo 12 and analysed.

#### 5.4.7.2 Rigour/ Trustworthiness

Researchers use several methods or approaches to ensure quality in research inquiry. Quantitative researchers dwell on reliability and validity, while trustworthiness or rigour has generally been used by qualitative researchers (Vaismoradi et al., 2013; Shkedi, 2019). Across the world, there have been many frameworks for ensuring quality during qualitative research, yet Lincoln and Guba1985 as cited in (Krefting, 2017), have been widely accepted and popularly used. Their approach rides on four aspects.

**Credibility:** The primary benchmark of rigour is the extent to which the researcher ensures accuracy in interpreting the data to reflect the true nature of the phenomena (Beck and Polit, 2003). Member checks, where transcripts are sent back to the participants for verification and amends, are elements of ensuring credibility. The researcher undertook member checks for all the nurses, 3 dyads of the stroke survivors and family caregivers. No differences were noted from these checks. During the interview, also words/phrases which were doubtful to the researcher were verified with follow-up questions. Peer debriefs were also conducted with colleagues and academic supervisors to ensure credibility. An audit trail was also conducted by another faculty (academic supervisor) of all research approaches, protocols, and materials in this study.

**Dependability:** refers to approaches to ensure consistency and stability in the approach to the research as time and conditions change (Creswell, 2013). The interview guides were comprehensively structured to capture adequate information to answer the research objectives. Conducting a pilot also allowed for amending it to ensure accuracy and reliable information was collected.

**Confirmability:** ensuring objectivity in data where two or more people achieved congruence. As indicated, the study was approached with openness and had quality checks from academic supervisors and other experts. Before the inquiry, the researcher stated his prior knowledge, ideas and superstitions about the phenomena and departed from same during the study. As such, bracketing was done to ensure no biases were introduced. During coding and generating themes the researcher had this objectively complemented by academic supervisors to ensure confirmability.

**Transferability:** generalisability of data denotes the ability of the findings of a study to be transferred to other settings/populations of similar contexts. Lincoln and Guba expressed the need for vivid and detailed descriptions of all the processes involved in the study for easy transferability and usage of the findings and data (Yin, 2016). As such thorough descriptions of the setting, design, summary of protocols and participants, and the processes and transactions during this inquiry, have been detailed. This will allow other people to replicate the study and use the results.

### 5.4.7.3 Thematic analysis

Following the processes described by Braun and Clarke (2006), thematic inductive analysis was conducted following the six stages. The process of thematic analysis is non-linear and recursive, enabling researchers to move back and forth between the phases. This process begins with identifying of themes and patterns and ends with reporting the content and meanings of patterns as described in the following stages.

**Stage one**: **Familiarisation with the data:** This stage involves the researcher becoming familiar with the data by repeatedly listening to the audio recordings and reading the transcripts in full. All the recordings of the interviews listened to several times, and each transcript was read several times. During this stage, initial notes were made as ideas emerged, and particular sections of interest were highlighted for close attention and scrutiny

**Stage two: Generating initial codes:** In the second stage, the data were coded, and all items relevant to the aims and objectives were given an initial code. Each script was read through, with each text segment of the same interest assigned a code that could potentially form the base of a theme. The coded text segments were highlighted, and a brief description was written next. Text segments assigned the same or similar codes were then grouped in a separate document.

**Stage three: Searching for themes:** In the third stage, items were grouped based on the initial codes. At this stage, codes were amalgamated or re-named to form initial patterns based on groups of codes that formed the initial themes.

**Stage four: Reviewing themes:** The themes were checked and cross-referenced to the initially coded extracts during this stage. Themes were reviewed and examined against the data to ensure that they were valid and represented the data. Themes were checked to ensure that they captured the ideas contained within the codes and that the meanings were coherent. The nature and the relationships between the themes were defined. Codes that did not fit within the identified themes were discarded.

**Stage five: Defining and naming themes:** The themes were defined and named in the fifth phase. A detailed analysis of each theme was conducted, and the ‘essence’

of each theme was identified. Definitions of the themes were determined by identifying the narrative of each theme and its significance.

**Stage six: Producing the report:** The sixth and final stage involved writing up the findings and refining the content and names of the themes. It involves constructing the analytic narrative and data extracts together. Representative quotations were selected to illustrate particular themes from a variety of participants. The aim was to tell the reader a coherent story about the data.

#### 5.4.7.4 Data management

Transcripts were assigned a unique identification number, which corresponded to the relevant number of the audio recording. The data was stored and managed in a qualitative software package (QSR International's NVivo 12), which was used to systematically code each transcript and relevant information from the researcher's field notes.

After repetitive reading of the transcripts, initial codes were identified by the researcher, and then one of the researcher's supervisors (PC) reviewed the codes. The researcher and PC reviewed, revised, and agreed on the codes. The researcher identified potential main themes and subthemes, which were then reviewed and refined with PC. Definitions of the themes were agreed upon with PC and the researcher's supervision team.

#### 5.4.7.5 Being an 'insider'

This research was carried out in a hospital where the researcher was trained as a nurse and worked part-time. The benefit of this was that the researcher was conversant with the study setting and understood the culture and context within which stroke survivors and family caregivers are treated. Notably, the researcher was able to initiate and establish a researcher-participant relationship with mutual trust and confidence through continual support from colleagues. Such an insider position provides an understanding of issues in the establishment (DeLyser, 2001; Galea, 2009). Conversely, the insider researcher position has its weaknesses. The prior knowledge and personal experience of working in the hospital indicated that 'taken for granted' assumptions may limit the researcher's ability to further explore the meaning or understanding of the phenomenon being studied and this can lead to some

significant issues being overlooked when analysing the interview data (Asselin, 2003). Understanding these advantages and disadvantages can, to some degree, help reduce the possible side effect of being an ‘insider’, better understand individual experiences in a particular context, and improve the trustworthiness or credibility of the qualitative study (van Heugten, 2004).

It was essential for participants to be able to describe their experiences in the context of their culture, as well as their characteristics and background from their perspectives. Throughout each interview, the researcher endeavoured to create an enabling atmosphere for participants to talk freely and openly about their experiences of stroke and participation in the research, and share their information needs. The researchers used an individual semi-structured interview approach to collect data. This approach offered a flexible medium of communicating freely about the topics of interest between the respondents and the interviewers (Anyan, 2013). In a face-to-face interview format, respondents were encouraged to speak candidly.

The researcher needed to sustain the interview situation by influencing the interviewees to stay and respond to the questions. As required of interviewers, the researcher attempted to build a healthy rapport with interviewees. So, after explaining to the interviewee why the researcher needed to record, the interviewees agreed to continue. Importantly for the researcher was that the interviewees for the study were convalescents. Therefore, it was important not to pressurise or coerce them during the interview to disclose sensitive information (Karnieli-Miller et al., 2009). As much as possible, the researcher endeavoured to enhance the rapport by discussing his academic background before each interview. This not only served to ease the tension which might have built up between the researcher and participants but also re-echoed the position that the researcher was only a student and not a medical officer. The interviewees were also given a chance to have a conversation with the nurse in charge to relieve any sense of emotional insecurity after the interviews (Brinkman and Kvale, 2005).

The researcher, as the interviewer, had to offer plausible explanations for the interviewee to relinquish the attempt at discontinuing the interview session so that the researcher could get the needed data. Consequently, it is evident that interviewees also determine the level of cooperation, the progression and the success or failure of

the interview. On the other hand, participants understanding that this research was conducted by a PhD student from a university in the UK and becoming used to the researcher may impact some participants' perceptions or expectations of the research study and the researcher. Consequently, participants' explanations may have been influenced subtly.

From the researcher's viewpoint, his previous knowledge and prejudiced thoughts about the study settings and friendship with the participants were considered an advantage rather than a disadvantage. A key concern was recognising ways to employ his 'insider' position to enhance rather than impede insights. The researcher has tried to detach his own experiences and previous assumptions from describing participants' experiences and perceptions in the data collection process and subsequent analyses. Though the researcher is linked to the culture and study settings, the researcher consciously consistently reported and interpreted the findings in an unbiased manner.

#### 5.4.7.6 Presentation of themes

Interviews with stroke survivors, family caregivers and nurses were treated as separate datasets and analysed separately. Stroke survivors' interviews were analysed first. However, during this dataset's analysis, similar themes emerged to those in the caregivers' interviews. Therefore, merging the findings from the stroke survivors' and family caregivers' interviews and presenting them simultaneously was considered. However, the decision was made to present the findings separately for clarity.

### 5.4.8 Ethical considerations

Prior to the interviews, ethical approval for the study was granted by the Committee on Human Research Publication and Ethics (CHRPE) of the School of Medical Sciences (SMS) at the Kwame Nkrumah University of Science and Technology (KNUST), Kumasi – Ghana alongside the feasibility trial. Following the research governance procedures, management permission was obtained from KATH. There were particular ethical considerations in the qualitative study relating to interviewing people with stroke. Firstly, while talking to stroke survivors and their family caregivers about stroke, some became emotional as they recounted their experiences of stroke during the interview. Participants were reminded that if they did not want to discuss

sensitive experiences, they had the right to decline and discontinue the interview whenever they felt distressed. Although using interviews to explore the thoughts of patients and their family caregivers is sometimes known to be therapeutic as it offers an opportunity for people to share their problems (Gysels et al., 2008), this was not the researcher's intention for using interviews. Being nurses, the researcher and his assistant have the expertise to debrief after an interview of a distressed participant. The researcher followed distressed participants up through a phone call to find out how they were doing later. No participant needed the services of a professional counsellor, but if they did, there were plans to refer them to the attending physician or the nurse in charge for further action.

The second issue is holding interviews with participants at their homes. There is currently no law in Ghana barring this practice, but the researcher did so with some risk. The researcher ensured his safety throughout the home interviewing by maintaining a log and notifying someone each time he went to a participant's home and when he was expected back. Again, a similar procedure was used for the interviews at KATH. The hospital was familiar to the researcher and did not raise many personal safety issues. The researcher always carried his identification cards (students' and insurance ID) and showed them to participants on request.

There were also ethical considerations about collecting and storing voice recordings and transcripts. This was carried out under the Data Protection Act (1998); research governance protocols and data were stored securely and encrypted on a password-protected server. Any information which could identify participants was removed from the transcripts and has not been included in the written report. Participants were made aware of these aspects through the Participant Information Sheets (Appendix 4), and participants agreed to this by giving verbal consent.

## 5.5 Summary of chapter

This chapter explains the methods used in the qualitative research phase of the study. It presented the justification for using a qualitative interview study design and the interview procedures. A one-on-one semi-structured interview approach was used to collect data from participants. All transcripts were analysed using an inductive thematic analytic approach. This technique is used to interpret identified logical patterns (themes) from within the data rather than using a predetermined coding system. The

data analysis was in keeping with Braun and Clarke's (2006) approach. First, the researcher read each transcript thoroughly and noted potentially important codes. Second, the researcher reread the codes and organised them to understand the experiences of stroke and information needs. Third, the researcher grouped codes to develop sub-themes of related ideas, and these were refined back and forth to create themes that interpret the data. Finally, all the themes emerging from the data were reassessed. The next chapter presents the findings from the qualitative interviews.

# Chapter Six

# Post-stroke education in Ghana: Qualitative findings and discussion

# 6.1 Introduction

This chapter presents the interview findings. The purpose was to explore the experiences of stroke and participation in the feasibility RCT as well as the nurses' perspectives on post-stroke education in Ghana. The chapter begins with the characteristics of the stroke survivors, and the subsequent sections present the findings related to family caregivers and nurses. The findings are presented in themes and subthemes with narrative descriptions and explanations of each theme's focus and content. Interviewees' quotes have been used to illustrate and support the themes, and subthemes presented.

# 6.2 Interviews with stroke survivors

## 6.2.1 Stroke survivors' characteristics

Participants for the interview were drawn from 38 stroke survivors who completed the outcome assessments for the feasibility trial. Of these, 19 received the post-stroke education intervention and 19 received usual care only. A total of six participants were recruited, comprising three from each arm of the trial. The remaining 31 stroke survivors did not participate for the following reasons: six were not willing to share their experiences about stroke, four had no time for the interview, six had travelled outside the region and were not available for the interview, and five did not respond to the telephone call placed by the researcher, one participated in the pilot interview, four had communication problems and five declined the interview without reasons.

Table 6.1 provides a summary of the key characteristics of the interviewees. A one-to-one interview was conducted privately with each stroke survivor, ranging in length from 30 to 40 minutes. For participants' anonymity, each interviewee had a pseudonym to conceal their identity. Stroke survivors' ages ranged from 51 to 61 years, with a mean age of 56. Only two stroke survivors were above 60 years old, four males and two females. Only males from the intervention group were interviewed because they were available to share their experiences with stroke and the intervention with the researcher. In terms of the duration of stroke since diagnosis, three interviewees had their stroke less than six months prior to the date of enrolment in the study, one between six and 12 months, and two had their stroke more than 18 months previously. Of the six stroke survivors, one was employed as a teacher,

another was a retired driver, and the others were self-employed; two were traders, one worked as a construction contractor, and one was a tailor.

### Table 6.1: Characteristics of stroke survivors interviewed

| Participant | Age in years | Gender | Employment | Treatment group | Time since stroke in months |
|---|---|---|---|---|---|
| **Papa** | 61 | Male | Trading | Intervention | 4 |
| **Nana** | 58 | Male | Construction contractor | Control | 6 |
| **Ama** | 53 | Female | Trading | Control | 18 |
| **Adwoa** | 56 | Female | Teaching | Control | 21 |
| **Ohene** | 61 | Male | Retired driver | Intervention | 2 |
| **Agya** | 51 | Male | Tailor | Intervention | 9 |

## 6.2.2 Themes and sub-themes

The analysis of the interviews identified four key themes. These themes were generated from related codes that reflected the descriptions of the experiences and information needed after stroke. Participants needed information to assist them in making sense of what had happened; living with stroke in the long term, addressing a lack of understanding about recovery and avoiding the risk of further strokes; and meeting their desire for stroke information. Table 6.2 shows an overview of the themes and sub-themes that emerged from the interviews.

### Table 6.2: Themes and sub-themes for stroke survivors

| Themes | Sub-themes |
|---|---|
| **1. Making sense of what happened** | 1. A stroke is a traumatic experience<br>2. Lack of prior knowledge of stroke<br>3. Delays in a formal diagnosis |
| **2. Living with stroke in the long-term** | 1. Feelings of weakness and reduction in mobility<br>2. Reduced employment prospects<br>3. The impact of superstition and the subsequent stigma<br>4. Acceptance of the condition and recovery prospects |
| **3. Lacking understanding about recovery and avoiding the risk of further strokes** | 1. Poor level of current knowledge<br>2. Failure to proactively seek information<br>3. Current education provisions are not structured<br>4. A desire for recovery |
| **4. Desiring stroke information** | 1. A desire to learn<br>2. Viewing the trial as a source of information<br>i. Increasing personal understanding<br>ii. Impact limited by written format<br>3. Viewing the trial as an opportunity to generate information for others |

## 6.2.3 Theme 1: Making sense of what happened

All six interviewees shared unique experiences about stroke and needed information to understand what happened to them. Their experiences were predominantly traumatic, and they lacked previous knowledge of stroke. The delays in formal diagnosis caused anxiety among interviewees.

### 6.2.3.1 A stroke is a traumatic experience

All participants developed sudden loss of body function, raising concerns about what had happened to them. The sudden inability to walk, speak, and carry out activities of daily living such as using the toilet and bathroom independently was seen as an extraordinary manifestation of the disease. After a stroke, participants' lives changed, and this made them anxious about their situation. They believed no one understood their situation and needed information to understand what had happened. This was

because the interviewees poorly understood the effects of stroke, although they described it as terrible and disruptive. All the stroke survivors recognised stroke as a 'serious' or 'bad' disease based on their experiences. One interviewee (Ohene) described stroke as a 'troublesome' illness because he could not do most of the activities he used to do before the stroke. As a result, participants were anxious about post-stroke disabilities and wanted practical information to self-manage. The excerpts below are examples of the traumatic experiences of some interviewees.

> *"Stroke is a disease that slows down your progress in life because it makes half of your body functionless. When I first had it, I could not sit for long without feeling pains in my buttocks. When I needed to use the washroom, I could not even sit on the toilet seat... ….. So, stroke is a serious disease, and you may not understand how it is until it affects you". (Agya)*

> *"Oooh, stroke is a bad disease, you cannot do anything when you have it, you become so weak. ……., it is bad. Stroke is not good…..".(Papa)*

However, one participant who had a 'mild' stroke reported a less painful experience. The stroke had less impact on his life, but he still had to adjust to his normal life pattern.

> *"It is not so much of a change. The only thing I used to do is not to stay out as long as I did. I can do everything I need to do. I just have to come home by 3 pm to eat and go for a walk. Latest by 6 pm I return home".(Nana)*

Although participants explained how stroke started, their descriptions showed a poor understanding of stroke symptoms, as discussed in the following section.

#### 6.2.3.2 Lack of previous knowledge of stroke and the risk factors

All six interviewees had good memories of how their stroke started but poorly understood what was happening to them. At the start of the stroke, participants reported headaches, changes in speech, and weakness of a limb with general bodily pains. However, no interviewee linked these symptoms to a stroke, even with the loss of speech and body weakness. Conversely, participants thought these symptoms resulted from fatigue or infections such as malaria. Medical treatment was, therefore, delayed with the expectation that the symptoms would resolve. However, the symptoms worsened. One interviewee deferred treatment at the beginning, thinking that the symptoms were a result of a minor illness until he had a loss of speech.

*"On one Wednesday, I did not feel well, but I did not take it seriously because I thought it was malaria or any of those usual illnesses that will resolve. I decided to rest on the bed for a while, and suddenly, I felt restless and awkward about my body in a way I had never felt before. I told my wife that am not feeling well, and she replied …."you like to complain a lot…..". My speech began to change when I tried to respond to her, which is how the sickness began". (Agya)*

Another participant had dizziness while carrying out her laundry but decided to rest, thinking the dizziness would resolve. However, the situation worsened, and she could not speak and lift her leg and arm. Although the family immediately took her to the hospital, the participant and the family had a poor understanding of stroke symptoms. The participant explained that she had seen people with stroke, but she could not relate what was happening to her as a stroke, suggesting that she had no previous knowledge of stroke.

*"I was washing my clothes in front of the house, and I had some flashes (dizziness) ….. I laid down for about 10 minutes and later wanted to use the washroom, but I realised I couldn't raise my right hand and couldn't lift my leg. Unfortunately, I could not talk too. All this time I did not know what was happening to me".(Adwoa)*

Except for one participant, all the participants recognised that hypertension or diabetes preceded stroke but lacked the understanding that these were chronic conditions and needed long-term management. For example, participants reported high blood pressure (hypertension) or diabetes prior to the stroke. However, some did not get treatment, while those on treatment stopped the antihypertensive medication. One participant acknowledged that he did not go for hypertension treatment because he had a limited understanding of hypertension control and stroke. This individual explained that having relevant information about stroke and knowing about hypertension and other stroke risk factors would have enabled him to take steps to control hypertension to avoid the risk of stroke.

*"That was one of the mistakes I made; one nurse told me that I should go and consult a doctor for the medication (antihypertension), but I did not listen to her advice. If I had gone to the doctor for antihypertension medications, I would*

*have taken steps to take care of my health, I would have avoided certain things that can lead to stroke….".(Agya)*

Another interviewee, while on antihypertension medication, discontinued the drugs as she was unaware that hypertension required long-term management. For this participant, hypertension was a spiritual disease; she thought she needed spiritual healing and traditional medicine to cure it.

*"I had high blood pressure, so I was on antihypertension drugs, but I stopped taking the medications because I felt I could not live on drugs for the rest of my life. I rather resorted to prayers, traditional remedies and other spiritual activities until stroke struck me".(Ama)*

The interviews showed that stroke survivors had a poor understanding of what happened, for they lacked knowledge of stroke. For instance, while all six stroke survivors experienced early symptoms, they did not associate them with medical emergencies. Providing stroke survivors with information on their symptoms and risk factors would assist them in monitoring and avoiding the risk factors to prevent stroke or seek early medical treatment after stroke.

### 6.2.3.3 Delays in a formal diagnosis

The poor understanding of stroke resulted in the late presentation of stroke survivors to the hospital, which delayed the formal diagnosis of stroke. The timing for obtaining a formal diagnosis and treatment depended on the stroke survivor's arrival at the right treatment centre and the readiness of the attending physicians and nurses to communicate the diagnosis. Deciding to defer medical treatment because the participants did not recognise stroke symptoms as medical emergencies meant a delay in reporting to a medical facility. Five of the six participants reported visiting the nearest healthcare facility more than 12 hours after noticing the stroke symptoms. This practice, they explained, was due to the lack of understanding of stroke symptoms. One interviewee, for example, visited a clinic more than 12 hours after realising that he was 'feeling sick' and had some weakness in his arm.

*"I began to feel sick and decided to go home. I felt my hands could not control my car's steering wheels so well on my way to driving back home. I informed my wife when I arrived home how I felt, and she asked me to rest until the*

*next morning because she suspected it could be due to fatigue. However, the situation did not change, so we walked to the nearby clinic the next morning".(Nana)*

The lack of capacity for primary and some secondary healthcare facilities to handle stroke was a barrier to obtaining a formal stroke diagnosis. Most participants sought medical treatment at local healthcare facilities immediately after stroke, but these facilities lacked the expertise and equipment to diagnose stroke. Additionally, participants were detained in these facilities due to misdiagnosis or lack of transport to convey stroke survivors to the teaching hospital - KATH, where more appropriate stroke care was accessible. The following excerpt is from a participant who described her delay in reaching KATH for a timely diagnosis.

*"I was rushed to the nearby clinic where the nurse on duty assessed me and referred me to KATH. Arranging for a taxi to KATH took us some time. I was seen at the emergency department at KATH and then transferred to the stroke unit where I got admitted for approximately three weeks".(Agya)*

One interviewee (Ama) declined admission to a private hospital and had outpatient treatment. The doctor had misdiagnosed and treated her for a different disorder. However, her condition worsened, and she was rushed back to the same hospital the following day, where she was later transferred to KATH. The lack of stroke awareness among healthcare workers and treatment protocols hindered the recognition of stroke symptoms.

*"…….so, the next morning it was getting worse I was now speaking through my nose, so my husband took me back to the hospital. I was admitted when we got there, and I could not stand on my feet. People who came to visit me suggested my husband take me to KATH. So, an ambulance brought someone to the hospital, and we asked them to take us to KATH".(Ama)*

Only one participant (Adwoa) was taken directly to KATH after her family noticed that she could not talk and had both arm and leg weakness.

Although all six participants got admitted to KATH, where there was the capacity to produce a formal stroke diagnosis, disclosing the diagnosis to stroke survivors and their families was delayed. Some participants only knew they had a stroke after

being informed by people other than the attending physician and nurses. For example, two stroke survivors were informed about their stroke at the physiotherapy department.

> *"….it was after I went to KATH, the physiotherapy department. They saw me and informed me that I had a stroke".(Papa)*

> *"…, for about a week, I was admitted to the hospital, nobody informed me that I was having a stroke. Some physiotherapists came to do the exercise for me, and I realised it was a stroke".(Adwoa)*

Another participant was also transferred to KATH without any information about his diagnosis.

> *"When I visited the nearby hospital, the doctor did not tell me what was wrong; he only checked my blood pressure and gave me drugs. The only thing I saw was that my brother came around and took me to Komfo Anokye (KATH)".(Ohene)*

The use of an ambulance to transport emergency patients is uncommon in Ghana (Mould-Millman et al., 2015). As a result, family members arranged either private or commercial transport such as a taxi to convey participants to the nearest healthcare facility before being transferred to KATH. All the formal stroke diagnoses were made in KATH, and appropriate stroke treatment commenced.

## 6.2.4 Theme 2: Living with stroke in the long-term

All six participants' accounts of life after a stroke provided insight into their life-challenging situations and demonstrated that they needed practical information to assist them in self-management. The interview data revealed five factors contributing to the long-term impact of living with stroke: feelings of weakness and a reduction in mobility; reduced employment prospects; acceptance of the condition and recovery prospects; and the impact of superstition and the subsequent stigma.

### 6.2.4.1 Feelings of weakness and a reduction in mobility

A significant impact of stroke occurred from impaired mobility due to body weakness. Interviewees talked about frustration and anxiety due to the inability to move certain body parts, such as the arms and legs. Five of the six participants described various

forms of post-stroke physical weakness and wanted information to help them decide on treatment. Stroke survivors expected quick restoration of functional activities and were frustrated if this was not achieved. This frustration sometimes prompted stroke survivors to 'shop' for healing between traditional herbal medicine and faith healers who promised them a cure and quick recovery. One participant describes his situation below.

> *"Look at my situation, stroke attacked my hand; this my hand has been rendered weak, it is bad. I wish I could get other treatments (herbal medicine) to bring back my hand to life (active) quickly". (Papa)*

With the feeling of weakness, one of the stroke survivors felt his energy levels were reduced, significantly reducing his work output. He attributed his inability to work for long hours on the farm to stroke and explained that his inability to work as before was a source of depression and anxiety.

> *"Now, when I go to the farm, I cannot work for long hours. The little thing I do I get tired, and once you get tired, you have to stop. But previously, I could work from morning until 12noon before I break, resume after 3 pm and leave the farm at 6 pm for home. However, for now, when I go to the farm, I can only work up to 10 am or 11 am, and I will be tired …. This is a source of worry to me as I don't know what to do".(Ohene)*

Other challenges stroke survivors were confronted with due to impaired mobility were the inability to move freely in their environment and to access public transport and buildings. Stroke survivors described the difficulties and frustration they experienced when moving around in their homes or places they wanted to visit, buildings and using public transport. Moving to places including the hospital for medical reviews was expensive as participants depended on the services of taxis since they could not board the vans (popularly called trotro), which are the common vehicles for intra-city transport in Ghana. Three interviewees shared these difficulties despite varying degrees of restricted movement (two could move within their homes and the other was chair bound and unable to stand on his feet). One stroke survivor shared his distress at being unable to walk to places he wanted to go.

> *"Stroke restricted my movements. Wherever I need to go, especially to the hospital for medical reviews, I have to hire a costly taxi because I cannot board*

*the public transport we have here. I cannot walk to the bus station because of a stroke, I used to walk a lot, but now I cannot do it anymore". (Agya)*

For one interviewee, it was frustrating due to her inability to walk to school and do her usual errands as she did before the stroke.

*"I could move around and go to school. A day before the stroke, I closed the classroom doors, walked to the market, went to the insurance company, and came home. I was just washing the next day, and that was it, I broke down". (Adwoa)*

For the third participant, he was unable to move out of his chair and explained his situation as:

*"….. stroke has rendered me immobile; I cannot go anywhere without assistance, I have to get help to sit in the car, transfer to the wheelchair and move around. I cannot do anything without help". (Papa)*

The loss of mobility meant that most stroke survivors required assistance and support from family members. Providing relevant information, the stroke survivors explained, would enable them to share in decision-making on their care and improve their confidence in coping with the disabilities. In addition, these weaknesses and reduced mobility affected the employment prospects of stroke survivors, as discussed in the following section.

### 6.2.4.2 Reduced employment prospects

The reduced prospect of employment was one of the impacts of living with stroke in the medium to long-term. Interviewees expressed anxiety over the inability to work after stroke, which affected their income. Three of the six interviewees reported that they could not continue their trade after a stroke and were worried about their business. Since this was their business, the inability to manage it after a stroke resulted in financial losses. The inability of participants to engage in regular income-generating activities was of particular concern to them, as their business funded their medical treatment. One participant stated that his business was ruined because he was 'down with stroke' and was not around to manage it.

*"I am here though, but I cannot work. When I left my shop due to stroke, many issues came up. The caretakers thought I was going to die, so they mismanaged my business ….". (Papa)*

Another participant shared his inability to continue his job because of a stroke.

*"Before I had the sickness, I used to be a tailor, sew clothes, and this is my shop over there". (Agya)*

This participant pointed to his tailoring shop, which had remained locked since his stroke, and he was worried about when he would be able to resume work. Participants generally expressed anxiety over returning to work due to the fear of stroke recurrence. For instance, one interviewee's husband was afraid she was not fully recovered from a stroke and could suffer a reoccurrence when allowed to continue with her trade and prevented her from working.

*"As for working in the shop, my husband said he will not allow me to work again because of what had happened (stroke) ……". (Ama)*

However, it seems that once the participants became aware of the reality of the impact of stroke on their lives, they wanted practical information to help them identify strategies to overcome their difficulties.

### 6.2.4.3 Acceptance of the condition and recovery prospects

All six interviewees wanted information on strategies to promote recovery. These strategies included knowing about stroke, recovery measures, and reducing the risk of a second stroke. All the participants adapted strategies to promote recovery - two interviewees were ready to comply with medical treatment and instructions to improve their condition. One interviewee was determined to take his medication regularly to promote his recovery.

*"I only accepted it (stroke) as it happened because there was nothing, I could do about it. ….. I am determined to take my medication so that I can recover". (Ohene)*

Another participant came to terms with what had happened to him by accepting stroke as any other medical condition. As a result, he wanted information about healthy eating and lifestyle to prevent another stroke.

> *"I took it (stroke) that it was just like any other sickness that has set in, and it will eventually go, but I needed to listen to the doctor and avoid certain things. It had already happened, so I must avoid certain things. Truly, I used to be someone who consumed a lot of minerals (soft drinks), coke to be precise. …… Because I do not take alcohol, I used to drink minerals frequently". (Agya)*

Agya recognised that unhealthy eating habits, such as consuming a lot of soft drinks such as coke instead of regular meals, are a risk factor for stroke. He also acknowledged that drinking alcohol was a risk factor, and avoiding it could lower his risk for another stroke and improve his recovery.

Another participant adopted a strategy of not thinking about his situation but seeking treatment to facilitate his recovery.

> *"For me, I decided not to think about the situation (stroke) when I realised it was stroke…. I just went to the hospital for treatment". (Papa)*

All the participants were relieved as they noticed signs of recovery, characterised by gaining more physical independence. These signs of relief were shared among participants, even those with some limitations. One stroke survivor recounted that:

> *"I can do most things for myself now. My only prayer is that I should be able to get up and do my daily activities, but my arms and legs are so weak. At first, I could not lift myself, but now I can move bit by bit". (Adwoa).*

Another interviewee also noted the regaining ability to carry out daily activities.

> *"But as for the household chores, I still do it, for instance, cooking and washing my clothing, but at first, I was scared, and I found it difficult to do it. Nevertheless, as time passed, I can now do some things; even when our room or the surrounding are dirty, I can sweep it with a long broom…." (Ama)*

Most of the respondents were also aware that recovery would take time. One participant reported sudden stroke onset, but the recovery was slow.

*"Stroke has affected my life; it is a type of sickness that attacks quickly, but recovery takes longer. For now, I am a bit stronger such that I can perform most of the things I used to do previously". (Agya)*

The interview findings indicated that stroke survivors experienced disabilities that significantly impacted their lives. These disabilities affected their mobility and employment prospects, and stroke survivors found it difficult to adjust to these disabilities. Although the participants accepted the condition and were hoping for recovery, superstition and stigma were challenges they faced.

#### 6.2.4.4 The impact of superstition and the subsequent stigma

In Ghana, stroke is regarded as a spiritual disease, and as a result, people have many misconceptions about it. For instance, a participant's neighbours believed that witchcraft caused the stroke. One participant recounted the gossip and rumours she heard about the cause of her illness and prognosis.

*"……., people were saying my husband had bewitched me ….. Others said my husband has used me for money rituals. ……. Much gossip about my condition was going round in the neighbourhood and beyond". (Ama)*

This participant also explained that her neighbour, who had a stroke before her, had a poor outcome because he could not deal with the neighbours' perceptions and gossip.

*"Because of shyness and stigmatisation, he thinks about had affected his recovery and he remained indoors for some time now. I was not concerned about what people talked about me, and I never listened to the gossip. Even though they said many bad things, I ignored them". (Ama)*

Misconceptions about the causes and treatment of stroke were a great concern for participants, and providing relevant information to improve participants' knowledge of stroke would be an important initiative.

### 6.2.5 Theme 3: Lacking understanding about recovery and avoiding the risk of further strokes

Stroke recurrence is common among stroke survivors. Interviewees were encouraged to discuss their thoughts about stroke recovery and the risk for further strokes. Four

reasons are associated with this theme; a poor level of current knowledge about stroke, failure to proactively seek information, current education provision not being structured and a desire for recovery.

#### 6.2.5.1 Poor levels of current knowledge about stroke

Poor stroke knowledge was common among stroke survivors. Although all the respondents had seen individuals with stroke, they could not relate to what had happened to them after a stroke. For instance, one respondent identified someone with a stroke (because of the physical disability) but recognised that he had limited knowledge about stroke.

> *"I didn't know much about stroke; I only remember my Sunday school teacher had a stroke. He has not fully recovered, which is about eight years now. He was the only person I saw with stroke, but I never approached him to discuss his condition". (Agya)*

Five of the six interviewees shared the same opinion of knowing a relative or neighbour with a stroke but provided accounts that reflected their poor knowledge about stroke symptoms. One participant reported his situation as follows;

> *"I did not know that much, but only when I meet sick people with some form of weakness in their arm or something like that, I know they have a stroke. However, I did not know what exactly stroke was until mine occurred". (Papa)*

Furthermore, this participant had no prior information about stroke and did not know how stroke occurs. Two other stroke survivors reported that they had leg weaknesses and speech changes, but they were unaware that these were stroke symptoms.

> *"When they took my blood pressure, I could not raise my right leg, and my hand was weakening". (Agya)*

> *"I did not know what was wrong because I did not know what the stroke is like". (Papa)*

All six stroke survivors only realised that hypertension or diabetes are risk factors for stroke later and wished they had prior information to enable them to prevent stroke. The excerpt below describes a participant who explained his limited knowledge of

stroke risk factors. For instance, he was uncertain whether hypertension or diabetes caused his stroke.

> *"For me, I do not know what causes stroke exactly; they only say that it is hypertension, and I think diabetes or so brings stroke". (Papa)*

There were some beliefs that stroke was a spiritual disease and caused by evil spirits (demons). Getting a stroke, therefore, was an act vengeance from an enemy or retribution from God. Pastors, prophets, and spiritualists entreated people to pray and perform rituals to revert or get cured of stroke. People at risk of stroke prayed instead of taking control measures to prevent a stroke. A participant initially diagnosed with hypertension stopped taking her antihypertension medications and sought spiritual healing.

> *"A pastor a week earlier told me he had a 'vision' that some 'spiritual forces' would break me down with stroke. So, I was washing on that fateful day to go and meet the pastor who told me about the stroke. I was supposed to meet him at 10:00 am for prayers, but unfortunately, I could not meet him because at 9:00 am, I broke down". (Adwoa)*

Interviewees lacked the understanding that stroke risk factors such as hypertension and diabetes required long-term management. This lack of understanding resulted in the non-adherence to long-term medication to control these conditions, increasing the risk of stroke.

#### 6.2.5.2 Failure to proactively seek information

In Ghana, posters, healthcare providers and families/friends are the most common sources of health information, with radio being the most used medium (Sokey and Adisah-Atta, 2017). People with higher educational status are more likely to access health information using the internet and television (Nangsangna and Vroom, 2019). However, all participants did not deliberately make efforts to look for information from the internet and libraries. Sometimes they listened to health talks and advertisements on radios and television about stroke. The use of the internet for health information is not common among people because of cost and poor network connectivity for those who can use the internet (Nangsangna and Vroom, 2019). Participants reported that they did not look for any additional information besides what they received from the

hospital. One stroke survivor in the intervention group observed that apart from meeting the researcher for the face-to-face discussion of the booklet, he had not looked for information elsewhere about stroke.

> *"I have not taken any other steps to seek additional information about stroke. My encounter with you (researcher), when I started visiting Komfo Anokye (KATH) for my medication, has enlightened me on certain things about stroke". (Agya)*

Another interviewee relied on her husband for stroke information.

> *"For me, I have not made efforts to look for information on stroke, but my husband likes talking with people, so whenever he interacts with people and the topic is on stroke, he asks questions and shares the information with me". (Ama)*

Individual attempts to look for information were generally low, but some participants often listen to adverts from traditional medicine practitioners on radios, television, and other platforms. The use of radio and television is common. Through these media, relevant health information gets to people. However, most radio health talk programmes and advertisements were predominantly on traditional herbal medicines whose practitioners promise a cure for several diseases. One participant mentioned that people selling herbal medicines talk about stroke on the radio.

> *"The people who sell herbal medicine are the people who usually provide this information on the radio,..". (Ama)*

Stroke survivors acknowledged that they received information after the stroke, but this information was not presented in a booklet and was not structured.

#### 6.2.5.3 Current education provision not structured

Participants received information about stroke mostly from nurses and other healthcare professionals in the hospital. However, this information was predominantly on a diet, communicated verbally and not written. Three participants received talks on diet from nurses and a dietician.

*"The nurses taught me something about my eating habit, my failure to exercise regularly and the habit of sleeping right after eating, which was not good practice". (Agya)*

*"…..it was the dieticians who were teaching us about our diet and how to eat healthily. That is the only thing they were telling us". (Papa)*

Participants reported that nurses at the stroke review clinic sometimes provided talks on stroke during medical reviews but did not share written information. These talks were not regular and the nurses on duty determined it. Stroke survivors generally wanted information to support them in self-management.

## 6.2.6 Theme 4: Desiring stroke information

The motivation for all six respondents joining the study was to acquire information to support self-management. Interviewees attributed three reasons for participating in the trial - a desire to learn; viewing the trial as a source of information; viewing the trial as an opportunity to generate information for others.

### 6.2.6.1 A desire to learn

Participants consistently discussed the desire to learn about stroke and its management. Although the desire for information varied among participants, all stroke survivors wanted information on healthy lifestyles. They believed that this would empower them with self-management strategies to facilitate recovery. For instance, some desired to learn about post-stroke dietary management regarding healthy eating and physical activities. Two participants wanted information on diet.

*"Some of the things I wish I knew were the things concerning my eating and sleeping habits because I am someone who does not engage in health walks". (Agya)*

*"…. information about my eating and diet implications, I heard them say that there is certain food that we must eat and others that we must not, so when you do not eat well, it can bring about the disease". (Ama)*

One stroke survivor sought medication information.

> *"…., I wish the doctors explain to me what every medication I am given does to my system". (Agya)*

Another two participants reported that they wanted information to facilitate recovery and prevent further strokes.

> *"I will ask them about what causes stroke, how it can be prevented and how it can be properly managed". (Papa)*

> *"Ooh, once I'm not fully recovered, I would like to have the information I can depend on to help me recover". (Ama)*

### 6.2.6.2 Viewing the trial as a source of information

All three stroke survivors who received the post-stroke education intervention stated that the information helped support them. Although participants reported that the information received increased their personal understanding of stroke, there were also reports of limitations of the written format.

**Increasing personal understanding**

Respondents regarded the intervention as a source of information that increased their personal understanding of stroke. One participant revealed that it was easy to understand the information with a glance through the booklet because all the medical jargon was explained in simple words.

> *"There are certain aspects that are purely medical terms, but you have been able to break it down to our level for us to understand and know what to do". (Agya)*

Another respondent agreed to be part of the trial because he wanted an opportunity to learn and understand the causes of stroke.

