Stroke Knowledge and Educational Needs in Malta: A Mixed Methods Study

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Abstract

Stroke remains a leading cause of morbidity and mortality worldwide. Recent medical advances in the treatment of stroke have been the key to changing a preventable catastrophe to a potentially treatable disease. However, treatment is restricted to a time-window, which has led to the aphorism “Time is Brain”. Prompt presentation to emergency services has been extensively linked to patients’ knowledge about their symptomatology and recommended actions in stroke, which is subsequently influenced by more complex psychological ‘barriers’.

The aim of this study was to explore and quantify stroke knowledge in Malta and to identify any potential educational lacunae in this respect. The data generated may in turn be used to adapt local practices and improve patients’ long-term outcomes. This required an in-depth investigation of the stroke experience as recalled by affected patients, followed by the development of a quantitative tool which was later used to generalise the findings. For these purposes, a mixed methods approach was utilised.

The findings showed that stroke and response knowledge in Malta are severely lacking and reflect what has been reported in the literature. Several variables were found to affect this knowledge, including demographic factors as well as broader social and cultural influences. The interactions between these factors were deemed crucial to understanding the underlying problem and were explored with respect to Bronfenbrenner’s ecological framework as well as by adapting several health-promotion theories and models. Various stroke educational strategies and campaigns were also reviewed to assess how stroke education attempts could become more effective. Finally, several recommendations regarding the local management, education, and improvement of stroke services have been presented.

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Abbreviations and acronyms

A&E	Accident and Emergency
ASPIRE	Acute stroke programme of interventions addressing racial and ethnic disparities
BRFSS	Behavioural risk factor surveillance survey
CME	Continuing medical education
CPD	Continuous professional development
CT	Computed tomography
EMS	Emergency medical services
FAST	Face arms speech time
GP	General Practitioner
i.v.	Intravenous
KSIC	Know stroke in the community
MT	Mechanical thrombectomy
NIHSS	National Institute of health's stroke scale
NINDS	National Institute of neurological disorders and stroke
OR	Odds ratio
PSA	Public service announcement
rtPA/rt-PA	Recombinant tissue plasminogen activator
SINAP	Stroke improvement national audit programme
SK	Stroke knowledge
SKT	Stroke knowledge test
STAT	Stroke action test
TIA	Transient ischaemic attack
t-PA	Tissue plasminogen activator
UK	United Kingdom
US	United States

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Declaration

I declare that I have conducted this study and that this thesis is entirely my own work. Where the work of others features in the text, this is indicated by referring to the original source. This thesis has not been submitted to any other academic body in fulfilment of a degree and it has not been previously published.

Signed:

Dated: 10th October 2019

Chapter 1 – Introduction

1.1 Statement of the problem

Stroke remains one of the leading causes of morbidity and mortality worldwide, and 37% of affected individuals succumb to the condition within 12 months (Thrift, Dewey, Macdonell, McNeil, & Donnan, 2000). Among those who survive their stroke, 51% report limitations in their activities of daily living and 50% exhibit cognitive impairment or dementia (Srikanth et al., 2004; Sturm et al., 2002). As a severe, often life-changing condition, stroke is best thought of as 'a brain attack' (Felberg, 2003). It occurs suddenly and unexpectedly and has been described as "an earthquake in the brain" (Johnson, 2007). Damage is not limited to permanent neurological deficits such as problems with mobility, speech, and co-ordination, but can also affect an individual's ability to "make sense of their social world" (Mason-Whitehead, Ridgway, & Barton, 2012). Thus, stroke does not affect only the patients but also impacts those around them.

We now know that the extent of irreversible brain damage during stroke is not only time dependent but may also be managed by timely intervention. Phrases such as 'Time is Brain' and the eponym 'Act FAST' not only highlight this but also serve as an aid-mémoire for individuals facing an acute stroke. Major advances in stroke treatment have been developed over the past decade, both in the acute phase and in the rehabilitation process. Treatment now focuses on holistic and multidisciplinary intervention by several stroke specialists with the aim of reducing stroke burden. Through "knowledge of brain function, restoration of blood flow and rehabilitative approaches in specialist services the outcome of stroke can be positively affected" (Goldstein & Rothwell, 2008).

The provision of state-of the art therapy also entails significant financial implications and has unintentionally resulted in a disparity in service provision among different geographical locations. Whitehead (1991) has compared this effect to 'a postcode lottery', while others have explored the direct link between stroke and poverty (Bonita & Beaglehole, 2007).

However, timely intervention is limited not only by the geographical availability of services. Acute stroke treatment has always been limited by a 'time window' after which treatment is ineffective and instead becomes deleterious. Hence, the recognition of signs and symptoms of stroke is paramount, as is the immediate taking of necessary action. One cannot place enough emphasis on the importance of public education regarding these aspects of stroke. Education should not only target people who are at risk for stroke, but also needs to reach the general public as it is the latter who commonly activate emergency services in the event of stroke.

1.2 Rationale for the study

Despite recent advances in stroke care, a looming epidemic of stroke persists. In Malta, stroke incidence equals 47.9 per 100,000 inhabitants annually (Stroke Alliance for Europe, 2018) and is expected to increase by more than half by 2035. This prevalence is predominantly accounted for by an increasingly aging population and the strong association between age and stroke incidence. The expected rise in stroke may not only increase the burden of the disease but may also overwhelm the resources currently available. In fact, it is alarming to note that the current estimated healthcare cost related to stroke in Malta is 8.8 million euro (Stroke Alliance for Europe, 2018). In addition to this national burden, the disruptive thunderbolt effect of stroke on an individual’s life cannot be negated, and a reduction in quality of life as an aftermath is typical.

Long-term planning is crucial to address this issue and needs to focus on disease prevention and education. Several health educational campaigns have succeeded in achieving this objective, and have been shown to be an effective cost-benefit solution. Thus, education is a major measure that can be taken to reduce the impact of stroke. To this extent, familiarity with stroke symptomatology and the appropriate response to stroke has been shown to reduce both mortality and morbidity associated with stroke.

1.2.1 Positionality

Since enrolling in medical school in 1999, I have developed a particular interest in the aetiology and treatment of stroke. As a medical doctor, who strives to help sick individuals, it was initially challenging to face stroke and its long-term effects. Although therapies for acute cardiac events had already been established during my undergraduate studies, effective stroke therapy in Malta was lagging behind. Intravenous 'clot-buster' treatment for stroke was only introduced in Malta in 2010 (Micallef, Mallia, Borg, & Aquilna, 2015), 15 years after the efficacy of tissue plasminogen activator (t-PA) was demonstrated in the NINDS trial (National Institute of Neurological Disorders and Stroke & rt-PA Stroke Study Group, 1995). Having worked with stroke patients in the neurology ward of St. Luke's Hospital (Gwardamangia, Malta), I felt an intrinsic drive to help these individuals. After completing specialist training in radiology in 2010, I moved into the sub-specialty of neuroradiology and experienced the first neuro-interventional cases in 2011 during my fellowship training in Dublin, Ireland. This coincided with the first attempts at mechanical removal of the causative blood clot in stroke. In 2015, following the publication of the MR CLEAN trial of endovascular treatment for acute ischemic stroke (Berkhemer et al., 2015), the clinical equipoise which surrounded mechanical thrombectomy ended and an effective treatment for acute ischaemic stroke was finally available.

Following innumerable meetings with the major stakeholders, I succeeded in introducing and performing the first mechanical thrombectomy in Malta in July 2015. Since then, I have been involved in establishing local guidelines for the treatment of acute stroke, and we have seen the development of a dedicated stroke unit and a 2-million-euro investment in the installation of a biplane angiosuite dedicated to neuro-intervention. The experience of almost miraculous instantaneous clinical improvement in affected patients was what drove me to introduce a 24/7 on-call stroke service, which I covered (on my own) for the next 3 years. The number of procedures increased steadily, and we experienced a tangible improvement in stroke outcomes.

I used to (and still do) feel sad and helpless when potential candidates (especially young patients) present late and have therefore missed the therapeutic window. The phrase from the Hippocratic Oath, which I uttered upon graduation from medical school, "I will prevent disease whenever I can, for prevention is preferable to cure", still resonates in my mind and has ultimately pushed me to undertake this research. I firmly believe that the solution to tackling these late presentations lies in community education. Over the past couple of years, I have delivered multiple lectures on the recognition of and potential treatment for stroke to both medical colleagues and the public. This study was therefore my opportunity to explore and quantify stroke knowledge and educational needs in Malta as well as to satisfy my research hunger.

Despite my insight and efforts to increase the trustworthiness of this study (as described in Chapter 3), I am aware of potential biases which may have influenced data collection and interpretation. I acknowledge having strong feelings about the area of study, particularly the role of community education regarding stroke. While acknowledging these potential biases, I also chose to perceive my positionality as an asset as it enhanced my interactions with participants and my understanding of the findings in a comprehensive manner.

1.3 Background

The medical world has experienced an overhaul in stroke treatment over the past two decades. Prior to 1995, the mainstay of treatment was conservative and aimed at reducing the chance of further strokes. This approach was completely superseded by the introduction of intravenous t-PA in 1995 and by mechanical thrombectomy in 2015, both of which target the underlying cause of stroke. The focus of therapy also shifted from reducing mortality to improving the quality of life of affected individuals.

1.3.1 Study setting

Surprisingly, a local audit showed that only 1.59% of acute stroke patients who presented to hospital were eligible for (and received) t-PA treatment (Micallef et al., 2015). Although this finding may partly be attributed to the numerous contra-indications for intravenous t-PA, late arrival to hospital was the most common reason why this treatment could not be administered. Considering the Maltese geographical boundaries and the fact that the main acute hospital is centrally located on the island, one can hardly blame this late arrival on geographical factors. In fact, Agius (1990) previously claimed that "one clear advantage resulting from small geographical size is easier access to the health care system". Both pre- and in- hospital delays are at least partly attributable to lack of stroke knowledge. Although other social and cultural barriers exist and may act as potential barriers to an adequate stroke response, lack of knowledge on how to recognise the symptomatology of stroke and engage in the necessary action appear to be the main factors causing delayed presentation to health services. This knowledge deficit seems to be a global issue, as previously reported by numerous authors (Jones, Jenkinson, Leathley, & Watkins, 2010; Yoon, Heller, Levi, Wiggers, & Fitzgerald, 2001b). A quick glance at the literature highlights the deficit of local studies investigating stroke knowledge, which has therefore led to an inability to determine and possibly tackle the causative factors for late presentation in stroke. It was thus considered that there was a desperate need to study this aspect of stroke and to highlight the major educational needs in Malta. The continuously changing guidelines in acute stroke treatment also mean that healthcare workers and medical doctors require continuous stroke education to ensure effective and timely treatment.

1.3.2 Research questions

In order to address the aim of the study, the following research questions guided the process:

> **What are the reflections of stroke sufferers on the way that they managed their stroke onset?**
>
> **How much knowledge does the Maltese population have with regards to stroke recognition and management?**

What findings emerge from comparing and merging data from the reflections of stroke sufferers to quantitative instrument data on the Maltese population's knowledge?

Which educational lacunae are present in relation to the Maltese population's knowledge about stroke recognition and management?

1.4 Method

Upon reflection on the research questions set out at the initial phase of this study, it emerged that neither qualitative nor quantitative methods would likely be adequate as a standalone approach in providing the answers required. Subsequently, the design of this study steered away from a monomethod investigation and towards an eclectic paradigm instead. After exploring several mixed-method approaches, the 'Sequential Exploratory design' as advocated by Creswell and Plano Clark (2011) was deemed most suitable to act as an effective guide to the research process and to yield rich results. Hence, an initial qualitative phase which consisted of 10 in-depth interviews with stroke patients was used to explore the problem in depth with subsequent analysis of the data. This phase was followed by the construction of an instrument for quantitative data collection. The latter phase of the study consisted of an online interview distributed to a representative sample of the general public and healthcare workers to enhance generalisability of the study. Throughout the study, trustworthiness, validity, and reliability of the data were given utmost importance and any processes and decisions taken were clearly documented to enhance transparency and reproducibility.

1.4.1 Theoretical and conceptual frameworks

Stroke response is a complex physical and psychological process which is affected by a multitude of intrinsic and external factors, including social and cultural barriers. The latter cannot be over-stressed and may not be fully appreciated unless seen in the light of several health promotion theories and models. A number of these models formed the basis of this thesis, which not only explored the local reasons for a delay in presentation of stroke patients but also attempted to understand the underlying mechanisms.

1.5 Conclusion

The aim of this study was to gain further understanding of stroke knowledge in the Maltese community and to explore the most burning educational needs. The collected data and subsequent analysis served to illuminate the major issues underlying pre- and in-hospital delays in local stroke treatment. The attempt to understanding the underlying local circumstances may also form the basis of future stroke educational campaigns, and it is suggested that this understanding will increase the cost effectiveness of such campaigns. As Bucchianeri (2011) states: “Well, if it can be thought, it can be done, a problem can be overcome”.

This introductory chapter is followed by a review and appraisal of the literature in Chapter 2 as well as a contemporary view of the subject under study. Chapter 2 also aims to identify any research gaps to which the current study may have contributed and explores stroke knowledge in the community, delays in acute stroke care, and educational strategies and campaigns currently or previously used in stroke.

The choice, justification, and employment of the research method used to guide this study are presented in Chapter 3. This is followed by two chapters dedicated to the data analysis and interpretation that emerged from the different phases of the study namely, Qualitative Analysis (Chapter 4) and Quantitative Analysis (Chapter 5). Chapter 6 integrates the findings that emerged from the different phases of the study and provides recommendations. It also explores potential limitations of the study. The final chapter (Conclusion) serves as an opportunity to revisit the research questions posed at the start and to reflect on how these questions were addressed in the study.

Chapter 2 – Literature Review

2.1 Background

The literature on stroke knowledge and education is vast and multi-tangential. This is not surprising because, as already described, the prevalence of this medical condition is high, and it is associated with high morbidity and mortality. This renders it a direct target of clinician and researcher focus in the attempt to understand, prevent, and manage stroke. The aim of this literature review is to explore the characteristics of stroke, with particular reference to knowledge, education, and initiatives to raise awareness of the condition. In addition to providing the reader with an overview of the topic of interest of this thesis, the information in this chapter will guide the construction of the tool used in this study, as described in Chapter 3. Although I have attempted to be as exhaustive and comprehensive as possible in the selection of specific topics to explore in this chapter, it seems appropriate to acknowledge that it is highly likely that this process has been influenced by my subjectivity arising from familiarity with the subject. However, it has been this same familiarity that has served as guidance in the inclusion and exclusion of relevant material from an ocean of literature that surrounds this topic.

This chapter consists of four main sections and various subsections. The thematic synthesis process described by Thomas & Harden (2008) and Braun & Clark (2006) was used for the integration of the studies that were accessed for inclusion in the literature review. This facilitated the structuring of the literature review chapter into different sections and subsections. Additionally, this process enhanced the transparent integration of the literature into the new tool constructed and used during Stages 2 and 3 of the study, as described in Chapter 3.

The first section of the literature review is dedicated to an exploration of stroke knowledge. This includes the variables that affect stroke knowledge followed by the major causes of delay in seeking help when faced with symptoms. My decision to address these topics was based on the objectives of this study, which involve the exploration of knowledge of the Maltese population in relation to stroke recognition and management.

The subsequent part involves an overview of existing educational strategies as well as a review of some of the main stroke awareness campaigns that have been implemented.

This section is followed by the variables that may play a part in the effectiveness of a given campaign. To this extent, health promotion theories and health literacy are included to provide insight into the devising and delivery of the stroke message. Finally, the outcome measures and evaluation strategies of a campaign are addressed.

The final part of the chapter is devoted to stroke knowledge in the local setting. This was considered imperative since the exploration of educational needs and attempts to enhance awareness need to rely strongly on a solid understanding of the target population.

2.2 Literature search

2.2.1 Data sources

An extensive electronic search was performed using ‘StarPlus – Library Catalogue’ and the Ovid MEDLINE database without language restrictions for studies published in the past 10 years. To enhance the sensitivity of the search, free text and subject headings (MeSH and EMTREE) were utilised.

Four main keywords were derived from the aims of this research: ‘stroke knowledge’, ‘stroke recognition’, ‘stroke education’, and ‘stroke preparedness’. Exploded headings relating to these keywords were combined with the Boolean operators ‘OR’ and ‘AND’ for use in the searches. Synonyms and wildcards were utilised to expand the search and increase its sensitivity.

In order to validate the search strategy, manual searching was next performed through the two journals that contributed the largest number of papers to this review, *Stroke: A Journal of Cerebral Circulation* and the *International Journal of Stroke* from 2007 to 2017. Reference lists of included studies were also checked to further validate the search. Table 2.1 presents an example of the search undertaken for ‘StarPlus’, whereas the Ovid MEDLINE search can be found in Appendix 11.

2.2.2 Selection criteria

In order to minimise bias and to strategically select those studies which could best contribute to the informational needs of this review, stringent inclusion and exclusion criteria were applied. The latter were developed beforehand and are summarised in Table 2.2. Potential studies for inclusion were further assessed by a validated quality assessment tool, the RTI item bank (Viswanathan & Berkman, 2012), to enhance consistency and uniformity in the appraisal.

Peer-reviewed quantitative and qualitative studies in any language with living human participants were included while animal and in vitro studies were excluded.

2.2.3 Data extraction

Titles and abstracts of retrieved studies were initially screened to identify eligible studies for inclusion. Full-text articles were then obtained for these studies as well as in cases where the primary evaluation was not sufficient to determine whether a study should be included or not. Any inclusion and exclusion decisions during this stage were documented and used to complete a Preferred Reporting Items for Systematic Review and Meta-analysis (PRISMA) flowchart (Moher, Liberati, Tetzlaff, & Altman, 2009). Articles that were not in the English language were translated. Reference management software (EndNote X7) was used to organise the articles retrieved and to exclude duplicate publications. Eligible papers were then grouped according to their main focus, which guided the development of chapters and sub-chapters within this literature review. Figure 2.1 shows the process followed in the selection of relevant articles for inclusion in the literature review.

Table 2.1 – 'StarPlus' Search Strategy

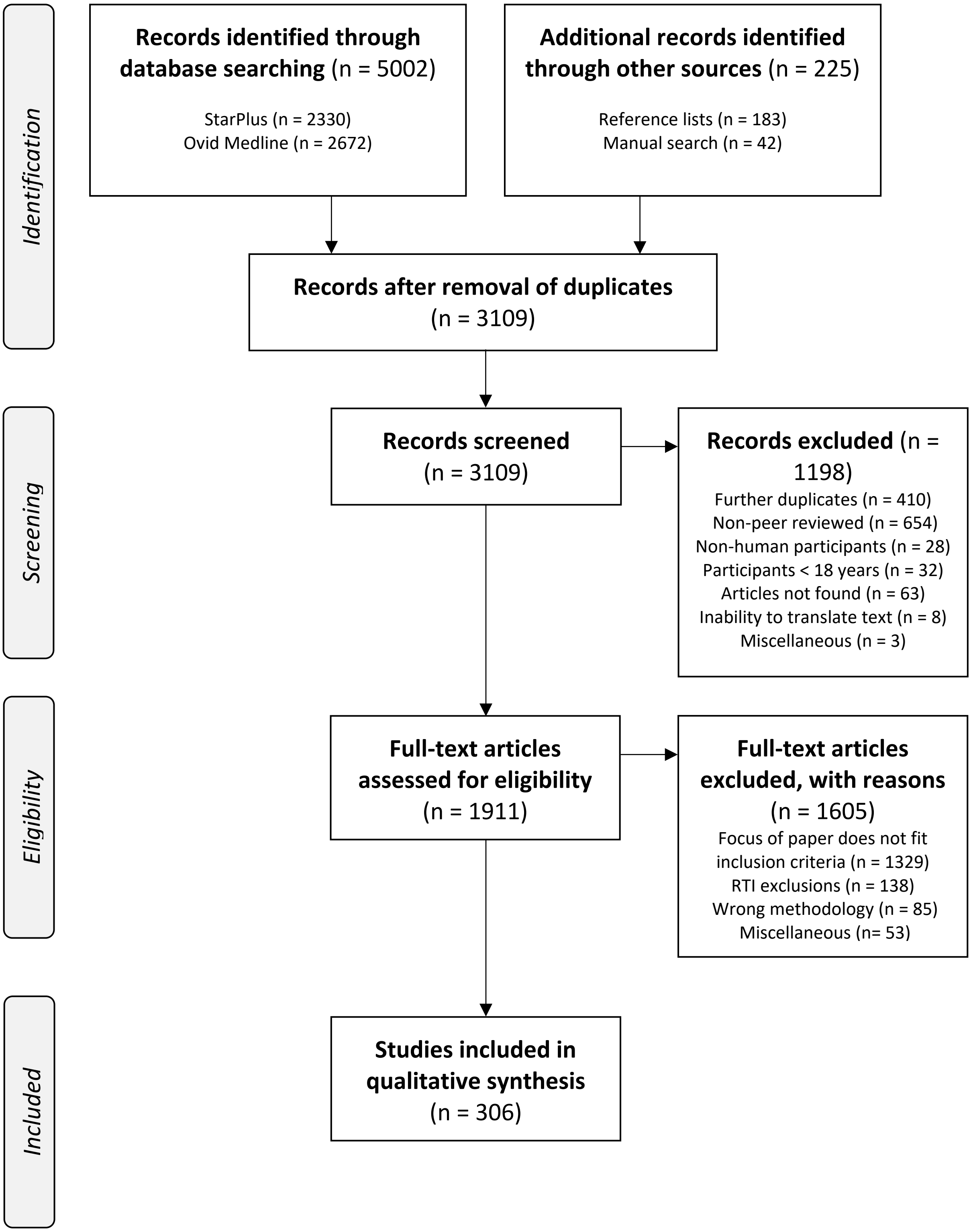
in the title	contains	stroke OR "(cerebral OR brain) infarction" OR AIS OR CVA	AND
in the title	contains	education* OR knowledge OR campaign OR awareness OR perception OR preparedness OR recognition OR presentation OR signs OR symptoms	

Retrieved articles n = 2738
Refined by "Peer-reviewed Journals" n = 2330

Table 2.2 – Inclusion and Exclusion Criteria

INCLUSION CRITERIA
Studies which focused on stroke education/knowledge/preparedness/recognition Experimental studies, quasi-experimental studies, qualitative studies, systematic reviews, and meta-analyses Published studies only Year of publication between 2007 and 2017 Peer-reviewed Human participants Participants aged 18 years or older All languages
EXCLUSION CRITERIA
Periodicals, other non-experimental studies, and other research designs which do not show strong levels of evidence Unpublished studies Subjects younger than 18 years of age Animal/in vitro studies Studies published prior to 2007 Grey literature

Figure 2.1 – PRISMA flow diagram



2.3 Stroke knowledge in the community

2.3.1 Introduction

It has been predicted that by 2020, stroke will be the leading cause of lost health life-years, secondary to an aging population worldwide (Jones et al., 2010). Prompt treatment of acute ischaemic stroke has been shown to decrease mortality and improve the quality of life of affected individuals. However, the treatment is not effective and is in fact deleterious if there is a delay in treatment commencement following an ictus (Hacke et al., 2004). Although multiple factors can lead to a delay in seeking acute stroke treatment, it is thought that the main contributor is a lack of public stroke knowledge and a failure to understand the urgency to activate emergency services (Evenson, Rosamond, & Morris, 2001; Yoon et al., 2001b).

2.3.2 Variables related to stroke knowledge

Stroke knowledge in the community is affected by a multitude of variables that need to be addressed during the planning process of an educational campaign. In this section, literature on the level of stroke knowledge in the community is explored in relation to the various factors that may play an important role in an individual's knowledge and awareness.

2.3.2.1 Age

Age is one of the variables that have been explored in a number of studies dedicated to stroke knowledge. In a review which included 39 studies, Jones et al. (2010) found that 40% of participants aged 45–64 years could name two stroke symptoms as opposed to 32% of participants aged > 65 years. This discrepancy was also demonstrated between the two groups in the awareness of risk factors for stroke. Fifty percent of patients aged < 65 years were aware of their potential risk factors, in contrast with 30% of the participants aged > 65 years. The main limitation of this study is that the review included published studies only, which may have resulted in publication bias.

Similarly, in a study by Yoon et al. (2001b), univariate analysis showed that younger age was associated with better stroke knowledge and the correlation was found to be statistically significant ($p = 0.001$). Data collection in this study was via a computer-assisted telephone survey, which may have led to selection bias with under-representation of specific population sub-groups. For example, in studies where data were collected via telephone interviews, people with cognitive impairment or communication problems (Greenlund et al., 2003) and those with language barriers (Johnston et al., 2003) may have been excluded and were likely under-represented. Additionally, the study by Yoon et al. (2001b) excluded households without telephones.

The finding that stroke knowledge seems to be poorer in older people was also reported in a survey carried out by Hickey et al. (2009). In this case, the researchers conducted home interviews among older people (> 65 years) living in Ireland. Less than 50% of participants were able to identify any stroke warning signs, with the exception of 'slurred speech' which was identified by 54% of participants. These values may have been overestimated by the use of a list format as opposed to open-ended questions to assess knowledge.

Older age was also shown to be correlated with a lower tendency to activate emergency services in the event of an acute stroke (Jurkowski, Maniccia, Dennison, Samuels, & Spicer, 2008). Another worrying fact is that stroke awareness campaigns have been shown to be less effective in the elderly (Reeves, Rafferty, Aranha, & Theisen, 2008b; Silver, Rubini, Black, & Hodgson, 2003).

This finding is problematic since older age, which in itself presents a higher risk of stroke, has been consistently shown to be negatively correlated with stroke knowledge.

By contrast, in a study by Marx et al. (2010) in which telephone interviews were performed among 500 members of the general public, a mean age of 59.5 years was associated with the highest stroke knowledge, which declined with decreasing and increasing age within the cohort. This presents a slight difference to the findings of other studies discussed since it seems as if, in this participant sample, Marx et al. (2010) highlighted a peak age for stroke knowledge level, thus implying that individuals younger than this age may not necessarily have better stroke knowledge. Thus, the picture may not be as simple and straightforward as presented in other studies showing that younger age equates to better knowledge. However, this finding has not been replicated in any other study on the subject and so further research may be required in this area.

2.3.2.2 Ethnicity, nationality, and geographical location

The act of being born or living permanently in a particular social group or country may also be linked to the level of stroke knowledge.

A plethora of research points towards the fact that the prevalence of stroke is highest among ethnic minorities who are also more prone to suffering from secondary consequences associated with stroke (Horner, Matchar, Divine, & Feussner, 1991; Jones et al., 2000; Shen, Washington, & Aponte-Soto, 2004). Despite this, several studies have shown that such ethnic minorities are less likely to recognise stroke warning signs and to take the appropriate action (DuBard, Garrett, & Gizlice, 2006; Reeves, Hogan, & Rafferty, 2002; Schneider et al., 2003).

In their integrative review, Jones et al. (2010) found that public knowledge about stroke symptomatology was poor among African American and Hispanic communities. The same ethnic groups were also consistently shown to have poor risk factor knowledge (Ferris, Robertson, Fabunmi, & Mosca, 2005; Reeves et al., 2002; Stern, Berman, Thomas, & Klassen, 1999).

The same issue featured in a cross-sectional study carried out by Lutfiyya et al. (2010), who explored the within-group stroke knowledge among Hispanics. The study included 2023 participants, which yielded a United States (US)-representative sample of Hispanics. Stroke knowledge among Hispanics was generally found to be extremely poor, with 33.2% of participants scoring in the low range on the composite heart attack and stroke symptom knowledge questions. In comparison, a previous study by the same authors showed that only 27.1% of African Americans and 12.6% of Caucasians achieved low-range scores (Lutfiyya, Lipsky, Bales, Cha, & McGrath, 2008). The data from both studies were retrieved from the Behavioural Risk Factor Surveillance Survey (BRFSS) and the two studies utilised a similar methodology, making direct comparison possible. There were, however, potential limitations in these studies. Primarily, data collection was performed via telephone interview, which may have excluded people of low socio-economic status due to poorer phone access. This selection bias may have been re-enforced by the fact that Hispanic migrants may have refused to participate as they feared that the study could jeopardise their immigration status. Finally, knowledge may have been overestimated by the use of closed-ended questions.

Similar findings were registered in a study by DuBard et al. (2006) which showed that Hispanics, including those who were English-speaking, had poor stroke knowledge. Stroke awareness in this study was significantly lower than that described in reports of public stroke awareness in the US (Greenlund et al., 2003).

In a study based in South Carolina, Malek et al. (2014) explored ethnic and racial disparities in the use of 911 by patients who had previously experienced stroke symptoms. Although Caucasians (77%) were more likely to attribute their symptoms to stroke compared with African Americans (67%), the latter were significantly ($p = 0.02$) more likely to call 911 in the event of stroke. This may be attributed to the fact that African Americans (91%) were more likely to recognise the urgency of stroke symptoms compared with Caucasians (78%).

Extensive research has also been carried out on the significance of nationality and geographical location in a study by Marx, Nedelmann, Haertle, Dieterich, and Eicke (2008) based in Germany, in which 65% of participants were able to list at least one acute stroke sign. The rate was lower (< 50%) in similar studies performed in the US (Kothari et al., 1997) and Australia (Yoon et al., 2001b). In fact, "studies in Germany generally reveal a better stroke knowledge than what is reported from investigations in the US, Australia and to some extent even in neighbouring European countries" (Marx et al., 2008).

Stroke knowledge in the community has been shown to be extremely poor in underdeveloped countries, including parts of India (Das, Mondal, Dutta, Mukherjee, & Mukherjee, 2007). This observation may be secondary to a lower education level and a poorer socio-economic status, as supported by data that emerged from a similar study in north-western India which identified statistical significant correlations between level of education ($p < 0.001$) and socio-economic status ($p < 0.005$) and public stroke knowledge (Pandian et al., 2005).

In a study by Hickey et al. (2009), participants living in Northern Ireland demonstrated poorer stroke knowledge compared with those living in the Republic of Ireland. Eighteen percent of participants living in Northern Ireland were unable to identify any of the established stroke symptoms as opposed to 7% living in the Republic of Ireland. In fact, adjusted odds ratio analysis confirmed a statistically significant geographical variation with an odds ratio of 2.1 ($p < 0.001$). This finding may be partly explained by the fact that the two jurisdictions have different health systems. The major limitation of this study is that different marketing companies conducted the surveys in Northern Ireland and the Republic of Ireland. Different interviewers may therefore have affected the response rates. It is also important to consider the effect of non-response bias due to different participation rates between Northern Ireland (89%) and the Republic of Ireland (64%).

2.3.2.3 Gender

Gender may be another factor that affects stroke knowledge in the community. A study by Marx et al. (2010) in Western Germany focused on identifying gender-specific differences in public stroke knowledge and found that 71.3% of female participants were able to list at least one stroke warning sign as opposed to 57.8% of male participants ($p < 0.01$). Women also performed better when asked to provide the emergency call number (33.3% vs 24.3%, $p < 0.05$) and when asked about the appropriate action in response to acute stroke (87.2% vs 70.1%, $p < 0.001$). As the gender sub-groups were matched and no confounding factors were reported, gender was at least partly responsible for the observed discrepancy.

Similarly, Yoon et al. (2001b) found a statistically significant correlation between female gender and public stroke knowledge with a *p* value of 0.03. Müller-Nordhorn et al. (2006) also found better stroke-related knowledge among females, although the association in this study was relatively weak.

Despite better knowledge, several studies have shown that women often arrive later at the emergency department compared with men (Barr, McKinley, Brien, & Herkes, 2006; Cheung, 2000; Menon, Pandey, & Morgenstern, 1998). The potential reasons for this behaviour merit further research. However, it is clear that the decision to seek treatment is a complex chain of events which is also influenced by socio-demographic and behavioural factors. This is discussed later, in Section 2.4.3 of this chapter.

2.3.2.4 Educational and socio-economic status

Several studies have shown that low literacy may compromise access to and limit utilisation of health services (Lasater, Davidson, Steiner, & Mehler, 2001; Wilson, Chen, Grumbach, Wang, & Fernandez, 2005). Similarly, people with literacy issues are less likely to benefit from stroke awareness campaigns, which often rely on written materials (Williams, Baker, Parker, & Nurss, 1998). It may also be the case that patients with low literacy may experience a sense of shame during healthcare visits (Baker et al., 1996). This feeling is often re-enforced when healthcare professionals are either unaware of or fail to recognise such literacy problems (Parikh, Parker, Nurss, Baker, & Williams, 1996). This creates hesitancy and apprehension among these patients, which often results in a delay in seeking medical care (Lee, 1999).

Pancioli et al. (1998) demonstrated that participants with a higher level of education were more likely to be familiar with acute stroke symptomatology. Similarly, in a study by Marx et al. (2010), regression analysis showed that the educational background of participants was associated with good stroke knowledge. Participants with a higher level of education were also more likely to be able to name a stroke symptom (Alkadry, Wilson, & Nicholas, 2006) and to understand the underlying physiology of stroke. Additionally, they were able to identify the brain as the end organ affected by stroke. The latter was also true for participants belonging to the upper socio-economic class (Jones et al., 2010).

In a parallel fashion, a low level of education has been consistently shown to be correlated with poorer stroke knowledge (Alkadry et al., 2006; Reeves et al., 2002; Yoon et al., 2001b). These findings were replicated in an integrative review by Nicol and Thrift (2005), which included 15 studies specifically on stroke knowledge. Although the authors did not specify the search strategy, the process might not have been exhaustive. Another potential limitation of this review stems from the fact that the included studies varied significantly in their methodology.

Similar findings were also found by Hickey et al. (2009), whereby participants who had a primary level of education only were shown to have a consistently poorer stroke knowledge. In fact, odds ratio analysis showed that people living in Ireland who had a secondary education or higher had better stroke knowledge (OR = 1.9, $p < 0.001$).

Conversely, in a study by Ellis, Wolff, and Wyse (2009), participants who were stratified in the lowest literacy group outperformed those at higher literacy levels in recognising three out of the four stroke warning signs. However, this finding should be interpreted with caution as the study only included a small number of participants ($n = 60$), with even smaller numbers within each of the three literacy sub-groups. The authors investigated the ability of Latinos living in South Carolina to recognise early stroke signs and their reaction to such symptoms. The coastal plains of South Carolina form part of the so-called 'Stroke Belt', where the incidence of stroke is the highest in the US. Despite this, stroke awareness in this study was found to be considerably low, with participants displaying less than 50% accuracy in identifying any of the stroke warning signs.

In a survey conducted in Australia by Yoon et al. (2001b) among 822 participants, a higher level of education and a high income were found to be independently correlated with stroke knowledge, with p values of 0.001 for both variables. However, there was no significant difference between participants in the intention to activate emergency services in case of an acute stroke based on educational status. Conversely, Ellis et al. (2009) showed a positive correlation between literacy levels and knowledge of the appropriate action to take if someone was having a stroke. 'Calling 911' was correctly identified by

85% of participants functioning at a higher literacy level as opposed to 63% of individuals in the lowest literacy group. Higher education was also found to be correlated with better knowledge of acute stroke treatment in a study by Kleindorfer et al. (2009) performed in the Greater Cincinnati/Northern Kentucky region.

Financial concerns were found to be negatively correlated with knowledge of stroke symptoms and treatment in a study carried out in Minnesota by Travis et al. (2003). These findings were also replicated in another study in the US by Lutfiyya et al. (2010), who found that participants who performed poorly in a stroke knowledge questionnaire were more likely to have postponed care because of financial implications (OR = 2.098), were likely not in possession of health insurance (OR 1.543), and did not have a healthcare provider (OR = 2.054).

2.3.2.5 People at risk

Certain factors are known to predispose an individual to a higher risk of stroke, including a history of stroke, cardiovascular disease, or diabetes. Perhaps it is assumed that individuals with these risk factors may have better knowledge of stroke than their non-affected counterparts. However, research shows that this may not always be the case.

For instance, Jones et al. (2010) found that individuals who were either at a high risk of stroke or had previous experience of stroke did not have increased knowledge about the condition compared with their peers. In their review, which included 39 studies, only 0%–65% of participants identified weakness as a stroke symptom. Similarly, Kothari et al. (1997) found that up to 39% of stroke victims in Cincinnati were not familiar with any stroke sign or symptom. Bellolio et al. (2007) prospectively recruited patients who presented to the emergency department (in Minnesota) with transient ischaemic attack (TIA) or acute ischaemic stroke. Despite the fact that a quarter of the cohort had already suffered from a TIA or stroke, only 51.4% of participants thought they were having an ischaemic attack and only 57% were aware of the importance of early presentation. These findings were replicated by Travis et al. (2003), who found that personal or family history of stroke did not correlate with improved stroke knowledge.

Lack of stroke knowledge among patients who had already suffered stroke is particularly concerning and could be secondary to the information given to these patients, which is often inappropriate or overly complicated. Additionally, knowledge retention among these patients could be hampered due to a variety of reasons (Rodgers et al., 1999).

Conversely, in a study by Williams, Bruno, Rouch, and Marriott (1997), patients with prior stroke had better knowledge of stroke symptoms (55% vs 30%) and warning signs (45% vs 16%) compared with a matched group with no history of stroke. Similarly, in a study by Yoon et al. (2001b), heart disease and family history of stroke were associated with increased stroke knowledge with *p* values of 0.02 and 0.009, respectively.

Weltermann, Driouach-Bleckmann, Reinders, Berndt, and Gesenhues (2013) explored stroke knowledge among diabetic patients whose stroke risk was increased 1.8–6 fold (Goldstein et al., 2011). They found that 40.4% of participants were aware that the brain was the end organ affected by stroke and 46.3% were aware that stroke treatment should be started before 3 hours from onset. Only 39.4% of this high-risk group knew two stroke signs and were aware of the appropriate necessary action. This study included a total of 231 subjects residing in the Ruhr area in Germany.

These findings highlight the rather important and concerning fact that patients who are aware of their risk factors and are at higher risk of stroke do not have better knowledge compared with healthier peers (Yoon et al., 2001b).

2.3.3 Characteristics of stroke knowledge

As discussed in the previous section, a number of variables can affect an individual's level of stroke knowledge. Having looked into these variables in detail, this section is dedicated to an exploration of the type of knowledge that seems to be present in the community and its characteristics.

2.3.3.1 Stroke symptoms

The clinical picture of stroke features various symptoms, some of which are obvious and alarming while others are less so. Since all symptoms are equally important in the detection of stroke, it is important to gauge the community knowledge with regards to each symptom. In a population-based survey of 1880 participants by Pancioli et al. (1998), only 57% were able to identify at least one of the five stroke warning signs. The study was carried out in Greater Cincinnati, Ohio, where the population reflects that of the entire US in terms of age and demographic, ethnic, and socio-economic variables. The most common stroke signs listed by participants in this study were dizziness and numbness, a finding replicated in the studies by Schneider et al. (2003) and Hickey et al. (2009). In a review by Nicol and Thrift (2005), which summarised 15 studies, 10%–60% of participants were unable to name a single stroke warning sign.

In an integrative review by Jones et al. (2010), numbness, weakness, and paralysis represented the stroke symptoms most commonly identified by the general public. Confusion and difficulty in producing or understanding speech followed, while dizziness proved to be the least known symptom. The percentages varied significantly between the different studies and according to the methodology used. The authors combined several search strategies to identify the majority of relevant studies included in their review. Similar findings were also reported by Kothari et al. (1997), who also found that weakness and numbness were the most common stroke signs recognised by patients who suffered a stroke. Similarly, Das et al. (2007) found that most stroke survivors and members of the general public were not ready to seek medical help for “minor symptoms like headache, dizziness or unilateral numbness”. The latter three symptoms are all important stroke warning signs as defined by the American Stroke Association and the National Institute of Neurological Disorder (NINDS, 2018). Although knowledge of stroke symptoms was generally very poor, “hemiparesis or unilateral heaviness” were the most mentioned in both groups.

In contrast, in a community-based survey by Yoon et al. (2001b), the most recalled symptom of stroke was visual problems followed by headaches, as identified by 24% and 22.3% of respondents, respectively. In this study, only 3.9%–9.0% of the 822 participants mentioned weakness or paralysis as stroke symptoms. Overall, 49.8% of participants mentioned one stroke sign, whereas 26.2% and 8.8% knew two and three clinical signs of stroke, respectively.

Williams et al. (1997) explored stroke symptom knowledge in patients who had already suffered a stroke. Only 25% of this cohort correctly identified their symptoms as an acute stroke while 29% believed that their symptoms represented something else. The main reason for late arrival to hospital was a failure to recognise the seriousness of the symptoms (86%), while 14% of patients were unable to call for help. By including hospitals of different complexities and by sampling a diverse population, the authors ensured increased generalisability of their results.

2.3.3.2 Sources of information

In order to target stroke awareness initiatives in an effective manner, it is crucial to identify sources of information used by community members.

In the review by Jones et al. (2010), the most common sources of public stroke knowledge were a relative or friend, a health professional, and personal experience, which contributed to 0%–60%, 0%–51%, and 20%–58% of participant knowledge, respectively. Personal experience involved gaining information through stroke survivors, including family members. The same review also highlighted the importance and efficacy of the media in conveying important health-related information. Both television and literature were mentioned by up to 82% of participants as a useful source of information as opposed to stroke campaigns and school teaching which were only mentioned by 27% and 16% of participants, respectively. Similarly, television (78%) and the internet (78%) were the most important sources of stroke knowledge in a survey about stroke awareness by Travis et al. (2003).

In a community-based study conducted by Yoon et al. (2001b), personal life experiences and acquaintances were the major sources of stroke knowledge, with health professionals and formal school programmes only contributing to 12.8% and 12.3% of sources, respectively. It is well established that interpersonal contacts can indeed be a highly effective medium for health education (Farquhar et al., 1977).

In a study based in India, Das et al. (2007) questioned stroke survivors and members of the general public regarding sources of stroke knowledge. The most important source was periodicals written in the local language followed by previous experience of stroke among relatives and friends. In contrast with developed countries, television was not a significant source of stroke knowledge in the community. Information provided by doctors and healthcare workers only contributed to 20%–27% of stroke knowledge within this cohort.