> *"I gladly accepted to be part, and I was waiting to find out what the study has to offer. So that I can learn from what causes stroke and how it can be eliminated to relieve humans of its burden". (Papa)*

The third participant deemed the information in the booklet adequate and easy to understand.

*“I feel that what you have done is okay because anyone can take the booklet and read the information to understand”. (Ohene)*

Although all three participants in the intervention group agreed that the trial increased their personal understanding of stroke, they recognised that individuals unable to read in English were disadvantaged.

**Impact limited by written format**

Two of the three participants who received the information booklet recounted varied opinions of the content and layout of the booklet. One participant described the information in the booklet as adequate. Even though he could not read, his brother could read the booklet, and he explained its content to him.

*“Nothing falls short on that document, the other time, even though I could not read the document, my brother explained the information to my understanding of how stroke occurs”. (Papa)*

To make the booklet more user-friendly, a participant suggested that the booklet should be designed with coloured pictures to appeal to users.

*“oh, it was nice, but if you could have made it like this…. (Pointing to a hard paper calendar on his table) with real (colourful) pictures, it will even attract you to have a look at it anytime you see it, that would have been nicer than this”. (Papa)*

In addition, another respondent wanted an audio or video version of the booklet for those unable to read. He implicitly requested the translation of the booklet to audio in the local languages for a better understanding of the information.

*“I will say, not everyone who knows how to read, if you can put it in an audio form like on a compact disc, if you even have to sell it to people, they will buy it. You will only need to explain to people the reason why you are selling the compact disc instead of giving it for free”. (Ohene)*

Generally, all the stroke survivors commented positively on the booklet and considered it clear and straightforward. In addition, participants felt that the intervention provided adequate information and needed no revision. However, one participant

recommended that the booklet's content be expanded to include education on medication.

> *"I believe it is educating us, but if it covers the medication aspect of the disease, it will be helpful to us". (Agya)*

Not only did stroke survivors regard the intervention as a source of information, but they also recognised it as an opportunity to generate information for other people.

**Viewing the trial as an opportunity to generate information for others**

Three stroke survivors accepted that the trial offered them an opportunity to share their experiences with other stroke survivors. Sharing his experiences motivated one participant to join the study. He joined the trial to share his experience developing an information booklet to help prevent stroke.

> *"What you were asking me about my condition and your intention of developing a booklet to provide me and others with information on how to prevent stroke is what I am looking for, and this makes me happy". (Papa)*

Another interviewee shared Papa's opinion, who believed her shared experience would benefit people in preventing stroke.

> *"I believe your interaction with those of us who have experienced a stroke will help you to communicate to others who have not experienced a stroke to take care of themselves in order not to get an attack (stroke)". (Ama)*

This participant further stressed that;

> *"I am happy to be part of this study so that our experience could be used to advise others". (Ama)*

Another stroke survivor felt that the trial was to assist her in getting information on stroke and, in return, share her experience.

> *"To assist me to get information about stroke and also give out my experience that will inform people about stroke". (Adwoa)*

A participant found the interview to be the interesting part of the study since it offered her the opportunity to share her experience that will be used to advise others to help prevent stroke.

*"Sharing our information with people will help them be careful of this sickness because nowadays it is widespread. The last time I was listening to the radio, the health workers: the doctors were saying that there are people who are not even aware they have pressure even though their pressure is very high, so when they are walking and unfortunately fall, they will get a stroke. So, this information will be resourceful for people to take care of themselves well". (Ama)*

Overall, the interviews found that stroke survivors have unmet information needs and had limited engagement with healthcare professionals. The early stroke symptoms were overwhelming and caused anxiety among participants. However, none of the respondents could link these symptoms to a stroke, signifying a lack of prior knowledge of stroke. Stroke was described as a 'bad disease' and perceived as a strange disease because of the disabilities associated with it, which disrupted the lives of stroke survivors. As a result, participants needed relevant information on the causes, management, and strategies to self-manage. For these reasons, stroke survivors were motivated to join the trial to get information to improve their understanding of stroke.

The family plays an essential role in the stroke survivor's life. All stroke survivors relied on their families for reassurance and practical support in their daily activities. In Ghana, where the state does not provide systems such as rehabilitation and community centres to assist stroke survivors, the family plays a significant role in providing care. Providing relevant information to stroke survivors and their family caregivers would be crucial if the family caregivers are to support stroke survivors - the subsequent section reports on the interview findings of the family caregivers.

## 6.3 Interviews with family caregivers

### 6.3.1 Family caregiver's characteristics

Six family caregivers were interviewed one-on-one. These interviews were carried out separately from the stroke survivors' interviews. The family caregivers were drawn together with the respective stroke survivors they cared for and comprised three caregivers from each arm of the trial. Each family caregiver interview lasted between

30 to 40 minutes. Table 6.3 provides a summary of the key characteristics of family caregivers. For anonymity reasons, every family caregiver had a pseudonym.

Except for one family caregiver above 67 years, all the caregivers were below 60 years, with the youngest caregiver being 29. The family caregivers were relatively younger than the stroke survivors. Of the six interviewees, two were males, and four were females. Only one of the caregivers was engaged as a teacher in a private school after retiring from public service, while the rest were self-employed. Three were trading, one was a taxi driver, and one was a farmer. Regarding the relationship with the stroke survivor, three were spouses (wives to the stroke survivors), and one was a brother, sister, and mother. The length of caregiving corresponded with the duration of stroke diagnosis of the stroke survivor at the time of enrolment.

### Table 6.3: Characteristics of family caregivers interviewed

| Participant | Age in years | Gender | Employment | Treatment group | Relationship to the stroke survivor | Length of caregiving (in months) |
|---|---|---|---|---|---|---|
| **Wife** | 47 | Male | Trading | Intervention | Brother | 4 |
| **Nana** | 54 | Female | Trading | Control | Husband | 6 |
| **Nanami** | 29 | Female | Trading | Control | Mother | 18 |
| **Kwame** | 51 | Male | Driver | Control | Sister | 21 |
| **Ohmae** | 46 | Female | Farming | Intervention | Husband | 2 |
| **Agyeman** | 67 | Female | Teaching | Intervention | Husband | 9 |

## 6.3.2 Themes and sub-themes

The analysis of the family caregivers' interviews resulted in four themes. All four themes were like those identified in the stroke survivors' interviews. These themes were making sense of what had happened; coping with the medium to the long-term impact of stroke; current education provisions not being structured and desiring for stroke information. Each theme was categorised into sub-themes, with each sub-theme named according to the content of the related codes. All family caregivers contributed to each theme, as presented in subsequent sections. Table 6.4 presents an overview of the themes and sub-themes that emerged from the interview data.

### Table 6.4: Themes and sub-themes

| Themes | Sub-themes |
|---|---|
| **1. Making sense of what had happened** | 1. Caregivers' interpretations of a stroke<br>2. Delays in a formal diagnosis<br>3. Lack of prior understanding of stroke |
| **2. Coping with the medium to the long-term impact of caring for stroke survivors** | 1. The emotional impact of caring for stroke survivors<br>2. Cost<br>3. Juggling responsibilities |
| **3. Current education provisions are not structured** | |
| **4. Desiring stroke information** | 1. A desire to learn<br>2. Viewing the trial as a source of information<br>i. Increasing personal understanding<br>ii. Impact limited by written format<br>iii. Breadth of information<br>3. Viewing the trial as an opportunity to generate information for others |

## 6.3.3 Theme 1: Making sense of what had happened

All six family caregivers discussed the events that led to their relative's stroke. These are summarised into four main sub-themes: caregivers' interpretations of a stroke, delays in a formal diagnosis and lack of prior understanding of stroke. All participants in the intervention and usual care groups contributed to this theme, describing their experiences after their relative had a stroke. Acquiring relevant information, the family caregivers explained, would have empowered them with knowledge and confidence to assist the stroke survivor.

To make sense of what had happened, the respondents gave varied narratives that reflected their interpretations of stroke. These descriptions were similar to those of the stroke survivors' traumatic experiences. They were based on the degree of disabilities and difficulties that family caregivers observed stroke survivors go through. Although family caregivers referred to stroke as 'not a good sickness', they deemed it embarrassing for stroke survivors to depend on caregivers for assistance to carry out certain activities of daily living, such as toileting. This situation could lead to caregiver

fatigue and cause the caregiver to abandon the stroke survivor when the disability is prolonged (Wife; Nanami).

Delays in obtaining formal diagnosis were a significant cause of family caregivers' anxiety concerning what had happened. The narratives were the same as the opinions shared by stroke survivors. However, family caregivers attributed the delays in obtaining formal diagnosis to the time spent getting investigations carried out. There were reported difficulties in carrying out investigations such as Computerised Tomography (CT) head scans because of cost and accessibility of the scanner. Participants' reasons for delays in getting a CT scan were their inability to make out-of-pocket payments for the services and the only faulty scanner in the facility. One caregiver's descriptions of the delay in getting a formal diagnosis depicted prolonged time for running a series of investigations.

> *It took about one week before we were informed that he had a stroke. Before then, the attending physician and nurses asked us to go for an x-ray (CT scan) of his head. This took the family about three days to carry out the scan because the machine was faulty, and we had to look for money to pay for this service". (Wife)*

Like stroke survivors, family caregivers' descriptions of the events leading to stroke suggested a poor understanding of stroke and its risk factors. Like stroke survivors, providing family caregivers with stroke information could improve their stroke knowledge, increase their confidence in sharing in decision-making about care and assist them in supporting the stroke survivor.

## 6.3.4 Theme 2: Coping with the medium to the long-term impact of caring for stroke survivors

All the caregivers' experiences reflected the negative impact of informal stroke care. Family caregivers consistently stated four difficulties they perceived as the negative impact of stroke on their lives - emotional impact, cost, juggling responsibilities and the burden of caring for a stroke survivor.

### 6.3.4.1 The emotional impact of caring for stroke survivors

All six interviewees were anxious and inadequately prepared to cope with the burden of informal stroke care. The anxiety and distress resulted from the difficulties families

of stroke survivors encountered. These difficulties were not only physical but financial and social. For instance, participants moved stroke survivors without aids or equipment. Therefore, getting information and training would support and improve the confidence of caregivers to give care. Two caregivers observed the difficulties families of stroke survivors encountered and were anxious about coping with such difficulties.

> *"Already I have gone through so many difficulties. I have seen how people suffer when their relatives have a stroke. What came into my mind was how I would handle this because it would be a burden - physically, financially, socially, everything". (Agyeman)*

> *"In fact, I know that when you have a stroke, there is much burden placed on the family because the person will be bedridden and unable to do many activities. You have to lift the person around, which is difficult without assistance. Also, people have said that treating stroke is difficult, so I felt I would suffer for some time". (Wife)*

One participant was anxious about the moving and handling of the stroke survivor.

> ***"****I have seen people who cannot get up, lift their hands, legs or any part of their bodies because they had a stroke. Which means I have to carry and lift him (husband) all the time". (Ohmae)*

Another caregiver was anxious about what had happened to the mother. Notwithstanding, the family caregiver believed that God would heal her. Many Ghanaians regard stroke as a spiritual disease; thus, people believe in spiritual healing. Believing in spiritual healing was one of the strategies family caregivers adopted to cope with stroke.

> *"I never knew stroke can affect your head, so I asked many questions, and they told me, she thinks a lot and in the course of that the vein working…. there was a burst like that which caused her stroke. At that moment, I knew there was nothing we could do unless God …". (Nanami)*

One caregiver stated that she was anxious and felt helpless. However, the information she received from the doctors and nurses helped relieved her anxiety.

> *"Well, as a human, it will be worrisome, but it had already happened, so there was nothing to do. He was given medications and then put on physiotherapy. We also got lectures on his eating habits, and things to do that will keep him healthy". (Nana)*

### 6.3.4.2. Cost

Families bear the cost of stroke treatment in Ghana, presenting a financial burden to family caregivers. While the National Health Insurance Scheme (NHIS) covered some bills for subscribers, the scheme did not cover the cost of treatment and other stroke care services. Thus, stroke survivors and their families made out-of-pocket payments for most of the treatment. Two caregivers complained of the cost of transportation for medical reviews. The cost covered the hiring of a taxi and drugs.

> *"……..and that also involved money, transporting him from where we are staying to hospital, so we decided to stop, and they taught us that in the house we can be managing some small exercises that may help him, that is what we did". (Agyeman)*

> *"All is about money. Transportation here and there to the hospital. If my car was here, I could have been taking her. That is the only worrying aspect". (Kwame)*

### 6.3.4.3 Juggling of responsibilities

Caring for stroke survivors requires a full-time commitment from caregivers. Family caregivers juggled their responsibilities to commit time to the care of their relatives. For instance, they stopped other daily activities to accompany the stroke survivor for medical reviews. In Ghana, patients do not get appointment time; therefore, seeing the physician is on a first-come, first-served basis. Caregivers and stroke survivors set off early from their homes to queue and it may take long waiting hours to see the physician. One caregiver closed her shop anytime the husband was going for review as she had to get up early to secure an early position to consult the physician.

*"We do not open our shop on his medical review days. I will take the lead to go and queue, then he joins later so when he gets there, his folder is closer for him to see the doctor". (Nana)*

Another caregiver stopped her business to take care of her mother.

*"I used to do my work, but ever since she took ill, I have stopped my work and am now taking care of her business, whilst I have employed someone to take care of mine". (Nanami)*

One caregiver relocated to the brother's house to care for him. With this, he juggled his responsibilities between his nuclear family and caring for his brother.

*"I thank God my wife understood me when I decided to relocate to my brother's house…. For the first four months of his condition (stroke), I was here throughout and never set eyes on my wife. We only talked on the phone because I had no one to help me, so I could not leave my brother and go to my family." (Wife)*

The impact of informal stroke care was overwhelming. As a result, family caregivers were anxious and needed information on strategies to cope with the burden of stroke care.

### 6.3.5 Theme 3: Current education provisions are not structured

Family caregivers reportedly received information after the relative had a stroke but wanted more information to equip them with the knowledge to support the stroke survivors. All caregivers received verbal instructions on a diet from doctors, nurses, dieticians, and physiotherapists. One caregiver reported that she received information about stroke from the attending physician.

*"I have not had anyone giving me talk about stroke. But when she had the stroke, the doctor sat us down and spoke to us about stroke when we came to the hospital". (Nanami)*

Another caregiver stated that she received information from a doctor and a nurse on how to feed her husband.

*"A doctor and a nurse told me that I have to give him food that contains low cholesterol and cut down fat, in short, they advised me about his feeding, not taking much salt, oily food, he has to take vegetables, plenty vegetables, white rice and whatever. For the feeding, they made me understand how to go around feeding him, and then he should not take sugar and all those things". (Agyeman)*

Although participants had received information, the information was not written. However, some participants wanted information booklets for reference. One caregiver received information from the dieticians and pharmacists through a course, but this was not structured, and he wished the information were compiled in a booklet for him.

*"I was questioning the trainers at the hospital why they cannot put all the training information in a pamphlet so that people can read on their own and get certain information. Because the information you (researcher) gave me, informed me a lot about certain things after reading it. There are certain life changes I have even adopted due to the information I had from you (researcher)". (Wife)*

### 6.3.6 Theme 4: Desire for stroke information

The desire for information emerged as a theme from the interview as family caregivers desired to learn and view the trial as a source of information for them and an opportunity to generate information for others.

#### 6.3.6.1 A desire to learn

Family caregivers wanted to learn about stroke to support the stroke survivors better. All the participants had little knowledge about stroke, and providing them with the relevant information will help in their quest to assist with the care of their relatives. Stroke was poorly understood, and once individuals had a stroke, the families were anxious about the diet and strategies to prevent another stroke. One caregiver in the intervention group reported that the trial offered her an opportunity to learn.

*"If you can recall, I said earlier that I needed someone to give me teaching about the things to avoid and those to encourage, so this was a great opportunity for me to learn". (Ohmae)*

Another caregiver agreed to participate in the study because he needed information to improve his knowledge about stroke to enable him to support his brother.

> *"I felt it was going to be helpful because if someone wants to provide you with information on something you have little knowledge on, it will be good, so I accepted to be part". (Wife)*

### 6.3.6.2 Viewing the trial as a source of information

Caregivers related several reasons why they viewed the trial as a source of information. Some of the reasons were increasing the understanding of stroke impact limited by the written format and breadth of information.

**Increasing personal understanding**

One reason caregivers agreed to join the trial was to increase their personal understanding of stroke. Providing stroke survivors and their family caregivers with information booklets was uncommon; therefore, giving booklets as part of the intervention was considered helpful. One caregiver stated that the trial had given him information that improved his understanding of stroke.

> *"It was beneficial because until I read the information booklet, I never knew stroke was related to the brain; even though I knew it was related to veins, I never knew it starts from our brain. We only knew was what we saw about the stroke survivor's disabilities and loss of speech. It was this education that made me know all these things". (Wife)*

This caregiver explained that the booklet was *'nice and self-explanatory, you understand it when you read it on your own'*, suggesting the content in the booklet increased his understanding of stroke.

**Impact limited by written format**

Although all three caregivers in the intervention group found the booklet useful, two caregivers reported limitations in using the booklet. They wanted the information translated from English into the local languages. One caregiver suggested that translating the booklet into Twi would benefit other users.

*"…, I have no difficulty using it, but I believe not all of us have been to school, and it is written in English; if we could translate it to other three popular local languages in Ghana like Akan, that is "Twi". I believe it will help those without formal education to read and understand when it is in the Twi language. Perhaps if you could also put it into Hausa, it will help". (Wife)*

Another caregiver stated that in addition to the above suggestion, the booklet's content should include more pictures and illustrations to benefit individuals with no formal education in English.

*"If this information is presented in a picture form, it will enable those of us who have not been to school to know what you (researcher) are talking about". (Ohmae)*

**Breadth of information**

The breadth of information was inadequate as participants felt it did not cover all their information needs and wanted the booklet expanded. Two of the three caregivers who received information from the trial wanted the content in the booklet to address some pertinent information needs, such as diet and exercises. One caregiver suggested that the booklet's content should include advice on post-stroke medications and physiotherapy.

*"All the information on the leaflet was great, but after we visited the physiotherapy section for the four weeks of training, I realised it would be nice if the information on a diet was added to the leaflet. Also, information on how we should take our medications will be good to have it on. It will inform us about why we may not have to buy medication without prescriptions. Information on exercise; that is, the physiotherapy aspect should be included". (Wife)*

Since there were many misconceptions about stroke, especially related to its cause, another caregiver suggested the booklet should tackle the myths surrounding stroke and offer advice on stroke risk factors such as cholesterol and hypertension. Providing information on the causes, management and prevention of stroke will improve their knowledge of stroke and reduce the stigma associated with stroke.

*"What I will like you to add is to tell your patients or people not to be suspicious about stroke. Because when we become suspicious, it becomes a burden; it*

*will dawn upon us that anything can happen to us. However, when we realise that we are sick or, from time to time, we need to go to the hospital to check our pressure, our cholesterol and all those things, it will help us, because I told you (researcher) that my father never had a stroke. However, he was hypertensive, and because my mother knew about it, she could handle him. He died not as a stroke patient, and he never had it". (Agyeman)*

#### 6.3.6.3 Viewing the trial as an opportunity to generate information for others

Five of the six caregivers interviewed regarded the trial as an opportunity to contribute to generating information. They felt that the trial's findings could help educate people about stroke. Two caregivers joined the trial because it allowed them to learn and share their experiences that can help advise others.

*"I am happy that my family is part of the study. We are learning from you and what we have said; others can also take advice from it if it is a book you are going to write. We are happy". (Nana)*

*"When we were called to be part of this, I was happy because it will help others who have not had a stroke to learn from the ideas you give them to help reduce the stroke affecting many people". (Nanami)*

One caregiver was not only thinking of getting information to support her husband's recovery but was looking forward to contributing to generating an information booklet that would be useful to discuss the myths surrounding stroke as being caused by 'bad spirits' and 'witchcraft'.

*"I learned that though my husband was sick, I was thinking about how he will get healed. Nevertheless, I was also happy that somebody has decided to make this a case study to write something down to help others to learn about stroke because, in Ghana, most people will associate stroke with bad spirits. You go to the villages, somebody has bewitched him, and somebody has done so. But it is sickness (stroke)". (Agyeman)*

Another caregiver wanted the information generated from this trial to target stroke survivors and the public and suggested that stroke information should be provided in churches, public places and not only at the hospital.

*"The other time I suggested that you do not have to wait for someone to get a stroke before you start teaching them about stroke if there is a general platform that will educate the public about the disease so that people will not have it all, will help. It should not be available at the hospital alone, in the churches and other organisations and other local clubs if you could get the opportunity to visit such people and get them the information so that they do not get the disease at all". (Wife)*

In conclusion, the findings of these interviews were that family caregivers had a poor understanding of stroke, which triggered anxiety about the care for stroke survivors. When provided, relevant information will improve the knowledge about stroke and increase caregivers' confidence in stroke care.

## 6.4 Interviews with nurses

### 6.4.1 Characteristics of nurses interviewed

Three nurses were interviewed face-to-face. They were drawn from the stroke unit and assisted in providing the intervention and collecting the outcome measures at three months follow-ups. All the nurses selected were females: the only male nurse at the stroke unit was unavailable. Each interview lasted between 30 to 40 minutes. Table 6.5 provides a summary of the main characteristics of the nurses. Each nurse was assigned a pseudonym to conceal their identity. One nurse was over 50 years old with 32 years of practice in nursing. The other two nurses were of the same age (36 years) and had 8 and 9 years of work experience, respectively. One had worked in the stroke unit for less than one year at the time of enrolment, while the other two nurses had worked for 5 and 6 years in the stroke unit. All three nurses were the high-ranked senior nurses in the unit and provided direct nursing care to stroke survivors and their family caregivers.

#### Table 6.5: Characteristics of nurses interviewed

| Participant | Age | Gender | Years of practice | Years in stroke nursing |
|---|---|---|---|---|
| **Mama** | 56 | Female | 32 | Less than 1 |
| **Akos** | 36 | Female | 8 | 5 |
| **Amata** | 36 | Female | 9 | 6 |

## 6.4.2 Themes and sub-themes

From the interview analysis, three main themes emerged from the nurses' narratives of their experiences regarding the provision of post-stroke education. These themes were the difficulties in providing post-stroke education, the need for the intervention and the perceived limitation of the intervention. Table 6.6 outlines each of these themes and the subthemes. Embedded in these themes were ten subthemes, which provided specific and contextualised meaning to the main themes.

### Table 6.6: themes and sub-themes

| Themes | Sub-themes |
|---|---|
| **1. The difficulties involved in providing post-stroke education** | 1. The demands of physical care need of the individual<br>2. Limited education for staff<br>3. Lack of time for education |
| **2. The need for the intervention** | 1. Recognition of ignorance about stroke<br>2. Promoting consistent information<br>3. Added benefits when combined with a follow-up visit<br>4. It gives people information to take away with them |
| **3. Perceived limitations of the intervention** | 1. Visual presentation<br>2. Incomplete information |

## 6.4.3 Theme 1: The difficulties involved in providing post-stroke education

Under this theme, all nurses shared their experiences on the difficulties of providing post-stroke information to stroke survivors and their family caregivers. Additionally, nurses had difficulties related to the demands of the physical care need of the individual, limited education and lack of time for education.

### 6.4.3.1 The demands of the physical care need of the individual

The demands associated with the physical care needs of stroke survivors were challenge providing post-stroke education. These challenges were two folds: the physical care demands linked with stroke and communication problems on the part of stroke survivors. Nurses acknowledged that after admission, the focus was to meet the physical care needs of stroke survivors. As a result, providing stroke information

was not considered a priority but was responsive rather than proactive. An excerpt from a nurse emphasised this:

> *"As a nurse, immediately after a patient is admitted, I monitor the blood pressure, the random blood sugar and fasting blood sugar. We do it hourly, then turn patients, intravenous fluids, frequently changing of diapers to prevent pressure sores and dehydration, we give fluids, water through the nasogastric tube". (Mama)*

On certain occasions when the nurses had the opportunity, the patient's inability to communicate because of loss of consciousness or their inability to talk made it difficult for nurses to provide post-stroke education.

> *"……, we also take the relatives through stroke education and depending on whether the patient can talk or the patient is conscious, we involve the patient at the time of arrival to the unit. But as I said, we admit critically ill patients yeah; the patients may be unconscious or semi-unconscious upon arrival. So right on admission, we sometimes begin with our patient and family education, but with difficulty because of communication problems with the patient". (Akos)*

#### 6.4.3.2 Limited education for staff

Another finding from the nurses' interviews was the lack of specialist stroke education. Nurses lacked specialist knowledge to educate stroke survivors and relied on general nursing education. Stroke nursing training is a vital strategy to equip nurses with the knowledge to impact stroke survivors and their family caregivers. One nurse relied on self-learned knowledge to render stroke care.

> *"I have not had formal training in stroke nursing; I have just had on-the-job training and reading from the internet and books. However, I think if staff have formal training and attend training courses on stroke, it would at least enhance our knowledge to properly educate patients and their families. But nurses just come in the stroke unit with only the knowledge from our general nursing education, and on-the-job training is inadequate". (Akos)*

While sharing their opinion on the lack of formal training for nurses, another nurse complained about the lack of opportunities for refresher courses in stroke. The nurses

felt that they were not equipped with emerging evidence to influence the provision of stroke information.

> *"…., something like upgrade courses for nurses to know what is happening in other parts of the world and new things about stroke, is not available for us (nurses). There are no opportunities for us to undertake courses on stroke to upgrade our knowledge. …. So, we do not get new ideas and knowledge to support stroke survivors and their families". (Amata)*

Frequent changes of nurses at the stroke unit and review clinic were one of the difficulties in providing post-stroke education. As a practice in the hospital, general nurses were moved from one ward or unit to the other regularly. Nurses who moved to new wards needed to know about the ward's routine, and it may take some time for nurses to adapt to their new ward. The movement of nurses from the unit affected the provision of stroke information, as knowledgeable and experienced nurses were replaced with those with limited knowledge and experience in stroke. This nurse's comment emphasised this:

> *"……at our place, we normally do changes, which means staff are frequently changed from ward to ward at least every two months. This means we lose knowledgeable and experienced nurses, and new nurses must be trained again." (Akos)*

#### 6.4.3.3 Lack of time for patient education

Lack of time for post-stroke education was a barrier to providing stroke information. The low number of nursing staff meant that much focus was on the training of relatives on specific aspects of post-stroke discharge care rather than providing education for patients. Nurses highlighted their focus was on training caregivers on feeding and moving stroke survivors.

> *"Stroke patients are normally discharged between 2 to 3 weeks after admission. ….. We teach the relatives how to feed the patient through the nasogastric tube by giving fluid, like porridge or a blended meal from the kitchen. Relatives are also taught to use rice and millet should be prepared light so it can pass through the NG tube for feeding". (Mama)*

Another nurse focused on preventing pressure sores by training relatives to turn patients frequently to relieve pressure areas such as sacral and iliac regions. Pressure sores are common after stroke because of prolonged stay in one position. Nurses explained that because of the limited time, they focused on maintaining the patient's skin and movement than providing stroke information.

> *"Then we also train them on how to take care of the patient; treat pressure areas; bathe the patient in the house, move the patient around with wheelchairs, assist the patient to walk, do all those things, and even how to feed patient through the nasogastric tube. Because most of our cases go home with the nasogastric tube, we do all those things". (Amata)*

Although the nurses provided stroke information to patients, it was only verbal without any written information to take home. However, whilst the nurses described the difficulties in providing stroke information, they also recognised the need to provide relevant information to assist stroke survivors and their family caregivers to self-manage.

### 6.4.4 Theme 2: The need for the intervention

The need for the intervention emerged as another theme in the nurses' interview. The reasons for this were recognition of ignorance about stroke, promotion of consistent information, added benefits when combined with a follow-up, and giving people information to take away with them.

#### 6.4.4.1 Recognition of ignorance about stroke

Low awareness about stroke was one reason nurses considered the initiation of post-stroke education an essential component of stroke care. All the nurses interviewed were excited to be part of the study because it allowed them to educate stroke survivors and their families about stroke. The nurses observed that during the study, stroke survivors and family caregivers showed low awareness and misconceptions about stroke. For instance, one nurse identified the lack of stroke knowledge among the trial participants.

> *"During the research, I educated a patient and a relative and the kind of questions and the answers they were giving, I do not even know what to say, it was amazing that they did not know certain common things about stroke;*

*meanwhile, the patient had a stroke. …., so, I was happy for the opportunity to educate the patients and their relatives on stroke". (Akos)*

Another nurse reported that there was misinformation about stroke. Therefore, implementing this intervention it will offer stroke survivors and their family caregivers the correct information about stroke.

*"……, I was pleased about the research because definitely it will help patients or relatives get more information about stroke, at least the right information. People are out there giving all sorts of information. Some are not true, but people are taking, but I was pleased when I saw that you developed a stroke information booklet". (Mama)*

There were misunderstandings about the causes of stroke; some stroke survivors and their family caregivers viewed stroke as retribution from the gods or spirits for wrongdoing. Stroke was strongly linked to spiritual causes, and in such situations, the nurses believed providing stroke information was needed to support people.

*"Some believed stroke was a curse in this part of our world. I think one person said having sex with a woman standing causes stroke. Some also attributed the cause of stroke to superstitions like offending the gods and other supernatural spirits. I saw pastors who had stroke, I saw ordinary church members who had stroke, I saw churchgoers who had stroke, those who don't even go to church, so it cuts across everywhere, so I didn't believe in those things, but some people had believed in those things". (Amata).*

### 6.4.4.2 Promoting consistent information

All the nurses recognised the need to implement the intervention to promote consistency in providing stroke information. The nurses believed this would enable all stroke survivors and their family caregivers to get standardised stroke information. The intervention was also to make provision of information easier using the information booklet. The following excerpt illustrates the view of one nurse:

*"I think it will rather make it easier for patient education. The current practice is that if a patient and relative come on admission, the level of education depends on the nurse the patient and relative come to meet. But if there is a booklet, it*

*means the information I will give to a patient will be the same information my colleague will give to the next patient". (Amata)*

#### 6.4.4.3 Added benefits when combined with a follow-up visit

One nurse believed combining a home visit with the information booklet would provide enormous support for the stroke survivor and the family. She recognised that visiting survivors and their families would be helpful in the intervention to explain stroke further.

*"… so, it is like our system here when the patient is discharged, they are left to themselves until they come to the hospital. Nobody asks about what is happening to them or how they are faring, so those we had the opportunity to follow were very happy and excited about the whole thing. So, I think introducing home visits into our health system will help. We just discharge the patient, and when he/she goes home, that is all until the patient comes for review and what is happening to the patient, nobody knows what is going on, it is not the best". (Amata)*

#### 6.4.4.4 It gives people information to take away with them

The nurses consistently discussed that the stroke information booklet offered stroke survivors and their family caregivers an opportunity to take an information booklet with them for reference. This action they thought was necessary to support them in understanding and to cope with stroke. They found the booklet to be a valuable resource to support people with practical information on stroke. They also recognised that the booklet provided guidelines to assist people living at home.

*"…., usually after stroke and after the patients have been discharged from the hospital, it gives the guidelines of what to do and how caregivers can support stroke patients, especially at home. This booklet includes all these things, so I find it helpful". (Akos)*

*"Yes, I was happy because they sometimes forget most of the things, we tell them. However, suppose have a leaflet, a pictorial document that you show to relatives or patients that they can read anytime. In that case, they can give to their children to read for them. They can refer to it any time they forget*

*something. But just saying it and going, sometimes even when you are talking to them, usually at the state of their relative lying down, they might not even understand most of the things you are talking about. But if you have a leaflet, you give it to them, and they can even read through it in their own time. So, I was very excited about the whole intervention". (Amata)*

The findings of the interviews indicated that the need for the intervention was long overdue. However, while expressing their views on the need for the intervention, the nurse pointed out some limitations of the stroke information booklet.

### 6.4.5 Theme 3: Perceived limitations of the intervention

The study findings indicated that nurses perceived the intervention to be limited in some areas and suggested ways to optimise the intervention. They reported areas they perceived as limitations: the visual presentation and incomplete information.

**Visual presentation**

The nurses reported one of the limitations of the intervention as the visual presentation. Participants believed enhanced illustrations within the stroke booklet would improve it, making it user-friendly and eye-catching.

*"I would like more pictures, more pictorial things because the pictures stick more than words. So, most of the things, pictures have to come in to illustrate what we talked about. I think if you add more pictures to the booklet, it will help". (Amata)*

For more engagement, one nurse recommended the pictures be printed in colour to bring out the demarcated blood clot or bleed in the brain.

*"….. I see black and white inscriptions, but if the pictures can be more colourful, we will see the red blood and then, we will see the blood flowing, the clot yea that one will also be helpful". (Akos)*

**Incomplete information**

Another limitation of the intervention discussed by the nurses was some of the content of the stroke information booklet. They felt the booklet failed to address some misconceptions about stroke, which should be included in a revised version.

*"After reading through the booklet, we live with people having extreme superstition in this setting. So, I wish we would have added the misconceptions, what people should know about the things that are not correct about stroke, let me say misconceptions of stroke yes, what other people say about stroke are not true. If you get to know about those things, it can help you. So, we should if you can add misconception in the information booklet, it would be helpful". (Akos)*

Sex after stroke was another concern of one nurse, which the booklet did not capture. The nurse reported that sex after stroke was a major concern for stroke survivors and their partners with whom she interacted and recommended that this should be included in the definitive trial.

*"Yes, I heard complaints throughout the research, it was not one gender; the males and all females were all complaining of the same thing; some will tell you "After this sickness (stroke) I cannot satisfy my partner, I cannot have an affair with my partner", that was the complaint most of them were keeping". (Amata)*

The findings from the nurses' interviews indicated that providing post-stroke education at the stroke unit was challenging because of the increased demand for physical care needs, limited staff, and logistics. Amidst these challenges, nurses considered the provision of post-stroke education important to stroke care. Additionally, nurses had identified low awareness and misconceptions about stroke that needed addressing through post-stroke education. Additionally, nurses believe that implementing the post-stroke education intervention would standardise the provision of stroke information and improve the quality-of-care delivery.

## 6.5 Discussion

These interviews aimed to ascertain the experiences and information needs of stroke survivors and their family caregivers to refine a definitive post-stroke education intervention in Ghana. Additional objectives were to examine the experiences of living with stroke and caring for stroke survivors and assess the thoughts of stroke survivors, family caregivers and nurses about the content and the delivery of the post-stroke education intervention delivered in the feasibility trial. Finally, it was also to identify

facilitators and barriers to delivering post-stroke education intervention in KATH from the nurses' perspectives.

A total of 15 participants were interviewed - six stroke survivors, their family caregivers (i.e., 12 participants) and three nurses. Half of the stroke survivors and their family caregivers (i.e., six participants) had received the structured post-stroke education, and half had not. Overall, the interviews with stroke survivors and their family caregivers demonstrated that the trial participants had unmet information needs and varied experiences that reflected the impact of stroke on their lives. Additionally, participants' experiences revealed a lack of understanding of stroke. While trying to understand what happened to them, stroke survivors and their family caregivers were anxious about living with stroke in the long-term following post-stroke physical disability that caused problems with employment, superstition, and stigma. The anxiety resulted from a lack of understanding about recovery, self-management, and the risk of stroke. Overall, stroke survivors and their family caregivers needed information to address these experiences and to help them self-manage stroke.

The interviews with the nurses found that providing post-stroke education was a need, but there were practical challenges to delivering the intervention to stroke survivors and their family caregivers. Among these challenges were the lack of formal stroke education for nurses and the demand to provide physical care needs to stroke survivors. Nurses identified some limitations of the intervention, including the lack of visual presentation and incomplete information in the booklet. Overall, post-stroke education in KATH was not structured and was delivered in an ad-hoc manner which did not meet the information needs of stroke survivors and their families.

The purpose of providing post-stroke education is primarily to equip people with knowledge to recognise stroke, its risk factors, and strategies to self-manage and prevent further strokes (Lowe et al., 2007). However, the existence of such information is limited in Ghana (Donkor et al., 2014). Therefore, this intervention was considered an important approach to increasing stroke awareness in people with stroke. Providing stroke information informs people about the benefits of lifestyle changes. It empowers stroke survivors and their caregivers with knowledge to share in decision-making and to improve outcomes such as anxiety and depression (Fosters et al., 2012). The

findings of this study showed that individuals were motivated to join the trial because they desired information to improve their personal understanding of stroke.

The interviews with stroke survivors and their family caregivers indicated that stroke was perceived as a terrible disease, although there was low awareness of stroke. Poor awareness of the risk factors for stroke was significant, and respondents could not recognise hypertension, the most significant risk factor in Ghana (Sanuade et al., 2018; Donkor et al., 2014). Increased awareness of stroke risk factors among people at high risk for stroke contributes to better compliance with preventive practices (Samsa et al., 1997; Kreuter et al., 1995). There is currently a high prevalence of stroke in Ghana, which could be a reflection, partly, of the poor awareness of risk factors for stroke observed in this study (Sarfo et al., 2015).

Many of the respondents were unable to recognise any of the key stroke symptoms such as facial palsy, arm and leg weakness, and slurred speech, observations which are consistent with research findings in developed and developing countries (Pontes-Neto et al., 2008; Cossi et al., 2012; Wahab et al., 2008; Hickey et al., 2009; Sug Yoon et al., 2001). The inability to recognise stroke symptoms is a serious concern in a stroke-burdened country like Ghana, as recognition of the symptoms is a predictor of early reporting to medical treatment centres (Zangerle et al., 2007; Grond, 2001). Although all respondents eventually reported to the hospital, this was delayed due to the observed poor recognition of stroke symptoms. The onset of stroke was vividly described by stroke survivors and family caregivers who believed that the symptoms they observed were resulted from infections such as malaria. Stroke survivors and their family caregivers believed they would have reported early to the hospital if they had prior knowledge of stroke symptoms.

In addition to the poor awareness of stroke risk factors and symptoms, participants had misconceptions about the causes of stroke. In Ghana and other parts of Africa, stroke is generally believed to be a spiritual disease, that requires spiritual or faith healing (Jenkins et al., 2018) or linking to witchcraft (Mshana et al., 2008). The religious attributes of stroke were observed in this study when a respondent reported that a pastor revealed that evil forces would strike her down with a stroke. At the same time, another respondent also stated that the neighbours believed that her stroke was

due to rituals carried out by her husband. Misconceptions about stroke, especially the causes and treatment, are predominant in Ghana due to the low awareness of stroke.

Although the findings suggest that some of the experiences shared by stroke survivors and their family caregivers are common to those reported in studies in high-income countries, some experiences are unique to stroke survivors in low-and middle-income countries. Predominant experiences, such as loss of body function, uncertainty, anxiety, and depression, change the stroke survivor's life and the family caregiver (Salter et al., 2008; Bulley et al., 2010). In addition, this study presents other issues, such as a lack of prior knowledge of stroke; delays in formal diagnosis; poor current knowledge of stroke; superstition and stigma; lack of proactivity in looking for information; poor communication and general low awareness of stroke. While illuminating the reasons influencing the provision of post-stroke education in a typical resource-poor setting, the findings further unravelled experiences peculiar to stroke survivors and their family caregivers in a setting where post-stroke education was not structured and delivered in an ad-hoc manner.