2.3.3.3 Stroke treatment

In addition to knowledge related to stroke symptoms, it stands to reason that knowledge about treatment is equally important, particularly since stroke management is time-sensitive.

In a survey by Pancioli et al. (1998), 21% of participants were aware of ‘clot-buster’ or ‘blood thinning’ drugs as appropriate treatments for stroke. In contrast, in a study by Kleindorfer et al. (2009), only 3.6% of participants were aware of rtPA or an approximation of it. The latter study took place in the Greater Cincinnati/Northern Kentucky region, and the demographics of the study population were representative of the population of the US. The very low rate of awareness may be secondary to the use of open-ended questions in the survey. Seventy-nine percent of participants who mentioned rtPA were also aware that this treatment is characterised by a limited time window and therefore indicated urgency in their response. Knowledge of stroke treatment in this study was positively correlated with a higher level of education, younger age, and white ethnicity. The major limitation of this study lies in its methodology, which utilised telephone-based surveys, as this may have led to selection bias.

In a study performed in Olmsted County, Minnesota, 32% of participants were unaware of the thrombolytic treatment window (Travis et al., 2003) and therefore did not appreciate the urgency of stroke therapy. In fact, 63% replied that they were more likely to seek medical attention if they were in pain (which is not a stroke warning sign) as opposed to experiencing weakness or paraesthesia.

2.3.3.4 Temporal trends

Kleindorfer et al. (2009) explored changes in public stroke knowledge over time by conducting three surveys within the Greater Cincinnati/Northern Kentucky region over a 10-year period. Knowledge about stroke symptomatology improved significantly between 1995 and 2000. Knowledge of a single stroke warning sign was similar (68%) in both 2000 and 2005, but knowledge of three warning signs improved constantly from 5% in 1995 to 12% and 16% in 2000 and 2005, respectively. Surprisingly, this type of longitudinal study seems to be lacking in the literature, which is of concern because the resulting data provide an important angle on research on the subject and may be particularly important in the evaluation of stroke campaigns.

2.3.4 Methods of data collection

Published data on public stroke knowledge varies significantly according to the method of data collection utilised. For example, in a review by Nicol and Thrift (2005), between 10% and 60% of respondents could not name a single acute stroke sign using free recall. However, correct identification of stroke signs increased drastically when the respondents were provided with a list of potential answers. Studies which have explored public stroke knowledge have done so by using open- and closed-ended approaches or a combination of both.

Open-ended questions are more representative of the respondent’s knowledge but are often more difficult to analyse, as the researcher needs to explore the intention of the response and group answers into similar categories. This coding process is also subjective and is therefore susceptible to bias. In order to increase their objectivity, Rowe, Frankel, and Sanders (2001), used two or more researchers when analysing the same data.

Closed-ended questions, on the other hand, evoke a different response type as they may provide an indication of what the answer should be. Closed-ended questions inherently result in higher identification of stroke symptoms by respondents as respondents tend to choose most of the symptoms, including the incorrect ones (Greenlund et al., 2003; Yoon, Heller, Levi, & Wiggers, 2001a). This is best seen in studies where both types of approaches are utilised. For example, in the study by Rowe et al. (2001), just 7%–24% of respondents correctly identified stroke symptoms as opposed to 77%–95% from the same cohort when using open-ended and closed-ended approaches, respectively. Closed-ended questions often over-estimate the true prevalence of knowledge. Data from the BRFSS (Croft et al., 2004) carried out in 17 states and the US Virgin Islands showed that 94.1% of participants in a telephone survey identified numbness or weakness as acute stroke signs. In the survey, there was just one incorrect stroke sign (chest pain) among the possible answers, and it was selected by 37.8% of participants. Similarly, in the study by Ellis et al. (2009) which utilised closed-ended questions to interrogate stroke knowledge among Latinos, 27% of participants chose ‘chest pain’ (the only incorrect answer) as a stroke warning sign, while 90% of participants who correctly identified all early strokes also incorrectly included ‘chest pain’ in their answer.

These findings highlight the importance of carefully assessing study methodology when interpreting data on public stroke knowledge.

2.3.5 Stroke knowledge: medics and paramedics

The management and treatment of stroke is constantly evolving, with drastic changes taking place every couple of years. For example, mechanical thrombectomy as an emergent treatment for acute ischaemic stroke only became widely acceptable in 2015.

Lack of recognition of early stroke symptoms both in the pre-hospital and in-hospital settings may result in delays that may compromise treatment and result in increased morbidity and mortality.

2.3.5.1 Aims of professional training

The primary aim of training medics and paramedics is to address gaps in stroke knowledge and to keep these professionals abreast of evidence-based treatment options. Sangeeta, Tiffany, and Roxanne (2013) found that only 56% of healthcare providers (which included physicians, nurses, residents, and medical students) knew the therapeutic window of t-PA and 62% of the same cohort were unfamiliar with the eligibility criteria of t-PA and the National Institute of Health's Stroke Scale (NIHSS) (National Stroke Association, 2014). This is particularly concerning, as these professionals need not only to make decisions regarding the eligibility of acute stroke therapy, but need to do so quickly. The authors also showed how a brief targeted intervention improved knowledge immediately and at a 6-month interval. Sangeeta et al. (2013) conclude that "lack of education of the health care providers may represent the largest barrier" to acute stroke treatment.

Harper (2007) found a knowledge deficit in acute stroke care among emergency nurses. Only 15% of this cohort had participated in continuous professional development (CPD) programmes about stroke in the previous 12 months. The authors also found that nurses who had read stroke literature in the previous 12 months demonstrated better stroke knowledge compared with those who had not read any literature ($p = 0.04$). These findings highlight the importance of education and the necessity for healthcare professionals to keep up-to-date with the recognition and management of stroke. Similarly, in a pre- and post-intervention study by Kirchoff-Torres et al. (2011), more than 50% of emergency department nurses incorrectly identified the maximum dose of rt-PA and the goal door-to-thrombolysis time. This is particularly concerning, as these nurses deal directly with acute stroke cases and need to make rapid decisions within a stressful environment. Sound knowledge in stroke management and treatment is therefore paramount in this setting. The authors found that only half of the cohort had received stroke education outside their department in the previous 12 months, and that stroke knowledge was directly correlated with such education. Park, Kim, Kang, Lee, and Chang (2015) also found that poor knowledge about subtle stroke signs in nurses was a major barrier to stroke care in nursing homes.

Stroke education of medical and allied health professionals has been shown to increase their stroke knowledge in a sustained fashion (Kawano et al., 2014). For example, nurses trained in the use of the Rosier scale produced similar results to that of a full neurological examination performed by a physician. Such training will therefore not only improve the process of triage in the emergency department but may also hasten the evaluation and treatment of acute stroke (Devon & Zrelak, 2012).

Similarly, appropriate training of ambulance paramedics in the recognition of stroke symptoms may expedite triage and facilitate the delivery of acute stroke therapies. The assessment of neurological deficits by ambulance paramedics showed good inter-observer agreement with physicians' examination when using the Face Arm Speech Test (FAST) (Nor et al., 2004). Moderate-to-excellent inter-rater agreement between research nurses and neurologists was also observed in the administration of the National Institute of Health Stroke Scale (NIHSS) (Dewey et al., 1999). Hence, professional training may represent a highly efficient means to address physician shortages and to improve the acute stroke workflow within emergency departments.

Professional education has been shown to improve the workflow of stroke management, which is expected to improve clinical outcomes. Wojner-Alexandrov, Alexandrov, Rodriguez, Persse, and Grotta (2005) showed how a holistic stroke intervention (which including paramedic, hospital, and community education) increased paramedic (stroke) diagnostic accuracy from 61% to 79%. This intervention also improved the rapid hospitalisation of stroke patients, with the percentage of patients admitted within 2 hours of symptom onset rising from 58% to 62% ($p = 0.002$). This led to an increase in acute stroke therapy in four out of the six participating institutions. Similarly Chenna, Anjum, Dasey, and Wani (2014) showed that accurate recognition of stroke by paramedics led to the fast-tracking of stroke patients to neuroimaging, which in turn resulted in a reduction in door-to-needle times and better clinical outcomes. Similarly, in the study by Rancatore, Dandapani, Schneider, and LeDuc (1999), stroke education (consisting of a 4-hour lecture followed by regular updates) to emergency medical services (EMS) personnel resulted in a 12.6% decrease in out-of-hospital delays.

2.3.5.2 Undergraduate training

Although stroke is a leading cause of disability and death, medical students receive at best a modest amount of training on the condition (Billings-Gagliardi et al., 2001). This deficiency had previously been pointed out by Alberts (1995), who found that medical students only received a mean of 3.2 hours of didactic teaching about stroke. Within the same cohort, which included 31 medical schools in the US and Canada, only 61% of students received clinical training in stroke. It is crucial that medical students learn about stroke symptomatology and its early treatment throughout their undergraduate training as this is likely to have a positive long-term impact on acute stroke patients. It is also advantageous to include stroke education in medical school before doctors enter sub-specialist training to ensure that all future physicians have a sound knowledge about stroke.

Billings-Gagliardi et al. (2001) conducted a pre- and post-intervention study and showed that the introduction of stroke education in the undergraduate medical school curriculum not only resulted in a significant increase in stroke knowledge ($p < 0.001$) but also an increase in students' confidence about their knowledge ($p < 0.001$).

Mason-Whitehead et al. (2012) explored stroke knowledge among final-year nursing students using a mixed quantitative and qualitative methodology. The authors discovered substantial knowledge gaps in some fundamental aspects of stroke, with 14%–87.2% of students demonstrating unacceptable levels of knowledge in symptomatology, risk factors, and treatment of stroke. In fact, the authors concluded that nursing students "may not be in tune with the profundity of this condition, its association with a contemporary life-style, its effects for individuals and their families and the role of the nurse in the prevention and treatment of stroke".

2.3.5.3 Postgraduate training and continuous professional development

Post-graduate medical training in stroke care is limited by inadequate opportunities for doctors in stroke medicine (Smith, Craig, Weir, & McAlpine, 2008). Similarly, the educational preparation of nurses for stroke rehabilitation is minimal and largely ineffective (Booth, Hillier, Waters, & Davidson, 2005). To date, “questions remain unanswered regarding the provision of stroke education to healthcare professionals including how much education is needed, what is its optimal nature and what is the most appropriate content in order to bring about a beneficial effect on patient outcome” (Smith et al., 2008). Despite the importance of stroke education, a national strategy for stroke education has never been implemented in the United Kingdom (UK). Instead, such education has been left solely at the discretion of the health service (Smith et al., 2008).

“Regardless of its name, continuous learning is considered an ethical obligation, and draws roots far in the past” (Morovic, Pjevac, & Demarin, 2012). However, a literature review conducted by Davis et al. (1999) showed that didactic sessions were ineffective in changing physicians’ performance. This review included 14 studies and may have been limited by publication bias and the methodology of the included studies.

Conversely, a number of studies have shown the effectiveness of CPD in changing physicians’ performance (Collins, 2009; Davis, Galbraith, American College of Chest Physicians, & Science Policy, 2009; Rinnerberger, Grafinger, Melchardt, & Sonnichsen, 2009). This is especially true when “live or multiple media and multiple educational techniques” are utilised (Davis et al., 2009). In fact, Collins (2009) suggests that lifelong learning “require(s) changes in the way teachers teach and learners learn, as teachers take on a more facilitative role and learners take more responsibility for setting goals, identifying resources for learning, and reflecting on and evaluating their learning”.

CPD also needs to be “be highly flexible and responsive to the personal and professional needs of the (nurse) learner” (Carter, Rukholm, & Kelloway, 2009). Carter et al. (2009) suggested a technology-supported programme which used three different but complimentary educational technologies (an educational website, web casting, and video-conferencing) to reach ‘busy working’ medical personnel. Similarly, Rinnerberger et al.

(2009) showed how a web-based enquiry service for general practitioners (GPs) facilitated evidence-based practice in primary care.

Acute care training for advanced practice and registered nurses comprises “less than 30 min didactic content on stroke, causing many nurses to have to learn stroke management ‘on the job’. This results in diverse levels of knowledge and clinical skills” (Alexandrov et al., 2012). For this reason, Alexandrov et al. (2012) implemented the NET SMART-AP Fellowship, an internet-based, hybrid didactic-clinical training programme in stroke management. This training was aimed at enhancing the early recognition and treatment of stroke. The programme turned out to be highly successful, and sponsoring physicians were unanimously confident regarding their graduates’ ability to appropriately select stroke patients for reperfusion therapy. In fact, the programme led to a rise in the rt-PA treatment rate from 3.3% to 11.6%.

Medics and paramedics are “required to keep up in a constantly changing knowledge-based environment, he or she must balance complex professional responsibilities, staffing shortages, and increased acuity among the patient population” (Carter et al., 2009). Hence, CPD is crucial in acute stroke care.

2.3.6 Existing stroke knowledge assessment tools

“Accurate assessment of stroke knowledge (SK) is fundamental to the successful understanding of, monitoring of, and intervening to improve the SK of patients and the public” (Hou et al., 2017). Improving such knowledge may reduce the prevalence of primary and secondary stroke (Inzitari et al., 2000) as well as result in improved clinical outcomes following an ictus. It may also enhance engagement in healthy lifestyle choices (Ellis, Rodger, McAlpine, & Langhorne, 2005).

At present, there is no consensus on the definition of stroke knowledge, and different authors tend to address different aspects of stroke knowledge in their research. Thus, stroke knowledge may refer to an individual’s understanding of the aetiology, risk factors, symptomatology, emergency response, treatment, and/or outcomes of the condition.

Since all of these aspects are important, it is probably best to include all of them in a more holistic definition of stroke knowledge.

Assessing stroke knowledge is therefore not a straightforward task. If pre-existing tools are to be used, one should ensure that these have been developed using a comprehensive conceptual framework and that quality tests for reliability, validity, and feasibility (Jordan, Osborne, & Buchbinder, 2011) have been performed to assess the tool's quality and performance.

Hou et al. (2017) performed a systematic review to identify and appraise tools for assessing stroke knowledge. Their appraisal checklist was based on Jordon's criteria (Jordan et al., 2011), the Consensus-Based Standards for the Selection of Health Measurement Instruments (Mokkink et al., 2010), and items of Health Technology Assessment reports (Fitzpatrick, Davey, Buxton, & Jones, 1998). Fifty-nine stroke knowledge tests were included in their analysis, 49 (83.1%) of which were used only in a single publication. The remaining ten tests were used to assess the knowledge of either the general public (7 studies) or stroke patients (3 studies). The BRFSS heart and stroke module (Centers for Disease Control and Prevention, 2001) was the most widely used test to assess stroke knowledge, although it appears to not have been validated and assesses only a few stroke knowledge concepts.

The Stroke Knowledge Test (SKT) (Sullivan & Dunton, 2004), assessing different aspects of stroke knowledge, was found to be the most comprehensive test. Although the content validity, discriminative validity, and face validity of the Stroke Action Test (STAT) have been sufficiently evaluated (O'Mahony, Rodgers, Thomson, Dobson, & James, 1997), the test is not based on a conceptual framework (Billings-Gagliardi & Mazor, 2005). Hou et al. (2017) found that only the SKT and STAT fulfilled all their feasibility criteria. Out of the included studies, Hou et al. (2017) found that only the SKT "was developed using rigorous methodology, covers a wide range of concepts, fits all feasibility criteria, and has validated psychometric properties". However the SKT was not developed using a specific conceptual framework and the validation of its psychometric properties is not exhaustive. Hou et al. (2017) therefore concluded that "no current SK test can be highly recommended for clinical and for research use".

The other major limitation of utilising the existing tools in the present study is the fact that they do not consider the local cultural, social, genetic, and demographic setting, which may be crucial to understand the aetiology and epidemiology of stroke in Malta. With this in mind, and with the intention of being as comprehensive as possible when assessing stroke knowledge in Malta, it was decided to develop a novel tool based on a mixed-methods approach and a synthesis of the relevant literature on stroke. Prior assessment of the psychometric properties of the development was required, as these properties are considered essential for any stroke knowledge test (Jordan et al., 2011; Mokkink et al., 2010).

2.3.7 Conclusion

The literature included in this section has provided insight into the complex nature of stroke knowledge. Studies exploring this subject have addressed it from multiple angles which has helped to present a detailed picture of the various characteristics of knowledge about stroke, especially with regards to the type of variables that seem to affect this knowledge. Although there is an abundance of studies on this issue, the method of data collection used in the different studies needs to be considered since the types of questions asked of participants in the different studies have been subject to critique regarding their ability to evoke a different response to that expected when using a different method. The next section will explore the relationship between knowledge and action since the desired response to stroke symptoms is ultimately only achieved if adequate knowledge is translated into action by affected individuals.

2.4 Response to stroke symptoms

2.4.1 Introduction

A crucial point to consider in pre-hospital delay is that a good level of stroke knowledge does not necessarily translate into appropriate action. The affected patient may in fact attribute his or her symptoms to acute stroke, but will either respond incorrectly or fail to respond to the symptoms. Interventions focusing on behavioural change may be necessary to promote the correct action by highlighting positive outcome expectations, minimising perceived barriers, and consolidating self-efficacy (Mandelzweig, Goldbourt, Boyko, & Tanne, 2006; Morgenstern et al., 2002; Moser et al., 2006).

The American Heart Association recommends that calling 911 should be the first and only response to stroke symptoms (American Stroke Association, 2016). This has been shown not only to reduce hospital arrival time but is also directly correlated with faster triage, imaging, and administration of intravenous thrombolytic therapy (Barsan et al., 1993; Deng et al., 2006; Maestroni et al., 2008; Morris, Rosamond, Madden, Schultz, & Hamilton, 2000; Moser et al., 2006; Williams et al., 1997). Calling 911 in acute stroke is a crucial factor in the 'stroke chain of survival' and is classified as 'Class I' in terms of usefulness and effectiveness by the American Stroke Association (Adams et al., 2007).

In this section, the association between stroke knowledge and the activation of emergency services will be explored. Barriers to seek help and factors resulting in delayed hospital presentation will also be discussed.

2.4.2 Appropriate response

In a population-based study in Michigan which included 4841 participants, Fussman, Rafferty, Lyon-Callo, Morgenstern, and Reeves (2010) assessed the initial response to stroke symptoms. They assessed participants' response when presented with three different stroke scenarios. The correct response (calling 911) was given by 20.4%–51.5%

of participants for the different scenarios. Only 14% of participants reacted appropriately to all three stroke scenarios. The authors also explored whether demographic variables within this cohort were correlated with adequate response. Age was positively correlated ($p < 0.01$) with adequate response in all three scenarios, with participants within the 18–24 years age group performing the poorest. A statistically significant difference in responses was also found between different ethnic groups, with Hispanics demonstrating the poorest response ($p < 0.01$). There was no significant relationship between gender, education, insurance, and household income and the intent to call 911.

Perhaps what is more interesting is that the study revealed a poor association between stroke warning signs and appropriate response. In fact, although 72%–87% of participants showed an understanding of the emergent nature of stroke by stating that the affected patient needed to be transferred to hospital, only 17.6% of those with adequate stroke knowledge reported calling 911 as their initial response for all three scenarios. The major limitations of this study were non-coverage and non-response bias, which are inherent to telephone surveys. A poor association between stroke knowledge and appropriate response was also demonstrated in studies by Williams et al. (1997) and Ritter et al. (2007). In a prospective study in 617 participants, Schroeder, Rosamond, Morris, Evenson, and Hinn (2000) showed an inverse relationship between stroke knowledge and activation of emergency services (OR = 0.63).

In the integrative review by Jones et al. (2010), the range of participants in the different studies who would call the emergency services if they suspected stroke ranged between 27% and 100%. Travis et al. (2003) found that only 42% of participants would call 911 if experiencing a stroke. The latter study, which used a survey methodology, included patients who had visited the Mayo Clinic or the Olmsted Medical Centre within the previous 3 years. However, the study may have been limited by the low participation rate (36%) and participation bias.

In a study based in Australia, calling an ambulance was the initial response of just 1.1%–20% of participants when presented with individual stroke warning signs (Yoon et al., 2001b). This finding may partly have been secondary to a failure of participants to recognise these warning signs of stroke. In fact, 67.3% of the same participants said that they would call an ambulance in the event of stroke. In the UK, only 48% of acute stroke patients present to hospital as an emergency (Harraf et al., 2002) as opposed to 82% of patients in Australia (Harriss et al., 2011).

Billings-Gagliardi and Mazor (2005) developed the STAT, a tool which assesses participant reaction to several stroke and non-stroke symptoms. On average, only 34.1% of participants within their study said they would call 911 if they or a family member experienced stroke symptoms. Possible answers in this study included ‘call 911 immediately’ (the appropriate action), ‘call doctor's office’, ‘wait 1 hour and then decide’, or ‘wait 1 day and then decide'. A major limitation of this study was the small number of participants (n = 249).