The interviews showed that stroke survivors and their caregivers were not proactive in looking for stroke information, partly due to the low awareness of stroke. Posters, leaflets, healthcare providers, and families/friends are familiar sources of health information in Ghana (Sokey and Adisah-Atta, 2017). In addition, individuals with a high level of education are likely to look for information using the internet and computer (Nangsangna and Vroom, 2019).

After establishing the potential value of post-stroke information to participants, the suitability of the intervention needs consideration. As it has been a practice with other infectious diseases, such as HIV/AIDS and tuberculosis, information booklets can be helpful in post-stroke education in Ghana. Various strategies for post-stroke education were explored, but the recommended strategy for delivering post-stroke education is active information provision (Foster et al., 2012). Within this strategy, information is given to stroke survivors and their family caregivers, allowing them an opportunity to freely ask questions about what they have not understood from the discussion. In a study that included face-to-face discussion, verbal reinforcement and written information helped participants retained information (Eames et al., 2013).

Previous research on the education needs of people living with stroke reported that patients' and caregivers' educational needs comprised knowledge about clinical aspects of stroke, prevention, treatment, and functional recovery, with the most reported needs of caregivers involving patients' moving and lifting, exercises, psychological changes, and nutritional issues (Hafsteinsdóttir et al., 2011). The authors concluded that respondents wanted tailored information to their situation. This study found that people wanted information on causes, treatment, and healthy lifestyles such as physical activities and healthy eating to support them. A stroke information booklet with the above content was what stroke survivors wanted to assist them in coping with stroke. Thus, respondents showed that participation in the trial was an opportunity to learn and increase their understanding of stroke.

The interviews and analysis of the study were conducted by the researcher, who was a part-time nurse at the stroke unit; this was both a strength and a limitation. This was a strength insofar as the researcher had a thorough, detailed and nuanced understanding of the context and culture of the organisation and participants attending the stroke unit and review clinic. This enabled the researcher to engage in discussions during the interviews and analyse based on prior knowledge and understanding of participants. It also placed the researcher on a level with the nurses when he carried out the interviews so that they may have been more able to speak knowledgeably about their practice. However, this was also a limitation because the researcher may have been more likely to overlook issues or seek less detailed explanations based on his prior knowledge and assumptions. Also, the participants may have been less likely to provide criticisms or negative comments about the post-stroke education since they wanted to learn about stroke.

There were also limitations regarding the recruitment of stroke survivors and family caregivers. Most stroke survivors declined the interview because they were unwilling to share their experiences, which led to the exclusion of their family caregivers as they were recruited in dyads. Although the stroke survivors and their family caregivers were selected from the two arms of the trial, they were selected based on their willingness to communicate their experiences. Therefore, they may have represented stroke survivors and their family caregivers with particular viewpoints - those who volunteered and those who could communicate their experiences and information needs. Therefore, it is possible that stroke survivors and their family caregivers who could not

communicate and had significantly different experiences and needs have not been captured in this study. The findings should, therefore, not be considered to represent the views and perspectives of all people living with stroke in Ghana.

Additionally, this qualitative study focused on recruiting stroke survivors, family caregivers and nurses from one teaching hospital in Ghana, so conducting a similar study at the second teaching hospital with a stroke unit and clinic would be worthwhile. Interviewing larger numbers of stroke survivors, family caregivers, and nurses may have deepened the understanding of the experiences of stroke. Therefore, the small sample size was a limitation of this study. The size of 15 participants was small, and the cessation of data collection was not achieved through data saturation. Large sample size would add to the robust nature of the study; however, this study provided valuable insight into the experiences and provision of stroke information in Ghana.

## 6.6 Conclusion

In conclusion, the key findings of the interviews were that stroke survivors and their family caregivers have unmet information needs and varied experiences of stroke and wanted practical information to address this experience. Post-stroke education was unstructured and not provided routinely on admission. Nurses identified the need for post-stroke education, but there were practical challenges to delivering stroke information at the stroke unit and review clinic. Providing stroke information in a written format with face-to-face discussion was an appropriate approach to delivering post-stroke education.

# Chapter Seven

# General discussion and conclusion

## 7.1 Introduction

The overall aim of this study was to evaluate the feasibility of conducting a definitive RCT of a post-stroke education intervention for stroke survivors and their family caregivers in Ghana. An objective was to identify existing evidence and strategies for providing post-stroke education intervention through a systematic review and to test the feasibility of this intervention in a feasibility trial. An additional objective was to understand the experiences of stroke and information needs of stroke survivors and their family caregivers, as well as the experiences of nurses who participated in the feasibility trial by conducting qualitative interviews. This chapter provides the final discussion and conclusion of this research. It draws together the results from the previous chapters. It provides an overview of the main findings of the three studies reported in this thesis, including concise summaries of the implications of the findings. The strengths and limitations of the research are then discussed. Finally, the implications of the findings for clinical practice and future research are considered.

## 7.2 Summary of the main research findings

**Systematic review**

Findings from the systematic review established that participants' involvement in a post-stroke education intervention resulted in improved knowledge of stroke compared with those in the usual care group. Even though the differences were not statistically significant in most trials, participants who received information had better knowledge of stroke than the usual group. However, no differences were observed between groups regarding improved anxiety and depression. Post-stroke education positively improves the knowledge of stroke but does not reduce anxiety and depression among stroke survivors and their family caregivers. The lack of trials from resource-poor countries demonstrated that the evidence was derived solely from developed countries, which have socio-cultural and healthcare systems that differ from those of low-income countries. Therefore, the evidence amassed cannot completely be transferred to resource-poor countries without critical evaluation. Nevertheless, the review identified simple and low technology methods of delivering post-stroke education, such as using written information compiled as booklets or leaflets with a verbal explanation worth replicating in developing countries like Ghana.

**Feasibility RCT**

Based on the review's findings and stakeholders' feedback, a stroke information booklet was developed and utilised to conduct the feasibility trial. It was possible to recruit participants, collect data and deliver the intervention according to protocol at the KATH stroke review clinic rather than the stroke unit. There were specific challenges, such as the inclusion of dyads, and follow-ups, which suggest the need for changes in the inclusion criteria and strategies to improve retention in a definitive trial. Most participant outcomes, especially knowledge of stroke, increased in the intervention group from baseline, implying that the intervention had potential effects on improving stroke knowledge.

**Qualitative interviews**

Four main themes emerged from the stroke survivors and their caregivers' interviews, indicating unmet information needs and the desire for information to cope with stroke. Participants had limited prior knowledge of stroke and could not recognise stroke symptoms. Before this study, stroke survivors and their family caregivers were not fully engaged, and post-stroke communication between them and healthcare providers was limited and reactive. As a result, participants wanted relevant information regarding the causes of stroke, management, and self-management strategies. The overall response to the post-stroke intervention was positive, and participants were motivated to join the trial because they wanted to learn. The post-stroke education intervention group participants valued the information booklet and verbal explanation.

The context provided insights into possible factors influencing the delivery of post-stroke education. Evidence supports the statement that in stroke care, the increasing demand for physical care needs and limited knowledge and resources are all barriers to providing information to patients and their families. All the nurses interviewed stated that they enjoyed participating in the study and offered several practical suggestions to improve post-stroke education.

## 7.3 The feasibility of post-stroke education for stroke survivors and their family caregivers

### 7.3.1 Study sample

#### 7.3.1.1 Recruitment

Recruitment was slower than expected from the stroke unit despite the use of a direct (face-to-face) approach and the researcher's significant time investment. Other factors that contributed to slow recruitment were limited bed space, high death rate and acuity of stroke problems. McGill et al. (2020) found that recruiting stroke survivors from the community six or more months after a stroke is more efficient than recruiting from the acute hospital setting. During the chronic stage of recovery, approaching stroke survivors for trial participation is better as the immediate psychological and physical implications have subsided (Scottish Stroke Care Audit, 2018; Royal College Physicians, 2017). Additionally, by recruiting stroke survivors within the community, there may be more time to form relationships, and this approach could increase trust during the recruitment conversation (Kong et al., 2014; George et al., 2014). Therefore, recruitment for the definitive trial should carefully consider other options for identifying stroke survivors; for example, multiple recruitment centres/hospitals, clinics or in the community, and setting up a stroke register may support this.

Another barrier to participant recruitment was the prolonged waiting time at the stroke clinic. Stroke survivors and their family caregivers waited for long hours to see a physician, and many complained that participating in the trial would further prolong their visit. For a future definitive trial, there would be the need to discuss the identification of potential participants before scheduled review visits. Creating a stroke register in the hospital would help identify people with stroke for easy contact. A balance of flexibility and pragmatism in identifying and recruiting participants outside the clinic visit time would be necessary to enhance recruitment in a future trial.

All the stroke survivors and their family caregivers who met the inclusion criteria for the study agreed to participate, with a response rate of 100%. This study's response rate is high compared to other studies recruiting stroke survivors for RCTs, ranging from 3% to 59% (McGill et al., 2020). The higher response rate in this study may have been due to using the face-to-face recruitment approach, which is an efficient recruitment strategy (McDonald et al., 2006). Moreover, data collected in the

qualitative interviews showed that participants were motivated by personal relevance in the intervention facilitated recruitment. This finding is consistent with previous studies, which found that stroke survivors were motivated to enrol on a research study when the intervention was perceived as having a positive outcome (Treweek et al., 2013; Elkins et al., 2006). In the interview study, most participants were motivated because they wanted information to improve their understanding of stroke and self-manage.

The sample size was appropriate for this feasibility RCT and comparable with similar research (Billingham et al., 2013). It addressed the study aims and was consistent with related research proposed by the UK National Health Service (NHS, 2018). Although it only represents a small number of stroke survivors and their family caregivers, these data have provided important information and insights to underpin planning another trial.

#### 7.3.1.2 Retention and attrition

Retention rates in RCTs are generally high (89%) in the UK (Walters et al., 2017), and this reflects in this study where the rate is 74%, losing 26% rate of attrition, which is lower than attrition rates found in other studies of RCTs with stroke survivors. However, these were in a western context (Forster et al., 2012). The reasons for the loss to follow-up include death, absence of caregiver or non-availability of one or both dyads, which were unrelated to the intervention, suggesting reviewing the dyad recruitment strategy. Brueton et al. (2013) identified numerous modifiable challenges to successfully retaining participants in a study. However, overcoming these challenges is by implementing various strategies to improve the retention of stroke survivors and their family caregivers, which needs considering in a definitive trial. These include:

- Support and reassure stroke survivors and their family caregivers during enrolment and data collection processes.
- Develop concise and user-friendly questionnaires.
- Ask for family caregivers' assistance when needed.
- Identify and address stroke survivors and their family caregivers' difficulties.
- Listen to and address the concerns of potential stroke survivors and their family caregivers concerning personal and confidential matters.

- Plan to address motivations such as incentives and reduce time spent during recruitment.

Eames et al. (2013) identified various strategies to improve the interest and retention of post-stroke education for stroke survivors and their family caregivers. One such strategy is tailoring the information with a face-to-face explanation of the content of the information and follow-up telephone calls to remind participants of the information. Although this research adopted the overall strategy proposed by Eames et al. (2013), the education was not specifically tailored, which merits attention in future trials. Another strategy proposed by the UK Stroke Association (2018) was to design concise stroke information booklets with pictures because stroke survivors have a limited attention span in retaining information (Spaccavento et al., 2019). This was also the feedback from the interviews in which respondents wanted information in pictures and audio-visuals in languages they understood.

### 7.3.2 Delivery of the post-stroke education intervention

The post-stroke education intervention was delivered successfully and as intended and was well received by stroke survivors and their family caregivers. The delivery strategy was in line with previous post-stroke education interventions (Eames et al., 2013; Hoffmann et al., 2007). The intervention enabled the researcher to elicit stroke survivors and their family caregivers' satisfaction with the stroke information booklet and gain insight into any challenges in using it. The flexibility of the intervention delivery with the content based on unmet educational needs and the format being simple to understand were positive features that enhanced the usage of the information booklet (Hafsteinsdóttir et al., 2011). Furthermore, the use of non-medical language and pictures to explain the content of the information was considered a facilitator for improving the use of the booklet.

However, the reasons for the inability of stroke survivors and their family caregivers to use the booklet were due to forgetfulness resulting from the stroke or busy schedules rather than the booklet's design. No previous study reported adherence rates using an information booklet for people with stroke, so it is not possible to make a direct comparison. However, acceptance of this strategy of delivering post-stroke education is consistent with Eames et al. (2013). Both stroke survivors and their family caregivers showed interest in the face-to-face discussion.

One aim of this study was to explore stroke survivors and their family caregivers' experiences and information needs, including what they wanted to know about stroke. However, there were some confounding variables, such as the level of education. These confounding variables could have impacted the adherence to the intervention and the outcome measures and, in hindsight, should have been addressed in this trial (Akinyemi et al., 2009).

Nurses identified low awareness of stroke and wanted a written information booklet to assist them in delivering consistent post-stroke education to stroke survivors and their family caregivers. They valued the importance of delivering stroke information and were ready to support the intervention.

## 7.4 The feasibility of using the study outcomes

The results of the present study are mainly consistent with broader research into post-stroke education, showing some increase in knowledge of stroke (Smith et al., 2004; Lowe et al., 2007; Franze'N-Dahlin et al., 2008). However, findings on the effect of post-stroke education on individual outcomes (such as anxiety, depression, and caregiver burden) have been inconsistent. For instance, this study's anxiety and depression scores are higher than similar research (Smith et al., 2004; Forster et al., 2012).

Based on the findings of the qualitative interviews, it can be argued from the perspective of stroke survivors and their family caregivers that acquiring knowledge of stroke is the most meaningful primary outcome measure. People wanted to acquire information to increase their knowledge of stroke to improve their disease self-management. Thus, making it imperative to retain this as the primary outcome measure. The background of this thesis presented evidence of the misconception that stroke contributes to its poor management in Africa. An anthropological study of the understanding of stroke among African people (Mshana et al., 2008) and another study exploring the knowledge, attitudes, and practices about stroke (Jenkins et al., 2018) showed that people regarded stroke as a spiritual disease in Africa and avoided hospital treatment.

This current study's findings were similar to those of Komolafe et al. (2015) that reported poor recognition of stroke. Stroke survivors and their families could not

recognise common stroke symptoms such as arm weakness and slurred speech. The inability to recognise these symptoms was a problem with early reporting to health centres for post-stroke treatment. Additionally, common stroke warning symptoms such as numbness were poorly recognised (Wahab et al., 2008). Therefore, post-stroke education to increase awareness about stroke in Ghana and other developing African countries is essential for stroke care.

Overall, previous research on the experiences of stroke survivors and their family caregivers reported similar findings to the present study. The results from the qualitative interviews highlighted that stroke survivors and their family caregivers had low stroke awareness and wanted post-stroke education to address their experiences. Findings from research conducted by Baatiema et al. (2017a) among urban community dwellers in Accra, Ghana, indicated that less than half of the 693 respondents could recognise any of the established stroke risk factors and any of the established stroke warning signs. Additionally, over 70% (n > 485) of the respondents either believed that stroke is a preventable disease, that lifestyle alterations can reduce the risk, or that stroke requires emergency treatment. If this low awareness and the poor experiences of stroke are not addressed during post-stroke education, they could further worsen the plight of stroke survivors and their family caregivers. Therefore, a future definitive trial should consider education on the risk, causes and symptoms of stroke to increase awareness about stroke to reduce the incidence.

## 7.5 Strengths and limitations of the research

### 7.5.1 Strengths of the study

The systematic review showed that there were no previous studies on the provision of stroke information in Ghana or Africa and that no other study has evaluated the acceptability and practicality of delivering post-stroke education in a developing country. To the researcher's knowledge, this was the first feasibility RCT of post-stroke education intervention in Africa and has demonstrated that conducting a definitive RCT would largely be feasible, subject to the limitations outlined in Chapter Four.

This study used a comprehensive mixed-methods approach based on the recommendations of the UK MRC for the development and evaluation of complex interventions to assess the feasibility of delivering post-stroke education intervention

in Ghana before a definitive trial (Craig et al., 2013; Skivington et al., 2021). This approach was novel in this context and a strength.

Another strength of this research is that The Health Belief Model and Adult Learning Theory underpin the intervention. This model advocates personalised education, highlighting relevant information to the individual, including risk factors. The model also emphasises the need to build on the person's self-efficacy (confidence in their ability) through education to achieve behavioural change (Sharma and Romas, 2008; Knowles et al., 2009). The training of the nurses based on the booklet emphasised the identification of personal risk factors such as hypertension, diabetes, and obesity. When these risk factors were identified, participants were given personal advice regarding a positive change in attitude.

In this study, a series of individual, face-to-face interviews were used to understand participants' experiences of stroke, the post-stroke education intervention, and their participation in the trial. This qualitative interview provided insights on how post-stroke information is delivered. The underlying considerations about the context in which post-stroke information was delivered to stroke survivors and their family caregivers became clearer. The interview data also revealed possible reasons for stroke survivors and their family caregivers to engage in the trial and their understanding of stroke. The qualitative interview cannot only help explain the results of the trial, but it can also shape future definitive trials of post-stroke education interventions for stroke survivors and their family caregivers.

### 7.5.2 Limitations of the study

Despite the study's strengths, some limitations that should be considered when analysing and interpreting the results presented. First, this study was small (n=50 dyads) and using small sample sizes in studies risks greater sampling variation that threatens the internal and external validity of the study (Faber and Fonseca, 2014; Higgins and Green, 2011). Therefore, conclusions drawn from the small sample study will be weaker (Faber and Fonseca, 2014; Higgins and Green, 2011). However, the size was appropriate for conducting a feasibility RCT within the time and resources available. The aim of this study was not to generate data regarding the effectiveness of post-stroke education intervention and make generalisations but to find out if such

a trial would be feasible. In this respect does lay the foundation for a future trial to undertake this.

Secondly, there was limited patient and caregiver involvement in developing of the booklet. Only two stroke survivors and their family caregivers were consulted, and most professional feedback was used. There may be disagreement between what professionals perceive as informational needs of patients and their actual needs (Ang et al., 2013). This disagreement can be addressed by consulting more patients and caregivers on developing the intervention. However, time and resources were an issue. Later in the interviews, participants provided feedback on the intervention and what they wanted to be included in the intervention. Conducting the qualitative interview before the intervention to address concerns about the content presentation and style could have made the intervention more culturally appropriate.

Although this study's strength is that it incorporated a qualitative perspective into the trial, there were considerable challenges throughout the research process. One such challenge is that acting as the interviewer and educator gives the impression that the researcher acted as a link or contact between the participants and the hospital management. As a result, the researcher sometimes felt that participants expected him to report their feelings, concerns, or frustrations to the administration so that they might be addressed. However, it is important to acknowledge that the interview participants may attempt to present themselves to the interviewer positively by providing answers they believe the interviewer wants to hear (van Heugten, 2004; Asselin, 2003). For instance, they may have been cautious about criticising the intervention delivered by the interviewer and about talking about their experience with the interviewer. Consequently, the researcher's presence could influence their accounts of the intervention and trial experience.

Even though all participants in the feasibility trial were invited to participate in the qualitative interview in order to provide a range of views but, as only six stroke survivors and their family caregivers agreed to take part in this aspect of the study. Therefore, the researcher was not able to gain a range of views. The number of stroke survivors, family caregivers and nurses interviewed was small. No junior nurse or other medical staff was interviewed. This exclusion might have implications for the findings.

Another limitation of the study was that it did not use an implementational science theory, such as the Normalisation Process Theory (NPT), to inform the development of the intervention and analysis of data from the qualitative interviews. NPT is a mid-range theory used prospectively and retrospectively to help understand how health technologies (such as educational interventions) are operationalised and sustained in practice (Nilsen, 2015). In evaluating complex interventions, NPT provides a conceptual framework and can help inform subsequent trials and implementation processes (Moir, 2018). NPT comprises four constructs: coherence, cognitive participation, collective action, and reflexive monitoring. Collectively, these allow researchers to evaluate factors that may promote and inhibit the routine incorporation of complex interventions into everyday practice (Murray et al., 2010; May et al., 2009). As a heuristic framework, NPT can help optimise a trial intervention in three ways: by supporting with intervention design, describing the context of a trial, and supporting with the interpretation of a trial's results (Brooks et al., 2015). Applying NPT would have ensured that effective post-stroke education normalisation require relationships between practice providers, staff, and hospital management. Since this study aims to implement the provision of post-stroke education into routine practice, it is recommended that the NPT be used to guide the implementation of a future definitive trial.

Finally, the feasibility RCT was carried out at one stroke care centre. Therefore, it is not possible to be certain that the findings are transferrable to other centres in Ghana. Nevertheless, there is no reason to assume that the population were more or less likely to participate in the study or to respond to the treatment intervention. Therefore, it seems reasonable to conclude that the critical findings concerning feasibility would be transferrable to other centres in Ghana.

## 7.6 Relevance to other studies

Healthcare interventions require rigorous evaluation, and most healthcare researchers agree that this is best achieved with an RCT. However, complex interventions of multiple components, such as post-stroke education, pose additional methodological challenges. The UK MRC's guidance on developing and evaluating complex interventions explicitly recommends thorough feasibility work as a crucial initial step in the phased approach to identifying problems that can occur in an RCT of a complex

intervention (Craig et al., 2008; Skivington et al., 2021). This important preparatory stage aims to deliver an RCT that is both robust (internal validity) and generalisable in a real-world context (external validity) (Bugge et al., 2013). On the other hand, designing and evaluating post-stroke education interventions, can pose a considerable challenge and require a substantial investment of time and effort. In this study, the low refusal rate and attrition, to some extent, are evidence of the feasibility of delivering the intervention and its acceptability to stroke survivors and their families. Previous studies on post-stroke education have produced conflicting evidence. It is also difficult to compare the findings of this study with trials where post-stroke education interventions are highly variable or conducted in settings where the healthcare systems are different.

***Factors influencing post-stroke education in routine practice***

The Adult Learning Theory provided a foundation for developing and delivering the post-stroke education intervention in this study. Adult Learning Theory helps to understand how adults learn and provide guidance on how to structure and deliver new information for optimal uptake and mastery (Palis and Quiros, 2014). Among several psychological and educational models of adult learning, Malcolm Knowles' concept of andragogy has become the most influential work. It is extensively used as a distinctive conceptual underpinning for adult education and learning. Six adult learning principles are highlighted: an adult's need to know; readiness to learn; motivation to learn; self-concept; orientation to learning; and the role of the learner's experiences (Knowles et al., 1998; Smith, 2002). These principles of adult learning concepts were considered in the design of the post-stroke education intervention for stroke survivors and their family caregivers in Ghana regarding the timing, content, and format. When Adult Learning Theory was incorporated into the development and delivery of the intervention, it had the potential to address not only the participants' information needs but also their particular needs and requirements as adult learners.

The aim of this study was to explore the practicality of delivering a definitive post-stroke education intervention to improve knowledge and understanding of stroke among stroke survivors and their family caregivers. In addition to stroke knowledge, the study examined the potential effect of the intervention on participants' psychological health. It was also considered important to explore how post-stroke

education influences participants' attitudes, behavioural performance and health changes in the questionnaire about the information booklet. Participants who received the post-stroke education intervention recalled that through the accessibility of post-stroke information, their adoption of healthy lifestyles, knowledge and feelings of control over situations were improved. They valued both the written and verbal information delivered during the intervention. The interview participants reported that they were motivated by the opportunity to engage with the trial and made several helpful suggestions concerning future post-stroke education interventions.

The qualitative interviews revealed the challenges in delivering stroke information. The reasons for not getting sufficient and useful post-stroke education fall into three broad areas: the heavy workload of staff, limited knowledge among staff, and a scarcity of resources. The nurses interviewed in this study identified unmet information needs and felt that stroke survivors and their family caregivers needed information. The stroke survivors and their family caregivers' experiences of gaps in post-stroke education are consistent with the findings in a review of the educational needs of patients with a stroke and their caregivers (Hafsteinsdottir et al., 2011).

***The heavy workload of nurses***

The inadequacies of post-stroke education were mainly attributed to staff nurses' heavy workload. The stroke unit in KATH, where this study was conducted, accommodates only six patients. There were only two to three nurses on duty in the daytime and one nurse on duty during the night. The low nurse-patient ratio places considerable pressure on ward nurses. The situation becomes even more problematic when extra removable beds are arranged in the corridor for patients to have a temporary stay if there is no patient room available. Nurses are constantly busy with a large amount of routine care and administration. In the stroke unit, nurses are overwhelmed with the increasing demand for physical care needs of stroke patients. This may be because the nurse's role in Ghana has traditionally and culturally been perceived as carrying out doctors' orders and administering medication. Neither doctors nor patients consider health education part of a nurse's responsibility (Choi et al., 2010).

The lack of time nurses could spend with stroke survivors resulted in minimal contact with patients and their families and a perceived lack of individualised information and

care. These findings are consistent with studies in China (Wu et al., 2011; Chan et al., 2007), the United States (Barber-Parker, 2002; Chobanian et al., 2003) and the United Kingdom (Casey, 2007). If increasing staff numbers is not possible, health care providers need to work together to seek ways to deliver post-stroke information more effectively and efficiently.

***Limited knowledge among nurses***

Another commonly mentioned barrier was the problem of nurses' limited knowledge of stroke and confidence in providing post-stroke information to patients and their family caregivers. In this study stroke survivors and their family caregivers noticed that health care providers often provided what they assumed to be necessary to their patients, with no one taking the time to check that patients and their families got the information they needed. This finding is consistent with previous studies describing patients' experiences while waiting for cardiac surgery (Ivarsson et al., 2004) and the experiences of patients' next of kin (Ivarsson et al., 2005b). It is vital for health care providers to avoid forms of paternalism wherein a treatment or service is 'carried out intentionally on behalf of a person other than oneself, against that person's wishes or without consent, with the explicit purpose of doing good for, or avoiding harm to, that person' (Cody, 2003, p288).

In Ghana, more attention needs to be paid to patient-centred care, enabling patients to decide on what and how much information they want. Since there is considerable variability in the amount and content of post-stroke information that patients desire, providing the same level of information may not meet the needs of a highly diverse group of people (Screeche and Powell, 2004). It is unrealistic to expect all stroke survivors and their family caregivers want to receive and discuss the same information. Listening to stroke survivors and their family caregivers and identifying their individual information needs may be the first step to providing appropriate and relevant information (Hoffmann et al., 2007). Ongoing patient and family assessment is an essential skill for nurses to identify the level of anxiety and its sources, patients' prior knowledge and understanding level, and to individualise education topics according to their specific circumstances (McHugh et al., 2001).

Patients' individual preferences for post-stroke information may vary, especially for information regarding potential risks and self-management. Du et al. (2016)

demonstrate that it is essential that health care providers discuss with patients about their requirements and preferences routinely. Patients can be distressed by disease-related information, mainly if the information constitutes bad news (Case et al., 2005). Nurses must provide sufficient and accurate information about the stroke disease trajectory (Du et al., 2016). Numerous strategies can be implemented to help patients understand the information conveyed, such as clear and simple explanations, interactive communication, use of simple language and visual images, welcoming patients' feedback and questions, and a trusting patient-staff relationship (Weiss, 2007; Rosser and Kasperski, 2001; Hall et al., 2001).

In addition, it was noted by all participants that post-stroke communication between nurses and patients appeared to be unidirectional and focused on patient teaching with the patient as a passive recipient of information. More interactive discussion between staff nurses and patients was appreciated. Previous studies have also demonstrated that patient relationships with staff appear to determine how satisfied patients are with the amount of information they receive (Forster et al., 2012).

***A scarcity of resources***

There are limited resources for stroke care, including the provision of post-stroke education in Ghana. Most of the resources and guidelines developed in western countries cannot be directly transferred for use in a country like Ghana with a different socio-cultural context. Learning needs and preferences differ from one cultural group to another, and the whole healthcare systems are not comparable (Suhonen and Leino-Kilpi, 2006). The participants described their appreciation of getting specific information about the risk factors, treatment, and self-care management strategies after stroke. Under the unique characteristics of the Ghanaian healthcare system, this kind of information can be considerably different from western countries.

In order to meet the needs of stroke survivors and their family caregivers in Ghana, more creative use of teaching materials and practice guidelines are necessary. These guidelines can help staff delivery and improve post-stroke education in practice. In post-stroke education, there was an expressed need for developing and using of booklets and audio-visuals about stroke management and care at home. This suggestion was consistent with the findings of a study which identified the educational needs of stroke patients and caregivers (Hafsteinsdottir et al., 2011; Du et al., 2016).

The period following a stroke is stressful, necessitating support for patients and their families to cope (Hjelmblink et al., 2010). However, only two hospitals currently provide specialist stroke care in stroke units and review clinics and in many hospitals in Ghana, stroke unit care does not exist (Sarfo et al., 2015). For continuity of care, post-stroke information should cover what patients need to know about stroke and their care after being discharged from the hospital.

As the digital revolution's impact on modern life is recognised, the production and use of videotapes, audiotapes or computer-assisted post-stroke education offer the advantage of being interactive and possibly more engaging to patients. Developing and using health education materials deserves more attention as rapid turnover and staff shortages make it difficult for nurses to deliver sufficient verbal information (Monsivais and Reynolds, 2003). Nevertheless, these education materials must be tailored to match stroke survivors' needs, characteristics, and preferences. Although developing these education materials involves the expenditure of time and resources, the significant clinical impact of post-stroke education warrants the expenditure of time and resources (Eames et al., 2013).

## 7.7 Context and implications of the research

### 7.7.1 Implications for practice

The main content of the current post-stroke education intervention was the provision of information focussing on clinical aspects of stroke, such as the cause, risk factors, self-management, and healthy living. Whilst this is not likely to be new information in western countries (Forster et al., 2012), it offers some evidence to justify the provision of stroke information in Ghana, where post-stroke education is less common. This could be useful for healthcare professionals, especially nurses, when providing stroke information. Previous research suggests that most people unaware of stroke (Baatiema et al., 2017b; Donkor et al., 2014). The qualitative research findings could assist with designing and delivering of context-appropriate post-stroke education in Ghana.

The actual intervention was simple and administered by issuing a booklet and face-to-face discussion that offered information for stroke survivors and their family caregivers. However, nurses routinely focus on physical care needs of patients despite the

growing demand for stroke information. They often failed to address the unmet informational needs and emotional issues of people living with stroke, especially when those nurses faced heavy workloads, limited time, and a lack of specialist stroke nursing knowledge and skills. As a result, training nurses specifically on stroke to equip them with the competencies to provide stroke information is recommended.

The provision of stroke information has not received sufficient attention in Ghana's hospitals. One reason is the lack of policy and support from the Ministry of Health. In the UK and other western countries, there is a general provision of information through nationally and locally developed information leaflets/booklets to support stroke survivors and family caregivers (Forster et al., 2012). A lack of a national or local policy on stroke information provision results in a lack of coherence in stroke information provision in Ghana's hospitals. Ghana's relatively low total per capita healthcare spending limits financial support that can be provided for stroke information.

Evidence-based policies on the delivery of stroke information are needed. They could trigger every hospital or institution in Ghana to acknowledge the importance of providing stroke information in care delivery by outlining the minimum service hospitals should deliver to people with stroke. Financial support from the government to hospitals would be essential for developing of stroke education and research in stroke care delivery.

Although the intervention in this study was designed to be simple, it would take at least 15-20 minutes for each stroke survivor and the family caregiver from the nurses' limited time if nurses implemented it at the stroke unit and stroke review clinic. It is possible to incorporate this into routine care, but it will inevitably increase nurses' workloads. Nurses working in specialist roles were seen to contribute positively to providing information, and their input reduced the workload of ward nurses (Olaiya et al., 2016). A study exploring the perceived role and impact of one nurse consultant in rheumatology (Ryan et al., 2006) found that the nurse consultant's role impacted service development, leadership, and education activities. The advanced nursing roles were found to impact patient outcomes positively and play an essential role in improving nursing quality in many areas (Peplau, 2003). The development of

advanced nursing roles in stroke care in Ghana could potentially contribute to optimising the provision of information in speed and efficiency.

Since there is a lack of research evaluating post-stroke education in Ghana, policymaking in this area is more likely to be based on international literature and international practice. Evidence showed that patient education in one country might function as a mirror for the quality improvement of patient education in other countries (Visser et al., 2001). Exploring and learning from experience with post-stroke education in other countries can contribute to developing innovative education interventions and improving health care services in Ghana. While it is acknowledged that compared to western countries, there may be different traditions regarding the delivery of information in Ghana, stroke survivors' desire for information about stroke and suggestions for improving the quality and effectiveness of post-stroke education seems consistent (Forster et al., 2012). Findings from other countries can enrich the understanding of post-stroke education interventions from a cross-cultural perspective (Eames et al., 2013).

However, it is unwise to directly apply post-stroke education interventions which have been effective in other countries in Ghana without further investigation. These interventions must be developed to suit Ghana's socio-cultural and economic conditions. The intervention designed in this study will likely apply across different countries and cultures by adjusting the implementation method according to the specific cultural and environmental contexts. As Pettigrew (1990) argued, when any change process takes place, a comprehensive analysis of the cultural and contextual influential factors is important such as exploring and evaluating the underlying obstacles and available resources under the given circumstances.

With the increasing incidence and substantial global burden of stroke, nursing care for stroke survivors and their family caregivers deserves worldwide attention. Health inequalities exist in the prevention, diagnosis, treatment, and follow-up of people with stroke. The need to integrate cultural competence into nursing education and practice becomes apparent as nursing's global consciousness evolves (de Leon Siantz, 2008). Given this, it is time for nurse leaders in Ghana to acknowledge the importance of engaging stroke nurses and researchers from other countries to contribute to the prevention, treatment, and care of people with stroke and people at high risk.

### 7.7.2 Implications for future research

The main implications arising from this research is related to the feasibility of conducting a definitive RCT of post-stroke education. Given the need to address the low awareness of stroke in sub-Saharan Africa, more research is needed to evaluate the delivery of stroke information to improve the quality of stroke care. Furthermore, the need to support people living with stroke in a resource-limited setting with information on stroke survivorship is documented (Donkor et al., 2014; Baatiema et al., 2017b). Considering the misconceptions of stroke as a spiritual disease, in-depth interviews on the views and experiences of stroke survivors and their family caregivers were not explored, which is important investigating. Further research about the information needs of stroke survivors and the family caregivers within the context of Ghana that considers the socio-cultural norms, the unique needs and the understanding of stroke would be worth exploring.

Additionally, the intervention could be enhanced to influence psychosocial outcomes. This enhancement may come from combining its provision with other active informational interventions. For instance, hands-on practical training for caregivers can reduce anxiety, depression, and burden (Kalra et al., 2004). Enhancement and provision of this tailored stroke education and support package may be one way of addressing this need.

## 7.8 Recommendation for future trial

The feasibility trial highlighted some limitations that need addressing before conducting a definitive trial. The following recommendations are to enhance the design and implementation of a future post-stroke education intervention.

- A future study could be conducted using an RCT design, which would need to be fully powered to determine the effectiveness of post-stroke education.
- The stroke review clinic would be a better site for recruitment than the stroke unit – although more sites would be an advantage or use community sites or access to a stroke register.
- It would be likely that a future trial should not use the dyad design
- In this study, stakeholders input into the design of the stroke information booklet to make it user-friendly. Refining the stroke information booklet is

essential, considering the needs and suggestions of stroke survivors, family caregivers and health care professionals in Ghana.

- As suggested by the participants, the content should include diet, exercise and sex after stroke in a future trial.
- There is a need to examine other methods of delivering information.

## 7.9 Conclusion

In summary, the systematic review demonstrated that post-stroke education has the potential to improve stroke awareness and outcomes, although the intervention types documented varied. However, this finding was from relatively wealthy countries, which limits generalisability to Ghana.

The feasibility trial indicated that recruiting and retaining participants and delivering the intervention was feasible. There was also a potential impact of post-stroke education on knowledge of stroke. Although numbers were small, the between-group mean showed a trend towards benefits for the post-stroke education group.

Overall, the qualitative interview study found that stroke survivors and family caregivers wanted practical information about stroke to help them self-manage and avoid risk factors for further strokes. Nurses also felt this was important and recognised the need for a more planned approach to how they delivered this.

This study has shown that an RCT of the delivery of post-stroke education intervention in Ghana, which was designed based upon available evidence, is mainly feasible. However, recruitment, dyad design and time scales need reviewing. A further definitive RCT is possible and would be important, timely and judicious given the increasing incidence and prevalence of stroke in Ghana and other African countries. Furthermore, the findings from this study suggest that the timely provision of post-stroke education to stroke survivors and family caregivers could have important implications on their knowledge of stroke and improve their self-management. The implications of a definitive study in this area are likely to be substantial.

# References

Aben, I., Verhey, F., Lousberg, R., Lodder, J. and Honig, A. (2002). Validity of the Beck Depression Inventory, Hospital Anxiety and Depression Scale, SCL-90, and Hamilton Depression Rating Scale as screening instruments for depression in stroke patients. **Psychosomatics** 43:386-93.

Abd-Allah, F. and Moustafa, R. R. (2014). Burden of stroke in Egypt: Current status and opportunities. **Int J Stroke** 9:1105-1108.

Abiodun, O. A. (1994). A validity study of the Hospital Anxiety and Depression Scale in general hospital units and a community sample in Nigeria **Br J Psychiatry** 165:669-72

Abo, K. A., Fred-Jaiyesimi, A. A. and Jaiyesimi, A. E (2008). Ethnobotanical studies of medicinal plants used in the management of diabetes mellitus in Southwestern Nigeria. **J Ethnopharmacol** 115:67-71.

Abu Bakar, I., Shuaib, I. L., Ari_ A. R. M., Naing, N. N. and Abdullah, J. M. (2005). Diagnostic cerebral angiography in spontaneous intracranial haemorrhage: a guide for developing countries. **Asian J Surg** 28:1-6

Abukari, Z., Kuyini, A. B. and Kuyini Mohammed, A. (2015). Education and Health Care Policies in Ghana: Examining the Prospects and Challenges of Recent Provisions. SAGE Open. https://doi.org/10.1177/2158244015611454

Acocella, I. (2012). The focus groups in social research: advantages and disadvantages. **Quality and Quantity** 46**:**1125-1136.

Acker, J. E., Pancioli, A. M., Crocco, T. J., Eckstein, M. K., Jauch, E. C., Larrabee, H., et al. (2007). Implementation Strategies for Emergency Medical Services Within Stroke Systems of Care: A Policy Statement From the American Heart Association/ American Stroke Association Expert Panel on Emergency Medical Services Systems and the Stroke Council. **Stroke** 38(11):3097-115.

Adams, H. P. Jr, del Zoppo, G. J., Alberts, M. J, et al. (2007). Guidelines for the early management of adults with ischemic stroke: a guideline from the American Heart Association/American Stroke Association Stroke Council, Clinical Cardiology Council, Cardiovascular Radiology and Intervention Council, and the Atherosclerotic Peripheral

Vascular Disease and Quality of Care Outcomes in Research Interdisciplinary Working Groups: the American Academy of Neurology affirms the value of this guideline as an educational tool for neurologists. **Stroke** 38:1655-1711

Adeloye, D. (2014). An estimate of the incidence and prevalence of stroke in Africa: a systematic review and meta-analysis. **PLoS One** 9 (6):e100724, 10.1371/journal.pone.0100724

Adibe, M. O. (2009). Prevalence of concurrent use of herbal and synthetic medicines among outpatients in a mission hospital in Nigeria. **Int J. Drug Dev. & Res**1(1):60.

Adua, E., Frimpong, K., Li, X. and Wang, W. (2017). Emerging issues in public health: a perspective on Ghana's healthcare expenditure, policies and outcomes. **EPMA J** 8:197-206. doi:doi:10.1007/s13167-017-0109-3pmid:29021830

Ager, S. (2018). "Omniglot". https://www.omniglot.com/writing/twi.htm [accessed on 12 December 2018]

Agyei-Baffour, P., Kudolo, A., Quansah, D. Y. et al. (2017). Integrating herbal medicine into mainstream healthcare in Ghana: clients' acceptability, perceptions and disclosure of use. **BMC Complement Altern Med** 17:513.doi:10.1186/s12906-017-2025-4

Agyei-Mensah, S. and de-Graft Aikins, A. (2007). Epidemiological transition and the double burden of disease in Accra [online]. Available at http://uaps2007.princeton.edu/download.aspx?submissionId=70383 [Accessed 24 April 2017].

Agyemang, C., Attah-Adjepong, G., Owusu-Dabo, E., De-Graft Aikins, A., Addo, J., Edusei, A., Nkum, B. and Ogedegbe, G. (2012). Stroke in Ashanti Region of Ghana. **Ghana Medical Journal** 46(2):12-17.

Akinyemi, R. O. and Adeniji, O. A. (2018). Stroke Care Services in Africa: A Systematic Review. **Journal of Stroke Medicine** 1(1):55–64. https://doi.org/10.1177/2516608518775233

Akinyemi, R. O., Ogah, O. S., Ogundipe, R. F., Oyesola, O. A., Oyadoke, A. A., et al. (2009). Knowledge and perception of stroke amongst hospital workers in an African community. **Eur J Neurol** 16:998-1003.

Akobeng, A. K. (2005a) Principles of evidence-based medicine. **Archives of Disease in Childhood** 90, 837-840.

Akobeng, A. K. (2005). Understanding randomised controlled trials. **Archives of Disease in Childhood** 90(8):840-844.

Alatinga, K. A. and Williams, J. J. (2014). Development Policy Planning In Ghana:The Case Of Health Care Provision **European Scientific Journal** 10(33):185–7881

Albers, G. W., Amarenco, P., Easton, J. D., Sacco, R. L. and Teal, P. (2004). Antithrombotic and thrombolytic therapy for ischemic stroke: the Seventh ACCP Conference on Antithrombotic and Thrombolytic Therapy. **Chest** 126:483S–512S.

Al-Busaidi, Z. Q. (2008). Qualitative Research and its Uses in Health Care. **Sultan Qaboos University Medical Journal** 8(1):11-19.

Ale, O. and Braimoh, R. W. (2017). Awareness of hypertension guidelines and the diagnosis and evaluation of hypertension by primary care physicians in Nigeria. **Cardiovascular journal of Africa** *28*(2):72–76. https://doi.org/10.5830/CVJA-2016-048

Alhassan, R. K., Nketiah-Amponsah, E. and Arhinful, D. K. (2016). A Review of the National Health Insurance Scheme in Ghana: What Are the Sustainability Threats and Prospects? **PLoS ONE** 11(11):e0165151. doi:10.1371/journal.pone.0165151

Almborg, A.H., Ulander, K., Thulin, A. and Berg, S. (2008) Patients' perceptions of their participation in discharge planning after acute stroke. J Clin Nurs 18:199-209. doi: 10.1111/j.1365-2702.2008.02321.x.

Amporfu, E. (2013). Equity of the premium of the Ghanaian national health insurance scheme and the implications for achieving universal coverage **International Journal for Equity in Health** 12:4

Anderson, C. (2010). Presenting and evaluating qualitative research. **American journal of pharmaceutical education** 74(8):141. https://doi.org/10.5688/aj7408141

Anderson, C.S., Linto, J. and Stewart-Wynne, E.G. (1995) A populationbased assessment of the impact and burden of caregiving for long-term stroke survivors. **Stroke** 26:843-9.

Appelros, P., Stegmayr, B. and Terent, A. (2009). Sex Differences in Stroke Epidemiology. **Stroke** 40(4):1082-1090.

Arain, M., Campbell, M. J., Cooper, C. L. and Lancaster, G. A. (2010). What is a pilot or feasibility study? A review of current practice and editorial policy. **BMC medical research methodology**10**:**67.

Arnold, J., Goodacre, S., Bath, P. & Price, J. (2009) Information sheets for patients with acute chest pain: randomised controlled trial. **British Medical Journal** 338:b541.

Asselin, M. E. (2003). Insider research: issues to consider when doing qualitative research in your own setting. **Journal For Nurses In Staff Development** 19:99-103.

Astrom, M., Adolfsson, R. and Asplund, K. (1993) Major depression in stroke patients. A 3-year longitudinal study. **Stroke** 24:976-982.

Ataklte, F., Erqou, S., Kaptoge, S., Taye, B., Echouffo-Tcheugui, J. B. and Kengne, A. P. (2015). Burden of undiagnosed hypertension in sub-Saharan Africa – A systematic review and meta-analysis. **Hypertension** 65:291–298

Atiim, G. A. and Elliott, S. J. (2016). The global epidemiologic transition: Noncommunicable diseases and emerging health risk of allergic disease in sub-Saharan Africa. **Health Educ Behav** 43(1):37S–55S

Attia, A. (2005). Bias in RCTs: confounders, selection bias and allocation concealment. **Middle East Fertil Soc J** 3:258–61

Atuoye, K. N., Vercillo, S., Antabe, R., Galaa, S. Z. and Luginaah, I. (2016). Financial sustainability versus access and quality in a challenged health system: an examination of the capitation policy debate in Ghana. **Health policy and planning** czw058.

Austin, Z. and Sutton, J. (2014). Qualitative research: getting started. **The Canadian journal of hospital pharmacy** 67(6):436–440. https://doi.org/10.4212/cjhp.v67i6.1406

Awah, P. (2006). Diabetes and traditional medicine in Africa. **Diabetes Voice** 51(3):24-26.

Ayanniyi, O., Akande, O. and Mustapha, A. F. (2006). Knowledge and perception of stroke among adults in Osogbo, Nigeria. **Afr J Med Med Sci** 35:447-452.

Aziato, L. and Antwi, H. O. (2016). Facilitators and barriers of herbal medicine use in Accra, Ghana: an inductive exploratory study. **BMC Complement Altern Med** 16:142.doi:10.1186/s12906-016-1124-y

Baatiema, L., Chan, C., Sav, A. and Somerset, S. (2017a). Interventions for acute stroke management in Africa: a systematic review of the evidence **Systematic Reviews** 6:213.

Baatiema, L., de-Graft Aikins, A., Sav, A., Mnatzaganian, G., Chan, C. K. Y. and Somerset, S. (2017b) Barriers to evidence-based acute stroke care in Ghana: a qualitative study on the perspectives of stroke care professionals **BMJ Open** 7**:**e015385. doi:10.1136/bmjopen-2016-015385

Baatiema, L., Otim, M., Mnatzaganian, G., De-Graft Aikins, A., Coombes, J. and Somerset, S. (2017). Towards best practice in acute stroke care in Ghana: a survey of hospital services **BMC Health Services Research** 17:108 DOI:10.1186/s12913-017-2061-2

Bagby, R. M., Ryder, A. G., Schuller, D. R. et al. (2004). The Hamilton Depression Rating Scale: has the gold standard become a lead weight? **Am J Psychiatry** 161:2163–2177.

Bailey, L. (2010) Strategies for decreasing patient anxiety in the perioperative setting. **AORN Journal** 92, 445-457.

Bailey, J. (2008). First steps in qualitative data analysis: transcribing. **Family Practice** 25(2):127-131.

Baker, S. and Edwards, R. (2012). How many qualitative interviews is enough? Expert voices and early career reflections on sampling and cases in qualitative research. **National Centre for Research Methods**.

Bandura, A. (1986) Social Foundations of Thought and Action: A Social Cognitive Theory. In Bandura, A. (ed.) **Models of Human Nature and Causality.** Prentice-Hall, Englewood Cliffs, NJ. pp. 18-22.

Bandura, A. (1997) Self-Efficacy: the Exercise of Control. In Bandura, A.(ed.) **Mediating Processes.** W.H. Freeman, New York. pp. 116-137.

Barber-Parker, E. D. (2002) Integrating patient teaching into bedside patient care: a participant-observation study of hospital nurses. **Patient Education and Counseling** 48:107-113.

Barbour, R. (2007). **Doing Focus Groups.** London:Sage Publications. 174. ISBN978-0-7619-4978-7.

Beck, A.T., Steer, R. A. and Garbin, M. G. (1988). Psychometric properties of the Beck depression inventory:twenty-five years of evaluation. **Clin. Psychol. Rev** 8:77–100.

Beck, A. T., Ward, C. H., Mendelson, M., Mock, J. and Erbaugh, J. (1961). An inventory for measuring depression. **Arch Gen Psychiatry** 4:561–571

Bennett, M. I. and Closs, S. J. (2011). Methodological issues in nonpharmacological trials for chronic pain. **Anaesthesia, Pain & Intensive Care** 14:126.

Benton, T. and Craib, I. (2011). **Philosophy of social science: the philosophical foundations of social thought.** 2nd ed. Basingstoke: Palgrave Macmillan

Bernard, H. R. (2002). **Research methods in anthropology: Qualitative and quantitative approaches** Walnut Creek, CA: Alta Mira Press.

Bernier, M. J., Sanares, D. C., Owen, S. V. and Newhouse, P. L. (2003) Preoperative teaching received and valued in a day surgery setting. **AORN Journal** 77:563-582.

Berwick, D. M. (2005) Broadening the view of evidence-based medicine. **Quality and Safety in Health** *Care* 14:315-316.

Bhatia, S. and Gupta, A. (2003) Impairments in activities of daily living in Parkinson's disease: Implications for management. **NeuroRehabilitation** 18:209-14.

Bhutta, Z. A., Sommerfeld, J., Lassi, Z. S., Salam, R. A. and Das, J. K. (2014). Global burden, distribution, and interventions for infectious diseases of poverty. **Infectious diseases of poverty** 3:21. https://doi.org/10.1186/2049-9957-3-21

Billingham, S., Whitehead, A. L. and Julious, S. A. (2013). An audit of sample sizes for pilot and feasibility trials being undertaken in the United Kingdom registered in the United Kingdom Clinical Research Network database. BMC Medical Research Methodology 13(104):1–6. http://dx.doi.org/10.1186/1471228813104

Binka, C., Nyarko, S. H., Awusabo-Asare, K. and Doku, D. T. (2018). “I always tried to forget about the condition and pretend I was healed”: coping with cervical cancer in rural Ghana. **BMC Palliative Care** 17:24.

Bishop, P.A. and Herron, R.L. (2015) Use and Misuse of the Likert Item Responses and Other Ordinal Measures. **Int J Exerc Sci.**1;8(3):297-302. PMID: 27182418; PMCID: PMC4833473.

Bjelland, I., Dahl, A. A., Haug, T. T. and Neckelmann D. (2002). The validity of the Hospital Anxiety and Depression Scale. An updated literature review. **J Psychosom Res** 52:69-77.

Boateng, D., Wekesah, F., Browne, J. L. et al. (2017). Knowledge and awareness of and perception towards cardiovascular disease risk in sub-Saharan Africa: A systematic review **PLoS One** 12 (12):e0189264

Boateng, E. A., East, L. and Evans, C. (2018). Decision-making experiences of patients with end-stage kidney disease (ESKD) regarding treatment in Ghana: a qualitative study. **BMC Nephrol** 19(1):1–12.

Bocéréan, C. and Dupret, E. (2014). A validation study of the Hospital Anxiety and Depression Scale (HADS) in a large sample of French employees. **BMC Psychiatry** 14:354. https://doi.org/10.1186/s12888-014-0354-0

Bosu, W. K. (2010). Epidemic of hypertension in Ghana: a systematic review. **BMC Public Health** 10(1):418.

Bosu, W. K. (2012). A Comprehensive Review of the Policy and Programmatic Response to Chronic Non-Communicable Disease in Ghana. **Ghana Medical Journal** 46(2):69–78

Bosu, W. (2013). Accelerating the Control and Prevention of Non-Communicable Disease in Ghana: The Key Issues. **Postgraduate Medical Journal of Ghana** 2.

Bothwell, L. E., Greene, J. A., Podolsky, S. H. and Jones, D. S. (2016). Assessing the Gold Standard--Lessons from the History of RCTs. **The New England Journal of Medicine** 374(22):2175-2181.

Bots, M., Elwood, P., Nikitin, Y., Salonen, J., de Concalves, A. F., Inzitari, D., et al. (2002). Total and HDL cholesterol and risk of stroke. EUROSTROKE: a collaborative

study among research centres in Europe. **Journal of epidemiology and community health** 56(1):i19-i24.51

Bowen, D. J., Kreuter, M., Spring, B., Cofta-Woerpel, L., Linnan, L., Weiner, D. and Fernandez, M. (2009). How We Design Feasibility Studies. **American Journal of Preventive Medicine** 36(5):452–457. http://doi.org/10.1016/j.amepre.2009.02.002

Bower, J. H., Diop, A. G., Gouider, R., and Schmutzhard, E. (2014). Addressing neurologic needs in sub-Saharan Africa: An opportunity for multisociety cooperation. **Neurology** 83(13):1207–1209. https://doi.org/10.1212/WNL.0000000000000810

Brainin, M., Teuschl, Y. and Kalra L. (2007). Acute treatment and long-term management of stroke in developing countries. **Lancet Neurology** 6(6):553–61.

Bracken-Roche, D, Bell, E, Macdonald, M. E. et al. (2017). The concept of 'vulnerability' in research ethics: an in-depth analysis of policies and guidelines. **Health Res Policy Syst** 15:8.

Braun, V. and Clarke, V. (2006). Using thematic analysis in psychology. **Qualitative Research in Psychology** 3(2):77-101.

Breakwell, G. M. (2006). 'Interviewing methods', in Breakwell, G. M., Fife-Schaw, C., Hammond, S. and Smith, J. (ed.). **Research Methods in Psychology** 3rd edn. London, UK: Sage, pp.232-253.

Breen, L. J. and Darlaston-Jones, D. (2010). Moving beyond the enduring dominance of positivism in psychological research: Implications for psychology in Australia. **Australian Psychologist** 45:67–76.

Brennan, C., Worrall-Davies, A., McMillan, D., Gilbody, S. and House, A. (2010). The Hospital Anxiety and Depression Scale: a diagnostic meta-analysis of case-finding ability. **J Psychosom Res** 69:371–8

Bristowe, K, Selman, L and Murtagh, F. E. M. (2015). Qualitative research methods in renal medicine: an introduction. **Nephrol Dial Transplant**. DOI:10.1093/ndt/gfu410.

Britten, N. (2006). Qualitative Interviews. In*:* POPE, C. & MAYS, N. (eds.) **Qualitative Research in Health Care.** Third ed. Oxford: Blackwell Publishers.

Broderick, J., Connolly, S., Feldmann, E., Hanley, D., Kase, C., Krieger, D. et al. (2007). Guidelines for the management of spontaneous intracerebral hemorrhage in adults: 2007 update: a guideline from the American Heart Association/American Stroke Association Stroke Council, High Blood Pressure Research Council, and the Quality of Care and Outcomes in Research Interdisciplinary Working Group. **Stroke** 38:2001–2023.

Browne, J. L., Kayode, G. A., Arhinful, D., Fidder, S. A, Grobbee, D. E. and Klipstein-Grobusch, K. (2016). Health insurance determines antenatal, delivery and postnatal care utilisation: evidence from the Ghana Demographic and Health Surveillance data. **BMJ open** 6(3):e008175.

Bugge, C., Williams, B., Hagen, S. et al. (2013). A process for Decision-making after Pilot and feasibility Trials (ADePT): development following a feasibility study of a complex intervention for pelvic organ prolapse. **Trials** 14:353. doi:10.1186/1745-6215-14-353.

Cadilhac, D. A., Carter, R., Thrift, A. G. and Dewey, H. M. (2009). Estimating the Long-Term Costs Of Ischemic and Hemorrhagic Stroke for Australia New Evidence Derived From the North East Melbourne Stroke Incidence Study (NEMESIS). **Stroke** 40(3):915-21.

Callaghan, P. and Li, H. C. (2002) The effect of pre-operative psychological interventions on post-operative outcomes in Chinese women having an elective hysterectomy. **British Journal of Health Psychology** 7:247-252.

Campbell Burton, C. A., Murray, J., Holmes, J., Astin, F., Greenwood, D. and Knapp P. (2013). Frequency of anxiety after stroke: a systematic review and metaanalysis of observational studies. **Int J Stroke** 8:545-559

Campbell, M., Fitzpatrick, R., Haines, A., Kinmonth, A. L., Sandercock, P., Spiegelhalter, D. and Tyrer, P. (2000). Framework 263 for design and evaluation of complex interventions to improve health. **BMJ** 321:694-696.

Carifio, J. and Perla, R. (2008) Resolving the 50-year Debate Around using and Misusing Likert Scales. **Med Educ** 42(12):1150-1152.

Carifio, J. and Perla, R.J. (2007) Ten Common Misunderstandings, Misconceptions, Persistent Myths and urban legends about Likert scales and Likert response Formats and their Antidotes. **J Social Sci** 3(3): 106.

Carnwath, T.C.M. and Johnson, D.A.W. (1987) Psychiatric morbidity among spouses of patients with stroke. **BMJ** 294:409-11.

Carter, S. M. and Little, M. (2007). Justifying knowledge, justifying method, taking action: Epistemologies, methodologies, and methods in qualitative research. **Qualitative Health Research** 11:1316-1328

Case, D.O., Andrews, J.E., Johnson, J.D. and Allard, S.L. (2005) Avoiding versus seeking: The relationship of information seeking to avoidance, blunting, coping, dissonance, and related concepts. J Med Libr Assoc 93:353-62.

Casey, D. (2007) Using action research to change health-promoting practice. **Nursing and Health Sciences** 9:5-13.

Castro, F. G., Kellison, J. G., Boyd, S. J. and Kopak, A. (2010). A Methodology for Conducting Integrative Mixed Methods Research and Data Analyses. **Journal of Mixed Methods Research** 4(4):342-360.

Central Intelligence Agency (2017). **The world factbook** [online]. Available at: https://www.cia.gov/library/publications/resources/the-worldfactbook/geos/print_gh.html [Accessed on 5 December 2019].

Centre for Reviews and Dissemination (2009). **Systematic Reviews: CRD's guidance for undertaking reviews in health care** York, Centre for Reviews and Dissemination, University of York.

Chalmers, A. F. (1999). **What is this thing called science?**. 3rd edn. Maidenhead: Open University Press.

Chan, S. S. C., Sarna, L., Wong, D. C. N. and Lam, T.-H. (2007) Nurses' tobacco-related knowledge, attitudes, and practice in four major cities in China. **Journal of Nursing Scholarship** 39:46-53.

Chobanian, A. V., Bakris, G. L., Black, H. R., Cushman, W. C., Green, L. A., Izzo, J. L., Jones, D. W., Materson, B. J., Oparil, S., Wright, J. T., Roccella, E. J. and National High Blood Pressure Education Program Coordinating Committee (2003) The seventh

report of the joint national committee on prevention, detection, evaluation, and treatment of high blood pressure. **The Journal of the American**

**Medical Association** 289:2560-2571.

Choi, W. H. H., Hui, G. K. H., Lee, A. C. K. and Chui, M. M. L. (2010) Student nurses' experiences and challenges in providing health education in Hong Kong. **Nurse Education Today** 30:355-359.

Chow, J.T.Y., Lam, K., Naeem, A. et al. (2017). The pathway to RCTs: how many roads are there? Examining the homogeneity of RCT justification. **Trials** 18:51. https://doi.org/10.1186/s13063-017-1804-z

Chtaou, N., Rachdi, L., Midaoui, A. E., Souirti, Z., Wahlgren, N. et al. (2016). Intravenous thrombolysis with rt-PA in stroke: Experience of the moroccan stroke unit. **Pan Afr Med J** 24:207.

Clarke, D. J. (2014) Nursing practice in stroke rehabilitation: systematic review and meta-ethnography. **J Clin Nurs**. 23(9-10):1201-1226. doi:10.1111/jocn.12334

Clarke, J. (2011). What is a systematic review? **Evidence-Based Nursing** 14**:**64.

Clegg, S. (2005). Evidence-based practice in educational research: a critical realist critique of systematic review. **British Journal of Sociology of Education** 26:415-428.

Clissett, P., Porock, D., Harwood, R. H., Gladman, J. R. F. (2013). Experiences of family carers of older people with mental health problems in the acute general hospital: A qualitative study. **Journal of Advanced Nursing** 69(12):2707–2716.

Cobden, S.D., Niessen, L.W., Barr, C.E., Rutten, F.F.H. and Redekop, W.K. (2010). Relationships among self-management, patient perceptions of care, and health economic outcomes for decision-making and clinical practice in type 2 diabetes. **Value in Health** 13(1):138-147.

Cody, W. K. (2003) Paternalism in nursing and healthcare: central issues and their relation to theory. **Nursing Science Quarterly** 16:288-296.

Collins, D. R., McCormack, P. M. and O'Neill, D. (2002). General perception of stroke. Poor knowledge of stroke can be improved by simple measures. **BMJ** 325:392.

Cooke, E., Hague, S., McKay, A. et al. (2016). The Ghana Poverty and Inequality Report, 2016. Available from: https://www.unicef.org/ghana/Ghana_Poverty_and_Inequality_Analysis_FINAL_Match_2016(1).pdf Accessed August 16, 2017.

Cossi, M. J., Preux, P. M., Chabriat, H., Gobron, C. and Houinato, D. (2012). Knowledge of stroke among an urban population in Cotonou (Benin). **Neuroepidemiology** 38(3):172-178.

Craig, P., Dieppe, P., Macintyre, S., Michie, S., Nazareth, I. and Petticrew, M. (2008). Developing and evaluating complex interventions: the new Medical Research Council guidance. **BMJ** 337:979-983.

Craig, P., Dieppe, P., Macintyre, S., Michie, S., Nazareth, I. and Petticrew, M. (2013). Developing and evaluating complex interventions: the new Medical Research Council guidance. **Int J Nurs Stud** 50(5):587-592. doi:10.1016/j.ijnurstu.2012.09.010

Creswell, J. W. (2013). **Research design: qualitative, quantitative and mixed methods approaches,** SAGE.

Creswell, J. W. and Plano Clark, V. L. (2011). **Designing and conducting mixed method research** 2nd edn. Thousand Oaks, CA: Sage.

Crowther, M. A. and Cook, D. J. (2007). Trials and tribulations of systematic reviews and meta-analyses. **Hematology** 493-497.

Coggon, D., Barker, D. and Rose, G. (2009). **Epidemiology for the Uninitiated** John Wiley and Sons.

Collaboration APCS (2005). A comparison of the associations between risk factors and cardiovascular disease in Asia and Australasia. **European Journal of Cardiovascular Prevention and Rehabilitation** 12(5):484-91.

Concato, J., Shah, N. and Horwitz, R. (2000). Randomised, Controlled Trials, Observational Studies and the Hierarchy of Research Designs. **New England Journal of Medicine** 342**:**1887-1892.

Connor, M. D., Walker, R., Modi, G. et al. (2007). Burden of stroke in black populations in sub-Saharan Africa. **Lancet Neurology** 6:269–78.

Cook, T. D. and Campbell, D. T. (1979). 'The design and conduct of true experiments and quasi-experiments in field settings' in Mowday, R. T. and Steers, R. M. (ed.) *Reproduced in part in Research in Organizations: Issues and Controversies*. Santa Monica, CA: Goodyear Publishing Company.

Cook, C. and Sheets, C. (2011). "Clinical equipoise and personal equipoise: two necessary ingredients for reducing bias in manual therapy trials," **Journal of Manual and Manipulative Therapy** 19(1):55–57.

Coulter, A., Entwistle, V. and Gilbert D. (1999) Sharing decisions with patients: Is the information good enough? BMJ 318:318-22. doi: 10.1136/ bmj.318.7179.318.

Cusin, C., Yang, H., Yeung, A. and Fava, M. (2010). Rating scales for depression. In: Baer L, Blais MA, editors. **Handbook of clinical rating scales and assessment in psychiatry and mental health.** New York: Humana Press, Springer 7-35

Dankner, R., Bachner, Y.G., Ginsberg, G., et al. (2016) Correlates of well-being among caregivers of long-term community-dwelling stroke survivors. **Int J Rehabil Res** 39:326–30.

de-Graft Aikins, A. (2007). Ghana's neglected chronic disease epidemic: a developmental challenge. **Ghana Medical Journal** 41(4):154-159

de-Graft Aikins, A. (2004). Strengthening quality and continuity of diabetes care in rural Ghana: a critical social psychological approach. **Journal of health psychology** 9(2):295-309.

de-Graft Aikins, A. (2003). Living with diabetes in rural and urban Ghana: a critical social psychological examination of illness action and scope for intervention. **Journal of health psychology** 8(5):557-572.

de-Graft Aikins, A. (2004). Strengthening quality and continuity of diabetes care in rural Ghana: a critical social psychological approach. **Journal of health psychology** 9(2):295-309.

de-Graft Aikins, A. (2005). Healer shopping in Africa: new evidence from rural-urban qualitative study of Ghanaian diabetes experiences. **BMJ** 331(7519):737.

de-Graft Aikins, A., Addo, J., Ofei, F., Bosu, W. K. and Agyemang, C. (2012). Ghana's burden of chronic non-communicable diseases:future directions in research, practice and policy.**Ghana Medical Journal** 46(2):1-3

de-Graft Aikins, A., Kushitor, M., Koram, K., Gyamfi, S., & Ogedegbe, G. (2014). Chronic non-communicable diseases and the challenge of universal health coverage: insights from community-based cardiovascular disease research in urban poor communities in Accra, Ghana. **BMC public health,** 14(Suppl2):S3. doi:10.1186/1471-2458-14-S2-S3

de Leon Siantz, M. L. (2008). Leading Change in Diversity and Cultural Competence. **Journal of Professional Nursing** 24(3):167-171.

Delyser, D. (2001). "Do you really live here?" Thoughts on insider research. **Geographical Review** 91:441-453.

Demaerschalk, B. M., Hwang, H-M. and Leung, G. (2010). Cost analysis review of stroke centers, telestroke, and rt-PA. **The American journal of managed care** 16(7):537-44.

Denzin, N. K. and Lincoln, Y. S. (Eds.). (2008). **The landscape of qualitative research** (3rd ed.). Sage Publications, Inc.

Department of Health (2010). **Equity and Excellence**: Liberating the NHS. Department of Health, London.

Di Carlo, A. (2009). Human and economic burden of stroke. **Age and ageing** 38(1):4-5.

DiCenso, A., Guyatt, G. and Ciliska, D. (2005) **Evidence-Based Nursing: A Guide to Clinical Practice.** Elsevier Mosby, St. Louis.

Dicicco-Bloom, B. and Crabtree, B. F. (2006). The qualitative research interview. **Medical Education** 40(4):314-321.

Diop, A. G., Gouider, R. (2014). Neurology in Sub-Saharan Africa: Development, opportunity, hope and challenges.

Dixon-Woods, M. (2001) Writing wrongs? An analysis of published discourses about the use of patient information leaflets. **Social Science and Medicine** 52:1417-1432.

Dombrowski, S. U., Mackintosh, J. E., Sniehotta, F. F., Araujo-Soares, V., Rodgers, H., Thomson, R. G., … White, M. (2013). The impact of the UK “Act FAST” stroke awareness campaign: content analysis of patients, witness and primary care clinicians’ perceptions. **BMC Public Health** (13):915. http://doi.org/10.1186/1471-2458-13-915

Donnan, G. A., Fisher, M., Macleod, M. and Davis, S. M. (2008). Stroke. **The Lancet** 371(9624):1612-23.

Donkor, E. S., Owolabi, M. O., Bampoh, P., Aspelund, T. and Gudnason, V. (2014a). Community awareness of stroke in Accra, Ghana. **BMC Public Health** 14:196.

Donkor, E. S., Owolabi, M. O., Bampoh, P. O., Amoo, P. K., Aspelund, T. and Gudnason, V. (2014b). Profile and health-related quality of life of Ghanaian stroke survivors. **Clinical interventions in aging** 9:1701.

Donnelly, M., Power, M., Russell, M., Fullerton, K. (2004). Randomized controlled trial of an early discharge rehabilitation service. **Stroke** 35:127-133.

Dorland, W. (2007). **Dorland’s medical dictionary for health consumers.** 31st edn. Philadelphia, PA: Saunders, an imprint of Elsevier.

Doyle, L., Brady, A.-M. and Byrne, G. (2009). An overview of mixed methods research. **Journal of Research in Nursing** 14(2):175-185.

Drislane, F. W., Akpalu, A. and Wegdam, H. H. (2014). The medical system in Ghana. **The Yale journal of biology and medicine** 87(3):321–326.

Eames, S., Hoffmann, T., Worrall, L., Read, S. and Wong, A. (2013). Randomised controlled trial of an education and support package for stroke patients and their carers. **BMJ Open** 3:e002538. doi:10.1136/bmjopen-2012-002538

Eccles, M., Grimshaw, J., Campbell, M. and Ramsay, C. (2003). Research designs for studies evaluating the effectiveness of change and improvement strategies. **Quality and Safety in Health Care** 12(1):47-52.

Edington, G. M. (1954). Cardiovascular disease as a cause of death in the Gold Coast African. **Transactions of The Royal Society of Tropical Medicine and Hygiene** 48(5):419–425, https://doi.org/10.1016/0035-9203(54)90143-1

Eggar, M., Dickerson, K. and Smith, G. (2008). Problems and limitations in conducting systematic reviews. *In:* EGGAR, M., SMITH, G. and ALTMAN, D. (eds.) **Systematic Reviews in Health Care: Meta-analysis in context.** 2nd Edn ed. London: BMJ Publishing Group.

Ekeh, B. C. (2017). Challenges of the Management of Stroke in sub-Saharan Africa: Evaluating Awareness, Access and Action. **J Pediatr Neurol Med** 2:3 DOI:10.4172/2472-100X.1000128

Ekeh, B. and Isamade, E. (2014). Time of presentation of stroke patients in a tertiary hospital in Northern Nigeria, West Africa. **J Med Investig Pract** 9:1-4.

Ekpenyong, C. E., Udokang, N. E., Akpan, E. E. and Samson, T. K. (2012). Double burden, non-communicable diseases and risk factors evaluation in sub-Saharan Africa: The Nigerian experience. **Eur J Sustain Develop** 1(2):249-270.

Eldridge, S. M., Lancaster, G. A., Campbell, M. J. et al. (2016). Defining feasibility and pilot studies in preparation for randomised controlled trials: development of a conceptual framework. **PLoS One** 11:e0150205. doi:10.1371/journal.pone.0150205.

Elkins, J. S., Khatabi, T., Fung, L., Rootenberg, J. and Johnston, S. C. (2006). Recruiting subjects for acute stroke trials a meta-analysis. **Stroke** 37(1):123–8.

European Medicines Agency (2002). Guideline for Good Clinical Practice. London: **European Medicines Agency**

Evans, D. (1999). **Conducting a systematic review**. Adelaide: The Joanna Briggs Institute for Evidence Based Nursing and Midwifery.

Evans, D. (2003). Hierarchy of evidence: a framework for ranking evidence evaluating healthcare interventions. **Journal of Clinical Nursing** 12:77-84.

Ezejimofor, M. C., Chen, Y., Kandala, N-B., Ezejimofor, B. C., Ezeabasili, A. C., Stranges, S. and Uthmanbet, O. A. (2016). Stroke survivors in low-and middle-income countries: a meta-analysis of prevalence and secular trends **J. Neurol. Sci.** 364:68–76

Ezejimofor, M. C., Uthman, O. A., Maduka, O., Ezeabasili, A. C., Onwuchekwa, A. C., Ezejimofor, B. C. et al. (2017). Stroke survivors in Nigeria: A door-to-door prevalence survey from the Niger Delta region. **Journal of the Neurological Sciences** 372:262–9.

Faber, J. and Fonseca, L. M. (2014). How sample size influences research outcomes. **Dental press journal of orthodontics** 19(4):27–29. https://doi.org/10.1590/2176-9451.19.4.027-029.ebo

Feigin, V. L. (2007). Herbal medicine in stroke: does it have a future? **Stroke** 38:1734–1736.

Feigin, V. L., Forouzanfar, M. H., Krishnamurthi, R., Mensah, G. A., Connor, M., Bennett, D. A et al. (2014). on behalf of the Global Burden of Diseases, Injuries, and Risk Factors Study 2010 (GBD 2010) and the GBD Stroke Experts Group, C. (2014). Global and regional burden of stroke during 1990–2010: findings from the Global Burden of Disease Study 2010**. Lancet** 383(9913):245–254.

Feigin, V. L., Lawes, C. M., Bennett, D. A., Barker-Collo, S. L. and Parag. V. (2009). Worldwide stroke incidence and early case fatality reported in 56 population-based studies: a systematic review. **The Lancet Neurology** 8(4):355-69.

Feigin, V. L., Mensah, G. A., Norrving, B., Murray, C. J., Roth, G. A., for the GBD 2013 Stroke Panel Experts Group (2015). Atlas of the Global Burden of Stroke (1990–2013): the GBD 2013 Study. **Neuroepidemiology** 45:230–36.

Feigin, V. L., Roth, G. A., Naghavi, M., Parmar, P., Krishnamurthi, R., Chugh, S., Mensah, G. A., Norrving, B., Shiue, I., Ng, M., Estep, K., Cercy, K., Murray, J. L. C., Forouzanfar, H. M. (2016). Global burden of stroke and risk factors in 188 countries, during 1990–2013: a systematic analysis for the Global Burden of Disease Study 2013. **Lancet Neurology** 15(9):913-924 https://doi.org/10.1016/S1474-4422(16)30073-4.

Fenny, A. P., Kusi, A., Arhinful, D. K and Asante, A. F. (2016). Factors contributing to low uptake and renewal of health insurance: a qualitative study in Ghana **Global Health Research and Policy** 1:18 DOI:10.1186/s41256-016-0018-3

Ferrell, B., Grant, M., Chan, J., Ahn, C. and Ferrell, B. (1995). The impact of care pain education on family caregivers of elderly patients. **Oncology Nursing Forum** 22(8):1211–1218.

Ferrús-Torres, E., Valmaseda-Castellón, E., Berini-Aytés, L. and Gay-Escoda, C. (2011) Informed consent in oral surgery: the value of written information. **Journal of Oral and Maxillofacial surgery** 69:54-58.

Field, A. (2013). **Discovering statistics using IBM SPSS Statistics: and sex and drugs and rock 'n' roll,** 4th edition. Sage, London. ISBN 9781446249178

Fitzgerald, B. M. & Elder, J. (2008) Will a 1-page informational handout decrease patients' most common fears of anesthesia and surgery? **Journal of Surgical Education** 65:359-363.

Fitzpatrick, E. and Hyde, A. (2005) What characterizes the 'usual' preopreative education in clinical contexts? **Nursing and Health Sciences** 7:251-258.

Flynn, D., Ford, G. A., Rodgers, H., Price, C., Steen, N., and Thomson, R. G. (2014). A time series evaluation of the FAST National Stroke Awareness Campaign in England. **PloS one** *9*(8):e104289. https://doi.org/10.1371/journal.pone.0104289

Ford, N. (1980) Relating information needs to learner characteristics in higher education. **J Doc** 36:99-114. doi: 10.1108/eb026692.

Forster, A., Brown, L., Smith, J., et al. (2012). Information provision for stroke patients and their caregivers **Cochrane Database Systematic Reviews** (11):CD001919.

Fothergill, R.T., Williams, J., Edwards, M. J., et al. (2013). Does use of the recognition of stroke in the emergency room stroke assessment tool enhance stroke recognition by ambulance clinicians? **Stroke** 44:3007-3012.

Fraenkel, J. R. and Wallen, N. E. (2006). **How to Design and Evaluate Research in Education**. McGraw Hill, London.

Franks, V. (2004) Evidence-based uncertainty in mental health nursing. **Journal of Psychiatric and Mental Health Nursing** 11:99-105.

Franze´n-Dahlin, A˚., Larson, J., Murray, V., Wredling, R., and Billing, E. (2008). A randomized controlled trial evaluating the effect of a support and education

programme for spouses of people affected by stroke. **Clinical Rehabilitation** 22:722-730.

Frazier, S. K., Moser, D. K., Riegel, B., Mckinley, S., Blakely, W., Kim, K. A. and Garvin, B. J. (2002) Critical care nurses' assessment of patients anxiety: reliance on physiological and behavioral parameters. **American Journal of Critical Care** 11, 57-64.

Freedman, B. (1987). Equipoise and the ethics of clinical research. **N Engl J Med** 317:141-5.

Friedman, L., Furberg, C. and Demets, D. (2010). **Fundamentals of Clinical Trials** London, Springer.

Furie, K. L., Kasner, S. E., Adams, R. J., Albers, G. W., Bush, R. L., Fagan, S. C, Halperin, J. L., Johnston, S. C., Katzan, I., Kernan, W. N., Mitchell, P. H., Ovbiagele, B., Palesch, Y. Y., Sacco, R. L., Schwamm, L. H., Wassertheil-Smoller, S., Turan, T. N., Wentworth, D. (2011) Guidelines for the prevention of stroke in patients with stroke or transient ischemic attack: a guideline for healthcare professionals from the American Heart Association/American Stroke Association. **Stroke** 42:227-276.

Gainotti, G. and Marra, C. (2002) Determinants and consequences of post-stroke depression. **Curr Opin Neurol** 15:85-89.

Gainotti, G., Antonucci, G., Marra, C. and Paolucci, S. (2001) Relation between depression after stroke, antidepressant therapy, and functional recovery. **J Neurol Neurosurg Psychiatry** 71:258-61.

Galabuzi, C., Agea, J. G., Fungo, B. L., & Kamoga, R. M. (2009). Traditional medicine as an alternative form of health care system: a preliminary case study of Nangabo sub-county, central Uganda. **African journal of traditional, complementary, and alternative medicines: AJTCAM** 7(1):11-16. https://doi.org/10.4314/ajtcam.v7i1.57224

Galea, A. (2009). Breaking the barriers of insider research in occupational health and safety**. Journal of Health and Safety Research and Practice** 1:3-12.

Gallacher, K., Morrison, D., Jani, B., Macdonald, S., May, C.R., Montori, V.M, *et al.* (2013) Uncovering treatment burden as a key concept for stroke care: A systematic review of qualitative research. PLoS Med 10:1-7. doi: 10.1371/journal.pmed.1001473.

Ganle, J. K., Parker, M., Fitzpatrick, R. and Otupiri, E. (2014). Inequities in accessibility to and utilisation of maternal health services in Ghana after user-fee exemption: a descriptive study. **International journal for equity in health** 13(1):89.