Two studies based in the US reported better initial responses to stroke. ‘Calling 911’ varied between 33% and 72% (Jurkowski et al., 2008) and 41% and 51% (Fogle et al., 2008). Interestingly, these two studies, among others, highlighted the fact that the type of action taken is associated with the presenting symptom. For example, Yoon et al. (2001b) found that 42% of participants were likely to activate emergency services if they experienced weakness or paralysis as opposed to 3% of those who experienced dizziness. Interestingly, 89.9% of participants within this study claimed they would call an ambulance or visit the emergency department if they were certain that they were experiencing a stroke. In contrast, only 3%–42% of the same participants answered in the same way when asked about their actions if they were experiencing stroke warning signs (without knowing directly or with certainty that their symptoms were attributable to a stroke). This outcome is somewhat concerning, since it is the combination of symptoms that may alert an individual that he or she is experiencing a stroke, and so sufficient knowledge and self-confidence are required to alert medical services without first seeking extensive reassurance that a stroke is indeed being experienced.

Jurkowski, Maniccia, Spicer, and Dennison (2010) explored whether a multimedia educational campaign could be effective in increasing the stroke patient’s intention to call 911. The campaign was effective, with the intervention group showing a 9%–12% increase in intention to call 911 compared with a matched comparison group.

2.4.3 Factors causing a delay in presentation

2.4.3.1 Process of help-seeking behaviour

Moloczij, McPherson, Smith, and Kayes (2008) conducted a study using qualitative methodology to explore the factors that influenced help-seeking behaviours in 20 stroke survivors. Decision-making among these participants turned out to be a complex process that went through three crucial steps, ‘recognition’, ‘interpretation’, and ‘negotiation’. Each of these steps was influenced by “making sense of symptoms, maintaining a sense of normality, presence and influence of another person and perception of medical services”, which hastened or delayed help-seeking behaviour. The latter was directly influenced by the time an individual spent in each step, particularly if the step was repeated several times. Patients prioritised their everyday commitments over their own health, particularly if they felt they were not sick enough to seek medical help. The authors also found that patients had different thresholds for considering whether their symptoms pertained to a serious condition. “A number of participants described monitoring their symptoms to see if they worsened, how long they lasted, and gauge how serious they perceived them to be. People appeared less likely to take action if they felt they could continue to function and if they did not experience pain” (Moloczij et al., 2008). This evaluation process delayed care-seeking behaviour and compromised the eligibility of acute stroke therapy. A delay in activating emergency services secondary to a failure to recognise the seriousness of stroke symptoms has also emerged in similar studies (Hsia et al., 2011; Mikulík et al., 2008). Some patients attributed their symptoms to other illnesses such as muscular problems, as well as ageing, especially when their symptoms did not fit their stereotype of stroke. Affected individuals were also influenced by the people around them in their decision to seek medical help. This was true for patients who were in the presence of another person but also for those who were alone at the time of the event and sought reassurance from another individual before activating emergency services. This interaction either facilitated or delayed care-seeking behaviour. Patients may have relied on other individuals “for a sense of safety, to validate their experience in some way, or to seek advice” (Moloczij et al., 2008). Dracup et al. (1995) highlighted the importance of including interactions with other people and environmental factors when developing a help-seeking theoretical model.

2.4.3.2 Barriers to activating emergency services

Apart from improving public stroke knowledge, an attempt should be made to consolidate the public perception that activating emergency services such as calling 911 may result in better outcomes in stroke. This is probably more challenging as it involves a behavioural change, which is generally more complex. Additionally, educational efforts should stress the importance and expected benefits of using EMS in cases of stroke. As discussed earlier, it seems as if most studies on the subject have reported that the public are unaware of the benefits of ambulance transfer to hospital as opposed to private transportation in acute ischaemic stroke (Deng et al., 2006; Morris et al., 2000; Moser et al., 2006; Williams et al., 1997).

Educational campaigns also need to consider barriers such as fear, perceived costs, and the embarrassment of being transported to hospital by ambulance. Some of these factors are discussed in further detail below.

2.4.3.3 Role of perceptual and behavioural factors

Self-efficacy, or a person’s perception of his or her abilities, has been found to be associated with behavioural change (Chesney et al., 2000; Gwaltney, Metrik, Kahler, & Shiffman, 2009) and a greater intent to seek emergency care (Zapka et al., 2000). Similarly, Skolarus et al. (2011) found that stroke self-efficacy was positively correlated with a behavioural intent to call 911 ($p = 0.046$) in the event of stroke. The authors concluded that “in addition to knowledge of stroke warning signs, behavioural interventions to increase both stroke self-efficacy and behavioural intent may be useful for helping people make appropriate 911 calls for stroke”.

“Perceiving control over symptoms (feeling able to control symptoms to some extent), attributing symptoms to problems other than stroke, hesitations about seeking help (verbalization of apprehension about seeking medical help), and an initial reaction of self-treatment or waiting to see what happens” were positively correlated with delays in seeking help and with hospital arrival times in a study by Mandelzweig et al. (2006). This study included 209 patients who presented to a tertiary care centre with stroke symptoms. Shorter time intervals were observed when the symptoms were perceived as severe, when others advised to seek help, and when the symptoms were first observed by others as opposed to by the patients themselves. The study also found that patients with high anxiety levels were less likely to self-treat and instead to seek immediate help compared with those who reported lower anxiety levels. In this study, female patients had a three-fold increase in delayed hospital presentation compared with men. The authors performed gender-specific analysis to attempt to explain this discrepancy and found that the delay could partly be attributed to the inclusion of a larger proportion of women who lived alone and a lower rate of immediate hospital referral to hospital by physicians.

In a study based in the Czech Republic, Mikulík et al. (2008) found that an adequate STAT score was correlated with participants’ knowledge that stroke is a serious condition (OR = 2.0) and that it can be potentially treated (OR = 2.1). This finding not only highlights the importance of the patient’s perception of disease severity and curability but also demonstrates how perception may affect behaviour. It is therefore crucial that public stroke awareness campaigns emphasise both the seriousness and treatability of stroke.

Hsia et al. (2011) found a large discrepancy between behavioural intent to call 911 and actual behaviour following a stroke. Within a population of predominantly urban African Americans, 89% of participants reported that their initial response to stroke would be to call 911. However, only 12% of affected patients had called 911 first. This study is mainly limited by selection bias and an unknown participation rate. The major barrier to activating emergency services was a failure by participants to appreciate the seriousness of their symptoms and a belief that the symptoms would self-resolve. These findings echo those described by Mikulík et al. (2008). Other studies have also shown that patients will only call 911 if they feel that their symptoms are sufficiently severe (Mandelzweig et al., 2006; Moloczij et al., 2008). Maestroni et al. (2008) found that severely affected stroke patients presented earlier to hospital, and that this relationship was statistically significant ($p < 0.001$).

Another barrier to calling 911 is the feeling that nothing can be done once a stroke occurs, which was responsible for up to 25% of patients arriving late to the emergency department in the study by Hsia et al. (2011). This finding suggests that educational campaigns should also educate the general public about the improved outcomes expected from an appropriate response in order to motivate stroke patients. Most campaigns to date have stressed the recognition of stroke symptoms and the need to call 911 as the initial response but have failed to emphasise the actual benefit of the latter action. In fact, perceptual barriers are also inter-related with lack of knowledge about stroke and the treatment available. Hsia et al. (2011) refer to this relationship as “informational barriers”.

In a study based in Flint, Michigan, Skolarus et al. (2011) explored potential barriers to calling 911 among a predominantly African American population and found that 17% of participants were convinced they could reach hospital earlier by using personal transport, 6% answered that they would avoid calling 911 due to financial implications, and 1% would be embarrassed to have an ambulance at their house. Other barriers to calling 911 included religious beliefs (7%) and knowing someone who had previously had a bad experience at hospital (3%). Since participants in this study were selected among church-goers, the main limitations were selection bias and poor generalisability.

In a study among general practice patients in Australia, Grady, Carey, and Sanson-Fisher (2014) explored awareness of the appropriate response to stroke. They found that response awareness was positively correlated with a history of stroke in a first-degree relative (OR = 1.99). This result may not only be secondary to previous knowledge through experience but may also be an effect of behavioural change, particularly when patients were successfully treated. Furthermore, 2.8% of participants answered that they would not call an ambulance if they experience a stroke because they “did not want to trouble anyone” (Grady et al., 2014). A significant proportion of patients wouldn’t call an ambulance as their initial response to stroke because they failed to recognise that their symptom was related to stroke. The study also revealed that only a proportion of those who chose the appropriate action would do so within 10 minutes of stroke onset, emphasising the importance of a timely reaction, which should be a crucial aspect of the ‘appropriate response’. The major limitation of this study was that the severity and suddenness of symptoms were not specified when assessing participant’s responses to acute stroke.

Another potential barrier to calling 911 may be an attitudinal barrier, that is, a mistrust in the healthcare system and its providers (Hsia et al., 2011). The latter study was carried out in Washington, DC. In fact, Jurkowski et al. (2008) found that respondents (based in New York) who had previously experienced a delay in receiving medical care were less likely to call 911 if they were to experience stroke symptoms. Similarly, Moloczij et al. (2008) found that help-seeking behaviour in acute stroke was influenced by the individual’s perception of medical services, particularly their previous experiences and interactions with such services.

2.4.3.4 Role of social and demographic factors

The behavioural model of healthcare utilisation described by Aday and Andersen (1974) describes key factors that determine healthcare use and outcomes and groups them into three categories, ‘predisposing’, ‘enabling’, and ‘need’. Socio-demographic characteristics including age, gender, marital status, ethnicity, and education constitute the ‘predisposing’ factors that contribute to the use of healthcare services. ‘Enabling’ factors are those that either stimulate or impede such use and include income, medical insurance, and healthcare costs. Finally, ‘need’ refers to the health status of individuals and symptoms which are either self-perceived or assessed by healthcare providers.

Seo, Begley, Langabeer, and Dellifraine (2014) found no significant relationship between ‘enabling’ or ‘need’ factors and intent to call 911 in acute stroke. There was, however, a statistically significant correlation between the intent to activate emergency services and age, gender, and ethnicity. Men (OR = 1.00), elderly (OR = 0.79), and unmarried individuals (OR = 1.00) were less likely to call 911 in the event of stroke. Minority groups including Asians, American Indians, and inhabitants of Alaska and the Pacific Islands were found to be more reluctant to call 911 compared with Whites, Blacks, and Hispanics (OR = 0.79). In contrast, Schroeder et al. (2000) found that elderly individuals were more likely to utilise emergency services in the event of stroke, with an odds ratio of 1.21 per every 5-year age increase.

Smith, Lisabeth, Bonikowski, and Morgenstern (2010) explored the effect of ethnicity and gender on hospital arrival time in acute stroke. They found that Mexican Americans were less likely to utilise emergency services compared with non-Hispanic Whites (OR = 0.6). Similarly, men were more likely to arrive at hospital via EMS compared with women (OR = 0.8). Skolarus et al. (2012) explored barriers to calling 911 in an African American community. Interestingly, the perceived and social barriers within this cohort varied between sub-groups according to age. Within the adult group, financial implications of stroke therapy and the ‘perceived social approval for calling 911 for stroke’ prevailed. Among younger people, barriers included “emotional state (fear, liability), lack of empowerment, anxiety about talking to EMS dispatchers and perceptions that the medical community does not care to help them” (Skolarus et al., 2012).

Hsia et al. (2011) found that participants with a lower level of education were more likely to use emergency services in cases of stroke (p = 0.012).

2.4.4 Conclusion

Response to stroke symptoms is a complex behavioural reaction which is triggered once these symptoms are attributed to stroke. Although stroke knowledge may be crucial to this step, it does not necessarily facilitate the rest of the response. The only appropriate action in stroke is to call 911 as the initial response, but this action is often affected or hindered by social and behavioural factors as well as by the presence of significant others. The response is also dependent on the individual’s perception of symptom severity. It is therefore critical that behavioural interventions form part of any educational campaign for stroke and that campaigns should focus on promoting the expected benefits of utilising the appropriate response in a timely fashion.

2.5 Delays in acute stroke care

2.5.1 Introduction

“Delay is the deadliest form of denial” (Hemmen, 2008). Delay in the evaluation and treatment of acute stroke may be broadly divided into pre-hospital and in-hospital delays. Pre-hospital delay is the time that elapses between symptom onset and hospital arrival time and remains the major contributor to overall delay. In-hospital delay refers to the time required to be seen by a specialist, perform computed tomography (CT) scanning, and start emergent treatment. The two stages of delay are not independent of each other, as shown by studies that have explored how pre-hospital delay may also affect in-hospital delay (Katzan et al., 2003; Morris et al., 2000). Delay can not only result in progressive irreversible brain damage in acute stroke (Saver, 2006) but may also preclude eligibility for stroke treatment (Dhamija & Donnan, 2007).

Several intervention studies have looked at implementing changes in an effort to reduce such delays. Attempts to reduce pre-hospital delay include campaigns to increase public stroke awareness, education about the appropriate response, and even system changes involving protocols for emergency dispatch and transportation (Culley, Henwood, Clark, Eisenberg, & Horton, 1994; Harbison, Massey, Barnett, Hodge, & Ford, 1999). Other studies have explored methods to improve in-hospital delay and include programmes for professional education (Alberts, Perry, Dawson, & Bertels, 1992; Behrens et al., 2002; Bray et al., 2005), the development of rapid emergency department assessment (Batmanian et al., 2007), and the introduction of a stroke team and alert system (Gomez et al., 1994; Hamidon & Dewey, 2007; Zweifler, Drinkard, Cunningham, Brody, & Rothrock, 1997).

2.5.2 Pre-hospital delay

“The weak link in the chain of events leading to prompt and effective treatment is patient delay in seeking care” (Moser et al., 2007). Similar to acute myocardial infarction (Herlitz et al., 1989), the delay from symptom onset to making the decision to seek help represents the most significant part of pre-hospital delay in acute stroke (Alberts, Bertels, & Dawson, 1990; Bratina, Greenberg, Pasteur, & Grotta, 1995). In a study by Chang, Tan, and Tseng (2004) conducted in Taiwan, the time between symptom onset and the seeking of medical help accounted for 45% of the entire pre-hospital delay. Similarly, an initial hesitation to contact emergency services contributed to 55.1% of pre-hospital delay in a study based in Norway (Faiz, Sundseth, Thommessen, & Rønning, 2013). Waiting for acute stroke symptoms to resolve is another major contributing factor in pre-hospital delay. Moser et al. (2007) describe this waiting as a "natural coping response to indecision". As discussed in Section 2.4.3, several barriers may aggravate pre-hospital delays. However, the actual transportation to hospital contributes to only a very small proportion of pre-hospital delay (Dracup et al., 1995; Meischke et al., 1995).

Lacy, Suh, Bueno, and Kostis (2001) explored arrival times to hospital following an acute stroke as well as any associated variables. They found that 46% and 61% of patients within their cohort arrived at the emergency department within 3 hours and 6 hours of symptom onset, respectively. These data are similar to those from previous studies performed both in the US and in Europe which reported ranges of 25%–59% and 35%–66% for the two time intervals (Alberts et al., 1990; Anderson, Broad, & Bonita, 1995; Azzimondi et al., 1997; Barsan et al., 1993; Harper, Haigh, Potter, & Castleden, 1992; Jorgensen, 1996; Kay, Woo, & Poon, 1992; Kothari et al., 1999a; Smith et al., 1998). Lacy et al. (2001) found that pre-hospital delay was significantly associated with multiple variables including age, gender, ethnicity, and mode of transportation to the emergency department, reflecting findings from similar studies exploring the effect of variables on low thrombolysis rates (Barber, Zhang, Demchuk, Hill, & Buchan, 2001; Demaerschalk, Bobrow, Paulsen, & Phoenix Operation Stroke Executive Committee, 2008; Johnston et al., 2001; Reed, Cramer, Blough, Meyer, & Jarvik, 2001). In contrast, Barsan et al. (1993), Kothari et al. (1999a), and Morris et al. (2000) failed to demonstrate an association between age or gender and pre-hospital delay. Other variables consistently found to influence pre-hospital delay include stroke severity, daytime onset of symptoms, and patients who lived on their own (Addo et al., 2012; Derex, Adeleine, Nighoghossian, Honnorat, & Trouillas, 2002; Innocenti et al., 2014; Jin et al., 2012; Lichtman et al., 2009). In a prospective study that included 778 patients who presented with acute stroke, Yang et al. (2014) concluded that “social living conditions and access to health care services are the major factors influencing pre-hospital delays in patients of acute ischemic stroke in China”. Moser et al. (2007) also considered behavioural responses and concluded that “the decision to seek treatment is heavily influenced by patients’ social context, cognitive processes, and emotional reactions, but these aspects of delay remain underexplored”.

Agyeman et al. (2006) described a longer pre-hospital delay for patients who suffered posterior (as opposed to anterior) circulation stroke. Since the majority of stroke education campaigns, including FAST, focus on anterior circulation deficits, there is a risk that posterior stroke symptoms (e.g. vertigo, ataxia, imbalance and unsteadiness) are indeed overlooked. However, this association was not present in the study of Faiz et al. (2013), in which pre-hospital delay was also related to the time of presentation, being significantly longer at night.

Evenson, Foraker, Morris, and Rosamond (2009) performed a systematic review of 123 peer-reviewed studies of pre-hospital and in-hospital delays in acute stroke published between 1981 and 2007. The authors found an annual decline in pre-hospital delay of 6% since the first published study. The decline subsequently slowed in the more recent studies. Despite the significant decline, studies published since 2000 continue to show that the 50th percentile of pre-hospital delay occurs between 3 and 4 hours after symptom onset. As mentioned above, this delay may not only compromise patient eligibility for thrombolytic therapy but may also increase subsequent in-hospital delay.

Educational stroke campaigns should target pre-hospital delay, particularly the delay in first seeking medical attention. However, the success of such campaigns is not guaranteed. In a population-based study in 1392 stroke patients in South London, Addo et al. (2012) failed to find a significant pre- and post-intervention difference ($p = 0.30$) in the proportion of patients arriving at the emergency department within 3 hours of symptom onset. The intervention was the ‘Act FAST’ campaign launched by the department of Health of England, which focused on the benefits of early treatment in stroke. This finding demonstrates that behavioural change, particularly in acutely affected patients, is a highly complex matter.

2.5.3 In-hospital delay

The National Institute of Neurological Disorders and Treatment of Acute Stroke published recommendations for acute stroke care in 1996 and established time-frames for the different steps required within the emergency department to avoid unnecessary delays. These goals include 10 minutes from hospital arrival to physician evaluation, 25 minutes to perform CT scanning, and 60 minutes from arrival time to starting thrombolytic treatment in eligible patients (National Institute of Neurological Disorders and Stroke, 1996). Evenson et al. (2009) found that only a few studies included in their systematic review met these requirements. The authors also reported that there was no appreciable improvement in emergency department delay in acute stroke. Similarly, although time to neurologist assessment and CT scan showed a 10% annual decline, it failed to reach statistical significance.

In a study performed among 22 hospitals in the UK, Harraf et al. (2002) explored the reasons for in-hospital delays in stroke. Their assessment highlighted major delays in patient assessment times that were mainly secondary to the labelling of stroke cases as ‘low priority’ by triage nurses because the patients were stable. This factor was further aggravated by a lack of established protocols for the treatment of acute stroke in the majority of participating hospitals. The latter resulted, for example, in delays in obtaining CT scan results, with only 10% of patients being imaged within the first 3 hours of arrival. Similarly, Alberts et al. (1990) concluded that part of the delay in stroke assessment arises because “paramedical personnel may not recognise early symptoms and signs of stroke”. These two studies underline the importance of medical and paramedical stroke education, which was discussed in Section 2.3.5.

Lacy et al. (2001) conducted a prospective study of 553 patients who presented at 10 hospitals in New Jersey with signs and symptoms of stroke. They explored factors that led to in-hospital delays in the diagnosis and treatment of stroke and found an association with patient ethnicity, with Hispanics experiencing a longer delay in being seen by a physician compared with Whites ($p = 0.004$). Upon arrival to the emergency department, Medicare patients were seen faster by physicians than Medicaid patients ($p = 0.047$).

Delays in initial physician examination were also positively correlated with increasing hospital complexity. The authors found that patients admitted to intensive care were seen quicker by physicians compared with those admitted to medical or surgical wards ($p = 0.0001$). This was also true for patients who arrived at the emergency department by ambulance as opposed to by private transportation ($p = 0.0001$). This finding can be partly explained by the perceived seriousness of the presenting condition by physicians, and reflects data from previous studies that showed a reduced delay between arrival time to the emergency department and physician assessment (Bratina et al., 1995; Kothari et al., 1999a). This study may have been limited by sampling and measurement errors, however, particularly in the measurement of pre-hospital delay times.

Campbell et al. (2014) investigated whether stroke patients presenting to the emergency department out of hours suffered further treatment delays. Data were extracted from the Stroke Improvement National Audit Programme (SINAP), which included 45,726 stroke patients. The authors found that out-of-hours presentation was associated with a delay in acquiring brain CT scanning results as well as a delay in admission to stroke units. They also revealed a higher mortality rate at 30 days among stroke patients who presented to emergency departments during weekends (OR = 1.14). Similar data were found in the studies conducted by Reeves, Bhatt, Jajou, Brown, and Lisabeth (2009) and Ogbu, Westert, Slobbe, Stronks, and Arah (2011). These three studies highlight serious inequalities in the provision of contemporary acute stroke care. However, the study by Campbell et al. (2014) lacks outcome data such as disability and quality of life after stroke, and merely compares mortality rates. The study is also limited by the unavailability of NIHSS at presentation, which is often used to grade stroke severity.