Garbusinski, J. M., van der Sande, M. A. B., Bartholome, E. J., et al. (2005). Stroke presentation and outcome in developing countries. A prospective study in the Gambia. **Stroke** 36:1388–93

Garcia, J. H., Ho, K. L. and Pantoni, L. (1998). **Pathology. In: Barnett HJM, Mohr JP, Stern BM, Yatzu FM (eds) Stroke**, Churchill Livingstone, New York/London pp 139-140

Garden, A. L., Merry, A. F., Holland, R. L. and Petrie, K. J. (1996) Anaesthesia information-what patients want to know. **Anaesthesia and Intensive Care** 24, 594-598.

Garrett, D. and Cowdell, F. (2005) Information needs of patients and carers following stroke. **Nurs Older People** 17:14-6. doi: 10.7748/ nop2005.09.17.6.14.c2386.

GBD 2016 Stroke Collaborators (2019). Global, regional, and national burden of stroke, 1990–2016: a systematic analysis for the Global Burden of Disease Study 2016. **Lancet Neurol** 18:376–93

Gbiri, C.A., Olawale, O.A. and Isaac, S.O. (2015) Stroke management: Informal caregivers' burdens and strians of caring for stroke survivors. **Ann Phys Rehabil Med** 58:98–103.

George, P. M. and Steinberg, G, K. (2015). Novel stroke therapeutic: unravelling stroke pathophysiology and its impact on clinical treatments. **Neurons** 87:297-309

George, S., Duran, N. and Norris, K. A. (2014). Systematic review of barriers and facilitators to minority research participation among African Americans, Latinos, Asian Americans, and Pacific Islanders. **Am J Public Health**. 104(2):e16–31.

Gertrude, N., Kawuma, R., Nalukenge, W., Kamacooko, O., Yperzeele, L., Cras, P., Ddumba, E., Newton, R. and Seeley, J. (2019) Caring for a stroke patient: The burden and experiences of primary caregivers in Uganda—A qualitative study. **Nursing Open** 6:1551–1558.

Ghana Health Service (2016). Annual report [online]. Available at: https://www.ghanahealthservice.org/ghs-item-details.php?cid=2&scid=52&iid=127 [Accessed on 25 April 2019]

Ghana Health Service (2014). Annual report [online]. Available at: *https://www.ghanahealthservice.org/downloads/Ghana_Health_Service_2014_Annual_Report.pdf* [Accessed on 25 April 2017]

Ghana Statistical Service (2008). Ghana Living Standards Survey: report of the fifth round (GLSS 5) [online]. Available at: *http://www.statsghana.gov.gh/docfiles/glss5_report.pdf* [Accessed on 25 April 2017].

Ghana Statistical Service (2012). 2010 Population and Housing Census: summary of final results [online] Available at: *http://www.ghana.gov.gh/images/stories/document/2010_phc_final_results.pdf* [Accessed on 24 April 2017]

Ghasemi, A. and Zahediasl, S. (2012). Normality tests for statistical analysis: a guide for non-statisticians. **International journal of endocrinology and metabolism** 10(2):486-489. https://doi.org/10.5812/ijem.3505

Giacomini, M. (2010). Theory Matters in Qualitative Research. *In:* BOURGEAULT, I., DINGWALL, R. & DE VRIES, R. (eds.) *The SAGE Handbook of Qualitative Methods in Health Research.* London: SAGE Publications.

Gillespie, D. and Campbell, F. (2011). Effect of stroke on family carers and family relationships. **Nursing Standard** 26(2):39-46.

Glasgow, R. E., Lichtenstein, E. and Marcus, A. C. (2003). Why Don't We See More Translation of Health Promotion Research to Practice? Rethinking the Efficacy-to-Effectiveness Transition. **American Journal of Public Health** 93(8):1261-1267.

Global Health Estimates (2015) **Deaths by age, sex and cause** (online). Available at *http://www.who.int/healthinfo/global_burden_disease/estimates/en/index2.html* (accessed 18 February, 2017)

Gocking, R. S. (2005). **The History of Ghana**. Westport, CT: Greenwood Press pp331

Godwin, K. M., Ostwald, S. K., Cron, S. G. and Wasserman, J. (2013) Long-term health-related quality of life of stroke survivors and their spousal caregivers. **J Neurosci Nurs** 45(3):147-54. doi: 10.1097/JNN.0b013e31828a410b. PMID: 23558977, PMCID: PMC3646534.

Goering, P. and Streiner, D. (2013). Reconcilable Differences: The Marriage of Qualitative and Quantitative Methods In*:* STREINER, D. (ed.) **A Guide for the Statistically Perplexed: Selected readings for clinical researchers***.* Toronto: University of Toronto Press.

Goldsmith, M. R., Bankhead, C. R. and Austoker, J. (2007). Synthesising quantitative and qualitative research in evidence-based patient information. **Journal of Epidemiology and Community Health** 61(3):262-270.

Goldstein, L. B., Bushnell, C. D., Adams, R. J., Apel, L. J., Braun, L. T. et al. (2011). Guidelines for the Primary Prevention of Stroke: A Guideline for Healthcare Professionals From the American Heart Association/American Stroke Association. **Stroke** 42(2):517-584.

Gomes, J. and Wachsman, A. M. (2013). **Types of Strokes. Handbook of Clinical Nutrition and Stroke** Springer pp.15-31.

Gould, A., Asare, H., Akpalu, A. et al. (2011). Development of stroke care in Ghana. **International Journal of Stroke** 6(2):150-151.

Govan, L., Langhorne, P. and Weir, C. (2007). Does the prevention of complications explain the survival benefit of organized inpatient (stroke unit) care? **Stroke** 38:2536-2540.

Government of Ghana (2012). Ghana at a glance: summary of Ghana at a glance [online]. Available at: *http://www.ghana.gov.gh/index.php/about-ghana/ghana-at-a-glance* [Accessed on 25 April 2017]

Green, J. and Thorogood, N. (2014). **Qualitative Methods for Health Research** London, SAGE.

Greenhalgh, T. (1997). How to read a paper: Papers that summarise other papers (systematic reviews and meta-analyses). **British Medical Journal** 315(7109):672-675.

Grimes, D. A. and Schulz, K. F. (2002). Bias and causal associations in observational research. **The Lancet** 359:248-252.

Grix, J. (2002). Introducing students to the generic terminology of social research. **Politics** 22(3):175-186.

Grond, M. (2001). Clinical thrombolysis in stroke. **Thromb Res** 103:135–142.

Gubrium, J. F. and Holstein, J. A. (2009) **Analyzing narrative reality**. Sage.

Guinhouya, K., Tall, A., Kombate, D., Kumako, V., Apetse, K., Belo, M. et al. (2010). Cost of stroke in Lomé (Togo). **Sante (Montrouge, France)**

Gurley, K. L. and Edlow, J. A. (2019). Avoiding Misdiagnosis in Patients With Posterior Circulation Ischemia: A Narrative Review. **Acad Emerg Med.** 26(11):1273-1284. doi: 10.1111/acem.13830. Epub PMID: 31295763.

Gysels, M., Shipman, C. and Higginson, I. J. (2008). Is the qualitative research interview an acceptable medium for research with palliative care patients and carers? **BMC medical ethics** 9:7.

Hackett, M. L. and Pickles, K. (2014). Part I: frequency of depression after stroke: an updated systematic review and meta-analysis of observational studies. **Int J Stroke**. 9:1017-1025. doi:10.1111/ijs.12357.

Hafsteinsdottir, T. B., Vergunst, M., Lindeman, E. and Schuurmans, M. (2011). Educational needs of patients with a stroke and their caregivers: a systematic review of the literature. **Patient Education and Counselling** 85(1):14–25.

Halabi, S., Smith, W., Collins, J., Baker, D. and Bedford, J. (2013). A document analysis of HIV/AIDS education interventions in Ghana. **Health Education Journal** 72(4):486-500

Hall, D. E., Prochazka, A. V. and Fink, A. S. (2012). Informed consent for clinical treatment. **CMAJ : Canadian Medical Association journal = journal de l'Association medicale canadienne.** 184(5):533-540. https://doi.org/10.1503/cmaj.112120

Hall, J. J. and Taylor, R. (2003). Health for all beyond 2000: the demise of the Alma-Ata Declaration and primary health care in developing countries. **Med J Aust.** 178(1):17-20.

Hall, M. A., Dugan, E., Zheng, B. & Mishra, A. K. (2001) Trust in physicians and medical institutions: what is it, can it be measured, and does it matter? **The Milbank Quarterly** 79:613-639.

Heikkinen, K., Helena, L.-K., Taina, N., Anne, K. and Sanna, S. (2008) A comparison of two educational interventions for the cognitive empowerment of ambulatory orthopaedic surgery patients. **Patient Education and Counseling** 73:272-279.

Heinemann, A.W., Magasi, S, Hammel, J, Carlozzi, N,E., Garcia, S,F,, Hahn, E,A,, *et al.* (2015) Environmental factors item development for persons with stroke, traumatic brain injury, and spinal cord injury. **Arch Phys Med Rehabil** 96:589-95. doi: 10.1016/j.apmr. 11.024.

Hjelmblink, F., Holmström, I. and Kjeldmand D. (2010) Stroke patients' delay of emergency treatment. **Scand J Caring Sci** 24:307-11. doi: 10.1111/j.1471-6712.2009.00721.x.

Hodgkinson, B., Evans, D. and O'neil, S. (2000) **Knowledge Retention from Preoperative Information: A Systematic Review.** The Joanna Briggs Institute for Evidence-Based Nursing and Midwifery, Adelaide.

Holt, J. (2009). Quantitative research: An overview **British Journal of Cardiac Nursing** 4(5):234-236.

Hooper, B. and Wood, W. (2002). Pragmatism and structuralism in occupational therapy: the long conversation. **American Journal of Occupational Therapy** 56(1):40-50.

Haley, W.E., Roth, D.L., Howard, G. and Safford, M.M. (2010) Caregiving Strain and Estimated Risk for Stroke and Coronary Heart Disease Among Spouse Caregivers Differential Effects by Race and Sex. **Stroke** 41:331–6.

Hamilton, H. and Clare, J. (2003). 'The shape and form of research writing'. **Writing research. Transforming data into text** 3-18.

Hamilton, M. (1960). A rating scale for depression. **Journal of Neurology, Neurosurgery and Psychiatry** 23:56-62.

Hanger, H.C, Walker, G., Paterson, L.A., McBride, S. and Sainsbury, R. (1998) What do patients and their carers want to know about stroke? A two-year follow-up study. Clin Rehabil 12:45-52. doi: 10.1191/026921598668677675.

Hankey, G. J. (2011). Stroke: fresh insights into causes, prevention, and treatment. **The Lancet Neurology** 10(1):2-3.

Hansson, M., Chotai, J., Nordstom, A., Bodlund, O., Hansson, M., Chotai, J. et al. (2009). Comparison of two self-rating scales to detect depression: HADS and PHQ-9. **Br J Gen Pract** 59:e283–8.

Hanson, W. E., Creswell, J. W., Clark, V. L. P., Petska, K. S. and Creswell, J. D. (2005). Mixed methods research designs in counseling psychology. **Journal of Counseling Psychology** 52(2):224-235.

Harbison, J., Hossain, O., Jenkinson, D., Davis, J., Louw, S. J. and Ford, G. A. (2003). Diagnostic accuracy of stroke referrals from primary care, emergency room physicians, and ambulance staff using the face arm speech test. **Stroke** 34:71-76.

Hawker, S., Payne, S., Kerr, C., Handey, M. and Powel, J. (2002). Appraising the Evidence: Reviewing Disparate Data Systematically. **Qualitative Health Research** 12(9):1284-1299.

Haynes, L., Goldacre, B. and Torgerson, D. (2012). **Test, learn, adapt: developing public policy with randomised controlled trials.** London: Cabinet Office

Health Research Authority (2014). **Consent and Participation** [Online]. Available: http://www.hra.nhs.uk/resources/before-youapply/consent-and-participation/ [Accessed 24/11/2018].

Health Research Authority (2017). **Patient adherence to post-operative restrictions after hip replacement.** Available: https://www.hra.nhs.uk/planning-and-improving-research/application-summaries/research-summaries/patient-adherence-to-post-operative-restrictions-after-hip-replacement/ [Accessed 15 October 2018].

Hemingway, H., Malik, M. and Marmot, M. (2001) Social and psychosocial influences on sudden cardiac death, ventricular arrhythmia and cardiac autonomic function. **European Heart Journal** 22:1082-1101.

Hey, S. P., London, A. J., Weijer, C. and Miller, F. (2017). Is the concept of clinical equipoise still relevant to research? **BMJ** 359:j5787

Heye, M., Foster, L., Bartlett, M. and Adkin, S. (2002) A preoperative education intervention for pain reduction, improved mobility, and self-efficacy. **Applied Nursing Research** 16:174-183.

Hickey, A., O'Hanlon, A., McGee, H., Donnellan, C., Shelley, E., Horgan, F. and l D (2009). Stroke awareness in the general population: knowledge of stroke risk factors and warning signs in older adults. **BMC Geriatriac** 9:35.

Higgins, J. and Green, S. (eds.) (2011). **Cochrane Handbook for Systematic Reviews of Interventions** The Cochrane Collaboration.

Hoffmann, T., McKenna, K., Worrall, L. and Read, S. J. (2007). Randomised trial of a computer-generated tailored written education package for patients following stroke. **Age Ageing** 36:280-6.

Holmes, K. K., Bertozzi, S., Bloom, B. R., et al. (2017). Major Infectious Diseases: Key Messages from Disease Control Priorities, Third Edition. In: Holmes KK, Bertozzi S, Bloom BR, et al., editors. Major Infectious Diseases. 3rd edition. Washington (DC): The International Bank for Reconstruction and Development / The World Bank; Nov 3. Chapter 1.

Hou, W-H., Hoffmann, T., Huang, Y. J., Wu, T-Y., Chen, S-S. and Hsieh, C-L. (2016). A Systematic Review of Tests Assessing Stroke Knowledge. **Journal of Cardiovascular Nursing** https://doi.org/10.1097/JCN.0000000000000345

Houle, S. (2015). An Introduction to the Fundamentals of Randomized Controlled Trials in Pharmacy Research. **Can J Hosp Pharm** 68:28-32.

Hundt, G. L., Stuttaford, M. and Ngoma, B. (2004). The SASPI team. The social diagnostics of stroke-like symptoms: healers, doctors and prophets in Agincourt, Limpopo Province, South Africa. **J Biosoc Sci** 36:433-43.

Hydén, L.-C. and Bülow, P. H. (2003). Who's talking: drawing conclusions from focus groups—some methodological considerations. **The International Journal of Social Research Methodology** 6(4):305-321.

Kerr, J., Hilari, K. and Litosseliti, L. (2010) Information needs after stroke: What to include and how to structure it on a website. A qualitative study using focus groups and card sorting. Aphasiology 24:1170-96. doi: 10.1080/02687030903383738

Kim, J.S. and Choi-Kwon, S.(2000) Poststroke depression and emotional incontinence: Correlation with lesion location. **Neurology** 54:1805-1810.

Kim, J.S., Lee, E.J., Chang, D.I., Park, J.H., Ahn, S.H., Cha, J,K., et al.( 2016) Efficacy of early administration of escitalopram on post-stroke depressive/emotional symptoms and neurologic dysfunction: a multicenter, double blind, randomized, placebo-controlled study. **Lancet Psychiatry** in press.

Kruithof, W.J., Post, M.W., van Mierlo, M.L., et al. (2016) Caregiver burden and emotional problems in partners of stroke patients at two months and one year post-stroke: determinants and prediction. Patient Educ Couns 99:1632–40.

Kutlubaev, M.A. and Hackett, M.L. (2014) Part ii: Predictors of depression after stroke and impact of depression on stroke outcome: an updated systematic review of observational studies. **Int J Stroke** 9:1026-1036.

Ihantola, E. M. and Kihn, L. A. (2011). Threats to validity and reliability in mixed methods accounting research. **Qualitative Research in Accounting and Management** 8(1):39-58.

Intercollegiate Stroke Working Party (2016). *National clinical guideline for stroke, 3rd edition*. London: Royal College of Physicians [online] Available at: https://www.strokeaudit.org/SupportFiles/Documents/Guidelines/2016-National-Clinical-Guideline-for-Stroke-5t-(1).aspx [accessed on 28/10/19]

Indredavik, B., Rohweder, G., Naalsund, E. and Lydersen, S. (2008). Medical complications in a comprehensive stroke unit and an early supported discharge service. **Stroke** 39:414-420.

Ivarsson, B., Larsson, S., Luhrs, C. and Sjoberg, T. (2005a) Extended written pre-operative information about possible complications at cardiac surgery-do the patients want to know? **European Journal of Cardio-Thoracic Surgery** 28:407-414.

Ivarsson, B., Larsson, S., Luhrs, C. and Sjoberg, T. (2007) Patient's perceptions of information about risks at cardiac surgery. **Patient Education and Counseling** 67:32-8.

Ivarsson, B., Larsson, S. and Sjöberg, T. (2004) Patients' experiences of support while waiting for cardiac surgery. A critical incident technique analysis. **European Journal of Cardiovascular Nursing** 3:183-191.

Ivarsson, B., Sjöberg, T. and Larsson, S. (2005b) Waiting for cardiac surgery-support experienced by next of kin. **European Journal of Cardiovascular Nursing** 4:145-152.

Ivnik, M. and Jett, M. Y. (2008). Creating written patient education materials. **Chest** 133:1038-1040.

Iwelunmor, J., Blackstone, S., Veira, D., Nwaozuru, U., Airhihenbuwa, C., Munodawafa, D. and Ogedegebe, G. (2015). Toward the sustainability of health interventions implemented in sub-Saharan Africa: a systematic review and conceptual framework. **Implementation Science** 11:43 http://doi.org/10.1186/s13012-016-0392-8

Jackson, E. (2013). "Choosing a Methodology: Philosophical Underpinning." **Practitioner Research in Higher Education Journal** 7(1)

Jackson, R. L., Drummond, D. K. and Camara, S. (2007). What Is Qualitative Research? **Qualitative Research Reports in Communication** 8(1):21-28.

Jagosh, J. and Boudreau, J. D. (2009) Lost and found in translation: an ecological approach to bilingual research methodology. **International Journal of Qualitative Methods** 8:102-114.

Jalaludin, B., Maxwell, M., Saddik, B., Lobb, E., Byun, R., Gutierrez, R. and Paszek, J. (2012). A pre-and-post study of an urban renewal program in a socially disadvantaged neighbourhood in Sydney, Australia. **BMC public health** 12:521. https://doi.org/10.1186/1471-2458-12-521

Jauch, E. C., Saver, J. L., Adams, H. P. Jr, et al. (2013). Guidelines for the early management of patients with acute ischemic stroke: a guideline for healthcare professionals from the American Heart Association/American Stroke Association. **Stroke** 44:870-947

Jenkins, C., Ovbiagele, B., Arulogun, O., Singh, A., Calys-Tagoe, B., Akinyemi, R., et al. (2018). Knowledge, attitudes and practices related to stroke in Ghana and Nigeria: A SIREN call to action. **PLoS ONE** 13(11):e0206548. https://doi.org/10.1371/journal.pone.0206548

Joanna Briggs Institute (2016). The Joanna Briggs Institute Critical Appraisal tools for use in JBI Systematic Reviews; Checklist for Randomized Controlled Trials [online] Available at *http://joannabriggs.org/research/critical-appraisal-tools.html* [accessed on 21 April 2017]

Johansson, K., Nuutila, L., Virtanen, H., Katajisto, J. & Salanterä, S. (2005) Preoperative education for orthopaedic patients: systematic review. **Journal of Advanced Nursing** 50:212-223.

Johnson, L., Akpalu, A., Anane, D., Cudjoeb, C. et al. (2017). Multi-disciplinary stroke care in developing countries – lessons from the Wessex-Ghana Stroke Partnership. **South Sudan Medical Journal** 10:84–86.

Johnson, R. B. and Onwuegbuzie, A. J. (2004). Mixed Methods Research: A Research Paradigm Whose Time Has Come **Educational Researcher** 33(7):14-26.

Johnston, S. C., Mendis, S. and Mathers, C. D. (2009). Global variation in stroke burden and mortality: estimates from monitoring, surveillance, and modelling. **The Lancet Neurology** 8(4):345-54.

Jones, M.P., Howitt, S.C., Jusabani, A. et al. (2012) Anxiety and depression in incident stroke survivors and their carers in rural Tanzania: a case-control follow-up study over five years. **Neurol Psychiatry Brain Res.** 18:12–128.

Joo, H. and Liang, D. (2017) Economic burden of informal care attributable to stroke among those aged 65 years or older in China. **Int J Stroke**: Off J Int Stroke So 12:205–7.

Kaddumukasa, M., Kayima, J., Kaddumukasa, M. N., Ddumba, E., Mugenyi, L., Pundik, S. and Katabira, E. (2015). Knowledge, attitudes and perceptions of stroke: a cross-sectional survey in rural and urban Uganda. **BMC Research Notes** (8)819. http://doi.org/10.1186/s13104-015-1820-6 690–704.

Kahan, B. C., Rehal, S. and Cro, S. (2015). Risk of selection bias in randomised trials. **Trials**16:405.

Kalra, L., Evans, A., Perez, I. et al. (2004). Training carers of stroke patients: randomised controlled trial. **BMJ** 328:1099.

Kaste, M. and Norrving, B. (2010). Editorials: From the World Stroke Day to the World Stroke Campaign: one in six: act now! **International journal of stroke** 5(5):342-3.

Katan, M. and Luft A. (2018). Global burden of stroke **Semin Neurology** 38:208-211

Kaur, P., Kwatra, G., Kaur, R. and Pandian, J. D. (2014). Cost of stroke in low and middle-income countries: A systematic review. **Int J Stroke** 9:678-682.

Kawachi, I., Colditz, G. A., Stampfer, M. J., Willett, W. C., Manson, J. E., Rosner, B., Speizer, F. E., Hennekens, C. H. (1993). Smoking cessation and decreased risk of stroke in women. **JAMA** 269:232-236.

Kayima, J., Wanyenze, R. K., Katamba, A., Leontsini, E. and Nuwaha, F. (2013). Hypertension awareness, treatment and control in Africa: a systematic review. **BMC cardiovascular disorders** 13(1):54.

Keates, A. K., Mocumbi, A. O., Ntsekhe, M., Sliwa, K. and Stewart, S. (2017). Cardiovascular disease in Africa: epidemiological profile and challenges. **Nature Reviews Cardiology** 4:273-293

Kenny, T., Wilson, R. G., Purves, I. N., Clark, J., Newton, L. D., Newton, D. P. and Moseley, D. V. (1998) A PIL for every ill? Patient information leaflets (PILS): a review of past, present and future use. **Family Practice** 15:471-479.

Kengne, A. P. and Mayosi, B. M. (2014). Readiness of the primary care system for non-communicable diseases in sub-Saharan Africa. **The lancet global health** 2(5):e247-8.

Kernan, W. N., Ovbiagele, B., Black, H. R., Bravata, D. M., Chimowitz, M. I., Ezekowitz, M. D., Fang, M. C., Fisher, M., Furie, K. L., Heck, D. V., Johnston, S. C., Kasner, S. E., Kittner, S. J., Mitchell, P. H., Rich, M. W., Richardson, D., Schwamm, L. H., Wilson, J. A. (2014). on behalf of the American Heart Association Stroke Council, Council on Cardiovascular and Stroke Nursing, Council on Clinical Cardiology, and Council on Peripheral Vascular Disease. Guidelines for the prevention of stroke in patients with stroke and transient ischemic attack: a guideline for healthcare professionals from the American Heart Association/American Stroke Association [published correction appears in Stroke. 2015;46:e54]. **Stroke** 45:2160-2236. doi: 10.1161/STR.0000000000000024.

Khedr, E. M., Fawi, G., Abdela, M., Mohammed, T. A., Ahmed, M. A., El-Fetoh, N. A., et al. (2014). Prevalence of ischemic and hemorrhagic strokes in Qena Governorate, Egypt: community-based study. **Journal of Stroke and Cerebrovascular Diseases** 23:1843-8.

Kidwell, C. S., Starkman, S., Eckstein, M., Weems, K. and Saver, J. L. (2000). Identifying stroke in the field: prospective validation of the Los Angeles prehospital stroke screen (LAPSS). **Stroke** 31:71-76.

Kirkwood, B. R. and Sterne, J. A. C. (2003). **Essential medical statistics** (2nd edn)., Blackwell Science, Oxford.

Knowles, M. S., Holton, E. F. and Swanson, R. A. (2005). **Andragogy in practice: expanding the usefulness of the andragogical model**. The adult learner. 6th edn. Amsterdam: Elsevier/Butterworth Heinemann.

Kolapo, K. O., Ogun, S. A., Danesi, M. A., Osalusi, B. S. and Odusite, K. A. (2006). Validation study of the Siriraj stroke score in African Nigerians and evaluation of the discriminant values of its parameters. A preliminary prospective CT scan study. **Stroke** 37:1997-2000

Kolling, M., Winkley, K. and von Deden, M. (2010). " For someone who's rich, it's not a problem". Insights from Tanzania on diabetes health-seeking and medical pluralism among Dar es Salaam's urban poor. **Globalization and health** 6:8. https://doi.org/10.1186/1744-8603-6-8

Komolafe, M. A., Obembe, A. O., Olaogun, M. O., Adebiyi, A. M., Ugalahi, T. et al. (2015). Awareness of stroke risk factors and warning signs in Nigerian adolescents compared with adults. **J Stroke Cerebrovasc Dis** 24:687-693.

Kong, D. T., Dirks, K. T. and Ferrin, D. L. (2014). Interpersonal trust within negotiations: metanalytic evidence, critical contingencies, and directions for future research. **Acad Manag J.** 57(5):1235–55.

Kothari, R. U., Pancioli, A., Liu, T., Brott, T. and Broderick, J. (1999). Cincinnati Prehospital Stroke Scale: reproducibility and validity. **Annals of Emergency Medicine** 33:373-378.

Kotoh, A. M. and Van der Geest, S. (2016). Why are the poor less covered in Ghana's national health insurance? A critical analysis of policy and practice. **International journal for equity in health** 15(1):34.

Kroeger, A. (1983). Anthropological and socio-medical health care research in developing countries. **Social science and medicine** 17(3):147-161.

Kvale, S. and Brinkmann, S. (2008). **Interviews: Learning the craft of qualitative research interviewing**. Thousand Oaks, CA: Sage Publications, Inc.

Langhorne, P. and Pollock, A. (2002). What are the components of effective stroke unit care? **Age and Ageing** 31:365-371.

Langhorne, P., de Villiers, L. and Pandian, J. D. (2012). Applicability of stroke-unit care to low-income and middle-income countries. **Lancet Neurol** 11(4):341–8.

Larkin, P. J., Dierckx De Casterlé, B. and Schotsmans, P. (2007) Multilingual translation issues in qualitative research. **Qualitative Health Research** 17:468-476.

Lawes, C. M., Bennett, D. A., Feigin, V. L., Rodgers, A. (2004). Blood pressure and stroke: an overview of published reviews. **Stroke** 35:776-785.

Lee, A., Chui, P. T. & Gin, T. (2003) Educating patients about anesthesia: a systematic review of randomized controlled trials of media-based interventions. **Anesthesia and Analgesia** 96:1424-1431.

Lemogoum, D., Degaute, J-P. and Bovet, P. (2005). Stroke prevention, treatment, and rehabilitation in Sub-Saharan Africa. **Am J Prev Med** 29:95–101

Lerdal, A., Kottorp, A., Gay, C. L., Grov, E. K. and Lee, K. A. (2014) Rasch analysis of the Beck Depression Inventory-II in stroke survivors: a cross-sectional study. **J Affect Disord** 158:48–52. doi:10.1016/j.jad.2014.01.013

Lewin, S., Glenton, C. and Oxman, A. D. (2009) Use of qualitative methods alongside randomised controlled trials of complex healthcare interventions: methodological study. **BMJ** 339-3496.

Lewis, M. A. and Newton, J. T. (2006) An evaluation of the quality of commercially produced patient information leaflets. **British Dental Journal** 201:114-117.

Lewis, S.C., Dennis, M.S., O'Rourke, S.J. and Sharpe, M. (2001) Negative attitudes among short-term stroke survivors predict worse long-term survival. **Stroke** 32:1640-5.

Li, Q., Xu, Y., Zhou, H., et al. (2016) Factors influencing the health-related quality of life of Chinese advanced cancer patients and their spousal caregivers: a cross-sectional study. **BMC Palliat Care** 15:72. doi: 10.1186/s12904-016-0142-3.

Liberati, A, Altman, D. G., Tetzlaff, J., Mulrow, C., Gøtzsche, P., Ioannidis, J. P. et al. (2009) The PRISMA statement for reporting systematic reviews and meta-analyses of studies that evaluate health care interventions: explanation and elaboration. **Ann Intern Med** 151:W-65-94.

Lindsay, P., Furie, K. L., Davis, S. M., Donnan, G. A. and Norrving, B. (2014) World Stroke Organization global stroke services guidelines and action plan. **International Journal Stroke** 9:4-13

Llanes, J. N., Kidwell, C. S., Starkman, S., Leary, M. C., Eckstein, M. and Saver, J. L. (2004) The Los Angeles Motor Scale (LAMS): a new measure to characterize stroke severity in the field. **Prehospital Emergency Care** 8:46-50.

Lloyd-Jones, D., Adams, R., Carnethon, M., et al. (2009) Committee, F. T. A. H. A. S. and Stroke statistics subcommittee. Heart Disease and Stroke Statistics—2009 Update: A Report from the American Heart Association Statistics Committee and Stroke Statistics Subcommittee. **Circulation** 119:e21-181.

Loh, A.Z., Tan, J.S., Zhang, M.W., et al. (2017) The global prevalence of anxiety and depressive symptoms among caregivers of stroke survivors. **J Am Med Dir Assoc** 18:111–6.

London, A. J. (2017) Equipoise in research: integrating ethics and science in human research. **JAMA** 317:525-526.

Lopez, G. I., Figureoa, M., Connor, S. E. and Maliski, S. L. (2008) Tanslation barriers in conducting qualitative research with Spanish speakers. **Qualitative Health Research** 18:1729-1737.

Lowe, D., Sharma, A. and Leathley, M. (2007). The CareFile project: a feasibility study to examine the effects of an individualised information booklet on patients after stroke. **Age and Ageing** 36:83-9.

Lozano, R., Naghavi, M., Foreman, K. et al. (2012). Global and regional mortality from 235 causes of death for 20 age groups in 1990 and 2010: a systematic analysis for the Global Burden of Disease Study 2010 [published correction appears in Lancet. 2013 Feb 23;381(9867):628. AlMazroa, Mohammad A [added]; Memish, Ziad A [added]]. **Lancet** 380(9859):2095-2128. doi:10.1016/S0140-6736(12)61728-0

Luker, J., Murray, C., Lynch, E., Bernhardsson, S., Shannon, M. and Bernhardt, J. (2017). Carers' Experiences, Needs, and Preferences During Inpatient Stroke Rehabilitation: A Systematic Review of Qualitative Studies. **Arch Phys Med Rehabil** 98(9):1852-1862.e13.

Maasland, L., Brouwer-Goossensen, D., den Hertog, H.M., Koudstaal, P.J., & Dippel, D.J. (2011). Health education in patients with a recent stroke or transient ischaemic attack: A comprehensive review. **International Journal of Stroke** 6(1):67-74. doi:10.1111/j.1747-4949. 2010.00541.x

Maasland, E., Koudstaal, P. J., Habbema, J. D. F. and Dippel, D. W. J. (2007). Effects of an individualised multimedia computer programme for health education in patients

with a recent minor stroke or transient ischemic attack - a randomized controlled trial. **Acta Neurological Scandinavica** 115:41-8.

Macphee, M. and Pratt, P. (2005) Evidence-based practice. **Journal of Pediatric Nursing** 20:396-398.

Mackay, J. and Mensah, G. A. (2004). The atlas of heart disease and stroke.

Mackenzie, N. and Knipe, S. (2006). Research dilemmas: Paradigms, methods, and methodology. **Issues in Educational Research** 16.

Magarey, J. (2001). Elements of a systematic review. **International Journal of Nursing Practice** 7:376-382.

Mahoney, J. and Goertz, G. (2006). A Tale of Two Cultures: Contrasting Quantitative and Qualitative Research**. Political Analysis** 14(3):227-249.

Maier, W., Buller, R., Philipp, M. and Heuser, I. (1988). The Hamilton anxiety scale: reliability, validity and sensitivity to change in anxiety and depressive disorders. **J Affect Disord** 14:61-68.

Maleka, M., Stewart, A. S. and Hale, L. (2012). The experience of living with a stroke in low urban and rural socio-economic areas of South Africa. **South African Journal of Physiotherapy** 68(3):25-29.

Maliski, S. L., Connor, S. E., Williams, L. and Litwin, M. S. (2010). Faith among low-income, African American/Black men treated for prostate cancer. **Cancer Nursing** 33:470-478 9p

Mant, J., Carter, J., Wade, D. T. and Winner, S. (1998). The impact of an information pack on patients with stroke and their carers: a randomized controlled trial. **Clinical Rehabilitation** 12:465-76.

Mantzoukas, S. (2008) A review of evidence-based practice, nursing research and reflection: levelling the hierarchy. **Journal of Clinical Nursing** 17:214-223.

Markus, R., Reutens, D. C., Kazui, S., et al. (2004). Hypoxic tissue in ischaemic stroke: persistence and clinical consequences of spontaneous survival. **Brain**127:1427-36.

Marsh, D. and Furlong, E. (2002). A skin not a sweater: Ontology and epistemology in political science. **Theory and Methods in Political Science** 2:17-41

Martinez-Martin, P., Benito-Leon, J., Alonso, F., Catalan, M.J., Pondal, M., Zamarbide, I. *et al*. (2005) Quality of life of caregivers in Parkinson's disease. Quality of Life Research 14:463-72.

Masuku, K.P., Mophosho, M. and Tshabalala, M. (2018) '"I felt pain. Deep pain…": Experiences of primary caregivers of stroke survivors with aphasia in a South African township', **African Journal of Disability** 7(0):1–7. https://doi. org/10.4102/ ajod.v7i0.368

Mathers, C. D. and Loncar, D. (2006). Projections of global mortality and burden of disease from 2002 to 2030. **PLoS medicine** 3(11):e442. https://doi.org/10.1371/journal.pmed.0030442

Maxwell, J. A. (2012). **A realist approach for qualitative research**. Sage.

May, C.R., Mair, F., Finch, T. *et al.* (2009) Development of a theory of implementation and integration: Normalization Process Theory. **Implementation Sci** 4:29. https://doi.org/10.1186/1748-5908-4-29

Mayou, R. A., Gill, D., Thompson, D. R., Day, A., Hicks, N., Volmink, J. and Neil, A. (2000) Depression and anxiety as predictors of outcome after myocardial infarction. **Psychosomatic Medicine** 62, 212-219.

Mbanya, J. C., Kengne, A. P. and Assah, F. (2006). Diabetes care in Africa. **The Lancet** 368(9548):1628-1629.

Mbanya, J.C.N., Motala, A.A., Sobngwi, E., Assah, F.K. and Enoru, S.T. (2010). Diabetes in sub-Saharan Africa. **Lancet** 375:2254-2266

McCloskey, J. C. and Bulechek, G. M. (2000). **Nursing interventions classification (NIC)**. St. Louis, MO: Mosby

McCready, J. S. (2010). Jamesian pragmatism: a framework for working towards unified diversity in nursing knowledge development. **Nursing Philosophy** 11:191-203.

McDonald, A. M., Knight, R. C., Campbell, M. K., Entwistle, V. A., Grant, A. M., Cook, J. A. et al. (2006). What influences recruitment to randomised controlled trials? A review of trials funded by two UK funding agencies. **Trials** 7(1):9.

McHugh, F., Lindsay, G. M., Hanlon, P., Hutton, I., Brown, M. R., Morrison, C. and Wheatley, D. J. (2001) Nurse led shared care for patients on the waiting list for coronary artery bypass surgery: a randomised controlled trial. **Heart** 86:317-323.

McGill K, Sackley CM, Godwin J, et al. (2020). A systematic review of the efficiency of recruitment to stroke rehabilitation randomised controlled trials. **Trials** 21(1):68.

McKevitt, C, Fudge, N, Redfern, J, Sheldenkar, A, Crichton, S and Rudd, A. R. (2011). Self-reported long-term needs after stroke. **Stroke** 42:1398-403.

Mcpherson, C.J., Wilson, K.G., Chyurlia, L. and Leclerc, C. (2011) The caregiving relationship and quality of life among partners of stroke survivors: A cross- sectional study. **Health Qual Life Outcomes** 9(29):1–10.

Meade, M., O. and Richardson, W., S. (1997). Selecting and appraising studies for a systematic review. **Annals of Internal Medicine**127:531-537.

Mendis, S., Abegunde, D., Yusuf, S., et al. (2005). WHO study on prevention of recurrences of myocardial infarction and stroke (WHO-Premise). **Bull World Health Organ** 83:820-28.

Mensah, G. A. (2008). Epidemiology of stroke and high blood pressure in Africa. **Heart** 94(6):697-705.

Mensah, G. A., Norrving, B. and Feigin, V. L. (2015). The global burden of stroke. **Neuroepidemiology** 45(3):143-5.

Mensah, J., Oppong, J. and Schmidt, C. (2010). Ghana's National Health Insurance Scheme in the context of the health Mdgs: an empirical evaluation using propensity score matching. **Health Econ** 19:95-106.

Mergenthaler, P., Dirnagl, U. and Meisel, A. (2004). Pathophysiology of Stroke: Lessons from Animal Models. **Metabolic Brain Disease** 19(3):151-167.

Miller, W. and Crabtree, B. 1999. Depth Interviewing. In*:* Crabtree, B. and Miller, R. (eds.) **Doing Qualitative Research***.* London: SAGE.

Miller, F. P., Vandome, A. F. and McBrewster, J. (eds) (2009). **History of Ghana**. Mauritius: Alphascript Publishing.

Ministry of Health. (2011). **National Policy for the Prevention and Control of Chronic Non-Communicable Diseases in Ghana.** [Online]. Available at: http://www.iccp-portal.org/sites/default/files/plans/national_policy_for_the_prevention_and_control_of_chronic_non-communicable_diseases_in_ghana(1).pdf [Accessed 6 January 2020].

Ministry of Health (2007). The health sector programme of work 2007-2011: creating wealth through health [online]. Available at: *http://www.moh*ghana.org/UploadFiles/Publications/5Yr%20POW%20III%20(20072011)120422153555. pdf [Accessed on 24 April 2017].

Moher, D., Shamseer, L., Clarke, M., Ghersi, D., Liberati, A., Petticrew, M., et al. (2015). Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015 statement. **Syst Rev** 4:1.

Moher, D., Liberati, A., Tetzlaff, J., Altman, D. G., PRISMA Group (2009). Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement. **BMJ** 339:b2535.

Moher, D., Tetzlaff, J., Tricco, A. C., Sampson, M. and Altman, D. G. (2007). Epidemiology and Reporting Characteristics of Systematic Reviews. **PLos Med** 4(3):e78.doi:10.1371/journal.pmed.0040078.

Monsivais, D. and Reynolds, A. (2003) Developing and evaluating patient education materials. **The Journal of Continuing Education in Nursing** 34:172-176.

Moran, A., Forouzanfar, M., Sampson, U., Chugh, S., Feigin, V. and Mensah, G. (2013) "The epidemiology of cardiovascular diseases in sub-Saharan Africa: the Global Burden of Diseases, Injuries and Risk Factors 2010 Study," **Progress in Cardiovascular Diseases** 56(3):234–239.

Morgan, D. L. (2007). Paradigms lost and pragmatism regained methodological implications of combining qualitative and quantitative methods. **Journal of Mixed Methods Research** 1(1):48-76.

Morrison, V., Pollard, B., Johnston, M. and MacWalter, R. (2005) Anxiety and depression 3 years following stroke: demographic, clinical, and psychological predictors. **J Psychosom Res** 59:209-213.

Mossman, J., Boudioni, M. and Slevin, M.L. (1999) Cancer information: A cost-effective intervention. **Eur J Cancer** 35:1587-91. doi: 10.1016/S0959-8049(99)00195-1.

Mould-Millman. N. K., Rominski, S. D., Bogus, J., et al. (2015). Barriers to accessing Emergency Medical Services in Accra, Ghana. Global Health: **Science and Practice**. 3(4): 577-590

Mozaffarian, D., Benjamin, E. J., Go, A. S., et al. (2016). Heart disease and stroke statistics—2016 update: a report from the American Heart Association. **Circulation** 133:e38-360.

Mshana, G., Hampshire, K., Panter-Brick, C. and Walker, R. (2008). Urban-rural contrasts in explanatory models and treatment-seeking behaviours for stroke in Tanzania. **J Biosoc Sci** 40:35–52.

Mulrow, C. and Oxman, A. (1997). The Cochrane Collaboration Handbook. London: **British Medical Journal Publishing Group**

Muncey, T. (2009). Does Mixed Methods Constitute A Change in Paradigm. **Mixed Methods Research for Nursing and the Health Sciences** 13-30.

Muntingh, A. D., van der Feltz-Cornelis, C. M., van Marwijk, H. W., Spinhoven, P., Penninx, B. W. and van Balkom, A. J. (2011). Is the Beck Anxiety Inventory a good tool to assess the severity of anxiety? A primary care study in The Netherlands Study of Depression and Anxiety (NESDA). **BMC Fam Pract** 12:66.

Murphy, C. A., Cupples, M. E., Percy, A., Halliday, H. L. and Stewart, M.C. (2008). Peer-mentoring for first-time mothers from areas of socioeconomic disadvantage: a qualitative study within a randomised controlled trial. **BMC Health Services Research** 8:46.

Nakibuuka, J., Sajatovic, M., Katabira, E., Ddumba, E., Byakika-Tusiime, J. and Furlan, A. J. (2014). Knowledge and Perception of Stroke: A Population-Based Survey in Uganda. **ISRN stroke**10. doi:10.1155/2014/309106

Nangsangna, R. D., and da-Costa Vroom, F. (2019). Factors influencing online health information seeking behaviour among patients in Kwahu West Municipal, Nkawkaw,

Ghana. **Online journal of public health informatics** 11(2):e13. doi:10.5210/ojphi.v11i2.10141

Napon, C., Dabilgou, A., Kyelem, J., Bonkoungou, P. and Kaboré, J. (2017). Therapeutic route of patients at the acute phase of their stroke in Burkina Faso. **J Neurol Sci** 372:75-77.

National Collaborating Centre for Chronic Conditions (NCC-CC) (2008). **Stroke: national clinical guideline for diagnosis and initial management of acute stroke and transient ischaemic attack (TIA)**. London: Royal College of Physicians.

National Institute for health and Clinical Excellence (NICE) (2008). **Stroke: Diagnosis and initial management of acute stroke and transient ischaemic attack (TIA)** [online]. National Health Service. Available at: http://www.nice.org.uk/nicemedia/live/12018/41331/41331.pdf[accessed 07/11/2019].

National Institute for Health Research (2018). Glossary | Feasibility studies. www.nets.nihr.ac.uk/glossary?result_1655_ result_page=P [accessed on 12 December 2018]

NHIA (2013). **NATIONAL HEALTH INSURANCE AUTHORITY 2013 ANNUAL REPORT** [online]. Available at: *http://nhis.gov.gh/files/2013%20Annual%20Report-Final%20ver%2029.09.14.pdf* [Accessed on 11 June 2017].

National Health Insurance Scheme (2017) **Overview of NHIS** [online]. Available at: *http://www.nhis.gov.gh/?CategoryID=158&ArticleID=82* [Accessed on 24 April 2017].

Newton, S. K. and Appiah-Poku, J. (2007). The perspectives of researchers on obtaining informed consent in developing countries. **Dev World Bioeth** 7:19-24. 10.1111/j.1471-8847.2006.00147.x.

Nicholls, C. (2011). The advantages of using qualitative research methods **Alexander Technique College** 1-9.

Nilsen, P. (2015) Making sense of implementation theories, models and frameworks. **Implementation Sci** 10:53. https://doi.org/10.1186/s13012-015-0242-0

Norrie, J. (2011). Randomised controlled trials of complex interventions. **Trials**12 (1):A142

Norrving, B., Barrick, J., Davalos, A., Dichgans, M., Cordonnier, C., Guekht, A., … Caso, V. (2018). Action Plan for Stroke in Europe 2018–2030. **European Stroke Journal** *3*(4):309-336. https://doi.org/10.1177/2396987318808719

Nyirenda, M. J. (2016). Non-communicable diseases in sub-Saharan Africa: understanding the drivers of the epidemic to inform intervention strategies. **Int Health** 8:157-158. https://doi.org/10.1093/inthealth/ihw021

Obembe, A. O., Olaogun, M. O., Bamikole, A. A., Komolafe, M. A. and Odetunde, M. O. (2013). Awareness of risk factors and warning signs of stroke in a Nigeria university. **J Stroke Cerebrovasc Dis**. In press.

O'Cathain, A., Hoddinott, P., Lewin, S. et al. (2015). Maximising the impact of qualitative research in feasibility studies for randomised controlled trials: guidance for researchers. **Pilot Feasibility Stud** 1:32. doi:10.1186/s40814-015-0026-y.

O'Cathain, A., Murphy, E. and Nicholl, J. (2007). Why, and how, mixed methods research is undertaken in health services research in England: a mixed methods study. **BMC Health Services Research** 7:1-11.

Ocampo, A. R. (2013). Health funding in Africa: How close is the AU to meeting Abuja targets? Devex.

O'Donnell, M. J., Xavier, D., Liu, L., Zhang, H., Chin, S. L., Rao-Melacini, P., et al. (2010). Risk factors for ischaemic and intracerebral haemorrhagic stroke in 22 countries (the INTERSTROKE study): a case-control study. **The Lancet** 376(9735):112-23.

O'Donnell MJ, Chin, S. L., Rangarajan, S., Xavier, D., Liu, L., Zhang. H., Rao-Melacini, P., Zhang, X, Pais, P, Agapay, S., Lopez-Jaramillo, P., Damasceno. A, Langhorne, P., et al (2016). Global and regional effects of potentially modifiable risk factors associated with acute stroke in 32 countries (INTERSTROKE): a case-control study. **Lancet** 388:761-775

Ogun, S.A., Ojini, F. I., Ogungbo, B., Kolapo, K. O. and Danesi, M. A. (2005). Stroke in southwest Nigeria: A 10 year review. **Stroke** 36:1120-1122.

Ojagbemi, A., Owolabi, M., Akinyemi, R., Arulogun, O., Akinyemi, J., Akpa, O., Sarfo, F. S., Uvere, E., Saulson, R., Hurst, S., Ovbiagele, B. (2017) Prevalence and

predictors of anxiety in an African sample of recent stroke survivors. **Acta Neurol Scand. Dec** 136(6):617-623. doi: 10.1111/ane.12766.

Ojagbemi, A., Owolabi, M., Akinyemi, R., et al. (2017) Prevalence and predictors of anxiety in an African sample of recent stroke survivors. **Acta Neurol Scand** 136(6):617-623.

Okada, Y., Yamaguchi, T., Minematsu, K., Miyashita, T., Sawada, T., Sadoshima, S., Fujishima, M. and Omae, T. (1989). Hemorrhagic transformation in cerebral embolism. **Stroke** 20:598-603.

Okoroh, J., Essoun, S., Seddoh, A. et al. (2018). Evaluating the impact of the national health insurance scheme of Ghana on out-of-pocket expenditures: a systematic review. **BMC Health Serv Res** 18:426. https://doi.org/10.1186/s12913-018-3249-9

Olaiya, M. T., Cadilhac, D. A., Kim, J., Ung, D., Nelson, M. R., Srikanth, V. K., Bladin, C. F., Gerraty, R. P., Fitzgerald, S. M., Phan, T. G., Frayne, J. and Thrift, A. G. (2016). Nurse-Led Intervention to Improve Knowledge of Medications in Survivors of Stroke or Transient Ischemic Attack: A Cluster Randomized Controlled Trial. **Frontiers in neurology** 7:205. https://doi.org/10.3389/fneur.2016.00205

Olaleye, O. A., Hamzat, T. K. and Akinrinsade, M. A. (2017). Satisfaction of Nigerian stroke survivors with outpatient physiotherapy care. **Physiotherapy Theory and Practice** 33(1):41-51 DOI:10.1080/09593985.2016.1247931

Onega, L. L. (2013). The Modified Caregiver Strain Index (MCSI). **Journal of Gerontological Nursing** 33(11):19-26.

Oni, O.D., Olagunju, A.T., Okpataku, C.I., Erinfolami, A.R. and Adeyemi, J.D. (2019) Predictors of caregiver burden after stroke in Nigeria: Effect on psychosocial well-being. **Indian J Psychiatry**. 61(5):457-464. doi: 10.4103/psychiatry.IndianJPsychiatry_395_18. PMID: 31579140; PMCID: PMC6767813.

Ossou-Nguiet, P., Otiobanda, G., Mawandza, P., Ikama, M., Ellenga-Mbolla, B., Ondze-Kafata, L. and Bandzouzi-Ndamba, B. (2016). Accessibility to rt-PA in Sub-

Owolabi, M.O. (2008) Determinants of health-related quality of life in Nigerian stroke survivors Trans R Soc **Trop Med Hyg**

Palis, A. G., and Quiros, P. A. (2014). Adult learning principles and presentation pearls. **Middle East African journal of ophthalmology** *21*(2):114–122. https://doi.org/10.4103/0974-9233.129748

Saharan Africa, Congolese stroke unit experience: Call for an urgent action. **International Journal of Stroke** 11(2):NP30–NP31. https://doi.org/10.1177/1747493015616642

Owolabi, M. O., Akarolo-Anthony, S., Akinyemi, R., Arnett, D., Gebregziabher, M., Jenkins, C., et al. (2015). The burden of stroke in Africa: a glance at the present and a glimpse into the future. **Cardiovasc J Afr.** 26(2 Suppl 1):S27–S38. doi:10.5830/CVJA-2015-038

Owolabi, M. O, Olowoyo, P., Popoola, F., Lackland, D., Jenkins, C., Arulogun, O., … Ovbiagele, B. (2018). The epidemiology of stroke in Africa: A systematic review of existing methods and new approaches. **Journal of clinical hypertension** (Greenwich, Conn.) 20(1):47–55. doi:10.1111/jch.13152

Parahoo, K. (2006) **Nursing Research: Principles, Process and Issues.** Palgrave Macmillan, Basingstoke.

Parke, H. L., Epiphaniou, E., Pearce, G., Taylor, S. J., Sheikh, A., Griffiths, C. J., Greenhalgh, T. and Pinnock, H. (2015). Self-Management Support Interventions for Stroke Survivors: A Systematic Meta-Review. **PloS one** 10(7):e0131448. https://doi.org/10.1371/journal.pone.0131448

Patton, M. Q. (2002) **Qualitative research & evaluation methods**. 3rd edn. London: Sage Publications.

Pawson, R., Greenhalgh, T., Harvey, G. and Walshe, K. (2005). Realist review□a new method of systematic review designed for complex policy interventions. **Journal of health services research and policy** 10:21-34.

Pearson, A., Wiechula, R., Court, A. and Lockwood, C. (2005). The JBI model of evidence-based healthcare. **International Journal of Evidence Based Healthcare** 3 (8):207-216.

Pellino, T., Tluczek, A., Collins, M., Trimborn, S., Norwick, H., Engelke, Z. K. and Broad, J. (1998) Increasing self-efficacy through empowerment: preoperative education for orthopaedic patients. **Orthopedic Nursing** 17:54-59.

Pendlebury, S., T. and Rothwell, P., M. (2008). Secondary prevention of stroke and post-stroke dementia. **Medicine** 36(7):382-385.

Pendlebury, S., T. and Rothwell, P., M. (2006). Management of stroke. **The foundation years** 2(5):199-205.

Peplau, H. (2003) Specialization in professional nursing. **Clinical Nurse Specialist** 17:3-9.

Perkins, M., Howard, V.J., Wadley, V.G., Crowe, M., Safford, M.M., Haley, W.E., et al. (2012) Caregiving Strain and All-Cause Mortality : Evidence From the REGARDS Study. **J Gerontol Ser B Psychol Sci Soc Sci.** 68(4):504–12.

Peters, K. and Halcomb, E. (2015). Interviews in qualitative research. **Nurse researcher** 22(4):6-7. 10.7748/nr.22.4.6.s2

Petitti, D. (1994). **Meta-Analysis, Decision Analysis, and Cost Effectiveness Analysis**. New York, NY: Oxford University Press.

Petticrew, M. (2003). Why certain systematic reviews reach uncertain conclusions. **British Medical Journal** 326(7392):756-758.

Petticrew, M., Anderson, L., Elder, R., Grimshaw, J., Hopkins, D., Hahn, R., Krause, L., Kristjansson, E., Mercer, S., Sipe, T., Tugwell, P., Ueffing, E., Waters, E. and Welch, V. (2013). Complex interventions and their implications for systematic reviews: a pragmatic approach**. Journal of Clinical Epidemiology** 66:1209-1214.

Pettigrew, A. M. (1990) Longitudinal field research on change: theory and practice. **Organization Science** 1:267-292.

Petrea, R. E., Beiser, A. S., Seshadri, S., Kelly-Hayes, M., Kase, C. S., and Wolf, P. A. (2009). Gender Differences in Stroke Incidence and Poststroke Disability in the Framingham Heart Study. **Stroke** 40(4):1032-1037.

Phelps, A. C., Maciejewski, P. K., Nilsson, M., Balboni, T. A., Wright, A. A., Paulk, M. E., Trice, E., Schrag, D., Peteet, J. R., Block, S. D. and Prigerson, H. G. (2009)

Religious coping and use of intensive life-prolonging care near death in patients with advanced cancer. **J Am Med Assoc** 301.

Phipps, J. W., Monaham, F. D., Marek, J. F. and Neighbors M. (2003) **Medical-Surgical nursing; Health and illness perspectives.** 7th ed. St. Louis: Mosby, pp1362-1383

Plano Clark, V. L., Schumacher, K., West, C., Edrington, J., Dunn, L. B., Harzstark, A., ... Miaskowski, C. (2013) Practices for Embedding an Interpretive Qualitative Approach Within a Randomized Clinical Trial. **Journal of Mixed Methods Research** *7*(3):219-242. https://doi.org/10.1177/1558689812474372

Polit, D.F. and Beck, C.T. (2012) **Nursing research: generating and assessing evidence for nursing practice** 9th ed. Philadelphia: Lippincott.

Pontes-Neto, O. M., Silva, G. S., Feitosa, M. R., de Figueiredo, N. L., Fiorot, J. A. Jr., Rocha, T. N., Massaro, A. R. and Leite, J. P. (2008) Stroke awareness in Brazil: alarming results in a community-based study. **Stroke** 39:292-296.

Pope, C., Ziebland, S. and Mays, N. (2006) 'Analysing qualitative data' in Pope, C. and Mays, N. (eds.) **Qualitative Research in Health Care**. 3rd edn. Oxford: Blackwell.

Popay, J., Roberts, H., Sowden, A., Petticrew, M., Arai, L., Rodgers, M. et al. (2006) Guidance on the conduct of narrative synthesis in systematic reviews. a product from the ESRC methods programme. Version 1. ESRC,

Powers, W. J., Rabinstein, A. A., Ackerson, T., Adeoye, O. M., Bambakidis, N. C., Becker, K., Biller, J., Brown, M., Demaerschalk, B. M., Hoh, B., Jauch, E. C., Kidwell, C. S., Leslie-Mazwi, T. M., Ovbiagele, B., Scott, P. A., Sheth, K. N., Southerland, A. M., Summers, D. V. and Tirschwell, D. L. (2018) American Heart Association Stroke Council. 2018 guidelines for the early management of patients with acute ischemic stroke: a guideline for healthcare professionals from the American Heart Association/American Stroke Association. **Stroke**.

Pravikoff, D. S., Pierce, S. T. and Tanner, A. (2005) Evidence-based practice readiness study supported by academy nursing informatics expert panel. **Nursing Outlook** 53(1):49-50.

Price, C., Shandu, D., Dedicoat, M., Wilkinson, D. and Gill, G. (2011). Long-term glycaemic outcome of structured nurse-led diabetes care in rural Africa. **QJM** 104(7):571-574.

Rapley, T. (2011). Some pragmatics of data analysis. *In:* SILVERMAN, D. (ed.) **Qualitative Research: Theory, Method & Practice** Third ed. London:Sage.

Rashotte, J. and Carnevale, F. A. (2004) Medical and nursing clinical decision making: a comparative epistemological analysis. **Nursing Philosophy** 5:160-174.

Ryan, S., Hassell, A., Thwaites, C., Manley, K. and Home, D. (2006) Exploring the perceived role and impact of the nurse consultant. **Musculoskeletal Care** 4:167-173.

Rhoda, A., Cunningham, N., Simon Azaria, S. and Urimubenshi, G. (2015) 'Provision of inpatient rehabilitation and challenges experienced with participation post discharge: Quantitative and qualitative inquiry of African stroke patients', **Biomed Central Health Services Research** 15:423. https://doi.org/10.1186/s12913-015-1057-z

Riessman, C. K. (2011). 'What's different about narrative inquiry? Cases, categories and contexts' in Silverman, D. **Qualitative Research**, 3rd edn. Sage, pp.310-330.

Rigby, H., Gubitz, G. and Phillips, S. A (2009). Systematic review of caregiver burden following stroke. **International Journal of Stroke** 4(4):285-92.

Risenga, P. R., Botha, A. and Tjallinks, J. E (2007). Shangaan patients and traditional healers' management strategies of hypertension in Limpopo Province. **Curationis** 30:77-84.

Robinson, B. (1983). Validation of Caregiver Strain Index. **J Gerontology** 38:344-8.

Robinson, R.G. and Jorge, R.E.(2016) Post-stroke depression: a review. **Am J Psychiatry** 173:221-231.

Robinson, R.G. and Spalletta, G.(2010) Poststroke depression: a review. **Can J Psychiatry** 55:341-349.

Rodgers, H., Bond, S., and Curless R. (2001). Inadequacies in the provision of information to stroke patients and their families. **Age Ageing** 30:129-33.

Rodgers, H., Atkinson, C., Bond, S., Suddes, M., Dobson, R. and Curless, R. (1999). Randomised controlled trial of a comprehensive stroke education program for patients and caregivers. **Stroke** 30:2585-91.

Roest, A. M., Martens, E. J., De Jonge, P. & Denollet, J. (2010) Anxiety and risk of incident coronary heart disease: a meta-analysis. **Journal of the American College of Cardiology** 56:38-46.

Rosamond, W., Flegal, K., Furie, K., Go, A., Greenlund, K., Haase, N., Hailpern, S. M., Ho, M., Howard, V., Kissela, B., Kittner, S., Lloyd-Jones, D., McDermott, M., Meigs, J., Moy, C., Nichol, G., O'Donnell, C., Roger V., Sorlie, P., Steinberger, J., Thom, T., Wilson, M. and Hong, Y. (2008). Heart disease and stroke statistics: 2008 update: a report from the American Heart Association Statistics Committee and Stroke Statistics Subcommittee. **Circulation** 117:e25-e146.

Rosser, W. W. and Kasperski, J. (2001) The benefits of a trusting physicianpatient relationship. **Journal of Family Practice** 50:329-330.

Roth, G. A., Forouzanfar, M. H., Moran, A. E., Barber, R., Nguyen, G., Feigin, V. L., et al. (2015). Demographic and epidemiologic drivers of global cardiovascular mortality. **New England Journal of Medicine** 372(14):1333-41.

Roth-Isigkeit, A., Ocklitz, E., Bruckner, S., Ros, A., Dibbelt, L., Friedrich, H.J., Gehring, H. and Schmucker, P. (2002) Development and evaluation of a video program for presentation prior to elective cardiac surgery. **Acta Anaesthesiologica Scandinavica** 46:415-23.

Royal College of Physicians (RCP) (2015). Sentinel Stroke National Audit Programme (SSNAP). Is stroke care improving? **Second SSNAP Annual Report prepared on behalf of the Intercollegiate Stroke Working Party**

Royal College of Physicians (2017). Sentinel Stroke National Audit Programme (SSNAP), **national clinical audit annual results portfolio**.

Rudd, M., Buck, D., Ford, G. A., et al. (2016). A systematic review of stroke recognition instruments in hospital and prehospital settings. **Emerg Med J** 33:818-822.

Rumsfeld, J. S. & Ho, P. M. (2005) Depression and cardiovascular disease. **Circulation** 111:250-253.

Ryan, D. and Harbison, J. (2011). Stroke as a medical emergency in older people. **Reviews in Clinical Gerontology** 21(1):45-54. doi:http://dx.doi.org/10.1017/S095925981000033X

Rycroft-Malone, J. (2006) The politics of the evidence-based practice movements: legacies and current challenges. **Journal of Research in Nursing** 11:95-108.

Sacco, R. L., Kasner, S. E., Broderick, J. P., Caplan, L. R., Connors, J. J., Culebras, A. et al. (2013). An Updated Definition of Stroke for the 21st Century: A Statement for Healthcare Professionals From the American Heart Association/American Stroke Association. **Stroke** 44(7):2064-89.

Sahlqvist, S., Song, Y., Bull, F., Adams, E., Preston, J. and Ogilvie, D. (2011). Effect of questionnaire length, personalisation, and reminder type on response rate to a complex postal survey: randomised controlled trial. **BMC Medical Research Methodology** 11(1):62.

Sahni, R. and Weinberger, J. (2007). Management of intracerebral hemorrhage. **Vascular Health Risk Management** 3:701-709.

Saka, Ö., McGuire, A. and Wolfe, C. (2009) Cost of stroke in the United Kingdom. **Age and Ageing** 38(1):27-32.

Sale, S., Dankishiya, F. S. and Gadanya, M. A. (2014) Validation of hospital anxiety and depression rating scale among HV/AIDS patients in Aminu Kano Teaching Hospital, Kano, North-Western Nigeria. **Journal of Therapy and Management in HIV Infection** 2:45-49.

Sale, J. M., Lohfeld, L. H. and Brazil, K. (2002) Revisiting the quantitative-qualitative debate: implications for mixed-methods research. **Quality and Quantity** 36:43-53.

Sanuade O. (2018) Understanding the cultural meanings of stroke in the Ghanaian setting: A qualitative study exploring the perspectives of local community residents. **Wellcome open research** *3*:87. doi:10.12688/wellcomeopenres.14674.2

Sanuade, O. A., Boatemaa, S. and Kushitor, M. K. (2018). Hypertension prevalence, awareness, treatment and control in Ghanaian population: Evidence from the Ghana demographic and health survey. **PloS one** 13:11 e0205985. https://doi.org/10.1371/journal.pone.0205985

Salter, K., Bhogal, S.K., Foley, N., Jutai, J. and Teasell, R. (2007) The assessment of poststroke depression. **Topics in Stroke Rehabilitation** 14:1-24.

Salter, K., Hellings, C., Foley, N. and Teasell, R. (2008) The experience of living with stroke: a qualitative meta-synthesis. **Journal Rehabilitation Medicine** 40:595-602

Sarfo, F., Acheampong, J., Oparebea, E., Akpalu, A. and Bedu-Addo, G. (2014) The profile of risk factors and in-patient outcomes of stroke in Kumasi, Ghana. **Ghana Med J** 48(3):127-34.

Sarfo, F. S., Akassi, J., Awuah, D., Adamu, S., Nkyi, C, Owolabi M, et al. (2015) Trends in stroke admission and mortality rates from 1983 to 2013 in central Ghana. **Journal Neurology Science** 357(1-2):240–5.

Sarfo FS, Awuah DO, Nkyi C, Akassi J, Opare-Sem OK, Ovbiagele B. (2016) Recent patterns and predictors of neurological mortality among hospitalized patients in Central Ghana. **Journal Neurology Science** 363:217-24.

Sarfo, F. S., Kyem, G., Ovbiagele, B., Akassi, J., Sarfo-Kantanka, O., Agyei, M., et al. (2017) One-Year Rates and Determinants of Poststroke Systolic Blood Pressure Control among Ghanaians. **Journal of Stroke and Cerebrovascular Diseases** 26(1):78-86

Sarpong, N., Loag, W., Fobil, J., Meyer, C., Adu‐Sarkodie, Y., May, J., et al. (2010) National health insurance coverage and socio‐economic status in a rural district of Ghana. **Tropical medicine & international health** 15(2):191-7.

Sauer, S., Ziegler, M. and Schmitt, M. (2013) Rasch analysis of a simplified Beck Depression Inventory. **Personality and Individual Differences** 54(4):530-535

Savini, S., Buck, H,G,, Dickson, V,V., et al. (2015) Quality of life in stroke survivorcaregiver dyads: a new conceptual framework and longitudinal study protocol. **J Adv Nurs** 71:676–87.

Screeche-Powell, C. and Owen, S. (2003) Early experiences of patients waiting to be accepted for CABG. **British Journal of Nursing** 12:612-619.

Schieber, G., Cashin, C., Saleh, K. and Lavado, R. (2012) Health financing in Ghana: World Bank Publications

Scotland, J. (2012). Exploring the philosophical underpinnings of research: relating ontology and epistemology to the methodology and methods of the scientific, interpretive, and critical research paradigms. **English Language Teaching** 5(9):9.

Scottish Stroke Care Audit (2018) Scottish stroke improvement programme, **national report**. 2018.

Sedgwick, P. (2014) Cross sectional studies: advantages and disadvantages. **BMJ** 348:g2276.

Semple, C. J. and Mcgowan, B. (2002) Need for appropriate written information for patients, with particular reference to head and neck cancer. **Journal of Clinical Nursing** 11:585-593.

Sene-Diouf, F., Basse, A. M., Ndiaye, M., Toure, K., Diop, M. S., et al. (2007) The management of cerebrovascular events in Senegal. **Rev Neurol (Paris)** 163: 823-827.

Setia, M. S. (2016) Methodology Series Module 3: Cross-sectional Studies. **Indian J Dermatol** 61(3):261-4.

Shanyinde, M., Pickering, R. M. and Weatherall, M. (2011) Questions asked and answered in pilot and feasibility randomized controlled trials. **BMC Med Res Methodol** 11:117. doi:10.1186/1471-2288-11-117.

Sharma, M. and Romas, J.A. (2008) Theoretical foundations of health education and health promotion. Sudbury: Jones and Bartlett Publishers

Shepperd, S., Charnock, D. and Gann, B. (1999) Helping patients access high quality health information. BMJ 319:764-6. doi: 10.1136/bmj. 319.7212.764.

Shepperd, S., Lewin, S., Straus, S., Clarke, M., Eccles, M. P., Fitzpatrick, R., Wong, G. and Sheikh, A. (2009) Can we systematically review studies that evaluate complex interventions? **PLoS Medicine** 6:e1000086.

Shadish, W., Cook, T. D. and Campbell, D. T. (2002) **Experimental and quasi-experimental designs for generalized causal inference.** Boston, MA: Houghton Mifflin.

Sharp, R. (2015). The Hamilton rating scale for depression. **Occupational Medicine (Lond)** 65(4):340

Silverman, D. (2006) **Interpreting Qualitative Data: Methods for Analyzing Talk, Text and Interaction.** 3rd edn. Sage.

Silverman, D. (2011) **Interpreting qualitative data**. 4th edn. Sage.

Silverman, D. (2015) **Interpreting qualitative data.** 5th edn. Sage.

Smith, M. K. (2002) **Malcolm Knowles, informal adult education, selfdirection and andragogy. The Encyclopedia of Informal Education** [Online]. Available from: www.infed.org/thinkers/et-knowl.htm [Accessed 20 March 2021].

Simon, C., Kumar, S. and Kendrick, T. (2008) Formal support of stroke survivors and their informal carers in the community: a cohort study. **Health and social care in the community** 16(6):582-92.

Skivington, K., Matthews, L., Simpson, S. A., Craig, P., Baird, J., Blazeby, J. M. et al. (2021) A new framework for developing and evaluating complex interventions: update of Medical Research Council guidance **BMJ** 374 :n2061 doi:10.1136/bmj.n2061

Smeltzer, S.C., Bare, B. G., Hinkle, J. L. and Cheever, K. H. (2008) **Brunner and suddarth's textbook of medical-surgery nursing**. 11th ed. Philadelphia. Lippincott William and Wilkins pp:2206-2229

Smith, J., Forster, A., and Young J. (2004) A randomized trial to evaluate an education programme for patients and carers after stroke. **Clinical Rehabilitation** 18(7):726-36.

Smith, M. K. (2002) Malcolm Knowles, informal adult education, self-direction and andragogy [Online]. Available from: http://www.infed.org/thinkers/et-knowl.htm [Accessed 20th June 2017].

Sokey, P. P. and Adisah-Atta, I. (2017) Challenges Confronting Rural Dwellers in Accessing Health Information in Ghana: Shai Osudoku District in Perspective. **Social Sciences** 6(2):66.

Song, J. W. and Chung, K. C. (2010) Observational studies: cohort and case–control studies. **Plast Reconstr Surg** 126(6):2234

Spaccavento, S., Marinelli, C. V., Nardulli, R., Macchitella, L., Bivona, U., Piccardi, L., Zoccolotti, P. and Angelelli, P. (2019). Attention Deficits in Stroke Patients: The Role

of Lesion Characteristics, Time from Stroke, and Concomitant Neuropsychological Deficits. **Behavioural neurology** 7835710. https://doi.org/10.1155/2019/7835710

Spitzer, R. L., Kroenke, K., Williams, J. B. W. & Lowe, B. (2006) A brief measure for assessing generalized anxiety disorder: The GAD-7. **Archives of Internal Medicine** 166:1092-1097.

Spradley, J. P. (1979) **The ethnographic interview**. New York: Holt, Rinehart and Winston.

Squires, A. (2008) Language barriers and qualitative nursing research: methodological considerations. **International Nursing Review** 55:265-273.

Squires, A. (2009) Methodological challenges in cross-language qualitative research: a research review. **International Journal of Nursing Studies** 46:277-287.

Steinhauser, K. E., Clipp, E. C., Hays, J. C., Olsen, M., Arnold, R., Christakis, N. A., Tulsky, J. A. (2006). Identifying, recruiting, and retaining seriously-ill patients and their caregivers in longitudinal research. **Palliative Medicine** 20(8):745-754. https://doi.org/10.1177/0269216306073112

Stern, C. and Lockwood, C. (2005) Knowledge retention from preoperative patient information. **International Journal of Evidence-Based Healthcare** 3:45-63.

Stern, A. F. (2014) The hospital anxiety and depression scale. **Occupational Medicine (Lond)** 64:393-394.

Stroke Foundation National Stroke Audit Acute Services. 2015; (online) Available at *https://informme.org.au/en/stroke-data/Acute-audits* accessed on 18 February 2017

Stroke Association (2018) *State of the Nation Stroke statistics;* (online) Available at https://www.stroke.org.uk/sites/default/files/state_of_the_nation_2018.pdf accessed on 18 December 2018

Stroke Unit Trialists' Collaboration (2013) Organised inpatient (stroke unit) care for stroke. **Cochrane Database of Systematic Reviews** 9. Art. No.:CD000197. DOI: 10.1002/14651858.CD000197.pub3.

Stroke therapy clinical guideline (2000) South African Medical Association – Neurological Association of South Africa Stroke Working Group. **S Afr Med J** 90:276-306.

Strong, K., Mathers, C. and Bonita, R. (2007) Preventing stroke: saving lives around the world. **Lancet Neurology** 6:182-7.

Stuckey, H. L. (2014) The first step in data analysis: Transcribing and managing qualitative research data. **Journal of Social Health and Diabetes** 2(1):6.

Sturgeon, J. D., Folsom, A. R., Longstreth, W. T. Jr, Shahar, E., Rosamond, W. D., Cushman, M. (2007) Risk factors for intracerebral hemorrhage in a pooled prospective study. **Stroke** 38:2718-2725.

Sturgeon, J. D., Folsom, A. R., Longstreth, W. T. Jr, Shahar, E., Rosamond, W. D., Cushman, M. (2008) Hemostatic and inflammatory risk factors for intracerebral hemorrhage in a pooled cohort. **Stroke** 39:2268-2273.

Sug Yoon, S., Heller, R. F., Levi, C. and Wiggers, J. (2001) Knowledge and perception about stroke among an Australian urban population. **BMC Public Health** 1:14

Suhonen, R. and Leino-Kilpi, H. (2006) Adult surgical patients and the informaiton provided to them by nurses: a literature review. **Patient Education and Counseling** 61:5-15.

Sullivan, M. (2008) The modified caregiver strain index (CSI). Am J Nurs. 108: 65-

Sullivan, K. A., White, K. M., Young, R. M., et al. (2009) Predicting behaviour to reduce stroke risk in at-risk populations: the role of beliefs. **Int J Ther Rehabil** 16:488-96.

Summers, D., A. Leonard, A., Wentworth, D., et al. (2009). Comprehensive Overview of Nursing and Interdisciplinary Care of the Acute Ischemic Stroke Patient: A Scientific Statement From the American Heart Association. **Stroke** 40(8):2911-2944.

Sussman, S., Burton, D., Dent, C. W., Stacy, A. W. and Flay, B. R. (1991) Use of Focus Groups in Developing an Adolescent Tobacco Use Cessation Program: Collective Norm Effects. **Journal of Applied Social Psychology** 21:1772-1782.

Szekely, A., Balog, P., Benko, E., Breuer, T., Szekely, J., Kertai, M. D., Horkay, F., Kopp, M. S. & Thayer, J. F. (2007) Anxiety predicts mortality and morbidity after

coronary artery and valve surgery-a 4-year follow-up study. **Psychosomatic Medicine** 69, 625-631.

Tagoe, H.A. and Dake, F.A.A. (2011) Healthy lifestyle behaviour among Ghanaian adults in the phase of a health policy change. **Globalization and Health** 7:7

Tashakkori, A. and Teddlie, C. (2003) Issues and dilemmas in teaching research methods courses in social and behavioural sciences: US perspective. **International Journal of Social Research Methodology** 6(1):61-77.

Taylor, R.S. (1962) Process of asking questions. **Am Doc** 13:391-6.doi: 10.1002/asi.5090130405.

Teye, A. (2013) Psychosocial Well-Being of individuals living with chronic non-Communicable diseases in Urban Poor Communities of Ghana: **University of Ghana**

Thabane, L., Ma, J., Chu, R., Cheng, J., Ismaila, A., Rios, L. P., Robson, R., Thabane, M., Goldsmith, C. H. (2010) A tutorial on pilot studies: The what, why and How. BMC Medical Research Methodology. 10:1-10.1186/1471-2288-10-1.

Thiese, M. S. (2014) Observational and interventional study design types; an overview. **Biochemia Med** 24:199–210.

Thomas, S. A., Chapa, D. W., Friedmann, E., Durden, C., Ross, A., Lee, M. C. Y. & Lee, H. J. (2008) Depression in patients with heart failure:prevalence, pathophysiological mechanisms, and treatment. **Critical Care Nurse** 28, 40-55.

Thommessen, B., Aarsland, D., Braekhus, A., Oksengaard, A.R., Engedal, K. and Laake K. (2002) The psychosocial burden on spouses of the elderly with stroke, dementia and Parkinson's disease. Int J Geriatr Psychiatry 17:78-84.

Thompson, E. (2015) "Hamilton rating scale for anxiety (HAM-A)," Occupational Medicine (London), 65(7):601.

Thompson, S. and Walker, L. (2011) Sexual Dysfunction after Stroke: Underestimating the Importance of Psychological and Physical Issues Sexual Dysfunction after Stroke: Underestimating the Importance of Psychological and Physical Issues. **WebmedCentral Phys Med.** 2(12):1–12.

Torrance, H. (2012). Triangulation, Respondent Validation, and Democratic Participation in Mixed Methods Research. **Journal of Mixed Methods Research** 6:111-123. 10.1177/1558689812437185.

Thornton, M. andTravis, S. (2003) Analysis of the reliability of the modified Caregiver Strain Index. **Journal of Gerontology: Social Sciences** 58B(2):S127–S132

Thorogood, M., Connor M. D., Kewando-Hundtm G., Tollman, S. and Ngoma B. (2004) SASPI project-team. Secondary prevention of stroke— results from the Southern Africa Stroke Prevention Initiative (SAPSI) study. **Bull World Health Organ** 82:503-08.

Treweek, S., Lockhart, P., Pitkethly, M., Cook, J. A., Kjeldstrøm, M., Johansen, M. et al. (2013). Methods to improve recruitment to randomised controlled trials:Cochrane systematic review and meta-analysis. **BMJ Open**. 3(2): e002360.

Thurman, R. J. and Jauch, E. C. (2002) Acute ischemic stroke: emergent evaluation and management. **Emergency Medicine Clinical of North America** 20:609-630.

Tirschwell, D., Smith, N., Heckbert, S., Lemaitre, R., Longstreth, W. and Psaty, B. (2004) Association of cholesterol with stroke risk varies in stroke subtypes and patient subgroups. **Neurology** 63(10):1868-75.

Towfighi, A., Ovbiagele, B., El Husseini, N. et al. (2017) “Poststroke depression: a scientific statement for healthcare professionals from the American Heart Association/American Stroke Association,” **Stroke** 48(2):e30–e43,

Towfighi, A., Ovbiagele, B., El Husseini, N., Hackett, M. L., Jorge, R. E., Kissela, B. M., Mitchell, P. H., Skolarus, L. E., Whooley, M. A. and Williams, L. S. (2017) on behalf of the American Heart Association Stroke Council; Council on Cardiovascular and Stroke Nursing; and Council on Quality of Care and Outcomes Research. Poststroke depression: a scientific statement for healthcare professionals from the American Heart Association/American Stroke Association. **Stroke**. 48:e30-e43.doi: 10.1161/STR.0000000000000113.

Trochim, W. M. K. (2000) **The research methods knowledge base** 2nd edn. Cincinnati, OH: Atomic Dog.

Truelsen, T. (2010) Stroke incidence studies in Africa. **Lancet Neurology** 9(8):755-7.

Tsigos, C. and Chrousos, G. P. (2002) Hypothalamic-pituitary-adrenal axis, neuroendocrine factors and stress. **Journal of Psychosomatic Research** 53, 865-871.