2.5.4 Conclusion

Delays in acute stroke care are preventable and have a significant impact on stroke morbidity and mortality. Although delays have been reduced in recent decades, the majority of stroke patients remain ineligible for emergent treatment as the time window has already expired before treatment can be administered. Effective healthcare programmes need to be implemented in order to minimise the evaluation time and treatment delay in acute stroke.

2.6 Educational strategies

2.6.1 Introduction

Following a randomised controlled trial by the National Institute of Neurological Disorders and Stroke rt-PA Stroke Study Group in 1995, the focus of stroke management and education shifted to the acute stage of the disease (National Institute of Neurological Disorders and Stroke & rt-PA Stroke Study Group, 1995). Prior to this trial, stroke care involved rehabilitation and secondary prevention measures following the initial ictus. The trial demonstrated that the administration of t-PA within 3 hours of stroke onset was associated with improved clinical outcomes. The time window for treatment administration was later extended to 4.5 hours following the ECASS III trial (Hacke et al., 2008).

Despite this extended time window, pre-hospital delay remains the greatest barrier to acute stroke treatment and may be partly attributed to a failure to understand urgency. In fact, only 2%–6% of affected individuals receive acute thrombolytic therapy within the optimal time window (CASPR-Investigators, 2005).

A study performed at Duke University (Alberts et al., 1990) showed that up to 60% of affected individuals sought medical care only after 24 hours had elapsed from the initial presentation. Similarly, just 45% of patients in the NINDS t-PA trial (Barsan et al., 1994) activated emergency services through a 911 call despite elaborate educational efforts.

Pre-hospital delay may be better understood using the ‘three sequential’ model proposed by Safer, Tharps, Jackson, and Leventhal (1979). The three stages are ‘appraisal delay’, which refers to the time required to recognise a symptom as part of an illness; ‘illness delay’, which corresponds to the time that elapses until one seeks professional care; and ‘utilisation delay’, which reflects the time required to reach hospital after professional care is consulted. All three stages need to be targeted in order to ensure an effective stroke educational strategy.

Research that focused on exploring the reasons for this delay concluded that poor public stroke knowledge may be a major contributing factor. To this extent, Kothari et al. (1997) found that 39% of patients included in their study were unable to list a single acute stroke sign or symptom. Similarly, Pancioli et al. (1998) showed that there was a knowledge gap within the general population regarding stroke warning signs and recommended that “considerable education is needed to increase the public's awareness of the warning signs and risk factors for stroke”.

Educational strategies for stroke often focus on behaviour modification, which can be broadly divided into two main categories: stroke prevention and stroke preparedness (Boden-Albala & Quarles, 2013). Preparedness implies certain competencies whereby lay persons not only recognise stroke warning signs but are also able to take the appropriate action in time (Boden-Albala et al., 2014). Thus, educational strategies should address both of these factors in order to increase public health literacy.

In addition to the inclusion of necessary information in educational strategies, Boden-Albala et al. (2014) emphasised the need to dedicate attention to the method of distributing information: “Traditional informational pamphlets along with public ad campaigns demonstrate suboptimal success possibly due to inadequate attention to health literacy, or cultural tailoring” (Boden-Albala et al., 2010). Hence, stroke education should move away from the traditional didactic method and instead attempt to exploit alternative methods to engage the target population and increase educational effectiveness.

A number of studies have utilised various educational strategies to ameliorate stroke preparedness and behavioural intent. The success of these interventions has varied significantly between different studies as well as between different cohorts, as will be explored in the following sections.

2.6.2 Culturally tailored education

Several studies that revolved around the implementation and evaluation of stroke educational campaigns have paid particular attention to cultural sensitivity.

“Know Stroke in the Community” (Emr, 2006) was a grassroots community educational programme on stroke established in five US cities with large Hispanic and African American communities. The authors proposed a model to overcome the challenges of increasing stroke awareness and disseminating knowledge, which is often limited by a lack of resources and local materials. Although the curriculum focused mainly on prevention information, it also included education on stroke recognition. The curriculum was set up with consideration to the cultural background of participants, and evaluation forms filled out by the same participants confirmed the cultural appropriateness. The programme targeted 65 community leaders who were then asked to introduce stroke educational material through existing community outreach programmes. At the time of publication, 413 outreach events had been organised by the participants, reaching up to 116,500 people. The success of this programme is attributable to the fact that community leaders are trusted ‘educators’ and have the facilities to distribute educational material, indicating that a grassroots outreach programme is an effective model for the dissemination of stroke education.

Tadros et al. (2009) explored a novel approach to stroke education that suited the cultural, medical, and economical needs of the target population. Their aim was to increase public stroke knowledge through an EMS-sponsored campaign. The strategy would be ideal for smaller communities in which mass media campaigns might be excessively expensive to implement. EMS personnel attended an educational course led by stroke experts. The group of EMS personnel then evaluated which educational media could be used to disseminate educational material. They also had to identify strategic locations within their community where they believed such educational material would have the largest impact. Each EMS agency was allowed to design and implement the strategy they believed suited best the community they served in. The agencies were provided printed educational materials, including brochures and bookmarks. Verbal messages were also delivered at strategic locations, including churches and pharmacies. The educational intervention during phase 1 of the trial was repeated at monthly intervals. This ‘pulsing approach’ to education was utilised as “previous research has demonstrated that staggered, repeated exposure to a message prevents memory decay and thus enhances long-term retention of the message” (Tadros et al., 2009). The intervention proved to be a success, as there was a statistically significant increase in knowledge of stroke symptomatology within the intervention community.

Boden-Albala et al. (2010) explored whether exposure to educational material could lead to reduced hospital arrival times following an acute stroke. SWIFT was a culturally tailored behavioural intervention to improve awareness and recognition of acute stroke warning signs. The authors also explored whether knowledge could help mediate a behavioural change. The study had a randomised design and prospectively enrolled patients who suffered from stroke or TIA. Participants were assisted in filling out a stroke knowledge and behaviour survey upon presentation and were divided into two groups, a ‘usual care’ group and an ‘intervention’ group. The intervention was based on an interactive and culturally sensitive programme, which moved away from the traditional didactic education. Specific measures were taken to produce a culturally tailored programme which included the use of bilingual material and visuals that incorporated familiar surroundings. Similarly, videos of previously affected individuals were produced in the participants’ own language. These measures were planned to help overcome shortages in health literacy. The design of culturally tailored interventions poses several challenges, including issues of trust in some communities and discrepancies in health literacy. The authors utilised logistic regression analysis for indicators of early presentation while introducing ethnicity and group membership of participants as co-variates. A linear regression analysis was also employed to quantify differences in arrival times at the emergency department. Data from this survey showed that the majority of patients had poor stroke knowledge and failed to understand the urgency of treatment. In fact, baseline data showed that less than 17% of patients arrived at the emergency department within 2 hours of symptom presentation. The data also demonstrated a strong ethnic discrepancy in stroke knowledge and behaviour. For example, Hispanics had a significantly shorter presentation time compared with Whites and Blacks, and a relatively smaller proportion of White patients used ambulance services. A major limitation of the study was that it failed to assess the educational impact on the family members of participants.

The "Acute Stroke Programme of Interventions Addressing Racial and Ethnic Disparities (ASPIRE)" (Boden-Albala et al., 2014) study focused on stroke preparedness with a final outcome of reduction in pre-hospital delay and subsequent increase in t-PA administration. Participants were selected from an underserved black community.

The intervention was an extensive, multi-level process targeting the community, hospitals, and EMS in three different phases. During Phase 1 (the pre-intervention phase), an advisory committee composed of a number of community stakeholders was established to assist with recruitment and to include culturally and linguistically tailored study material. The committee's feedback was also crucial for interpreting the data collected from focus groups, surveys, and interviews. Previously described stroke-related tools were used in the trial (Boden-Albala, Carman, Moran, Doyle, & Paik, 2011), (Boden-Albala et al., 2010), (Wall, Beagan, O'Neill, Foell, & Boddie-Willis, 2008). However, similar to the SWIFT trial, educational material was modified to culturally conform to the target population. The trial focused on stroke preparedness and omitted more detailed stroke information in order to focus on stroke recognition. Research co-ordinators collected the demographic data and stroke parameters of patients who presented with stroke at one of the participating hospitals. Regular meetings with EMS were set up to optimise pre-existing stroke protocols and promote further utilisation of EMS.

In Phase 2 (the intervention phase), educational sessions were delivered at multiple strategic locations including schools, churches, and health centres. An individual was identified at each location and trained to provide ongoing education. Medics and paramedics in participating hospitals were also targeted through clinical training and research efforts. EMS altered their stroke protocol so that all suspected stroke cases were taken directly to recognised stroke centres.

During Phase 3 (post-intervention evaluation), structured interviews were carried out upon arrival at the emergency department to assess the stroke knowledge, potential barriers to calling 911, and risk factors of affected individuals. The interviews also explored whether patients had been previously exposed to stroke education.

The authors assessed the statistical significance of the change in stroke therapy administration prior to and after the intervention period. They also utilised logistic regression models to assess the effects of demographic, ethnic, and socio-economic factors on this change.

Following the intervention, the mean presentation time to the emergency department decreased from 27 hours to 23.7 hours and the proportion of patients reaching hospitals within the ‘treatment window’ increased from 25% to 28%. The success of the intervention can likely be attributed to an educational strategy tailored to the needs of the community and to the use of culturally sensitive material. It also showed how a simple, effective message may be more effective for altering practice as opposed to overwhelming participants with more elaborate information.

2.6.3 Mass media as an educational medium

Mass media communications are typically trusted by both readers and viewers and may therefore offer a highly effective means of community education. Kothari et al. (1997) carried out a survey in stroke patients to investigate from where they would seek information about stroke. Interestingly, only 2% of the cohort indicated that they would ask a medical professional as opposed to 11% who said they would seek information from mass media sources.

Becker et al. (2001) demonstrated the effectiveness of a mass media campaign in Washington, US to increase the general public’s knowledge about stroke. Public service announcements (PSAs) were repeatedly broadcasted on television and also appeared in local newspapers. The announcements targeted the elderly population at risk of stroke and were estimated to have reached the majority of elder people an average of six times. This repeated exposure was identical to the strategy employed by Tadros et al. (2009), and was shown to increase the long-term educational effect. The message delivered on TV was: “Stroke is a brain attack. Know the symptoms. Call 911”, and hence provided education on both stroke symptomatology as well as the appropriate action to take. Some of the newspaper articles were translated into several languages and distributed among low-income groups in order to reach the greatest proportion of the target population. The pre-intervention study revealed a high deficit of knowledge regarding stroke in the community, particularly in the elderly, certain ethnic groups, and the low socio-economic faction of the community. Advertising research (Pieters & Bijmolt, 1997; Singh, Mishra, Bendapudi, & Linville, 1994) demonstrates that the time at which PSAs are broadcasted, the frequency of broadcasting, and the shows during which they are shown can not only affect the recall rate of the message but also target different groups in the community. All of these factors need to be considered when planning a mass-media-based health educational campaign. The improvement in knowledge of stroke signs was not reflected in the intention to call 911 among the participants. Both were addressed in the same educational strategy, and this discordance may thus be attributable to the fact that behavioural intent is more difficult to modify. Patient behaviour is not necessarily altered after educating patients (Ho, Eisenberg, Litwin, Schaeffer, & Damon, 1989), which is worthy of consideration because the ultimate goal of stroke education is to reduce pre-hospital delay.

Morgenstern et al. (2002) reported a statistically significant increase in the administration of intra-venous tPA within the intervention group of the Temple Foundation Stroke Project. This increase was attributable to a multilevel educational programme that promoted behavioural change. The interventions targeted both hospital and community physicians with the purpose of increasing stroke identification skills and modifying the social norms and outcome expectations of patients. In the first phase of the study, the authors established focus groups with stroke patients to identify and quantify contributors to pre-hospital delay. Interventional strategies were subsequently developed using data collected from this initial phase. It immediately emerged that an effective stroke strategy did not simply involve education about the disease and asking those affected to call emergency services. A more intricate framework was necessary, and the authors instigated a massive campaign to advertise the correct response to stroke. The strategy included advertisement by role models on mass media and the distribution of brochures and posters in strategic locations. Volunteers were also trained in stroke symptom recognition, and subsequently trained their peers. The strategy also targeted healthcare providers, who set up protocols and guidelines to deal with acute stroke.

Emergency physicians and paramedics were contacted individually and updated on stroke guidelines. They also participated in mock exercises. Interestingly, the strategy prompted affected patients to be more assertive and demand stroke therapy from reluctant physicians. The unequivocal success of this study supports the effectiveness of an aggressive educational strategy that includes both community and professional education. The authors concluded that positive re-enforcement and motivation through expected improved clinical outcomes likely had the largest impact.

In phase 3 of the study, Morgenstern et al. (2003) assessed the long-term effectiveness of their intervention as they claimed that "the ultimate test of an educational intervention is the sustainability of the effect after the intervention ceases". Treatment for acute stroke in the intervention group continued to increase, even after 6 months. The success of this intervention can be attributed to the fact that it tackled problems from a number of different perspectives and could truly "provide(s) a framework to craft a health promotion campaign to increase acute stroke therapy".

Silver et al. (2003) explored the effectiveness of different advertising media channels to increase public knowledge about stroke symptoms by devising a controlled pre- and post-intervention study. Participants were divided into four groups: a group exposed to printed adverts, two groups targeted by a low-level and a high-intensity TV advertising strategy, and a control group. Interventions included a PSA aired on TV as well as printed newspaper adverts based on the television advert.

Print advertising failed to improve knowledge when compared with the more expensive TV campaign, which was considered successful. The study also showed that a less intensive and intermittent TV advertising strategy was at least as effective as a continuous and intensive campaign.

The campaign also failed to increase knowledge within the elderly population and the authors postulate that the way the advert was produced was perhaps unappealing to this demographic group. This outcome was disappointing, as it meant that the advert failed to target the group with the highest risk for stroke.

Different trends in educational success have also been observed between persons in different socio-economic groups and of different genders within the same community.

For example, television adverts were more effective in individuals with a secondary education level or lower. This finding is similar to the results obtained by Becker et al. (2001). Since mass media campaigns are often very expensive to run, it is necessary that the campaign is ‘not only effective but also cost-effective’ (Silver et al., 2003). Hence, the target population should be carefully identified and studied prior to embarking on a mass media educational strategy. This study failed to explore whether increased stroke knowledge as a result of an educational strategy would eventually translate to a behavioural change.

Conversely, Hodgson, Lindsay, and Rubini (2007) explored whether a mass media educational campaign on stroke could reduce pre-hospital delay. A number of previous studies had failed to demonstrate a correlation between stroke knowledge and hospital arrival time (Becker et al., 2001; Carroll, Hobart, Fox, Teare, & Gibson, 2004; Cheung, 2000). However, some behavioural studies have shown that raising awareness and increasing knowledge about a condition are necessary before a change in behaviour can be expected (Prochaska, Wright, & Velicer, 2008). The educational strategy involved two television advertising campaigns with a duration of 8 and 9 months, respectively. The campaign cost $3.7 million and was aired during prime-time shows, targeting people aged 45 years and older. The advert listed the five acute stroke signs and a voiceover described the appropriate action that should be taken in the event of a stroke. The study confirmed that there was a positive correlation between mass media education and public knowledge of stroke signs. However, the study also showed that continuous advertisement was necessary not only to further enhance stroke knowledge but also to sustain awareness. The data collected also confirmed that timely presentation to the emergency department increased by 9% within the target population. Hence, the study showed that properly designed mass media campaigns not only increase awareness but can also lead to behavioural change. Similar results were observed in other studies that investigated the role of mass media interventions on the utilisation of health services (McVey & Stapleton, 2000; Noar, 2006).

Marx et al. (2008) explored the differential effects of a 3-month educational campaign on public stroke knowledge in Germany. The authors targeted television and radio stations as well as using printed flyers, posters, and newspaper adverts. Messages on posters were in the form of short slogans or cues to action. TV and radio stations broadcasted interviews with stroke experts and stories about people who had suffered a stroke. Similarly, stories and reports about the local stroke unit appeared regularly in newspapers. Although a moderate improvement was observed in public general knowledge about stroke, the improvement in detailed knowledge about symptomatology was somewhat disappointing. The educational benefit was most apparent among the low socio-economic group, women, and younger people. TV broadcasts and newspaper adverts proved to be the most effective media channels and reached people who were particularly at risk of stroke. Data analysis also highlighted the fact that simple and clear messages were much more effective than complex, poorly understood educational attempts. In contrast to the results reported by Hodgson et al. (2007), the number of people seeking immediate care for acute stroke did not change significantly following the educational campaign. The authors suggested that the educational benefit may be increased by utilising "new approaches like promoting dialogue between previous patients and high-risk individuals or to address problems of denial and decision making skill".

(Fogle et al., 2010) carried out a comparison study to investigate the effect of a 20-week educational campaign on public knowledge of stroke symptomatology. The authors also investigated whether there was a change in emergency service activation within the intervention group. Educational messages addressed the signs and symptoms of stroke and the need to act fast, and were aired on television and radio programmes as well as appearing in newspaper adverts. Brochures and magnets were distributed to households and strategic locations within the community such as pharmacies and churches. The intervention turned out to be a success and the authors concluded that an intense educational campaign can increase public knowledge of stroke symptoms and awareness of seeking immediate help.

Miyamatsu et al. (2012) explored the effects of a year-long television educational campaign on public knowledge of acute stroke symptoms. The authors collected pre- and post- intervention data by means of a telephone survey and included a control cohort in their design. The campaign utilised minute-long audio-visual spots which were broadcasted at least twice daily. Weekly highlight programmes featuring 33 different topics were also aired on TV. The campaign was planned and produced by an expert team consisting of medical and broadcasting experts to ensure that the messages delivered had accurate scientific content and were attractive to the target audience. A large number of people within the intervention group reported that they had seen the short spots and programmes. Knowledge increased significantly within the intervention group compared with the control group. Similar to the study performed by Marx et al. (2008), the educational effect was shown to be significantly higher in women. This may in part be explained by the higher TV audience rates of women. The study failed, however, to assess changes in behavioural intent in the case of acute stroke.

Worthmann et al. (2013) carried out an extensive stroke educational campaign in Hannover, Germany. The campaign included the use of flyers, posters, mass media advertisement, and multiple public events over a 6-month period. Posters and flyers were placed at strategic locations including hospitals, pharmacies, and in ambulances. Newspapers and radio stations covered public events and published expert interviews and reports. The authors devised a pre- and post-intervention campaign to assess the effect of this strategy, the aims of which were to increase public stroke knowledge and reduce pre-hospital delay. There was a statistically significant increase in both stroke symptomatology awareness and the intention to seek immediate care following the intervention.

Although most stroke educational campaigns delivered via mass media have been successful, the costs of running such campaigns need to be considered. Hodgson (2008) states that “to be effective, mass media needs adequate reach and frequency to break through the advertising ‘clutter’—which requires significant and sustained funding”. This approach may turn out to be prohibitively expensive, particularly if the educational messages are repeated at short intervals. In the study by Hodgson et al. (2007), the educational strategy cost was in excess of 1 million US dollars. The study by Tadros et al. (2008), which was discussed in an earlier section, explored alternative and less expensive educational strategies that could still be successfully implemented.

2.6.4 Educational videos

Stroke education using traditional written and verbal means may be sub-optimal. In contrast, health education through video interventions has been shown to be effective and can influence participants' behaviour (O'Donnell, Doval, Duran, & O'Donnell, 1995).

Feigin (2007) explored the effectiveness of a DVD-based culturally tailored stroke educational campaign that taught the target population about the pathogenesis, management, and appropriate response to stroke. The development of the educational DVDs followed an initial evaluation of educational needs in stroke survivors. The authors performed a qualitative data analysis which resulted in a positive appraisal of their educational strategy. The authors concluded that observational learning tools may form the basis of an effective educational strategy, although they suggested that a randomised controlled trial should be initiated to further assess this conclusion.

Chan et al. (2008a) interrogated the effect of a 12-minute educational video shown in the waiting room of an emergency department. The location was chosen in order to preferentially target at-risk patients. The authors devised a controlled trial and assessed pre- and post-intervention stroke knowledge using a 13-question quiz. Stroke knowledge improved significantly within the intervention group both immediately and 1 month after watching the video. This shows that passive watching of a health educational video is an effective educational method and may change emergency waiting time into a productive teaching exercise. Such an educational strategy can be delivered with minimal supervision and cost. The major limitations of this study include a high attrition rate (61%) at the 1-month follow up, which may have biased the knowledge retention data. The authors also failed to assess whether the video resulted in a change in behavioural intent among participants.

Similarly, He et al. (2014) evaluated the effectiveness of a video-based educational campaign in raising public awareness about acute stroke symptomatology. Videos were distributed to village doctors within the intervention community. Stroke knowledge not only increased after the intervention but was also correlated with the number of visits to the doctor's clinic. A higher educational benefit in women compared with men may also have been attributable to a higher attendance rate among females. These results complement those reported by Chan et al. (2008a) and support the effectiveness of video-based stroke education.