Tuckett, A. G. (2005) Applying thematic analysis theory to practice: a researcher's experience. **Contemporary Nurse** 19(1-2):75-87.

Tully, P. J., Baker, R. A. & Knight, J. L. (2008) Anxiety and depression as risk factors for mortality after coronary artery bypass surgery. **Journal of Psychosomatic Research** 64:285-290.

Turnbull, F. (2003) Effects of different blood-pressure-lowering regimens on major cardiovascular events: results of prospectively designed overviews of randomised trials. **Lancet** 362:1527-1535.

Turner, S. F., Cardinal, L. B. and Burton, R. M. (2017). Research Design for Mixed Methods: A Triangulation-based Framework and Roadmap. *Organizational Research Methods*, *20*(2), 243–267. https://doi.org/10.1177/1094428115610808

Tyrer, P. and Methuen, C. (2006) Rating Scales in Psychiatry. In: Freeman C, Tyrer P (eds.) Research Methods in Psychiatry. 3rd ed. Royal College of Psychiatrists, London, UK

Urimubenshi, G., Cadilhac, D. A., Kagwiza, J. N., Wu, O. and Langhorne, P. (2018). Stroke care in Africa: A systematic review of the literature. **International Journal of Stroke** 13(8):797–805. https://doi.org/10.1177/1747493018772747

Urimubenshi, G. and Rhoda, A. (2011) Environmental barriers experienced by stroke patients in Musanze district in Rwanda: A descriptive qualitative study. **African Health Sciences** 11:398-405.

Van Heugten, K. (2004) Managing insider research. **Qualitative Social Work** 3:203-219.

van Exel, N. J. A., op Reimer, W. J. M. S., Brouwer, W. B. F. et al. (2004) Instruments for assessing the burden of informal caregiving for stroke patients in clinical practice: a comparison of CSI, CRA, SCQ and self-rated burden. **Clinical Rehabilitation** 18:203-14.

Van Nes, F., Abma, T., Jonsson, H. and Deeg, D. (2010) Language differences in qualitative research: is meaning lost in translation? **European Journal of Ageing** 7:313-316.

Van Zuuren, F. J., Grypdonck, M., Crevits, E., Vande Walle, C. and Defloor, T. (2006) The effect of an information brochure on patients undergoing gastrointestinal endoscopy: a randomized controlled study. **Patient Education and Counseling** 64:173-182.

Venkat, A., Cappelen-Smith, C., Askar, S., Thomas, P. R., Bhaskar, S., Tam, A. et al. (2018) Factors associated with stroke misdiagnosis in the emergency department: a retrospective case-control study. **Neuroepidemiology**. 51:123-127. doi: 10.1159/000491635

Visser, A., Deccache, A. and Bensing, J. (2001) Patient education in Europe: united differences. **Patient Education and Counseling** 44:1-5.

Vuletić, V., Sapina, L., Lozert, M., Lezaić, Z. and Morović, S. (2012) Anxiety and depressive symptoms in acute ischemic stroke. **Acta Clin Croat** 51:243-246.

Wade, D., Gage, H., Owen, C., Trend, P., Grossmith, C. and Kaye, J. (2003) Multidisciplinary rehabilitation for people with Parkinson's disease: a randomised controlled study. **Journal of Neurology, Neurosurgery and Psychiatry** 74:158-162.

Wahab, K. W., Kayode, O. O. and Musa, O. I. (2015) Knowledge of stroke risk factors among Nigerians at high risk. **J Stroke Cerebrovasc Dis** 24:125-129.

Walker, K. (2003) Why evidence-based practice now?: a polemic. **Nursing Inquiry** 10:145-155.

Walker, R. W., Jusabani, A., Aris, E., Gray, W. K., Whiting, D., Kabadi, G. et al. (2011) Post-stroke case fatality within an incident population in rural Tanzania. **Journal of Neurology, Neurosurgery & Psychiatry** 82:1001-5.

Walker, R. W., Rolfe, M., Kelly, P. J., George, M. O. and James, O. F. W. (2003) Mortality and recovery after stroke in the Gambia. **Stroke** 34: 1604-09.

Walker, R., Whiting, D., Unwin, N., Mugusi, F., Swai, M., et al. (2010) Stroke incidence in rural and urban Tanzania: a prospective, community-based study. **Lancet Neurology** 9:786-792.

Walsh, D. and Shaw, D. G. (2000) The design of written information for cardiac patients: a review of the literature. **Journal of Clinical Nursing** 9: 658–667.

Walters, S. J., Bonacho Dos Anjos Henriques-Cadby, I., Bortolami, O., Flight, L., Hind, D., Jacques, R. M., Knox, C., Nadin, B., Rothwell, J., Surtees, M. and Julious, S. A. (2017). Recruitment and retention of participants in randomised controlled trials: a review of trials funded and published by the United Kingdom Health Technology Assessment Programme. **BMJ open** *7*(3):e015276. https://doi.org/10.1136/bmjopen-2016-015276

Wardlaw, J. M., Murray, V., Berge, E., and del Zoppo, G. J. (2014) Thrombolysis for acute ischaemic stroke. **Cochrane Database of Systematic Reviews** 7. Art. No.: CD000213. DOI: 10.1002/14651858.CD000213.pub3.

Wang, Y., Rudd, A. G. and Wolfe, C. D. (2013). Age and ethnic disparities in incidence of stroke over time: the South London Stroke Register. **Stroke** 44:3298-3304.

Watkins, C. L., Leathley, M. J., Jones, S. P., et al. (2013) Training emergency services' dispatchers to recognise stroke: an interrupted time-series analysis. **BMC Health Serv Res** 13:318.

Weijer, C., Bruni, T., Gofton, T. et al. (2016) Ethical considerations in functional magnetic resonance imaging research in acutely comatose patients. **Brain**139:292-9

Weiss, B. D. (2007) **Health Literacy and Patient Safety: Help Patients Understand. 2nd ed.** American Medical Association Foundation and American Medical Association, American Medical Association

White, H. and Sabarwal, S. (2014) Quasi-experimental design and methods. **Methodological Briefs: Impact Evaluation** 8:1-16.

Williams, D. and Garner, J. (2002) The case against 'the evidence': a different perspective on evidence-based medicine. **British Journal of Psychiatry** 8-12.

Wiredu, E. K. and Nyame, P. K. (2001) Stroke-related mortality at Korle Bu Teaching Hospital, Accra, Ghana. **East African Medical Journal** 78(4):180-184.

Wludyka, P. (2011) **Study designs and their outcomes.** Epidemiology for Advanced Nursing Practice. Jones & Bartlett Learning, USA 81-115.

Wolfenden, B. and Grace, M. (2012). Identity continuity in the face of biographical disruption: “It’s the same me.” **Brain Impairment** 13:203-211. doi:10.1017/BrImp.2012.16

Wong, E. M. L., Chan, S. W. C. & Chair, S. Y. (2010) Effectiveness of an educational intervention on levels of pain, anxiety and self-efficacy for patients with musculoskeletal trauma. **Journal of Advanced Nursing** 66:1120-1131.

The World Bank. (2016) **Country and Lending Groups.** [Online]. Available at: http://data.worldbank.org/about/country-and-lending-groups#Lower_middle_income [Accessed 6th November 2019].

WHO, Ghana (2018) Annual report 2018 {online} available on

https://www.afro.who.int/sites/default/files/201909/WHO%20Ghana%202018%20Annual%20Report.pdf accessed on

World Health Organization (2016a) World health statistics 2016: monitoring health for the SDGs, sustainable development goals. *http://www.who.int/gho/publications/world_health_statistics/2016/EN_WHS2016_TOC.pdf?ua=1*

World Health Organization (2016b) Country office for Ghana, Annual Report 2015 [online]. Available at:

*www.afro.who.int/index.php?option=com_docman&task=doc_download* [Accessed on 31 March 2017].

World Health Organization (2015) Ghana: WHO country profile [online]. Available at: *http://www.who.int/gho/countries/gha.pdf?ua=1* [Accessed on 24 April 2017]

World Health Organization (WHO) (2014) Noncommunicable Diseases Country Profile. **Geneva**

World Health Organization (2014a) WHO Country Cooperation Strategy at a glance [online]. Available at: http://apps.who.int/iris/bitstream/10665/136860/1/ccsbrief_gha_en.pdf [Accessed on 31 March 2017].

World Health Organization. (2013) **WHO Traditional Medicine Strategy 2014-2023.** [Online]. Available at: http://apps.who.int/iris/bitstream/10665/92455/1/9789241506090_eng.pdf?ua=1 [Accessed 11 August 2019].

World Health Organization (2009) WHO Country Cooperation Strategy 2008 – 2011: Ghana [online]. Available at: *http://apps.who.int/iris/bitstream/10665/136005/3/ccs_ghana.pdf?ua=1* [Accessed on 31 March 2017].

World Health Organization (WHO) (2006) editor Bridging the "Know–Do" Gap. Meeting on knowledge translation in global health **Geneva**: WHO.

World Health Organization (2004) Global Burden of Disease (GBD) 2002 estimates. World Health Report 2004. Geneva, Switzerland: WHO.

World Health Organization. (2003) **Traditional Medicine Fact Sheet No 134.** [Online]. Available at: http://www.who.int/mediacentre/factsheets/2003/fs134/en/ [Accessed 11 August 2019].

World Health Organization (2002) The World Health Report 2002: reducing risks, promoting healthy life. Geneva, Switzerland: WHO.

World Medical Association (2013) Guidance on good clinical practice CPMP/ICH/135/95. **World Medical Association**

Woo, D., Gebel, J., Miller, R., Kothari, R., Brott, T., Khoury, J., Salisbury, S., Shukla, R., Pancioli, A., Jauch, E. and Broderick, J. (1999) Incidence rates of first-ever ischemic stroke subtypes among blacks: a population-based study**. Stroke** 30:2517-2522.

Woo, D., Sauerbeck, L. R., Kissela, B. M., Khoury, J. C., Szaflarski, J. P., Gebel, J., et al. (2002) Genetic and environmental risk factors for intracerebral hemorrhage Preliminary results of a population-based study. **Stroke** 33 (5):1190-6.

Wu, Y., Deng, Y. & Zhang, Y. (2011) Knowledge, attitudes, and behaviors of nursing professionals and students in Beijing toward cardiovascular disease risk reduction. **Research in Nursing and Health** 34:228-240.

Yeh, M.-L., Chen, H.-H. & Liu, P.-H. (2005) Effects of multimedia with printed nursing guide in education on self-efficacy and functional activity and hospitalization in patients with hip replacement. **Patient Education and Counseling** 57:217-224.

Young, M.E., Lutz, B.J., Creasy, K.R., et al. (2014) A comprehensive assessment of family caregivers of stroke survivors during inpatient rehabilitation. Disabil Rehabil 36:1892–902.

Zangerle, A., Kiechl, S., Spiegel, M., Furtner, M., Knoflach, M., Werner, P., Mair, A., Wille, G., Schmidauer, C., Gautsch, K., Gotwald, T., Felber, S., Poewe, W. and Willeit, J. (2007) Recanalisation after thrombolysis in stroke patients: predictors and prognostic implications. **Neurology** 68:39-44.

Zenebe, G., Asmera, J. and Alemayehu, M. (2005) How accurate is Siriraj stroke score among Ethiopians? A brief communication. **Ethiop Med J** 43:35-38.

Zigmond, A. S. and Snaith, R. P. (1983) The hospital anxiety and depression scale. **Acta Psychiatr Scand** 67:361-70

Zimmerman, M., Ruggero, C. J., Chelminski, I. and Young, D. (2008) Is bipolar disorder overdiagnosed? **J Clin Psychiatry** 69:935-940

# Appendix 1 – Database Search Strategy

**Search History (MEDLINE Database)**

| | Searches | Results |
|---|---|---|
| 1 | Randomized Controlled Trials as Topic/ | 114107 |
| 2 | randomized controlled trial/ | 465933 |
| 3 | Random Allocation/ | 93126 |
| 4 | Double Blind Method/ | 147889 |
| 5 | Single Blind Method/ | 24767 |
| 6 | clinical trial/ | 522248 |
| 7 | clinical trial, phase i.pt. | 18860 |
| 8 | clinical trial, phase ii.pt. | 30398 |
| 9 | clinical trial, phase iii.pt. | 13987 |
| 10 | clinical trial, phase iv.pt. | 1500 |
| 11 | controlled clinical trial.pt. | 94208 |
| 12 | randomized controlled trial.pt. | 465933 |
| 13 | multicenter study.pt. | 229903 |
| 14 | clinical trial.pt. | 522248 |
| 15 | exp Clinical Trials as topic/ | 314911 |
| 16 | 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 14 or 15 | 1131237136 |
| 17 | (clinical adj trial$).tw. | 295012 |
| 18 | ((singl$ or doubl$ or treb$ or tripl$) adj (blind$3 or mask$3)).tw. | 156188 |
| 19 | PLACEBOS/ | 35019 |
| 20 | placebo$.tw. | 193725 |
| 21 | randomly allocated.tw. | 23093 |
| 22 | (allocated adj2 random$).tw. | 26074 |
| 23 | 17 or 18 or 19 or 20 or 21 or 22 | 538946 |
| 24 | 16 or 23 | 1441736 |
| 25 | case report.tw. | 257107 |
| 26 | letter/ | 969409 |
| 27 | historical article/ | 348202 |
| 28 | 25 or 26 or 27 | 1560833 |
| 29 | Acute stroke.mp. or exp Stroke/ | 113590 |
| 30 | Brain Ischemia/ or Brain Ischaemia.mp. | 44391 |
| 31 | Cerebral Hemorrhage/ or Intracranial Hemorrhages/ | 35761 |

| | | |
|---|---|---|
| 32 | Ischemic Attack, Transient/ or Cerebral ischa?mia.mp. | 21393 |
| 33 | exp Cerebrovascular Disorders/ | 326582 |
| 34 | ((cerebrovasc* or brain* or isch#em* or cerebral* or intracranial*) adj3 (attack* or disorder* or disease* or event* or accident*)).mp. | 173343 |
| 35 | 29 or 30 or 31 or 32 or 33 or 34 | 433617 |
| 36 | exp Patients/ | 55588 |
| 37 | exp inpatients/ | 17358 |
| 38 | Stroke patients.mp. | 21033 |
| 39 | Stroke survivors.mp. | 3399 |
| 40 | Carers.mp. or exp Caregivers/ | 35115 |
| 41 | Informal carers.mp. | 690 |
| 42 | Informal caregivers.mp. | 1764 |
| 43 | Family carers.mp. | 896 |
| 44 | Family caregivers.mp. | 4829 |
| 45 | 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43 or 44 | 114305 |
| 46 | education.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] | 678702 |
| 47 | exp Health Education/ | 154950 |
| 48 | exp Patient Education as Topic/ | 80478 |
| 49 | Support.mp. | 8773061 |
| 50 | Caregiver support.mp. | 462 |
| 51 | Caregivers education.mp. | 73 |
| 52 | Carers education.mp. | 8 |
| 53 | Stroke education.mp. | 167 |
| 54 | exp Books/ | 22929 |
| 55 | exp Telephone/ | 20130 |
| 56 | exp Pamphlets/ | 3645 |
| 57 | exp Manuals as Topic/ | 3722 |
| 58 | exp Audiovisual Aids/ or audiovisual.mp. | 106304 |
| 59 | exp Tape Recording/ | 15466 |
| 60 | exp Video Recording/ | 36557 |
| 61 | exp Medical Records/ | 132244 |
| 62 | Information provision.mp. | 1068 |
| 63 | exp Information Dissemination/ | 13938 |
| 64 | Educational program*.mp. | 13329 |
| 65 | Educational intervention.mp. | 5114 |

| | | |
|---|---|---|
| 66 | 46 or 47 or 48 or 49 or 50 or 51 or 52 or 53 or 54 or 55 or 56 or 57 or 58 or 59 or 60 or 61 or 62 or 63 or 64 or 65 | 569467739 |
| 67 | exp Knowledge/ or exp Health Knowledge, Attitudes, Practice/ | 103028 |
| 68 | stroke knowledge.mp. | 200 |
| 69 | exp Anxiety/ | 70978 |
| 70 | exp Depression/ | 97809 |
| 71 | exp Patient Compliance/ or exp Self Efficacy/ | 82762 |
| 72 | Satisfaction.mp. | 168736 |
| 73 | exp Patient Satisfaction/ | 77380 |
| 74 | Caregiver burden.mp. | 2581 |
| 75 | exp Risk Factors/ | 704725 |
| 76 | 67 or 68 or 69 or 70 or 71 or 72 or 73 or 74 or 75 | 115782 |
| 77 | (24 and 35 and 45 and 66 and 76) not 28 | 589 |

## Search History (CINAHL Database)

| # | Query | Limiters/Expanders | Results |
|---|---|---|---|
| S67 | S15 AND S27 AND S37 AND S56 AND S66 | Search modes - Boolean/Phrase | 302 |
| S66 | S57 OR S58 OR S59 OR S60 OR S61 OR S62 OR S63 OR S64 OR S65 | Search modes - Boolean/Phrase | 407,561 |
| S65 | (MH "Risk Factors+") | Search modes - Boolean/Phrase | 142,210 |
| S64 | (MH "Patient Compliance+") | Search modes - Boolean/Phrase | 36,463 |
| S63 | (MH "Caregiver Burden") | Search modes - Boolean/Phrase | 7,289 |
| S62 | (MH "Patient Satisfaction") OR "Satisfaction" | Search modes - Boolean/Phrase | 97,024 |
| S61 | (MH "Self-Efficacy") | Search modes - Boolean/Phrase | 14,467 |
| S60 | (MH "Depression") | Search modes - Boolean/Phrase | 75,382 |
| S59 | (MH "Anxiety+") | Search modes - Boolean/Phrase | 29,561 |

| | | | |
|---|---|---|---|
| S58 | "stroke knowledge" | Search modes - Boolean/Phrase | 115 |
| S57 | (MH "Knowledge+") | Search modes - Boolean/Phrase | 42,860 |
| S56 | S38 OR S39 OR S40 OR S41 OR S42 OR S43 OR S44 OR S45 OR S46 OR S47 OR S48 OR S49 OR S50 OR S51 OR S52 OR S53 OR S54 OR S55 | Search modes - Boolean/Phrase | 988,929 |
| S55 | "Educational intervention" | Search modes - Boolean/Phrase | 2,770 |
| S54 | "Educational program*" | Search modes - Boolean/Phrase | 6,674 |
| S53 | "Information dissemination" | Search modes - Boolean/Phrase | 243 |
| S52 | "Information provision" | Search modes - Boolean/Phrase | 645 |
| S51 | (MH "Audiorecording") OR (MH "Videorecording+") OR (MH "Medical Records+") | Search modes - Boolean/Phrase | 136,172 |
| S50 | "audio-visual aids" | Search modes - Boolean/Phrase | 37 |
| S49 | "manuals" | Search modes - Boolean/Phrase | 1,626 |
| S48 | (MH "Pamphlets") | Search modes - Boolean/Phrase | 2,687 |
| S47 | (MH "Telephone+") OR (MH "Cellular Phone+") | Search modes - Boolean/Phrase | 20,927 |
| S46 | (MH "Books+") | Search modes - Boolean/Phrase | 14,848 |
| S45 | "Stroke education" | Search modes - Boolean/Phrase | 406 |
| S44 | "Carers education" | Search modes - Boolean/Phrase | 4 |
| S43 | (MH "Caregiver Support") | Search modes - Boolean/Phrase | 3,716 |

| | | | |
|---|---|---|---|
| S42 | "support" | Search modes - Boolean/Phrase | 266,089 |
| S41 | "Caregivers education" | Search modes - Boolean/Phrase | 1,638 |
| S40 | (MH "Patient Education+") | Search modes - Boolean/Phrase | 63,987 |
| S39 | (MH "Health Education+") | Search modes - Boolean/Phrase | 102,020 |
| S38 | (MH "Education+") | Search modes - Boolean/Phrase | 695,389 |
| S37 | S28 OR S29 OR S30 OR S31 OR S32 OR S33 OR S34 OR S35 OR S36 | Search modes - Boolean/Phrase | 248,236 |
| S36 | "Family caregivers" | Search modes - Boolean/Phrase | 4,206 |
| S35 | "Family carers" | Search modes - Boolean/Phrase | 870 |
| S34 | "Informal caregivers" | Search modes - Boolean/Phrase | 1,224 |
| S33 | "Informal carers" | Search modes - Boolean/Phrase | 551 |
| S32 | (MH "Caregivers") | Search modes - Boolean/Phrase | 24,424 |
| S31 | "Carers" | Search modes - Boolean/Phrase | 8,527 |
| S30 | "Stroke survivors" | Search modes - Boolean/Phrase | 2,348 |
| S29 | "inpatient" | Search modes - Boolean/Phrase | 25,219 |
| S28 | (MH "Patients+") OR (MH "Stroke Patients") | Search modes - Boolean/Phrase | 202,843 |
| S27 | S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 | Search modes - Boolean/Phrase | 70,923 |
| S26 | "transient ischemic attack" | Search modes - Boolean/Phrase | 2,244 |

| | | | |
|---|---|---|---|
| S25 | "Cerebrovascular events" | Search modes - Boolean/Phrase | 809 |
| S24 | "Cerebrovascular accidents" | Search modes - Boolean/Phrase | 327 |
| S23 | "Cerebrovascular diseases" | Search modes - Boolean/Phrase | 498 |
| S22 | "brain ischemia" | Search modes - Boolean/Phrase | 401 |
| S21 | (MH "Cerebrovascular Disorders") | Search modes - Boolean/Phrase | 5,152 |
| S20 | (MH "Cerebral Hemorrhage+") | Search modes - Boolean/Phrase | 4,894 |
| S19 | (MH "Intracranial Hemorrhage+") | Search modes - Boolean/Phrase | 10,903 |
| S18 | (MH "Cerebral Ischemia+") | Search modes - Boolean/Phrase | 12,788 |
| S17 | (MH "Stroke+") | Search modes - Boolean/Phrase | 50,228 |
| S16 | "Acute stroke" | Search modes - Boolean/Phrase | 4,607 |
| S15 | S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 | Search modes - Boolean/Phrase | 1,200,187 |
| S14 | TX allocat* random* | Search modes - Boolean/Phrase | 11,592 |
| S13 | (MH "Quantitative Studies") | Search modes - Boolean/Phrase | 15,862 |
| S12 | (MH "Placebos") | Search modes - Boolean/Phrase | 10,176 |
| S11 | TX placebo* | Search modes - Boolean/Phrase | 76,417 |
| S10 | TX random* allocat* | Search modes - Boolean/Phrase | 11,592 |
| S9 | (MH "Random Assignment") | Search modes - Boolean/Phrase | 43,196 |

| | | | |
|---|---|---|---|
| S8 | TX randomi* control* trial* | Search modes - Boolean/Phrase | 172,278 |
| S7 | TX ( (trebl* n1 blind*) or (trebl* n1 mask*) ) | Search modes - Boolean/Phrase | 6 |
| S6 | TX ( (tripl* n1 blind*) or (tripl* n1 mask*) ) | Search modes - Boolean/Phrase | 411 |
| S5 | TX ( (doubl* n1 blind*) or (doubl* n1 mask*) ) | Search modes - Boolean/Phrase | 897,099 |
| S4 | TX ( (singl* n1 blind*) or (singl* n1 mask*) ) | Search modes - Boolean/Phrase | 15,474 |
| S3 | TX clinic* n1 trial* | Search modes - Boolean/Phrase | 257,969 |
| S2 | PT Clinical trial | Search modes - Boolean/Phrase | 80,037 |
| S1 | (MH "Clinical Trials+") | Search modes - Boolean/Phrase | 215,152 |

**Search History (Embase Database)**

| | Searches | Results |
|---|---|---|
| 1 | Clinical Trial/ | 522248 |
| 2 | randomized controlled trial/ | 465933 |
| 3 | exp controlled clinical trial/ | 555332 |
| 4 | multicenter study/ | 229903 |
| 5 | phase 3 clinical trial/ | 0 |
| 6 | Phase 4 clinical trial/ | 0 |
| 7 | exp RANDOMIZATION/ | 93126 |
| 8 | single blind procedure/ | 0 |
| 9 | crossover procedure/ | 0 |
| 10 | double blind procedure/ | 0 |
| 11 | exp placebo/ | 0 |
| 12 | randomi?ed controlled trial$.tw. | 128117 |
| 13 | rct.tw. | 14617 |
| 14 | (random$ adj2 allocat$).tw. | 28504 |
| 15 | single blind$.tw. | 15166 |
| 16 | double blind$.tw. | 138396 |

| | | |
|---|---|---|
| 17 | ((treble or triple) adj blind$).tw. | 576 |
| 18 | placebo$.tw. | 193760 |
| 19 | Prospective Study/ | 461165 |
| 20 | 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 | 1448134 |
| 21 | exp case study/ | 1888775 |
| 22 | case report.tw. | 257157 |
| 23 | abstract report/ or letter/ | 969638 |
| 24 | Conference proceeding.pt. | 0 |
| 25 | Editorial.pt. | 439861 |
| 26 | Conference abstract.pt. | 0 |
| 27 | Letter.pt. | 969638 |
| 28 | Note.pt. | 0 |
| 29 | 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 | 3153535 |
| 30 | 20 not 29 | 1413783 |
| 31 | Stroke.mp. or exp cerebrovascular accident/ | 256062 |
| 32 | Acute stroke.mp. | 12435 |
| 33 | exp brain ischemia/ or Brain Ischa?mia.mp. | 95939 |
| 34 | Intracranial Haemorrhage.mp. or exp brain hemorrhage/ | 64888 |
| 35 | Cerebral Haemorrhage.mp. | 976 |
| 36 | exp brain ischemia/ or Cerebral ischa?mia.mp. | 96571 |
| 37 | Cerebrovascular Disorders.mp. or exp cerebrovascular disease/ | 327120 |
| 38 | exp transient ischemic attack/ or Cerebrovascular events.mp. | 22660 |
| 39 | 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 | 446771 |
| 40 | inpatient.mp. or exp hospital patient/ | 60255 |
| 41 | *patient/ | 12425 |
| 42 | exp stroke patient/ | 0 |
| 43 | Stroke survivors.mp. | 3401 |
| 44 | Carers,.mp. or exp caregiver/ | 35117 |
| 45 | Informal carers.mp. | 690 |
| 46 | Informal caregivers.mp. | 1764 |
| 47 | Family carers.mp. | 897 |
| 48 | Family caregivers.mp. | 4830 |
| 49 | 40 or 41 or 42 or 43 or 44 or 45 or 46 or 47 or 48 | 111232 |
| 50 | exp health education/ | 154950 |
| 51 | exp education/ or exp education program/ | 674474 |
| 52 | exp patient education/ | 80478 |

| | | |
|---|---|---|
| 53 | Support.mp. | 8773398 |
| 54 | caregiver support/ | 0 |
| 55 | Caregivers education.mp. | 73 |
| 56 | Carers education.mp. | 8 |
| 57 | Stroke education.mp. | 167 |
| 58 | exp book/ | 22929 |
| 59 | exp telephone/ | 20130 |
| 60 | pamphlets.mp. | 4379 |
| 61 | manuals.mp. | 5543 |
| 62 | leaflets.mp. | 8328 |
| 63 | audiovisual.mp. or exp audio-visual equipment/ | 9655 |
| 64 | exp audio-visual aid/ | 103659 |
| 65 | tape recording.mp. or exp recording/ | 4548 |
| 66 | exp videorecording/ | 36557 |
| 67 | medical record/ | 65023 |
| 68 | exp medical information/ or Information provision.mp. | 1068 |
| 69 | exp information dissemination/ | 13938 |
| 70 | Educational intervention.mp. | 5114 |
| 71 | 50 or 51 or 52 or 53 or 54 or 55 or 56 or 57 or 58 or 59 or 60 or 61 or 62 or 63 or 64 or 65 or 66 or 67 or 68 or 69 or 70 | 9455312 |
| 72 | stroke knowledge.mp. | 200 |
| 73 | knowledge/ | 9812 |
| 74 | exp anxiety/ | 70978 |
| 75 | exp depression/ | 97809 |
| 76 | Self-efficacy.mp. or self concept/ | 78204 |
| 77 | exp satisfaction/ or exp patient satisfaction/ | 92420 |
| 78 | exp caregiver burden/ | 0 |
| 79 | exp patient compliance/ | 67248 |
| 80 | exp risk factor/ | 704725 |
| 81 | 72 or 73 or 74 or 75 or 76 or 77 or 78 or 79 or 80 | 1057128 |
| 82 | 30 and 39 and 49 and 71 and 81 | 303 |

**Search History (PsychoINFO Database)**

| | Searches | Results |
|---|---|---|
| 1 | exp Cerebrovascular Accidents/ or Acute stroke.mp. | 18248 |
| 2 | exp Cerebral Ischemia/ or Stroke.mp. | 30727 |
| 3 | Brain Ischemia.mp. | 536 |
| 4 | exp Cerebral Hemorrhage/ or Intracranial Haemorrhage.mp. | 1856 |
| 5 | exp Cerebrovascular Disorders/ | 24452 |
| 6 | Cerebrovascular diseases.mp. | 445 |
| 7 | Cerebrovascular events.mp. | 266 |
| 8 | Transient ischemic attack.mp. | 589 |
| 9 | 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 | 35465 |
| 10 | exp PATIENTS/ | 90013 |
| 11 | exp Hospitalized Patients/ or inpatient.mp. | 35352 |
| 12 | Stroke patients.mp. | 5502 |
| 13 | Stroke survivors.mp. | 1372 |
| 14 | exp Caregivers/ or exp Family Members/ or Carers.mp. | 155215 |
| 15 | exp CAREGIVERS/ | 23909 |
| 16 | Informal carers.mp. | 413 |
| 17 | Informal caregivers.mp. | 1274 |
| 18 | Family carers.mp. | 758 |
| 19 | exp Caregivers/ | 23909 |
| 20 | 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 | 265666 |
| 21 | Patient education.mp. or exp Client Education/ | 5226 |
| 22 | exp EDUCATION/ | 302083 |
| 23 | exp Health Education/ | 16755 |
| 24 | support.mp. | 408481 |
| 25 | Caregiver support.mp. | 470 |
| 26 | Caregivers education.mp. | 36 |
| 27 | Carers education.mp. | 3 |
| 28 | Stroke education.mp. | 50 |
| 29 | exp BOOKS/ | 5844 |
| 30 | Telephone.mp. | 22959 |
| 31 | pamphlets.mp. | 604 |
| 32 | manuals.mp. | 2792 |
| 33 | leaflet.mp. | 492 |
| 34 | exp Videotapes/ or exp Audiotapes/ or tape recording.mp. | 3173 |
| 35 | exp Educational Audiovisual Aids/ or audio-visual aids.mp. | 591 |

| | | |
|---|---|---|
| 36 | exp Medical Records/ | 3220 |
| 37 | exp Digital Video/ or video recording.mp. | 2173 |
| 38 | Information provision.mp. | 567 |
| 39 | exp Information Dissemination/ | 1446 |
| 40 | exp Educational Programs/ or Educational program*.mp. | 62245 |
| 41 | Educational intervention.mp. | 2620 |
| 42 | 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 | 723702 |
| 43 | Knowledge.mp. | 265085 |
| 44 | stroke knowledge.mp. | 70 |
| 45 | exp ANXIETY/ | 61716 |
| 46 | Depression.mp. | 273882 |
| 47 | exp Self-Efficacy/ | 18708 |
| 48 | exp SATISFACTION/ or exp CLIENT SATISFACTION/ | 52738 |
| 49 | patient satisfaction.mp. | 4229 |
| 50 | exp Caregiver Burden/ | 5177 |
| 51 | exp Treatment Compliance/ or exp Compliance/ or Patient compliance.mp. | 17681 |
| 52 | exp Risk Factors/ | 65892 |
| 53 | 43 or 44 or 45 or 46 or 47 or 48 or 49 or 50 or 51 or 52 | 701180 |
| 54 | 9 and 20 and 42 and 53 | 483 |

**Search History (ASSIA Database)**

| | Searches | Results |
|---|---|---|
| 1 | exp Cerebral Ischemia/ or exp Cerebrovascular Accidents/ or Stroke.mp. | 293168 |
| 2 | Acute stroke.mp. | 12435 |
| 3 | exp Cerebral Hemorrhage/ or Brain Ischaemia.mp. | 31526 |
| 4 | Intracranial Haemorrhage.mp. | 1631 |
| 5 | exp Cerebral Ischemia/ or exp Cerebrovascular Accidents/ | 155757 |
| 6 | exp Cerebrovascular Disorders/ | 326582 |
| 7 | Cerebrovascular events.mp. | 3620 |
| 8 | Transient ischaemic attack.mp. | 1520 |
| 9 | 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 | 445735 |
| 10 | exp PATIENTS/ | 55588 |
| 11 | Stroke patients.mp. | 21044 |
| 12 | Stroke survivors.mp. | 3401 |
| 13 | exp Caregivers/ or exp Family Members/ or Carers.mp. | 308474 |

| | | |
|---|---|---|
| 14 | Informal carers.mp. | 690 |
| 15 | Informal caregivers.mp. | 1764 |
| 16 | Family carers.mp. | 897 |
| 17 | Family caregivers.mp. | 4830 |
| 18 | 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 | 383004 |
| 19 | exp EDUCATION/ or exp HEALTH EDUCATION/ | 674543 |
| 20 | Patient education.mp. | 92464 |
| 21 | Stroke education.mp. | 167 |
| 22 | Caregivers education.mp. | 73 |
| 23 | Carers education.mp. | 8 |
| 24 | Information provision.mp. | 1068 |
| 25 | exp Educational Programs/ or Educational needs.mp. | 2538 |
| 26 | Educational intervention.mp. | 5114 |
| 27 | 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 | 689212 |
| 28 | Knowledge.mp. | 598373 |
| 29 | stroke knowledge.mp. | 200 |
| 30 | exp ANXIETY/ | 70978 |
| 31 | Depression.mp. | 338395 |
| 32 | exp Self-Efficacy/ | 16374 |
| 33 | exp SATISFACTION/ | 15308 |
| 34 | exp Caregiver Burden/ | 0 |
| 35 | 28 or 29 or 30 or 31 or 32 or 33 or 34 | 994393 |
| 36 | 9 and 18 and 27 and 35 | 268 |

# Appendix 2 - Modified JBI MAStARI standardised data extraction form

Study:

Reviewer: Date:

Method:

Setting:

| | | |
|---|---|---|
| Participants | | |
| Number of participants | Post-stroke education | Usual care |
| | | |
| Nature of intervention or usual care | Post-stroke education | Usual care |
| | | |
| Age of participants (mean) | | |
| Outcome Measures | | |
| Results | | |
| Author's conclusion | | |
| Reviewer's comments | | |

# Appendix 3 - Summary of the reviewed randomised controlled trials

| Author/Setting | Population | Intervention | Comparator | Follow-ups | Outcome measures | Findings |
|---|---|---|---|---|---|---|
| Eames et al. (2013); Acute stroke unit of two public tertiary hospitals in Brisbane, Australia | 138 stroke patients and carers (randomly allocated: Intervention group (n = 67) and control group (n =71) | Stroke education and support package that includes Tailored written stroke information booklet and at least 3 times tailored stroke face-to-face discussions prior to discharge and at least 3 times telephone calls approximately one-month interval for 3months and an available contact for calls with questions from participants. Duration of face-to-face discussion not given | Standard stroke unit care that includes medical, nursing and allied-health assessment and treatment, which included the provision of unstructured informal verbal education and advice from various members of the treating team | A 3-month follow-up by a blind assessor<br><br>119 (86.23%) stroke patients and carers followed up (intervention (patients (n=31) and carers (n=28) and control (patients (n= 35) and carers (n=25)<br><br>19 lost to follow-up; 8 control and 11 intervention | **Primary:**<br>Stroke knowledge (25 item Knowledge of Stroke Questionnaire (KSQ))<br><br>**Secondary**<br>1. Self-efficacy<br>• Cope with stroke<br>• Access practical help<br>• Access emotional help<br>• Manage stress<br>• Access stroke information<br>• Understand stroke information<br>• Talk with a doctor<br>• Talk with health professionals<br>• Prevent (another) stroke<br><br>2. Anxiety and depression (Hospital Anxiety and Depression Scale (HADS))<br><br>3. Feeling informed | Not significant (p=0. 256)<br><br>1.<br>• P=0. 600<br>• P=0. 483<br>• P=0.909<br>• P=0.584<br>• **P=0. 004**<br>• P=0. 077<br>• P=0. 651<br>• P=0.567<br>• P=0.608<br><br>2. P=0.559<br>P=0.377<br><br>3. **Significant. The intervention group was satisfied with the information (p=0. 008**) |

| | | | | | | |
|---|---|---|---|---|---|---|
| | | | | | 4. Importance of information (10-point Likert scale)<br>5. Satisfaction with information (10-point Likert scale)<br>• Medical information<br>• Practical information<br>• Service and benefits<br>• Prevention information<br><br>6. Quality of life (patient) (Stroke and Aphasia Quality of Life Scale – 39 Generic (SAQOL-39g))<br><br>7. Caregiver burden (carer) (Caregiver Strain Index) | 4. Not significant (p= 0.615)<br>5. Significant<br><br>• **P<0.001**<br>• **P=0.008**<br>• **P=0.036**<br>• **P<0.001**<br><br>6. Not significant (p=0.496)<br><br>7. Not significant (p=0.932) |
| Franze´n-Dahlin et al. (2008); Stroke Unit, Sweden | 100 spouses of stroke patients (Randomly allocated: Intervention (n=50) and control (n-50) | Usual care with 20 to 30 minutes lecture for groups of 10 spouses in 6 meetings over 6 months with an additional follow-up meeting. Lectures and discussions were on symptoms and the occurrence of stroke, risk factors, treatment, prevention, personality changes and social aspects led | Usual care of 90 minutes of stroke information session given weekly in the stroke unit by a stroke specialist physician | 6- and 12-months follow-up<br><br>At 6 months follow-up; 92 (92%) carers (intervention (n=46) and control (n=46)<br><br>At 12 months follow-up; 91 (91%) carers (intervention (n=46) and control (n=45) | **Primary**<br>Psychological health (Comprehensive Psychopathological Rating Scale-Self-Affective (CPRS-S-S-A)<br><br>**Secondary**<br>1. Perceived social support<br>• Availability of social support (Abbreviated Swedish version of the Interview Schedule for Social Interaction (AVSI)<br>• Availability for attachment (AVAT) | Not significant at 6 and 12 months (p=0.280)<br><br>1. Not significant at 6 and 12 months (p=0.176) |

| | | | | | | |
|---|---|---|---|---|---|---|
| | | by a stroke nurse specialist | | | 2. Sense of coherence (Antonovsky's questionnaire)<br>• Perception of comprehensibility<br>• manageability and<br>• meaningfulness<br>3. Knowledge of stroke (13-item questionnaire)<br>4. Functional ability (Barthel Index)<br>5. Perceived health state (Visual Analogue Scale (VAS)<br>6. Perceived economic status (VAS)<br>7. Satisfaction with intervention (11-item questionnaire) | 2. Not significant at 6 and 12 months (p=0.280)<br>3. **Significant at 6 and 12 months** (**P=0. 041**)<br>4. Not significant<br>5. Not significant at 6 and 12 months (p=0.898)<br>6. Not significant at 6 and 12 months (p=0.119)<br>7. Not significant at 6 and 12 months (p=0.911) |
| Hoffmann et al. (2007); Stroke Unit, Brisbane, Australia | 138 stroke or TIA patients (Randomly allocated; intervention (n=69) and control (n=69) | Computer-generated tailored written information covering how stroke occurs, risk factors, understanding and | Generic written information comprises a series of three stroke fact sheets produced by the Stroke | 3 months follow-up<br>133 (96.4%) patients followed up (intervention (n=66) and control (n=67) | 1. Knowledge of stroke (KSQ 0-25)<br>2. Self-efficacy (Self-Efficacy to Perform Self-Management Behaviours Scale) | 1. Not significant (p=0.79)<br>2. Not significant |

| | | | | | | |
|---|---|---|---|---|---|---|
| | | managing the effects of stroke, reducing stroke risk, treatment and rehabilitation, and managing after discharge. Assessing patient informational need through interview generated tailored information is printed and given to the patient | Association of Queensland which covered topics such as how stroke occurs, risk factors, and physical, cognitive, and emotional changes following a stroke | | • To get information about the disease<br>• To obtain help from family, community and friends<br>• To communicate with the doctor<br>• To control/manage depression<br>• To manage the disease in general<br>• To manage symptoms<br><br>3. Anxiety and<br><br>4. Depression (Hospital Anxiety and Depression Scale (HADS))<br><br>5. Perceived health status (COOP chart)<br>• Physical fitness<br>• Feelings<br>• Daily activities<br>• Social activities<br>• Pain<br>• Change in health<br>• Overall health<br>• Social support<br>• Quality of life | • P= 0.27<br>• P= 0.32<br>• P= 0.20<br>• P= 0.27<br>• P= 0.49<br>• P= 0.64<br><br>3. **Significant** (**p=0.03**)<br>4. Not significant (p=0.99)<br><br>5. Not significant<br>• P= 0.97<br>• P= 0.57<br>• P= 0.96<br>• P= 0.48<br>• P= 0.93<br>• P= 0.34<br>• P= 0.34<br>• P= 0.39<br>• P= 0.15 |

| | | | | | | |
|---|---|---|---|---|---|---|
| Lowe et al. (2007); Acute Stroke Unit, United Kingdom | 100 acute stroke patients (randomly allocated; intervention (n= 50) and control (n=50) | Stroke education with a CareFile that contains telephone numbers for stroke-related services, local agencies, general stroke information and information on secondary stroke prevention personal to the patient. The content of the CareFile was discussed with the patient for 15-20 minutes and patient allowed to ask questions and take CareFile home for reference or consult GP in the advert of an arisen question | Usual stroke unit cares that include Stroke Association information leaflets and a follow-up in Stroke Review Clinic | 3- and 6-months follow-ups<br><br>At 3 months follow-up 85 (85%) (intervention (n=45) and control (n= 40)<br><br>At 6 months follow-up 84 (84%) (intervention (n=44) and control (n=40) | **Primary**<br>Knowledge of stroke (KSQ)<br><br>**Secondary**<br>1. Satisfaction with information given<br>2. Utilization of CareFile (KSQ)<br>3. Blood pressure<br>4. Participation<br>5. Mood (Yale single question) | **Significant at 3 & 6 months, intervention group had higher knowledge (p<0.005 at 3 and 6 months)**<br><br>1. Not significant<br>2. Not significant<br>3. Not significant<br>4. Not significant (p>0.05)<br>5. Not significant |
| Maasland et al. (2007); Netherlands | 65 TIA patients (Randomly allocated but number allocated to treatment groups not stated. The study, however, analyse 57 patient results: intervention (n= | A 20 – 25 minutes individualized computer mediated education program on the general introduction of diagnosis, prescribed medication and four risk factors for stroke or some | Standard health education (not stated what this entails) by at the consulting physician | 1week and 12weeks follow-up | **Primary**<br>1. Knowledge of stroke (14 questionnaire validated tool)<br><br>**Secondary**<br>1. Functional (modified Rankin score)<br>2. Compliance to risk factors prevention<br>• Blood pressure | 1. No significant difference between groups (p=0.09)<br><br>1. No significant difference between groups |

| | | | | | | |
|---|---|---|---|---|---|---|
| | 30) and control (n=47) | general information on frequent vascular risk factor | | | • Cholesterol level<br>• Weight<br>• Cigarette and alcohol consumption<br>Physical activity | No significance in all but they were an indication that patient compliance to risk factor prevention were high |
| Mant et al. (1998); Acute Stroke Unit, Oxford, United Kingdom | 93 acute stroke patients (Randomly allocated: Intervention (n=48) and control (n=45)<br><br>71 carers (intervention (n=37) and control (n=34) | A collection of eight Stroke Association leaflets that describes what stroke is, its causes, effects, problems and how to deal with stroke presented to patients and carers in a folder on discharge or one month after the stroke | Usual care and received no information pack | 6 months follow-up 71 (76.34%) patients (intervention (n= 37) and control (n=34) and 49 (94.23%) carers (intervention (n= 29) and control (n= 29) | **Primary**<br>1. Knowledge about stroke (57=knowledge questionnaire)<br>2. Satisfaction with information received (questionnaire)<br><br>**Secondary**<br>3. Patient behaviour (contact with any particular type of healthcare professional or type of support group/healthcare facility, family attendance or disability living allowance, orange badge for car<br>4. Health status and quality of life<br>a. Anxiety (HADS)<br>b. Depression (HADS)<br>c. Handicap (London Handicap Scale)<br>d. Quality of life (SF-36)<br>e. Caregiver strain (Caregiver Strain Index) | 1. Not significant<br><br>2. Not significant<br><br>3. Not significant (p=0.08, Mann-Whitney U)<br><br>4. Not significant |

| | | | | | | |
|---|---|---|---|---|---|---|
| Rodgers et al. (1999): Stroke Unit, North Tyneside General Hospital, England, UK | 204 stroke patients (Randomly allocated: Intervention (n= 121) and control (n=83)<br><br>176 carers (Intervention (n=107) and control (n=69) | A multidisciplinary stroke education program that comprises; the nature of stroke, treatment and recovery of stroke. The role of the multidisciplinary team members to stroke recovery. This was done in one 1-hour small-group educational sessions for inpatients and their informal carers and followed up with a six 1-hour educational sessions after discharge from hospital. | Usual care that includes routine communication with nurses, doctors and therapy staff throughout inpatient stay, information leaflets about stroke services usually given to patients and carers, Stroke Association leaflets on a number of topics display in the ward and the Stroke Care Pathway, a multidisciplinary record are used for all inpatients. The patients and carers are usually given information on aspects of stroke and given a 'hotline' to contact after discharge. | 6 months follow-up<br>154 (75.49%) patients (intervention (n=90) and control (n=64)<br><br>106 (60.23%) carers (intervention (n=65) and control (n=41) | **Primary**<br>1. Patient's and informal carer's perceived health status (SF-36)<br><br>**Secondary**<br>1. Patient and carer Knowledge of stroke (26 item Knowledge of Stroke Scale)<br>2. Satisfaction with services<br>3. Anxiety and<br>4. Depression (HADS)<br>5. Carer's emotion (General Health Questionnaire 30)<br>6. Disability (Nottingham E-ADL)<br>7. Handicap (Oxford Handicap Scale) | 1. Not significant difference of patients and carers SF-36 between groups, but significant difference on separate analysis of patient and carer (p=00. 4)<br><br>1. Signifiant (Patients : **p=0.02** & carers: **p=0.01**)<br>2. Not significant<br>3. Not significant (p=0.47)<br>4. Not significant (p=0.93)<br>5. Not significant (p=0.29)<br>6. Not significant (p=0.29)<br>7. Not significant (p=0.291) |

| | | | | | | |
|---|---|---|---|---|---|---|
| Smith et al. (2004); Stroke Unit, England, United Kingdom | 170 stroke patients (Randomly allocated: Intervention (n= 84) and control (n= 86)<br><br>97 carers (intervention (n= 49) and control (n=48) | A stroke recovery programme manual that contains information about stroke causation and its consequences, stroke recovery, financial benefits, relevant services and has a specific section for carers. A 20-minute meeting for discussion of the manual with a multidisciplinary stroke team every two weeks | Usual care that includes a folder of information about stroke causation, consequences and recovery previously devised by the ward staff and a variety of Stroke Association leaflets were available and prominently displayed within the stroke unit. Members of the stroke unit multidisciplinary team were free to discuss aspects of treatment and respond to any specific queries from patients and carers | 3- and 6-months follow-up<br><br>3 months follow-up<br>144 (84.70%) patients (intervention (n=74) and control (n=70)<br>77 carers (intervention (n=43) and control (n=37)<br><br>6 months follow-up<br>133 (78.24%) patients (intervention (n= 69) and control (n=64)<br>76 carers (intervention (n=40) and control (n=36) | **Primary**<br>1. Knowledge of stroke (questionnaire)<br><br>**Secondary**<br>1. Anxiety and<br><br>2. Depression (HADS)<br>3. Physical and social function (Barthel Index, Frenchay Activities Index (FAI), handicap (London Handicap Scale (LHS) | 1. Not significant at 3 and 6 months (p=0.24)<br><br>**1. Significant (at 3months (p=0.034) and at 6months (p=0.021)**<br><br>2. Not significant<br>3. Not significant |

# Appendix 4 - Participant Information Sheet

**Title of Research:**

Delivering post-stroke education for stroke patients and their family caregivers in Ghana: A feasibility Randomised Controlled Trial (RCT) with qualitative evaluation

**Name(s) and affiliation(s) of researcher(s):**

This study is being conducted by Philemon A. Amooba, a PhD student at the University of Nottingham and a lecturer in the Department of Nursing, KNUST and is being supervised by Dr Linda East, Dr Philip Clissett and Professor Avril Drummond, all lecturers in the School of Health Sciences, University of Nottingham.

**Background**

Providing education and information is an important aspect of caring for patients with long-term conditions including stroke. Giving education can assist you and your family know about stroke and be able to share in decision-making about your care and other support services. Lack of information and not knowing what to do after stroke can lead to psychological distress such as anxiety, fear and misconception that can worsens one's stroke condition. Elsewhere, after stroke, patient and their families are usually given information about stroke on how to cope with the illness by providing them with leaflets, face-to-face talks, and videos. Although the number of stroke cases in Ghana is increasing, there is no any known available structured information programme for stroke patients and their families to support them cope with the disease. In order to deliver effective and acceptable education to stroke patients and families in Ghana, we need to understand what the patient and family need to know about stroke and in what format. This the purpose for conducting this study, to find out and request for suggestions what the patient and family need to know about stroke and in what way it should be presented?

**Purpose of research**

The aim of this research is to assess the feasibility (possibility) of delivering education after stroke to both patients and their families. Through this study we will know whether it will be possible to include stroke education to your care in this hospital.

**Procedure of the research, what shall be required of each participant and approximate total number of participants that would be involved in the research:**

This study is in two phases, the first phase will involve both the patient and a family caregiver randomly assigned to either receive education after stroke or usual care in the hospital. Before the random assignment, patient and caregiver particulars will be given a questionnaire to complete. Those assigned to the education group will received a leaflet and a face-to-face discussion on the leaflet which will last for about 15-30 minutes. After the education, patient-caregiver (whether you were given the education or not) will be given another questionnaire to complete at three months during a scheduled review date.

The second phase of the study will be an interview for 3 selected patient-family caregivers each from both groups. This interview will also be conducted in the hospital and will be done immediately after you have completed the questionnaire for the first phase, and you have also agreed to be part of this. The interview will last for 10-15 minutes and will be audio-recorded, you also free to speak in English or twi. This will focus on your experience and perception of the study and as well as what you and your family caregiver want to be included for education and in what format.

You and your family caregiver are therefore being invited to participate in this research because you have been diagnosed with stroke and your ideas are needed to help us offer best care in terms of education to you and others who have been affected by stroke.

**Risks**

There are no risks involved if you take part in this study and efforts will be made not to inconvenience you or your caregiver.

**Benefits**

There are no direct benefits in taking part in the study. However, this may be an opportunity for you to learn about stroke and adapt strategies to cope with it. Also, your experiences and ideas will help modify and sharpen education after stroke in Ghana.

**Confidentiality**

All information that will be gathered through this research will be treated as highly confidential. Only the research team will have full access to everything you say and, even in this, we will ensure that it does not reveal your identity. The completed questionnaires recorded interviews and transcripts will be kept securely on a computer with a password. Your name and any other information that may cause somebody to know your identity will be replaced by identification numbers and/or false names in the transcripts and in any reports that will be generated from them.

**Voluntariness:**

Your participation in this research is purely voluntary. Thus, you will not be under any obligation to participate in the study after the aim and objectives have been explained to you although your participation will be much appreciated. If you choose not to participate, this will not affect your care in this hospital in any way.

**Withdrawal from the research**

You may choose to withdraw from the research at any time during the interview without having to provide detailed explanation. Choosing to withdraw from the study will not affect your care in any way. However, information that you might have provided before the withdrawal may be used in the analysis.

**Costs/Compensation:** You will be given souvenirs such as key rings or scarfs at the end of the interview just to say 'thank you' for your time. The researcher may also address some key issues that may arise during the interview through education or by refering you to the appropriate office so you can get the best support available.

**Contacts:** If you have any question concerning this study, please do not hesitate to contact **Mr Philemon A. Amooba on 0207085376.**

# Appendix 5: Favourable ethics opinion from the UoN

# Appendix 6: Ethics approval letter

## Appendix 7: Research study poster

# Research Study:

# Post-stroke education in Ghana

We are conducting a study on giving information about stroke to patients and their family members.

The study is seeking to recruit both stroke survivors who have been admitted to the Stroke Unit or who are attending the Stroke Review Clinic with their family caregivers.

The purpose of the study is to improve care for stroke survivors and their families.

If you would like more information, or are willing to participate in this study, please contact research nurse **Philemon Amooba on 0207085376** or ask any staff member in the Unit/ Clinic.

# Appendix 8: Consent Form

**Title of Research:**

Delivering post-stroke education to stroke patients and family caregivers in Ghana: A feasibility Randomised Controlled Trial (RCT) with qualitative equation

**Name(s) and affiliation(s) of researcher(s):**

This study is being conducted by Philemon A. Amooba, a PhD student at the University of Nottingham and a lecturer in the Department of Nursing, KNUST and is being supervised Dr Linda East, Dr Philip Clissett and Professor Avril Drummond, all lecturers in the School of Health Sciences, University of Nottingham.

**Statement of person obtaining informed consent:**

I have fully explained this research to _____ and have given sufficient information about the study, including that on procedures, risks, and benefits, to enable the prospective participant to make an informed decision to or not to participate.

DATE: _____ NAME: _____

**Statement of person giving consent:**

I have read the information on this study or have had it translated into a language I understand. I have also talked it over with the interviewer to my satisfaction.

I understand that my participation is voluntary (not compulsory).

I know enough about the purpose, methods, risks, and benefits of the research study to decide that I want to take part in it.

I understand that I may freely stop being part of this study at any time without having to explain myself.

I have received a copy of this information leaflet and consent form to keep for myself.

NAME: _____

DATE: _____ SIGNATURE/THUMB PRINT: _____

**Statement of person witnessing consent (Process for Non-Literate Participants):**

I (Name of Witness) certify that information given to (Name of Participant), in the local language, is a true reflection of what l have read from the study Participant Information Leaflet, attached.

WITNESS' SIGNATURE (if participant is non-literate): _____

# Appendix 9: Stroke survivor background information

## Delivering post-stroke education in Ghana

Interviewer initial: …… Date of Interview: ……/……./……

Participant's ID: ……

---

Name: ……

Address……

Telephone: ……

1. DOB: ……/……/……
2. Gender: M F
3. Religion: ……
4. Type of stroke diagnosed: ……
5. Date of diagnosis ……/……/……
6. Have you ever had stroke before (Previous stroke)? Yes No
7. Any other known condition ……
8. Level of education completed:
   a. Primary b. Middle school c. Junior High School (or JSS)
   d. Senior High School (or SSS, Vocational and Technical schools)
   e. Apprenticeship/trade
   f. Training college (Teaching, Nursing, Agricultural etc) ……
   g. Tertiary (Polytechnic, University etc) ……
   h. No formal education
9. Occupation: ……
10. Marital status: a. single b. married c. divorced/separated
    d. widowed/widower e. other (specify) ……
11. Living situation: a. alone b. spouse c. family/relative d. friend
    e. other (specify) _____

12. Have you received any written Information on stroke before: Yes No

13. If yes, name source …….

# Appendix 10: Knowledge of stroke questionnaire

The following questions are about your understanding of stroke. Please answer by ticking **(√) one box** (the most appropriate) that best correspond to whether the statement is **True, False or Don't know** for each of the 25 questions

| | True | False | Don't know |
|---|---|---|---|
| 1. A stroke is another name for a heart attack. | ☐ | ☐ | ☐ |
| 2. A stroke is caused when the blood supply to part of the brain is cut off. | ☐ | ☐ | ☐ |
| 3. A stroke can be caused if a blood vessel in the brain bursts and causes bleeding into the brain. | ☐ | ☐ | ☐ |
| 4. A stroke is caused by a sudden mental shock. | ☐ | ☐ | ☐ |
| 5. High blood pressure may lead to a stroke. | ☐ | ☐ | ☐ |
| 6. A stroke may happen because there is a family history of stroke. | ☐ | ☐ | ☐ |
| 7. You can reduce the chance of having another stroke by doing less exercise. | ☐ | ☐ | ☐ |
| 8. Your risk of having a stroke is increased if you have heart disease. | ☐ | ☐ | ☐ |
| 9. Drinking too much alcohol can lead to a stroke. | ☐ | ☐ | ☐ |

| | True | False | Don't know |
|---|---|---|---|
| **Which of these signs will prompt you to seek medical attention for stroke? This statement only applies to 10-14** | | | |
| 10. Weakness of one side of the body | ☐ | ☐ | ☐ |
| 11. Chest pain | ☐ | ☐ | ☐ |
| 12. Altered sensation in an arm | ☐ | ☐ | ☐ |
| 13. Difficulty breathing | ☐ | ☐ | ☐ |
| 14. Difficulty understanding speech | ☐ | ☐ | ☐ |

Please tick **(√) one box** (the most appropriate) that best correspond to whether the following statement is **True, False or Don't know**

| | | | |
|---|---|---|---|
| 15. Having diabetes puts you at increased risk of having a stroke. | ☐ | ☐ | ☐ |
| 16. High cholesterol levels can lead to heart disease but not stroke. | ☐ | ☐ | ☐ |
| 17. Seek medical attention immediately you think you are having a stroke. | ☐ | ☐ | ☐ |
| 18. If you have had a TIA ('mini-stroke') in the past, this does not increase your risk of having a stroke. | ☐ | ☐ | ☐ |

**A person who has had a stroke might have which of these difficulties. This statement only applies to 19 – 23:**

| | | | |
|---|---|---|---|
| 19. A weak arm | ☐ | ☐ | ☐ |
| 20. Earache | ☐ | ☐ | ☐ |
| 21. Poor balance | ☐ | ☐ | ☐ |
| 22. Eyesight problems | ☐ | ☐ | ☐ |
| 23. Nose bleeds | ☐ | ☐ | ☐ |

---

Please tick **(√) one box** (the most appropriate) that best correspond to whether the following statement is **True, False or Don't know**

| | | | |
|---|---|---|---|
| 24. Being overweight puts you at risk for a heart attack, not stroke. | ☐ | ☐ | ☐ |
| 25. If you have smoked for years, you can lower your risk of having a stroke by quitting. | ☐ | ☐ | ☐ |

# Appendix 11: Hospital Anxiety and Depression Scale (HADS)

Date: ----------

Participant Number ----------

**Tick the box beside the reply that is closest to how you have been feeling in the past week.**

**Don't take too long over you replies: your immediate is best.**

| D | A | | D | A | |
|---|---|---|---|---|---|
| | | **I feel tense or 'wound up':** | | | **I feel as if I am slowed down:** |
| | 3 | Most of the time | 3 | | Nearly all the time |
| | 2 | A lot of the time | 2 | | Very often |
| | 1 | From time to time, occasionally | 1 | | Sometimes |
| | 0 | Not at all | 0 | | Not at all |
| | | | | | |
| | | **I still enjoy the things I used to enjoy:** | | | **I get a sort of frightened feeling like 'butterflies' in the stomach:** |
| 0 | | Definitely as much | | 0 | Not at all |
| 1 | | Not quite so much | | 1 | Occasionally |
| 2 | | Only a little | | 2 | Quite Often |
| 3 | | Hardly at all | | 3 | Very Often |
| | | **I get a sort of frightened feeling as if something awful is about to happen:** | | | **I have lost interest in my appearance:** |
| | 3 | Very definitely and quite badly | 3 | | Definitely |
| | 2 | Yes, but not too badly | 2 | | I don't take as much care as I should |
| | 1 | A little, but it doesn't worry me | 1 | | I may not take quite as much care |
| | 0 | Not at all | 0 | | I take just as much care as ever |
| | | **I can laugh and see the funny side of things:** | | | **I feel restless as I have to be on the move:** |
| 0 | | As much as I always could | | 3 | Very much indeed |
| 1 | | Not quite so much now | | 2 | Quite a lot |
| 2 | | Definitely not so much now | | 1 | Not very much |
| 3 | | Not at all | | 0 | Not at all |
| | | **Worrying thoughts go through my mind:** | | | **I look forward with enjoyment to things:** |
| | 3 | A great deal of the time | 0 | | As much as I ever did |
| | 2 | A lot of the time | 1 | | Rather less than I used to |

| | | | | | |
|---|---|---|---|---|---|
| | 1 | From time to time, but not too often | 2 | | Definitely less than I used to |
| | 0 | Only occasionally | 3 | | Hardly at all |
| | | **I feel cheerful:** | | | **I get sudden feelings of panic:** |
| 3 | | Not at all | | 3 | Very often indeed |
| 2 | | Not often | | 2 | Quite often |
| 1 | | Sometimes | | 1 | Not very often |
| 0 | | Most of the time | | 0 | Not at all |
| | | **I can sit at ease and feel relaxed:** | | | **I can enjoy a good book or radio or TV program:** |
| | 0 | Definitely | | 0 | Often |
| | 1 | Usually | | 1 | Sometimes |
| | 2 | Not Often | | 2 | Not often |
| | 3 | Not at all | | 3 | Very seldom |

Please check you have answered all the questions

Scoring:

Total score: Depression (D) _____ Anxiety (A) _____

0-7 = Normal

8-10 = Borderline abnormal (borderline case)

11-21 = Abnormal (case)

# Appendix 12: Family Caregiver background information

## Delivering post-stroke education in Ghana

Interviewer initial: ……  Date of Interview: ……/……/……

Participant's ID: ……

---

Name: ……

Address: ……

……

Telephone: ……

1. DOB: ……/……/…….
2. Gender: M F
3. Religion: ……...
4. Caregiver's relationship with patient: ……
5. How long have you been caring for the patient ……..?
6. Level of education completed:
   a. Primary b. Middle school c. Junior High School (or JSS)
   d. Senior High School (or SSS, Vocational and Technical schools)
   e. Apprenticeship/trade
   f. Training college (Teaching, Nursing, Agricultural etc) …….
   g. Tertiary (Polytechnic, University etc) ……...
   h. No formal education
7. Occupation: ……
8. Marital status: a. single b. married c. divorced/separated
   d. widowed/widower e. other (specify) ……
9. Have you received any written Information on stroke before: Yes No
10. If yes, name source ……

# Appendix 13: Modified Caregiver Strain Index (MCSI)

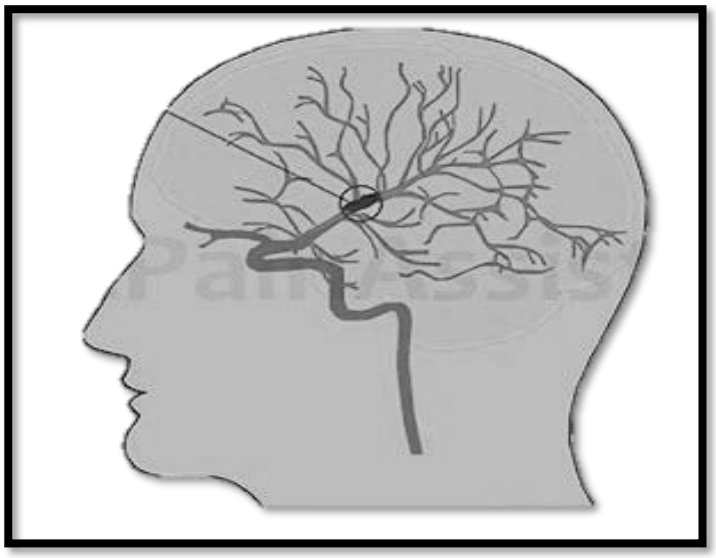
The following questions are about the difficulties of a caregiver. Please put a tick **(√)** in the columns that apply to you. We have included some examples that are common caregiver experiences to help you think about each item. Your situation may be slightly different, but the item could still apply

| | **Yes, On a Regular Basis** | **Yes, sometimes** | **No** |
|---|---|---|---|
| **My sleep is disturbed** (For example: the person I care for is in and out of bed or wanders around at night) | | | |
| **Caregiving is inconvenient** (For example: helping takes so much time, or it is a long drive over to help) | | | |
| **Caregiving is a physical strain** (For example: lifting in or out of a chair; effort or concentration is required) | | | |
| **Caregiving is confining** (For example: helping restricts free time or I cannot go visiting) | | | |
| **There have been family adjustments** (For example: helping has disrupted my routine; there is no privacy) | | | |
| **There have been changes in personal plans** (For example: I had to turn down a job: I could not go on vacation) | | | |
| **There have been other demands on my time** (For example: Other family members need me) | | | |
| **There have been emotional adjustments** (For example: Severe arguments about caregiving) | | | |
| **Some behaviour is upsetting** | | | |

| | | | |
|---|---|---|---|
| (For example: incontinence; the person cared for has trouble remembering things, or the person I care for accuses people of taking things.) | | | |
| **It is upsetting to find the person I care for has changed so much from his/her former self.**<br>(For example: he/she is a different person than he/she used to be) | | | |
| **There have been work adjustments**<br>(For example: I have to take time off for caregiving duties) | | | |
| **Caregiving is a financial strain** | | | |
| **I feel completely overwhelmed**<br>(For example: I worry about the person I care for; I have concerns about how I will manage) | | | |
| **Total score** | | | |

# Appendix 14 - Stroke Information booklet

## ‘Stroke Information’



Name: ……

**What is a stroke?**

A stroke occurs when blood flow to an area of the brain is interrupted. When this happens, the brain cells in this area begin to die.

A stroke is sometimes called a ‘brain attack’ because it is similar in many respects to a ‘heart attack’. Both are sudden, serious and life threatening and needs urgent medical attention.

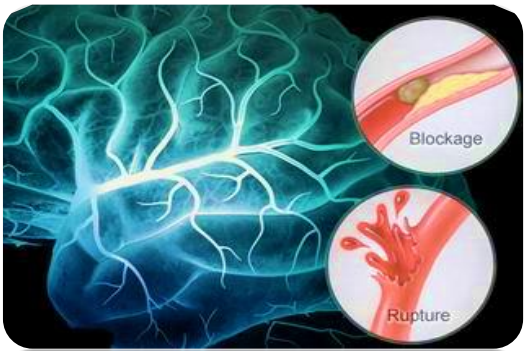
**What are the causes of stroke?**

There are **two (2)** main causes of stroke.

1. A blocked blood vessel by a clot that prevent or reduce blood to the brain. This is called an **ischaemic** (is-KEE-mic) stroke. About two-thirds of all strokes are this type.

2. A stroke can also occur if a blood vessel in the brain bursts and causes bleeding into the brain. When this happens, it is called a **haemorrhagic** (haem-or-AJ-ic) stroke. This type is more common among Africans and cause two-thirds of deaths in stroke

Figure 1: shows both ischaemic and haemorrhage strokes




**What are the risk factors for a stroke?**

**Risk factors** are medical problems and other factors that increase your chance of having a stroke.

**Some risk factors are treatable –** this means that you can do something to help reduce your risk of having stroke (or a further stroke if you have already had one).

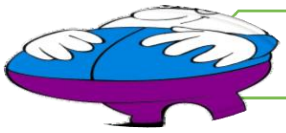
The most important treatable risk factors for stoke are shown below – please speak to a nurse if you need help with these.



Uncontrolled high blood pressure, also referred to as hypertension



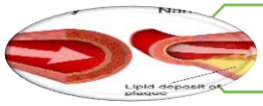
Diabetes (high blood sugars)



Obesity (over weight)



Heart diseases – atrial fibrillation (rapid and irregular heart beat



High cholesterol (high fat in blood)



Smoking & Excessive alcohol consumption

**Problems you may experience after stroke**

Each stroke is different depending on the part of the brain injured, how bad the injury is, and the person's general health.

Some of the effects of stroke are:

- **Physical problems:**
  - Paralysis – numbness or weakness of the face, arm or leg. This usually affect one side of the body
  - Difficulty in movement (because of the paralysis)
  - Pain and numbness – e.g., shoulder pain, leg pain
  - Swallowing problems
  - Communication problems (problems using and understanding language)
  - Poor vision
  - Getting tired easily
  - Urinary problems (unable to control urine flow)

- **Psychological problems:**
    - Problems with memory, thinking, attention or learning
    - Emotional disturbances e.g., laughing, quick tempered, anger or crying
    - Depression and anxiety e.g., feeling sad or “down”
    - Loss of interest in things that you used to enjoy and changes in your relationships

**But there are things you and your family can do to recover**

**Recovery after stroke**

The process of recovering from stroke begins with treatment at the hospital with rehabilitation.

The treatment at the hospital helps to prevent another stroke and treats any other medical problem.

People with stroke may have trouble with many activities that were easy before.

Some problems are obvious right after the stroke, but others may not be noticed until you are back home and trying to do something for the first time since your stroke.

Rehabilitation helps you gain back lost abilities and keep them. Your recovery depends on the efforts your put in the rehabilitation programme. This starts in the hospital and continues at home

Figure 2: the rehabilitation team helping a stroke survivor to practice walking



**When at home to do the following:**

- Make your home safe by removing rugs and other items that can cause accident
- Rearrange your room or house for easy passage to prevent falls
- Try to sit or stand often, with assistance if necessary, during the day and reduce prolonged bed rest
- Use chairs with arms that will assist you to get up and sit down with ease
- Do simple activities such as taking a walk around the neighbourhood or engaging in household chores
- Use a walking stick to aid you in walking and to prevent falling
- Do not lie on one side or sit for a long time, turn frequently at least every 1 – 2 hours to prevent bedsores
- Visit friends and family if you can keep active
- Ask for help from family members and friends when using the bathroom and avoid using tight clothing
- Do exercises such as moving your hands up and down, swing the shoulders to minimise pain
- Remember to eat well, avoid fatty foods, and add fruits and vegetables to your meals.

**What can family caregivers do to support you?**

- Assist you to continue with regular exercise such as walking
- Assist you to walk and make the environment safe for you by removing potential obstructive objects
- Emotionally support you by encouraging and reassuring you
- Encourage other family members to visit and talk with you
- Remind you to take your medication regularly and keep hospital review dates
- Report anything unusual that they observe to the doctor
- Participate in education and other activities offered for stroke patients and their families. Learn as much as you can and how you can help
- You can relax together doing thing that you both enjoy such as playing cards, watching television, listening to the radio or playing games such as ludo or oware

- Remember to take care of themselves as well as you. Eating well, getting enough rest, and taking time to do things that you enjoy is important for everyone.

**How do I prevent another stroke?**

After you have had a stroke, your doctor may put you on medication to prevent another stroke.

- Take your medication regularly as prescribed
- Remain physically active and rest often
- If you smoke, stop smoking or reduce smoking
- Stop or reduce alcohol consumption
- Report immediately to the hospital anytime you feel unwell or experience any of the following:
    - Sudden weakness or numbness of the face, arm, or leg
    - Sudden severe headache
    - Sudden confusion and inability to speak or understand simple commands

**Important points to remember**

- A stroke is a disorder of the brain and affects both the body, mind, and your feelings
- The risk factors for stroke can be controlled to reduce the risk of another stroke
- After stroke remain active
- Keep hospital review dates for follow-up care
- Recovery after stroke is possible but is a gradual process – be patient and kind with yourself.

**For any inquiries, contact Philemon**

# Appendix 15: Interview guide for stroke survivors

- General introduction
- Recap purpose of the study
- Obtain verbal consent to participate on tape – turn on recorder

**Start recording**

1. **Background information**

   I will start by asking you about some general questions about life and stroke

   a. Who are you living with at your home?
      - Prompts - husband/wife or other relations
      - How many are younger or older than you
      - How do these family members help you in your day-to-day activities?

2. **Please describe the history of your stroke to me**

   a. When did you have your stroke?
      i. Prompts - when did you first find out that you were ill?
      ii. What symptoms did you experience?
      iii. What did you think was happening to you?
      iv. What actions did you take to get well?
      v. When were you first told that you had stroke?
      vi. How did you feel when you found out that you had stroke?
      vii. What did you think might have caused your stroke?
      viii. What made you think those factors might have caused your stroke?

   b. Please tell me what you knew about stroke before your diagnosis?
      i. Had you heard anything about stroke? How did you get to know that? Did you know anybody with stroke? Has any relative of yours had stroke before?

   c. Can you tell me how you feel about your stroke?

      Prompts: Do you feel it has affected your life in any way? Do you feel it is still affecting your life in any way?

   d. Please tell how you have been managing with this stroke
      - Prompt – how long have you been with this condition? Is there any help from relations?

3. **Post-stroke information**

   Next, I am going to ask you about stroke information you have accessed since your stroke

   a. Have you received any information on stroke?
      i. Prompt - written or oral, if yes, where, from who and what aspect of stroke did this information cover
      ii. Did you look for sources of information yourself, e.g on the internet
   b. Could you please tell me what aspects of stroke would you like/wish to have information on?
      i. Prompt – what kind of stroke information would you want or expect from the nurse or the doctorand
   c. Is there any information you wish you had heard before your diagnosis?

4. **Participation in the study**
   a. Please tell me how felt when you were asked to join this study?
   b. What do you understand about the study – can you explain what the study was about
      - Prompt – were you happy being randomly assigned to a group
   c. What were your expectations for joining this study?
      - Prompt - is there any part of this study that is particularly interesting to you
      - Is there any part of this study that you find difficult or not interesting?
   d. Please explain to me the experiences you had for taking part in this study

5. **The leaflet and discussion (for intervention group only)**
   a. What aspects of stroke would you like more education on?
   b. What would you like to be included in a stroke educational leaflet?
   c. How did you find the information you received after the stroke?

      Prompt – how useful was it? Which aspect of the leaflet was more useful to you? Did you have any difficulty using it?
   d. Please tell me how you found the general layout of the leaflet
      i. Prompt – how is the content
   e. Is there any other information you wish could be added to the leaflet?

6. **Closing questions**
    a. Is there anything you would want us to discuss concerning stroke?
    b. Do you have any question on what we have discussed?

Thank you for your time

**End of interview**

# Appendix 16: Interview guide for family caregiver

- General introduction
- Recap purpose of the study
- Obtain verbal consent to participate on tape – turn on recorder

**Start recording**

1. **Background information**

   I will start by asking you about some general questions about life and living with a person with stroke

   a. How many other people are you living with at home (including X)
      - Prompt - husband/wife or other relations

2. **Please describe the history of x stroke to me**

   a. When did x have stroke?
      - Prompts - when did you first find out that x were ill?
      - What symptoms did x experience?
      - What did you think was happening to x?
      - What actions did you take for x to get well?
      - When were you first told that x had stroke?
      - How did you feel when you found out that x had stroke?
      - What did you think might have caused x stroke?
      - What made you think those factors might have caused x stroke?

   b. Please tell me what you knew about stroke before x diagnosis?
      - Had you heard anything about stroke? How did you get to know that? Did you know anybody with stroke? Has any relative of yours had stroke before?

   c. Can you tell me how you feel about x stroke?

      Prompts: Do you feel it has x stroke has affected your life in any way? Do you feel it is still affecting your life in any way?

   d. Please tell how you have been managing with x stroke
      - Prompt – how long have you been caring for x? Is there any help from relations?

   e. What are some of the information that you knew or heard about stroke?

   f. How did you feel when you learnt that X had stroke?

g. How have you been managing taking care of X
    - Prompt – how do you combine taking her of X with your other responsibilities? Any recent problem

**3. Post-stroke information**

Next, I am going to ask you about stroke information

a. Have you received any information on stroke?
    - Prompt - written or oral, if yes, where, from who and what aspect of stroke did this information cover
    - Did you look for sources of information on stroke yourself, e.g on the internet

b. Could you please tell me what aspects of stroke would you like/wish to have information on?
    - Prompt – what kind of stroke information would you want or expect from the nurse or the doctor

**4. Participation in the study**

a. How did you feel when were asked to join this study?

b. What do you understand about the study – can you explain what the study was about
    - Prompt – were you happy being randomly assigned to a group

c. What were your expectations for joining this study?
    - Prompt - is there any part of this study that is particularly interesting to you
    - Is there any part of this study that you find difficult or not interesting?

d. Please explain to me the experiences you had for taking part in this study

**5. The leaflet and discussion (for intervention group only)**

a. What aspects of stroke would you like more education on?

b. What would you like to be included in a stroke educational leaflet?

c. How did you find the information you received after the stroke?

    Prompt – how useful was it? Did you have any difficulty using it?

d. Please tell me how you found the general layout of the leaflet
    - Prompt – how is the content

6. **Closing questions**
    a. Is there anything you would want us to discuss concerning stroke?
    b. Do you have any question on what we have discussed?

Thank you for your time

**End of interview**

# Appendix 17: Interview guide for nurses

- General introduction
- Recap purpose of the study
- Obtain verbal consent to participate on tape – turn on recorder

**Start recording**

How long have you been working with stroke patients?

Can you please describe to me how stroke patients are cared for in this hospital?

How are patients referred to the stroke unit?

1. **Post-stroke education process**

I am going to ask you about the stroke education you gave to patients and their family caregivers in this study

a. What challenges do you face as a nurse who takes care of stroke patients?

b. Have you given any information on stroke to patients and their family caregivers in this unit?

- Prompt - written or oral, if yes, when and what aspect of stroke did this information cover

c. Were you happy being part this study? If yes, why and if no, why

d. What do you understand about the study - can you explain what the study was about?

- Prompt – how did you feel when we had to randomly assigned groups to participants?

e. What were your expectations for being part of this study?

- Prompt - is there any part of this study that is particularly interesting to you
- Is there any part of this study that you find difficult or not interesting?

f. How did you find the information given to the participants?

g. What will you like to be included in a post-stroke educational leaflet?

h. Is it possible to include this education as a routine process?

- Prompt – what challenges are anticipated

i. What can do to improve stroke education among patients and their families

**2. Closing questions**

a. Is there anything you would want us to discuss concerning post-stroke education?

b. Do you have any question on what we have discussed?

Thank you for your time

**End of interview**