2.6.5 Music and education

Another approach that has been explored in the facilitation of the educational process in stroke is the use of music. The school-based “Hip Hop Stroke” (Williams, DeSorbo, Noble, & Gerin, 2012a; Williams, DeSorbo, Noble, Shaffer, & Gerin, 2012b; Williams & Noble, 2008) intervention showed how music and catchy phrases could increase stroke knowledge and induce patients to activate emergency services. This study targeted a high-risk community and the educational strategy was tailor-made in that music and dance were both culturally and age appropriate. An interactive curriculum was delivered over 3 days and included the ‘FAST’ mnemonic. The latter was incorporated into the chorus of the programme’s theme song, which also included calling 911 in the event of an acute stroke and featured the term ‘brain attack’. The study targeted elementary-school children and showed how they can be given information about stroke and how to appropriately activate emergency services. Children were also provided with information packages to act as a catalyst for discussions with their parents. In this way, children increased their own knowledge and also educated their parents and relatives. Theoretically, this can be a very effective method of teaching because up to 45% of stroke knowledge is in fact derived from relatives or friends (Müller-Nordhorn et al., 2006). Another health educational campaign has successfully utilised children to improve adult health (Evans, Clark, Levison, Levin, & Mellins, 2001). The primary aim of the study was to examine the programme’s educational efficacy in delivering information about stroke to children. The team responsible for delivering the “Hip Hop” curriculum consisted of education as well as health professionals. This holistic approach of teaching was likely the reason for the programme’s success. The strategy succeeded in increasing children’s knowledge about stroke, and this was also demonstrated at the 3-month follow-up. The authors attributed the programme’s success to the innovative educational strategy:

"music and dance likely enhance program objectives through activities perceived as fun rather than uninteresting or primarily educational". The educational potential of music has already been shown to be effective in improving vocabulary (Garvin, 2006) and mathematical skills (Capps, 2003) in young children.

2.6.6 Game-based education

Learning through games is an innovative educational medium and can be both engaging and challenging for participants. Several studies have interrogated game-based medical education in undergraduate courses (Mann et al., 2002; Saunders & Wallis, 1981) and as an educational tool for practitioners (Kramer, 1995; Kuhn, 1995). Games can connect theory and practice and allow for immediate feedback (Henry, 1997). The challenging effect of games and their ability to reiterate important material means that game-based methods are not only viable but are also effective.

Telner et al. (2010) devised a controlled trial to compare the effectiveness of a continuing medical education (CME) programme delivered via a novel game-based method versus more traditional case-based teaching. Family physicians attending a conference were targeted using a game based on 'Snakes and Ladders', and multiple-choice and true-or-false questions regarding stroke education were developed. The authors measured stroke knowledge immediately after delivery and at 3 months following the strategy. They also measured participant satisfaction using surveys. The results showed that the effectiveness of the two teaching methods was similar, although the group assigned to game-based teaching reported a more satisfying learning experience. The authors concluded that game-based education can not only offer an alternative and yet effective educational medium but may also stimulate group discussion and interaction, resulting in a better educational experience. The major limitation of this study was the small number of participants, largely the result of recruitment challenges.

Similarly, Williams, Hecht, Desorbo, Huq, and Noble (2014) explored the effect of an educational video game on stroke knowledge in children. They targeted children aged 9–10 years using a pre- and post-intervention design to assess the educational efficacy of their tool. The same authors (Williams et al., 2012a) had previously demonstrated the positive impact of educating children on parents' stroke knowledge. After playing a 15-minute clot-buster stroke game at school, children were asked to continue playing the game at home and were given passwords in order to access the game remotely. There was a significant increase in knowledge following the intervention, which also included an appreciable behavioural change in calling 911. A single 15-minute exposure was enough to increase stroke knowledge, and participants retained this knowledge for at least 7 weeks when an unannounced post-test evaluation was performed. Furthermore, 26% of participants accessed the game remotely as a leisure activity. The authors concluded that "a stroke video game may be an innovative method for improving and sustaining actionable stroke knowledge among young children".

2.6.7 Education through comic books and cartoons

Another stroke educational medium that has been previously explored is the use of comic books and animated cartoons.

Shigehatake et al. (2014) produced an animated cartoon and manga to disseminate stroke knowledge among junior high-school students. They presented three stroke stories in a comic book and a 10-minute long cartoon. These materials graphically described the early symptoms of stroke using the FAST message and the appropriate action to be taken. The strategy proved to be successful, as stroke knowledge increased immediately after the intervention and had been retained after 3 months. This result can be partly attributed to the fact that manga, which is an inherent part of Japanese culture, suited the cultural background of the target population.

The effectiveness and feasibility of a similar educational strategy was also assessed in elementary-school children (Sakamoto et al., 2014). The authors devised a pre- and post-intervention design to assess stroke knowledge which targeted stroke symptoms but also the appropriate action that needed to be taken in acute stroke. The educational material was delivered via a 30-minute tutorial whereby teachers used a cartoon and a manga devised for a previous intervention (Shigehatake et al., 2014). Children were also given magnets bearing the FAST message and urged to attach it to refrigerators within their households. Post-intervention data confirmed that this strategy increased stroke knowledge and improved the appropriateness of emergency action taken. Although the knowledge level remained above baseline at 3 months after the intervention, the percentage of children that would correctly activate the appropriate emergency services decreased and was similar to the baseline level. This finding contrasts with the outcome of the study by Shigehatake et al. (2014) in which the 3-month appropriate response to stroke was sustained. The authors speculate that this discrepancy may have resulted from two related factors. First, the educational cartoon and manga used were initially developed for junior high-school students, and the material portrayed may not have been as appealing for elementary-school children. Second, the educational material used the FAST message, which the children may have had trouble memorising as the mnemonic is an acronym in the English language. This outcome highlights the importance of using educational material tailored to the target population.

Ohyama et al. (2015) conducted a controlled trial to evaluate the effectiveness of traditional teaching versus education using an animated cartoon and manga. In a similar way to Shigehatake et al. (2014), the authors targeted junior high-school students. Teaching material evolved around early stroke signs and symptoms summarised in the FAST mnemonic and the action that needed to be taken if these were observed or experienced. Both groups within the study demonstrated increased stroke knowledge immediately and at 3 months after the intervention, indicating that tailor-made cartoons and comics may represent important and cost-effective teaching aids in stroke education.

2.6.8 Use of children's literature

Traditional teaching methods may not be particularly effective for delivering modern educational necessities. However changing education "in a way that fosters a sense of salience, clinical imagination and professional development, while maintaining the academic rigor necessary to ensure student success" (Ponder, 2013) may prove to be a difficult task that is not without opposition. Ponder (2013) evaluated the effectiveness of teaching nursing concepts using a children's book called *My Grandpa Had a Stroke*. The book is a narrative account of a young boy whose grandfather has suffered a stroke (Butler, 2007). The book describes and graphically illustrates the story from the initial symptoms of acute stroke to the long-term management of the affected patient. The story formed the basis for a robust case study, which was then followed by group discussions and focused questions. The students followed the story attentively, with some even becoming emotionally involved. The authors concluded that this educational strategy has the potential to change passive education into a more interactive, enjoyable, and effective means of education.

2.6.9 Education exploiting strategic locations

The location in which education is delivered is crucial and depends on the cultural background and traditions of the target population. "Beauty Shop" was a community-based intervention that focused on African American women (Kleindorfer et al., 2008). Participants not only demonstrated improved knowledge about stroke and an enhanced ability to react when affected but were also able to maintain this knowledge for a period exceeding 5 months. This educational project targeted Black women through local beauty salons. Women have a higher stroke risk compared with men (Mozaffarian et al., 2016), and African American ethnicity increases the risk further. This particular ethnic group has also been shown to have the least knowledge about stroke (Ferris et al., 2005). The educational strategy was tailor-made to the target population, which is likely the main factor that contributed to the project's success. Participating beauticians in the target community were taught about stroke signs and risk factors and a stroke survivor also shared her experiences with these participants. The stroke knowledge of beauticians was assessed both before and after the presentation. Participating beauticians were given study packets to distribute to some of their regular clients. While styling hair, the beauticians would teach their clients about the warning signs of stroke and the appropriate action to take. They also handed out brochures to their clients to read at home. The strategy focused on the 'FAST' mnemonic as well as the use of visual depictions to explain stroke signs. The 'FAST' message was developed from the Cincinnati Prehospital Stroke Scale (Kothari, Pancioli, Liu, Brott, & Broderick, 1999b) and has been shown to be highly sensitive in identifying acute stroke symptoms (Kleindorfer et al., 2007) as well as being catchy and easy to remember. These factors may explain why participants could recall stroke symptoms (summarised in the 'FAST' mnemonic) but could not remember the risk factors associated with stroke in the same study. The success of this educational strategy likely derives from a perfect combination of clients (a captive audience) who trust their beauticians (i.e. a trusted educator). Mnemonics have been shown to be effective in improving health literacy, even in other conditions (Noble, Hedmann, & Williams, 2015).

Several stroke educational trials have also targeted local pharmacies and churches (Fogle et al., 2010; Tadros et al., 2009). Zahuranec et al. (2008) assessed the feasibility of a church-based stroke educational campaign. The strategy focused on the prevention and modification of risk factors within the target population. Awareness and the ability of participants to recognise stroke signs and symptoms was fair. Interestingly, more than 80% of participants were willing to participate in future church-based health-promotion events.

Chan et al. (2008a) reported that passive watching of an educational video in the waiting room of an emergency department successfully improved stroke knowledge. Similarly, the strategy employed by He et al. (2014), in which educational videos were distributed to village doctor practices, was also successful. The use of hospitals and clinics for stroke education is advantageous as it targets chronically ill patients who may have a higher risk for stroke.

Inoue, Honda, Watanabe, and Ando (2015) devised a point-of-purchase stroke educational campaign within local supermarkets. Flyers containing coloured illustrations were distributed during a 3-week campaign with the aim of increasing public knowledge about stroke and how to respond in such an event. The flyers were distributed at cash points within two supermarkets. A slogan to activate emergency services was displayed in the local dialect "to attract attention, facilitate understanding, and psychologically imprint the process of calling EMS". The authors assessed stroke knowledge before and 3 months after the campaign using surveys distributed in the out-patient department of the main regional hospital. A significant increase in stroke knowledge and improvement in behavioural intent was observed following the intervention, confirming the effectiveness of this short-term, simple educational strategy.

2.6.10 Formal education

“Kids Identifying and Defeating Stroke” (KIDS) (Morgenstern et al., 2007) was designed to encourage stroke witnesses to activate emergency services. The study targeted middle-school children and was designed as a randomised controlled trial. Over 95% of emergency calls in the setting of stroke come from relatives or bystanders as opposed to the affected individuals themselves (Wein et al., 2000). Stroke suffers often develop aphasia and hemiparesis and are therefore unable to activate emergency services on their own. Hence, it is crucial that stroke education targets not just individuals at risk but also potential bystanders. The curriculum was taught over 3 years and emphasised the recognition of stroke symptomatology and how to improve behavioural intent (calling 911). The educational strategy used was based on social cognitive theory. Apart from formal teaching, several educational strategies were used to increase children’s knowledge including role play, the production of a public service announcement about stroke, the development of an interactive website, and the viewing of stroke-related motivational videos. The website reflected the cultural and environmental backgrounds of participants whereas the video portrayed the success story of a local teacher who had suffered from stroke. The success of this trial can probably be attributed to the use of tailor-made messages and the positivity of the messages delivered as opposed to a strategy focusing on fear. The authors concluded that, “rather than fear, encouragement and motivation in the form of improved outcome expectations were key to that intervention’s success”. Another part of the trial focused on the participants acting as educators. Children were given assignments to carry out at home in order to share their knowledge and skills with their parents. Participation was encouraged using small incentives. However, the educational effect on parents was disappointing and the authors concluded that an alternative strategy was required to target this group. This finding contrasts with “Hip Hop Stroke”, whereby children successfully taught their parents about stroke. The study was also limited by a high attrition rate, which may have biased the results. However, the trial outcome suggests that “a theory-based, scientifically developed educational intervention program” may be an effective way to educate lay persons about stroke symptomatology and the appropriate action to seek.

The ‘StrokeSafe’ seminar kit was developed by the National Stroke Foundation (NSF) to increase public awareness and the profile of acute stroke. The kit was a collection of evidence-based resources for use by healthcare professionals when organising stroke prevention seminars. ‘Ambassadors’ who were recruited and trained to lead stroke presentations conducted 242 educational presentations, reaching over 7000 people. Werner, Trobbianni, Burton, Lalor, and Bolam (2012) investigated the effectiveness of the ‘StrokeSafe’ kit by performing surveys among those who had attended the seminars. The authors identified improved stroke knowledge among attendees compared with a nationally comparable sample. However, the long-term effectiveness of the kit requires evaluation.

In a descriptive article by Navarro, Baroque, and Lokin (2013), an overview of the joint effort between academic institutions and professional organisations in the Philippines resulted in the development and introduction of a formal systematic undergraduate curriculum on stroke education. This effort was complemented by regular continued medical education (CME) activities and quality assurance of residency programmes. In 2011, a certification course on stroke medicine was organised by the University of Santo Tomas in association with the Faculty of Medicine and Surgery, which was followed by a masters course in 2013. An extensive stroke awareness campaign for the general public was also designed to run in parallel. This campaign included the distribution of flyers, delivery of lectures to the public and government health workers, an annual parade, and the use of mass media to disseminate knowledge about stroke. Conclusively, there was an increase in participation in stroke research and trials. However, Navarro et al. (2013) failed to assess the impact of this extensive stroke education strategy.

2.6.11 Conclusion

Multiple educational strategies have been used to increase public stroke knowledge and to hasten the activation of emergency services. Specific studies have combined multiple strategies in an attempt to increase the success of interventions. Although most studies reported a clear educational benefit, common challenges were faced, particularly the long-term decline in acquired knowledge (Hodgson et al., 2007) and the cost of running such educational campaigns. The use of social media for stroke education may not be as restricted by these factors and should therefore be explored (Alberts, 2012).

2.7 Existing stroke campaigns

2.7.1 Introduction

Although stroke awareness in Malta is still in its infancy, a number of existing stroke campaigns from other countries can be explored and potentially adapted to inform local actions. In the following section, the most prominent stroke campaigns found in the literature are reviewed.

2.7.2 National stroke campaigns

The Act FAST campaign in the UK was launched in 2009 (Public Health England, 2014) by the Stroke Association (a charitable organisation) in partnership with the UK Department of Health. The campaign focused on public education regarding stroke symptomatology and emphasised that stroke is a treatable condition. It also urged potential patients and bystanders to quickly take the appropriate action because "The faster you act the more of the person you save". FAST was employed as an acronym to capture both the most common symptoms of stroke (<u>F</u>acial drooping, <u>A</u>rm weakness, and <u>S</u>peech difficulties) as well as timely and appropriate intervention (Time to call emergency services). The campaign presented several genuine case scenarios and included the use of role models. The campaign included television adverts, posters, and billboards, and the launch of a dedicated website (National Health Service). The latter provided information about stroke and how a quick assessment could be performed. Furthermore, educational material in the form of leaflets and audio files could be downloaded from the website. Separate activities were aimed at the black and minority ethnic (BME) community, as these subsets of the population are twice as likely to suffer a stroke compared with people of European origin (Public Health England, 2014). More recently, it became possible to follow and support the campaign via social media. The Stroke Association (UK) also runs a number of other activities which include ‘Know Your Blood Pressure’, ‘Action on Stroke Month’, ‘My Stroke Victory’ and ‘Ask First’ (Stroke Association, 2016).

In the US, the National Institute of Neurological Disorders and Stroke (NINDS) launched the ‘Know Stroke. Know the Signs. Act in Time’ campaign in 2001 (National Institute of Neurological Disorders and Stroke, 2015). Again, the focus of the campaign was to educate the public about the symptoms of stroke and the potential benefits of acting quickly. One of the key messages of the campaign was ‘SUDDENS’, which summarises the five most common stroke symptoms: Sudden numbness, Sudden confusion, Sudden trouble seeing, Sudden trouble walking, and Sudden severe headache. Phrases such as ‘Stroke Strikes Fast. You should too. Call 9-1-1’ also urged potential stroke suffers to take immediate action. An 8-minute video discussed the symptoms of acute stroke and the action that should be taken, and included stories about previous stroke sufferers who had recovered from the condition. The target audiences of the campaign were those at high risk of stroke, including certain ethnicities (primarily African Americans and Hispanics) and the elderly. The educational messages were delivered via mass media, several partnerships, grassroots outreach, and community education. Family members, caregivers, and healthcare professionals were also targeted in this campaign as bystanders often play a crucial role in activating emergency services. Interestingly, the website offered an option to change the language to Spanish in order to target the Spanish-speaking Hispanic community. In 2004, NINDS also launched ‘Know Stroke in the Community (KSIC)’ in partnership with the Heart Disease and Stroke Prevention branch of the Centres for

Disease Control and Prevention. KSIC trained persons (referred to as 'Stroke Champions') within each community on how to use stroke educational materials, and then charged them with conveying the campaign messages to their community. Downloadable material on the website included a 'Community Education Kit'.

Although 'FAST' is catchy and easily remembered, it is not comprehensive regarding all stroke symptoms (Kleindorfer et al., 2007). Since stroke often presents with a single sign or symptom, there is a risk that certain signs are not captured by FAST. For this reason, the Stroke Collaborative (a joint effort of the American Academy of Neurology, the American Stroke Association, and the American College of Emergency Physicians) launched a new, more comprehensive mnemonic: 'Give Me 5 for Stroke'. The latter is easily remembered and includes all of the symptoms (Walk, Talk, Reach, See, and Feel) summarised in 'SUDDENS'. An online survey of 1000 participants (Dansereau, 2008) showed that the recall rate for all stroke signs was twice as high as that for 'SUDDENS'. Despite this, Lisabeth, Brown, Hughes, Majersik, and Morgenstern (2009) argued that a minority of strokes, particularly in women, presented with less typical symptoms, which were still not represented in 'Give Me 5 for Stroke'. The authors admitted, however, that "adding more information to the current public stroke messages could also add complexity and confusion".

In 2006, the World Stroke Association introduced a yearly event known as 'World Stroke Day', which is observed on the 29th of October (Medical News Today, 2010). The association chooses a specific theme every year. Stroke associations around the world organise events to highlight the serious nature of the condition and to raise awareness on the prevention and treatment of stroke. This event was preceded in the 1990s by a European awareness day celebrated on the 10th of May and organised by the European Stroke Initiative (Kaste, 2010). In 2009, the World Stroke Association extended 'World Stroke Day' to a year-round campaign to promote the awareness and prevention of stroke. Through its website, the World Stroke Association provides online education and teaching materials regarding stroke. A toolkit of campaign resources is also available online, which provides brochures, posters, and social media resources available in several languages (World Stroke Association, 2017).

“Recognise STROKE. Think F.A.S.T.” was launched by the Stroke Foundation in Australia. The foundation’s webpage offers comprehensive information about stroke, including its symptomatology, tips on prevention, and treatment. It also organises StrokeSafe seminars for healthcare professionals on a regular basis and also organises Stroke Foundation awards including a ‘courage’ and ‘creative’ award (Stroke Foundation Australia, 2017). Role models and previous stroke sufferers share their experiences and promote early stroke treatment by emphasising that stroke is potentially a reversible disease. The Stroke Foundation has also launched ‘#fightstroke’ on Twitter to target people using social media. Apart from advertising events organised by the foundation, the Twitter campaign provides educational videos, pictures, and comments on a daily basis.

Similarly, the Stroke Foundation of New Zealand runs the ‘See a Stroke FAST’ campaign, which helps New Zealanders to learn about the signs and symptoms of stroke and describes the appropriate action that should be taken. It also provides information and guidelines to health professionals to ensure that they are familiar with recent developments in the treatment of stroke. The Foundation also runs a number of preventive campaigns including ‘The Big New Zealand Blood Pressure Check’, ‘Salt Reduction’, and ‘Smokefree’.

The mission of the National Stroke Association in the US is “to reduce the incidence and impact of stroke by developing compelling education and programmes focused on prevention, treatment, rehabilitation and support for all impacted by stroke” (National Stroke Association, 2016). The association organises stroke groups and maintains a helpline for affected individuals and caregivers. A large number of resources are available on their homepage including information about stroke, its prevention, and its treatment. The association also promotes continued professional education for healthcare professionals and motivates them to raise awareness. It runs a number of campaigns including ‘Come back Strong’, ‘Faces of Stroke’, ‘Power to End Stroke’, ’Comeback Trail 5K series’, and ‘Time2Talk’.

‘Together to End Stroke’ is a joint initiative of the American Heart Association and the American Stroke Association that aims to educate Americans that stroke is a preventable and treatable condition. The initiative targets stroke care in a holistic fashion from prevention to acute treatment and post-stroke rehabilitation. The campaign highlights the

‘FAST’ warning signs of stroke and motivates people to activate emergency services at the first sign of stroke. The two associations also issue a magazine called *Stroke Connection* in which stroke success stories act as an inspiration to stroke survivors and their relatives. The magazine focuses on post-stroke care but also provides general information about the aetiology and symptomatology of the condition.

‘Stroke Heroes Act FAST’ was launched in 2006 by the Department of Public Health in Massachusetts to increase stroke recognition and promote early stroke treatment. It includes an award-winning animated video as well as posters and brochures. The educational materials are available in English, Spanish, and Portuguese to ensure that the educational message reaches the majority of the general public.

In 2010, the Department of State Health Service in Texas published a document called the ‘Stroke Public Education Campaign Tool Kit’. This comprehensive document describes the necessary steps to set up and implement a stroke educational campaign. It includes samples for press releases, letters to request funding for the campaign, an introduction letter to recruit stakeholders, and evaluation forms for the media campaigns. Although this campaign may not be fully applicable to other countries, it offers a vast collection of educational material that may be tailored to suit a particular location or community.

2.7.3 Conclusion

Although existing stroke campaigns can serve as an important template, it is imperative to note that no single campaign can be literally adapted without any amendments, particularly given the importance of considering cultural and other issues explored earlier in this review. Thus, prior to implementing any campaign, the local needs, values, and customs must first be thoroughly investigated in order to enhance the adoption of the campaign in the target population.

2.8 Theoretical framework

Theory plays a crucial role in behavioural science by “organizing major putative constructs and their inter-relationships in explaining the potential drivers underlying key behaviours in the health promotion arena” (King, 2015). For this reason, ecological frameworks have become very popular in recent decades in an attempt to understand and conceptualise an individual’s behaviour and its effects within different levels of society. Theories and frameworks that explicitly bridge different levels of influence are likely to have the greatest impact on public health. Such bridging approaches span two or more environments including behavioural, social, cultural, and physical constructs. Certain theories have therefore been proposed which consider or unify different levels of impact.

Several health promotion theories and models attempt to offer an understanding of such behavioural phenomena, and propose a guideline on how health-related behaviour may be optimised. The most relevant theories with respect to the current study are discussed in the following sections.

2.8.1 Health promotion theories and models

A major criticism of existing public health strategies is the fact that they lack a sound theoretical basis and may contrast with the target population’s values (Bauer et al., 2003; Stokols, 1996). Upon reflecting on this limitation, it may be considered beneficial to reflect on health promotion theories to facilitate the identification of target populations and select the most appropriate educational strategies. By contrast, Pring (2000) contended that “common sense or professional judgement” may form a more robust base for educational strategies as excessive theoretical focus may be unrealistic and therefore unnecessary.

A review of the literature highlights a number of popular health promotion theories/models that have been readily applied to health-related educational campaigns due to their pragmatic stance, applicability, and acceptability. On this basis, the models and theories discussed in the forthcoming subsections are the Health Belief Model, Transtheoretical Model, Social Learning Theory, Social Ecological Model, Theory of Reasoned Action, and Theory of Planned Behaviour.

2.8.1.1 Health belief model

One of the most influential health promotion models, the Health Belief Model, was described by Irwin Rosenstock in 1966 and attempts to explain why individuals may or may not adopt certain health behaviours and use health services. The model identifies four core constructs which determine a subject's behaviour: 'perceived susceptibility', 'perceived severity', 'perceived barriers', and 'perceived costs of adhering to the proposed intervention' (Rosenstock, 1966). Later, the model was modified to include 'compliance to medical directives' and, more recently, it evolved to address 'health prevention', 'detection concerns', and 'risk behaviours'.

In its application, the aim of this model is to emphasise the perceived susceptibility and seriousness of a particular health condition based on the notion that an individual's perceived susceptibility to a condition and his or her perception of preventive action explains his or her readiness to take acute preventative or management action. These individual perceptions are likely influenced by environmental and socio-economic factors which, along with 'cues to action', determine the likelihood of taking the recommended action (Becker & Maiman, 1975). 'Cues to action' include medical and peer advice, public health campaigns, and previously affected relatives and family members.

Since its development, the Health Belief Model has been well-tested and widely researched – this has generated evidence for the effectiveness of each of its components (Carpenter, 2010; Glanz, Rimer, & Viswanath, 2015).

However, this model assumes that health behaviour is modulated only by conscious and rational choices. Another major criticism of the model is that it is centred around the individual as opposed to assuming a more holistic approach whereby socio-physiological and demographic variables are also considered. It also focuses on negative rather than positive motivation to prompt behavioural change (Roden, 2004).

In relation to stroke, individuals will only activate emergency services if they understand and believe the perceived seriousness of stroke. This may subsequently lead to the conclusion that the benefits of action outweigh the perceived barriers, which will result in the desired behaviour.

In this light, the Health Belief Model may be applied by educating the target population about the prevalence, incidence, and risk of stroke as well as the potential multi-faceted consequences of the condition. Along the same lines, stroke educational strategies and campaigns need to focus on the potential benefits of early stroke treatment as this may alter an individual’s immediate actions.

2.8.1.2 Transtheoretical (Stages of Change) model

The Transtheoretical Model is a heuristic model which postulates that the willingness and readiness of individuals to change a health-related behaviour varies between individuals but also within individuals over time (Prochaska, DiClemente, Velicer, & Rossi, 1992). The model describes six key stages of behavioural change: ‘precontemplation’, ‘contemplation’, ‘preparation’, ‘action’, ‘maintenance’, and ‘relapse (resuming)’. The first stage describes an individual who is, as yet, unaware or unwilling to change. This is followed by the ‘contemplation’ phase, which corresponds to a person’s desire to change and intention to take action within the next 6 months. The ‘preparation’ phase is when the individual plans ways to achieve the desired change, and when the new behaviour is manifested on a regular basis, the individual has moved to the ‘action’ stage. ‘Maintenance’ is achieved when the new behaviour has been displayed consistently for at least 6 months. The final stage of ‘relapse’ refers only to those individuals who revert back to unhealthy behaviours following a period during which they would have otherwise successfully quit the undesirable behaviour. At each stage, interventional strategies may help individuals to progress to the next stage.

The Transtheoretical Model was modified to include three other concepts or core constructs in addition to the six stages of change. ‘Processes of change’, which is the first added concept, refers to ten covert and overt processes (or activities) undertaken by an individual in order to progress through the stages. The second core construct, ‘decisional balance’, outlines the action of debating the pros and cons of changing one’s behaviour. ‘Self-efficacy’ describes an individual’s confidence in him- or herself to not revert to the unhealthy behaviour in the face of temptation (Prochaska & Velicer, 1997). The authors also claim that the six ‘stages of change’ must be matched with the ‘processes of change’ in order for an individual to alter the behaviour. However, Riemsma et al. (2003) disagreed with this assertion by showing that interventions in which stages and processes of change were matched were not superior to non-staged interventions.

Similar to the Health Belief Model, the Transtheoretical Model places limited focus on the effect of social, political, and economic factors on behavioural change. Some authors have also criticised this model by pointing out that the separation between the different stages is somewhat blurred (West, 2005) and that the transition between the described stages may not necessarily occur in the described sequence (Littell & Girvin, 2002). Furthermore, the evidence base underlying this model is limited and inconclusive, as shown in a number of systematic reviews (Cahill, Lancaster, & Green, 2010; Salmela, Poskiparta, Kasila, Vähäsarja, & Vanhala, 2008; Tuah et al., 2011).

In relation to stroke education, the Transtheoretical Model may serve as an aid in its ability to incorporate various strategies that target the different stages that population constituents may be in. For instance, for individuals in the pre-contemplation phase, educational efforts may be placed on enhancing the acute awareness and mindfulness of the effects of the current behaviour and the potential benefits of a behaviour change. One way of achieving this is using testimonials by stroke sufferers, especially visual techniques that portray the effects of stroke in its victims. Such means have been successfully employed in smoking cessation strategies, such as the one by Health Canada (2012). Subsequently, healthy role models can be used to specifically target individuals in the contemplation phase who are contemplating the ways that a behavioural change may alter their identity. On reflection, the take-home lesson presented in this model is that a single behavioural change strategy may not be suitable for the entire target population, particularly if the intervention is not sustained.

2.8.1.3 Social Cognitive theory/Social Learning theory

The Social Cognitive Theory (Bandura, 1963) is the most popular feeder theory in health education (Macdonald, 2000). It stipulates that behaviour is moulded though observation and imitation as well as by positive reinforcement. The six main constructs of the theory are ‘reciprocal determinism’, ‘behavioural capability’, ‘expectations’, ‘self-efficacy’, ‘observational learning’, and ‘reinforcements’. Behavioural change is influenced through a continuous interaction between environmental, social, and personal factors, referred to as ‘reciprocal determinism’ in this model. ‘Self-efficacy’, or one’s confidence in his or her ability to take action, is crucial to triggering this process and is also a key construct of the Transtheoretical Model discussed above. Among others, the various applications of the Social Learning Theory include psychotherapy (Mineka & Zinbarg, 2006), media violence (Anderson & Bushman, 2001), and criminology (Akers & Jensen, 2011). Its relative simplicity and optimism may be features that enhance the theory’s applicability potential. However, the main criticism of this theory revolves around its assumptions that changes in the person’s environment may lead to behaviour change, which may not always be the case. Furthermore, the theory’s main focus is the learning process, whereas other factors such as biological predispositions, emotions, and motivation are omitted (McLeod, 2016).

The core concept of the Social Learning Theory is that individuals learn not just through their past experiences but also by observing the actions of others and the resulting benefits. Thus, the importance of role models in ‘observational learning’ can again be appreciated as a potentially effective means to promote behavioural change. Such campaigns should focus on positive re-enforcement, that is, highlighting the benefits of seeking emergent behaviour in acute stroke as opposed to portraying the consequences of not taking the necessary actions. Well-designed educational campaigns may also stimulate self-efficacy by promoting simple messages and easy-to-understand instructions such as those that characterise the FAST campaign. Finally, motivational stimuli can also be symbolic, such as the use of fictional characters and movies (Bandura, 1972).

2.8.1.4 Social Ecological models

Social ecological models focus on the effect of environmental factors on an individual's behaviour. One of the most influential models of this kind is the Ecological Framework for Human Development by Bronfenbrenner (1979). This theory describes the individual as a central and key agent within the ecological system. An individual's biological makeup and physiology are continuously moulded by the 'microsystem' (which represents the immediate physical and social environments). Such a system will interact with similar systems within a broader environment called the 'mesosystems'. The next level of influence, also known as the 'exosystem', includes broader social, political, and economic factors. The latter are in turn influenced by attitudes and general beliefs exhibited by other members of the society (referred to as 'macrosystems'). Behaviour is shaped by both intra- and inter-level interactions within the described systems. This model highlights the complexity of human behaviour but also identifies potential targets for behaviour modification. In the case of stroke response, background knowledge remains a pre-requisite for adequate response, but a complex behavioural process will ultimately determine whether an individual engages in such a response.

The specific Social Ecological Model described by McLeroy, Bibeau, Stickler, and Glanz (1988) builds on the multilevel approach of Bronfenbrenner and presents multiple levels of influence, including 'individual/intrapersonal', 'interpersonal', 'organisational/institutional', 'community', and 'public policy'. Furthermore, it endeavours to explore how these levels influence and are influenced by the individual's behaviour. The model suggests that creating an environment receptive to change is crucial for an individual to adhere to the suggested behavioural change.

Social Ecological Models have been adapted to a number of strategies such as the Colorectal Cancer Control Program (Centers for Disease Control and Prevention, 2015) and sexual violence prevention at work (Washington Coalition of Sexual Assault Programs, 2010). The foremost limitation that has been presented in relation to this model is that in practice it may prove to be so broad and comprehensive that its effectiveness is jeopardised, and that the outcomes of the interventions may lack clarity. On the other hand, a broad and comprehensive perspective may represent a strength as it facilitates an understanding of the individual in his or her social and cultural environment rather than as a standalone entity (Thorogood & Coombes, 2010).

In stroke promotion, it may be beneficial to use a strategy that is both person-focused and environment-focused as this is likely to boost the effectiveness of a campaign. In this regard, stroke educational efforts should also target institutions and the community in general as these stakeholders continuously interact and affect an individual’s behaviour. Figure 2.2 depicts the multiple levels of influence in the Social Ecological Model described by McLeroy et al. (1988) and their application in stroke education.

Level of Influence	**Definition**	**Application in Stroke Education**
Individual/Intrapersonal	Individual characteristics e.g. knowledge, attitudes, behaviour, self-concept, skills, and developmental history	In addition to mass campaigning, there is the need to offer individual-focused support such as support groups and peer counselling
Interpersonal	Social network and social support systems e.g. family, work, and friendships	In this regard, stroke education may: - Focus on other, e.g. young children, in addition to the population sample with the highest risk - Attempt to change the norms within existing networks, e.g. reluctance to call emergency services
Organisational/institutional	Social institutions that have rules for operation	Highlights the need for stroke strategies to explore how organisations and institutions can be used to support behavioural change
Community	Relationships among institutions, organisations, and informal networks	Prior to the construction of a stroke strategy, it may be useful to explore the community network to attempt to form a chain of

		support, e.g. informal networks may be very useful for delivering the message but may lack the funds to do so and thus need help from formal organisations
Public policy	Local, state, and national laws/policies	Promoting change at a public policy level may result in a regulatory effect which protects community health. Thus, stroke strategists need to liaise with policy makers and decipher which parts of the strategy may be included in a formal policy

Figure 2.2: The Multiple Levels of Influence in the Social Ecological Model (McLeroy et al., 1988) and their Application in Stroke Education

2.8.1.5 Theory of Reasoned Action

The Theory of Reasoned Action is a psychological persuasion model with three main constructs: ‘behavioural intention’, ‘attitude’, and ‘subjective norms’ (Gillmore et al., 2002).

An individual’s behaviour (‘behavioural intention’) is determined by his or her intrinsic behavioural intentions, which are based on his or her ‘attitude’ towards the behaviour in question and beliefs on whether other people (‘subjective norms’) would support such behaviour (Fishbein, 1975). In other words, people consider the consequences of their behaviour before engaging in that behaviour. The attitude towards a particular behaviour is moulded by the individual’s outcome expectations and the values of such expectations.

Although the Theory of Reasoned Action has been given prominence in social psychology, its main criticism revolves around the contention that it is not falsifiable (Trafimow, 2009). It has also been argued that intentions may not always necessarily be the best indicators and determinants of behaviour (Sommer, 2011).

Importantly, when it comes to stroke strategies, this theory may explain the discrepancy demonstrated in a number of studies described in Section 2.6 whereby educational strategies, despite managing to improve stroke knowledge in the community, often fail to alter behavioural intent. Affected patients will likely consider all factors, including ‘subjective norms’, before making the call to activate emergency services in acute stroke. For instance, in a given culture, if the activation of emergency services is viewed as a personal weakness and an inability to tolerate suffering, individuals may show reluctance to engage in this desired behaviour. In such situations, role models may also be crucial as they help an individual to approve the behaviour in question. This theory also highlights the importance of any stroke education strategy for demonstrating the benefits of early treatment, as this may modify an individual’s ‘attitude’ towards that behaviour. Hence, similar to the Social Cognitive Theory, positive reinforcement in delivering a stroke education programme is paramount.

2.8.1.6 Theory of Planned Behaviour

The Theory of Planned Behaviour described by Ajzen (1985) is an extension of the Theory of Reasoned Action and introduces the concept of an individual’s perceived behavioural control. It states that, apart from subjective norms and attitudes towards the behaviour, behavioural intention is reliant on a person’s perceived control of opportunities and resources as well as the skills needed to perform such behaviour. Perceived behavioural control is similar to the ‘self-efficacy’ concept in the Social Cognitive Theory. Individuals may not have conscious control of behavioural decisions as, for example, when they fail to carry out a behaviour due to lack of confidence and control. The Theory of Planned

Behaviour predicts that the likelihood of behavioural change is directly dependent on the individuals ‘self-efficacy’ and their control over their behavioural intent.

This theory has been successfully applied to a number of health promotion initiatives such as smoking cessation, drinking, substance misuse, and breast feeding (Bashirian, Hidarnia, Allahverdipour, & Hajizadeh, 2012; Giles et al., 2014; Swanson & Power, 2005; Topa & Moriano, 2010). In this regards, it has proven to be more advantageous than the Health Belief Model. Several studies have contributed to the sound evidence base behind this theory and have shown in particular that it is more effective at predicting behavioural intention than the Theory of Reasoned Action in a number of fields such as exercise and diet (Conner, Kirk, Cade, & Barrett, 2003; Nguyen, Potvin, & Otis, 1997). However, this theory is commonly criticised as being limited in its consideration of extraneous factors (such as environmental and economic factors) and unconscious behavioural influences (Sniehotta, Presseau, & Araújo-Soares, 2014).

In stroke education, the application of the constructs that characterise the Theory of Planned Behaviour may primarily facilitate the prediction of the person’s action in risk-conducive situations, in this case the decision whether or not to activate emergency services when subjected to possible stroke symptoms. This is possible through the identification of factors that may influence the individual’s decision and volitional control. Thus, when setting up a stroke education campaign, it is beneficial to keep in mind that individuals are more likely to change their behaviour if (a) they belief that this results in health benefits (e.g. limiting negative stroke consequences by seeking early help); (b) they have the approval of others (e.g. their spouse supports the activation of emergency services in the face of possible stroke symptoms; (c) they have the appropriate skills (ability to identify the prominent stroke symptoms); and (d) the necessary resources are accessible (accessible emergency services) (Ajzen, 1991).

2.8.2 Stroke education and health models/theories

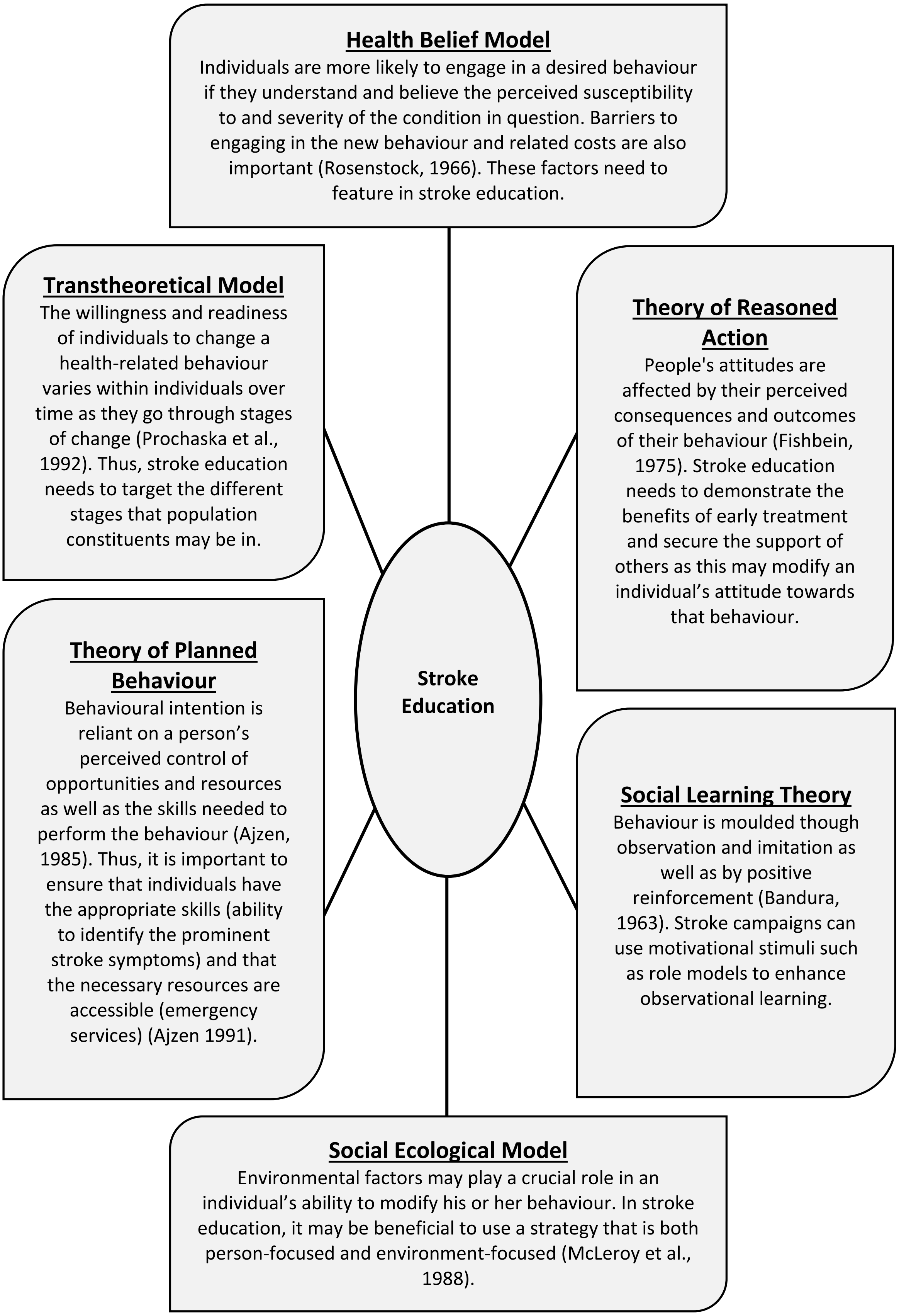
A review of the prominent health promotion models and theories certainly shows that behavioural change is a highly complex matter that requires careful initial planning and sustained action to increase the chances of success. Upon reflection on the main constituents of these models/theories, a number of points emerge in relation to stroke education. Primarily, it may be the case that stroke care – and indeed health promotion in general – needs to shift from crisis management towards prevention and behavioural change science. Additionally, stroke strategies need to identify the level of change that should be targeted, specifically whether a particular strategy should target the individual level, a broader population level, or perhaps aim for a structural change. This may not only increase the potential success of a strategy but may also determine its cost-effectiveness.

It is also crucial to consider the epidemiology of stroke and to keep in mind the customs, beliefs, and demographics of those affected. The incidence, morbidity, and mortality of stroke varies significantly between different ethnic groups. Trust – or rather lack of it – is a major concern among low socio-economic groups, African American, and Hispanic communities (Becker & Newsom, 2003; Lewis & Green, 2000; Monheit & Vistnes, 2000). These factors likely explain the sub-optimal results achieved with the earliest educational campaigns, which were generic and failed to recognise place and culture (Boden-Albala & Quarles, 2013). This observation highlights the necessity for any stroke strategies to be tailor-made to the target population in their content and method of dissemination. Culturally appropriate strategies are more likely to influence personal and community 'attitudes' and 'subjective norms' and therefore to promote the intended behavioural change.

Another issue to consider is that education strategies should ideally involve community engagement initiatives, particularly conversation with the target community, the introduction of collaborative leadership, and the promotion of dialogue and resource-sharing (Horowitz, Robinson, & Seifer, 2009).

Finally, it should be noted that preparedness behaviour is a key area of behaviour modification in acute stroke and necessitates that potential sufferers achieve competency skills through brief interventions with re-enforcements (Boden-Albala, Tehranifar, Stillman, & Paik, 2011) to enhance the 'maintenance' of their behaviour. Such competency skills can be improved through well-designed, culturally appealing education strategies aimed at increasing an individual's 'self-efficacy' and his or her 'perceived behavioural control'. Campaigns should focus on positive enforcement and highlight the expected benefits of early treatment. As predicted by the health promotion models and theories discussed previously, this focus may be more effective when employing role models.

Figure 2.3 depicts the principles of the health promotion theories and models described and their potential contributions to stroke education.



Health Belief Model

Individuals are more likely to engage in a desired behaviour if they understand and believe the perceived susceptibility to and severity of the condition in question. Barriers to engaging in the new behaviour and related costs are also important (Rosenstock, 1966). These factors need to feature in stroke education.

Transtheoretical Model

The willingness and readiness of individuals to change a health-related behaviour varies within individuals over time as they go through stages of change (Prochaska et al., 1992). Thus, stroke education needs to target the different stages that population constituents may be in.

Theory of Reasoned Action

People's attitudes are affected by their perceived consequences and outcomes of their behaviour (Fishbein, 1975). Stroke education needs to demonstrate the benefits of early treatment and secure the support of others as this may modify an individual’s attitude towards that behaviour.

Stroke Education

Theory of Planned Behaviour

Behavioural intention is reliant on a person’s perceived control of opportunities and resources as well as the skills needed to perform the behaviour (Ajzen, 1985). Thus, it is important to ensure that individuals have the appropriate skills (ability to identify the prominent stroke symptoms) and that the necessary resources are accessible (emergency services) (Ajzen 1991).

Social Learning Theory

Behaviour is moulded though observation and imitation as well as by positive reinforcement (Bandura, 1963). Stroke campaigns can use motivational stimuli such as role models to enhance observational learning.

Social Ecological Model

Environmental factors may play a crucial role in an individual’s ability to modify his or her behaviour. In stroke education, it may be beneficial to use a strategy that is both person-focused and environment-focused (McLeroy et al., 1988).

Figure 2.3: Application of Health Promotion Theories to Stroke Education

2.8.3 Selected theory

The *Ecological Framework for Human Development* by Bronfenbrenner (1979), described in Section 2.8.1.4, captures most of the principles discussed in the above theories and can be regarded as a somewhat eclectic approach to understanding human knowledge and behaviour. For this reason, this framework was selected to guide and enhance understanding during the research process followed in the current study.

2.8.4 Conclusion

To devise a cost-effective stroke education campaign, previous campaigns should be revisited to identify the features that made these campaigns successful. As previously discussed, health campaigns are often extremely expensive to run, and improving their cost effectiveness is therefore crucial. A number of health promotion theories and models should also be considered to understand more complex interactions between knowledge and behaviour. It may also be beneficial to study the characteristics of other successful medical (Condie, Rivara, & Bergman, 1993; Dzenowagis, 1996; Kiwanuka-Tondo, Hamilton, & Katz Jameson, 2009), political (Erickson & Lilleker, 2012), and marketing campaigns (Etter, Grossglauser, & Thiran, 2013).

2.9 Devising and delivering the stroke message

2.9.1 Introduction

Any stroke educational campaign requires an easy-to-remember message that describes stroke symptomatology and the action that needs to be taken. The content of the message should be easily understood by lay persons to increase its effectiveness. When describing the symptoms of acute stroke, the message needs to be comprehensive yet not overly complex and exhaustive. For example, although the ‘FAST’ message, developed from the Cincinnati Prehospital Stroke Scale (Kothari et al., 1999b), only incorporates three acute stroke symptoms/signs, it has been shown to be highly sensitive in identifying acute stroke patients (Kleindorfer et al., 2007). However, the message in the ‘Know Stroke’ campaign from the National Institute of Neurological Disorders and Stroke (NINDS) launched in 2012 was much more sensitive and comprehensive. Its five ‘sudden’ points included additional signs and symptoms of acute stroke but, as a result of its comprehensiveness, it was much more difficult to recall and therefore less practical.

Mnemonics translate complex messages into simpler forms and aid information retention. It has been suggested that even the process of learning the conversion used for the mnemonic may aid long-term memory. ‘FAST’ is a perfect example of this, and apart from describing stroke symptoms it incorporates the factor of ‘time’ and the necessity to promptly activate emergency services. However, the mnemonic needs to be suited to the target population. For example, in a study by Sakamoto et al. (2014) participating children in Japanese schools had trouble memorising the ‘FAST’ mnemonic as the acronym was in English, a language that these elementary school children did not speak.

The message used should be catchy and easily remembered to aid long-term retention. Interestingly, in a study by Kleindorfer et al. (2008), participants could not recall the risk factors for stroke but remembered its signs and symptoms though the ‘FAST’ mnemonic. Similarly, incorporating the stroke message into songs (Williams & Noble, 2008) and cartoons (Shigehatake et al., 2014) has been shown to be an effective strategy. Visual depictions may also aid in understanding the signs and symptoms of acute stroke (Kleindorfer et al., 2008). While devising the stroke message, it is important to consider health literacy in order to enhance effectiveness, as explored in the following section.

2.9.2 Health literacy

Health literacy is “the ability to obtain, process, and understand health information and services needed to promote better health” (Sanders et al., 2014). Apart from representing a major barrier to reducing risk factors in patients at risk of stroke, inadequate health literacy has been linked to an inability to understand medical advice (Kalichman et al., 1999, Chew et al., 2004) and to lack of compliance with the prescribed treatment (Mayeaux et al., 1996, Hope et al., 2004). “Health literacy represents a constellation of skills to perform health-related tasks, and may be significantly worse than functional literacy because of the unfamiliar context and vocabulary of the health care system” (Hahn, 2015).

Health literacy is equally important for clinicians, who need to speak the language of their patients and take their cultural backgrounds into account if they are to aid the implementation of the knowledge conveyed to those patients (Benjamin, 2010b). Bass et al. (2002) found that clinicians assessed their patients’ literacy skills very poorly and often overestimated their ability. Powell and Kripalani (2005) also found that even when clinicians were aware of a patient’s low literacy level, they failed to take the appropriate action to enhance communication.

Recent data suggest that less than 50% of adults possess the required skills to meet healthcare literacy demands (Statistics., 2006). Poor health literacy was also associated with a lower socio-economic status and increased prevalence of risk factors for preventable conditions (Joshi et al., 2014).

2.9.2.1 Health literacy and stroke

A large proportion of stroke patients have a poor level of health literacy, which complicates their understanding of the condition. Hahn (2015) found that stroke patients had the lowest level of health literacy among three sub-groups in their study, namely patients with stroke, spinal cord injury, and traumatic brain injury. Similarly, Fang et al. (2009) found significant gaps in health literacy among patients at high risk of stroke. Health literacy within this cohort was also directly proportional to educational achievement. These findings were replicated in a study by Sanders et al. (2014), who found that inadequate health literacy was more prevalent within a high-risk population.

The concept of health literacy is particularly important in patients with recurrent stroke. These patients would normally receive education (either formal or informal) during their hospital stay, and the retention of this knowledge is crucial because the risk of a further stroke is as high as 11% at 1 year (Mohan et al., 2011). Bushnell et al. (2013) conducted a study in which 90 stroke patients were provided with individualised tailor-made coaching. The authors concluded that health literacy played a crucial role in tailor-made education and was associated with a reduction in hospital readmissions.

Quarles et al. (2013) explored factors within the community that are related to stroke knowledge and preparedness by carrying out a culturally tailored stroke educational intervention among 423 members of the community. The authors found a strong correlation between the level of health literacy and stroke knowledge ($p = 0.0001$).

2.9.2.2 The impact of health literacy on stroke education

Sanders et al. (2014) explored the effect of health literacy on the retention of stroke education in a prospective cross-sectional study. They found that patients with adequate and marginal health literacy had better stroke information recall compared with those having inadequate literacy ($p = 0.006$ and $p = 0.020$, respectively). These results highlight the necessity of stroke educational programmes that accommodate for these discrepancies in health literacy in order to increase their effectiveness. The authors failed, however, to assess the long-term retention of the educational material conveyed in the three literacy sub-groups.

Similarly, Appleton et al. (2015) have suggested that health literacy needs to “be a priority for policymakers and clinical service designers to improve primary and secondary stroke prevention”. Literacy in stroke may not only bridge the knowledge gap regarding stroke as a preventable disorder but may also prompt patients to improve their modifiable risk factors.

Conversely, in a pre- and post-intervention study by Quarles et al. (2013), the level of health literacy among participants did not correlate with post-intervention competency (p = 0.116). The authors concluded that “appropriate intervention can overcome disparities in health literacy to improve stroke education for all”. The authors also tried to simplify standard stroke educational material, which is often written at a high-school level or higher, meaning that a large proportion of people who can only read and comprehend at a lower level struggle to understand the message portrayed. The authors used aggressive editing to simplify the standard material but failed to achieve their target reading level. This shows that terms and concepts routinely used in stroke education are highly complex and cannot easily be replaced with simpler terms while preserving the desired message. Similarly, Wallace and North American Primary Care Research (2006) found that more than 80% of non-prescription medical websites were written at a tenth grade reading level, which is well above the average lay-person’s level.

“Inadequate health literacy is a pervasive problem with major implications for reduced health status and health disparities” (Sanders et al., 2014), which has led the US Surgeon General to list improvement in heath literacy as a national priority (Benjamin, 2010a).

2.9.3 Delivering the message

The educational message should ideally reach the entire target population and be repeated to ensure that it is communicated effectively and can be recalled. As seen in Section 2.6, the choice of delivery medium has a significant impact not only on the percentage of the population reached but also on the demographic and socio-economic groups that are more likely to be influenced (Pieters & Bijmolt, 1997; Singh et al., 1994).

One should also consider whether a stroke educational campaign is primarily targeted at those at risk of stroke as opposed to potential bystanders. Stroke is often a severe, acutely debilitating condition, and the victim may be unable to activate emergency services on their own. Thus, some campaigns have targeted children (Sakamoto et al., 2014; Williams & Noble, 2008), who may not only relay the educational message to their relatives but may also witness an acute stroke. As discussed previously, educational messages need to be repeated at regular intervals to enhance their effectiveness. The educational benefit tends to decline over time following the intervention and repeated brief messages have been shown to achieve better long-term educational effects (Tadros et al., 2009). This pulsed approach has also been utilised in a study by Becker et al. (2001). The effectiveness of stroke education may also be increased by targeting strategic locations within the community. Places which are regularly frequented by a large number of people such as churches, pharmacies, and waiting areas have been shown to be effective sites for health education (Fogle et al., 2010).

2.9.4 Campaign sustainability

Running a stroke educational campaign can prove to be very costly, particularly when repeated exposures are necessary. Nowadays, the emphasis in healthcare is on preventive measures to avoid or reduce disease in the first instance. Educational campaigns may still prove to be cost-effective in the long term, as the morbidity and mortality of stroke can present huge financial implications. The quality of life of affected patients should also be considered – particularly because of the availability of early stroke treatment, which can be very effective. Irrespective of which strategy is chosen, the likelihood is that the cost of devising the campaign, recruiting the necessary personnel, and delivering the educational messages is significant. For example, a mass media stroke educational campaign by Hodgson et al. (2007) cost $3.7 million. The cost may prove to be even more excessive if repeated exposures are to be employed. This led Tadros et al. (2008) to explore and implement alternative and less-expensive stroke education strategies.

Additionally, Alberts (2012) suggested the use of social media to tackle the prohibitive costs of traditional educational campaigns.

2.9.5 Conclusion

As discussed in the previous sections, the feasibility of a stroke educational campaign lies in its cost effectiveness, especially when local healthcare budgets are already stretched due to ever-increasing healthcare demands. Adequate planning to devise an effective stroke message and in choosing an optimal delivery method is therefore crucial to convince relevant stakeholders of its value.

2.10 Outcome measures of the campaign and impact evaluation

2.10.1 Introduction

The primary objective of any stroke educational campaign should be an improvement in long-term clinical outcomes. It is not sufficient to educate people about the symptomology of stroke unless they are educated and urged to activate emergency services. Moreover, stroke campaigns are often prohibitively expensive and their short- and long-term benefits cannot be guaranteed. It is therefore a pre-requisite for anyone considering embarking on a stroke educational campaign to thoroughly assess the direct and indirect effects of similar campaigns in order to determine which strategies may be most cost-effective. Thus, it is crucial to explore why discrepancies between stroke knowledge and a reduction in pre-hospital delay may persist, and to try to tackle the causative factors. A rigorous auditing system should also be established to monitor the effectiveness of the educational strategy employed and to enhance the primary outcomes.

2.10.2 Effect on public stroke knowledge

Trobbiani et al. (2013) evaluated the effectiveness of three nationwide stroke awareness campaigns, FAST, SUDDENS, and FAST in England, Canada, and Australia, respectively, by comparing surveys in target populations before and after the respective campaigns. Data collection was heterogeneous. While phone interviews were used to collect data in Canada and Australia, in-home interviews were carried out in England. All interviews were conducted within 2 months of the campaign launch to facilitate recall. Knowledge of stroke symptomatology was highest in England in both the pre- and post-campaign surveys. The authors also found that the campaign was most effective in England, with a 19%, 12%, and 10% improvement in the knowledge of symptoms affecting face, arm, and speech, respectively. The discrepancy in improvement between England and the other two countries was statistically significant ($p < 0.001$). Only 67% of Canadian participants (both before and after the campaign) reported that they would call an ambulance in the event of stroke, compared with 97% and 90% of participants in England and Australia, respectively.

Becker et al. (2001) and Hodgson et al. (2007) also showed that educational campaigns were effective in increasing stroke knowledge. Marx et al. (2009) evaluated the effect of a 3-month multimedia campaign that targeted several sub-groups including those at high risk for stroke. Data were collected via computer-assisted telephone interviews in central Germany. Statistically significant improvements were found both in stroke knowledge and individual risk perception. The main limitation of this study was the collection of data via telephone surveys, which may have excluded certain parts of the population.

Similarly, Bray et al. (2013) showed that the National Stroke Foundation (NSF) campaign in Australia was effective in increasing public awareness of stroke symptomatology. The recall rates of various acute stroke symptoms increased significantly between the pre- and post-intervention periods. The main limitations of the study were that data collection was carried out very close to campaign saturation, and that it only included English-speaking participants. The authors concluded that public stroke education was worthwhile, and echoed the suggestions of Marx et al. (2009) in that stroke educational campaigns should target more vulnerable sub-groups.

Lee, Lee, Kong, and Go (2014) assessed the effects of a traditional Korean medicine stroke prevention education programme (TKM-SPEP). The study included 149 participants and the programme was delivered over four sessions. Participants demonstrated improved knowledge of stroke warning signs ($p = 0.0269$), its causes ($p = 0.0002$), and the long-term effects of the condition ($p = 0.0002$). The authors failed, however, to assess whether the educational programme influenced participants' behaviour and whether the educational efforts reduced stroke incidence.

In a narrative synthesis summarising the effectiveness of stroke educational campaigns, Rasura et al. (2014) found that almost all included studies were at least partially effective in increasing stroke awareness or in altering the behaviour of participants. This review included studies up to 2012 and included a number of e-health tools and online campaigns. Other media-driven awareness campaigns have also been shown to positively impact stroke knowledge (Reeves et al., 2008b; Silver et al., 2003).

By contrast, Blades et al. (2006) showed how a high-intensity 3-month educational campaign failed to influence the outcomes of their study, namely awareness of the signs and risk factors of stroke and the need to call 911. Similar results were observed by Mazor and Billings-Gagliardi (2003), who carried out an interventional study to assess the impact of printed educational material on stroke knowledge among lay people. The authors assessed stroke knowledge at an average of 18 days following the distribution of one of five versions of information packets. The interventional strategy had a minimal effect on stroke knowledge, despite measuring the effects very early on after the intervention. Mazor and Billings-Gagliardi (2003) concluded that "print materials … may not be an effective means of increasing stroke knowledge in the general public, at least not without supplemental instruction or repeated exposure". The study also revealed that the delivery of stroke education was more effective using fictionalised material as opposed to expository material. The main limitation of the study was the lack of a control group.

A study by Kleindorfer et al. (2009) highlighted an important aspect of stroke educational campaigns. The authors assessed temporal variations in stroke knowledge over a 10-year period during which multiple public awareness campaigns were carried out. Despite an initial improvement in stroke knowledge between 1995 and 2000, knowledge did not improve further between 2000 and 2005. This demonstrates that campaigns may reach a saturation level, where further educational effort does not necessarily translate into improved knowledge.

2.10.3 The 'disconnection' between knowledge and action

Pre-hospital delay is a highly complex process in which a number of influential factors interact with stroke knowledge, including the perceived seriousness of the condition, embarrassment in calling emergency services, and the perceived control over the situation (Moser et al., 2006). Hodgson et al. (2007) also states "there are many factors that may influence presentation for stroke and awareness of the warning signs may be only one".

Fussman et al. (2010) showed that improved stroke knowledge may not necessarily translate into rapid and appropriate action in the event of a stroke, and that a 'disconnection' exists between the two. Marx et al. (2008) also showed that increased knowledge following a multimedia campaign failed to trigger a change in intended behaviour in stroke.

Dombrowski et al. (2015) assessed the effects of a standard 'Act FAST' campaign leaflet in their controlled study performed in Newcastle-upon-Tyne. Participants within the intervention group were able to recall more elements of the FAST mnemonic compared with the control group ($p < 0{\cdot}001$). However, there was no significant difference between the two groups in their ability to recognise stroke or in their response to stroke-based scenarios. These findings reflect the difficulty experienced by potential stroke sufferers in matching their perceived stroke symptoms to the individual elements contained in the

FAST mnemonic, which was also highlighted by Bray, Connell, Gilligan, Livingston, and Bladin (2010) and Dombrowski et al. (2013).

Similarly, in their systematic review Lecouturier et al. (2010), found that mass media campaigns aimed at the public were effective in raising awareness about the symptomatology of stroke but had no impact on behaviour. The review included ten studies of mass media interventions, six of which were aimed exclusively at the public while four also targeted professionals. The authors found that campaigns may have a more significant impact on professionals and could improve the organisation of stroke services. The review was limited by the heterogeneity of methods and study designs used in the selected studies. Furthermore, only three studies included a control, meaning that it is difficult to assess whether any changes could have been attributed to the intervention. The major limitations of the study were a lack of ethnic diversity within the study population and a low response rate of 33%.

Mellon, Hickey, Doyle, Dolan, and Williams (2014) also revealed the inefficacy of stroke media campaigns in translating knowledge into appropriate action. The authors postulate that this is likely secondary to the fact that “prehospital delay in accessing acute stroke services is a complex process with involvement of factors other than stroke knowledge and intention to call 911”.

In the controlled study by Fogle et al. (2010), the impact of a 20-week stroke educational campaign carried out in Montana was assessed. Stroke knowledge increased in all sub-groups within the intervention group as opposed to the control group in which no significant change was documented. However, this knowledge failed to translate into appropriate action as there was no significant change in the intention to call 911 if a stroke was witnessed in either group. Interestingly, certain acute stroke symptoms (e.g. numbness and loss of sensation) elicited the need to call 911 within the control group. This finding reflects the complex processes involved in translating stroke knowledge into behaviour. The major limitation of the study was the collection of data via telephone surveys, meaning that households without telephones were excluded.

Similar results were also obtained by Mikulík et al. (2011), who showed that despite an improvement in public stroke knowledge following a moderate-intensity nationwide educational campaign, there was no significant change in the intention to call 911. Similarly, public health campaigns for myocardial infarction failed to reduce the time interval from onset to presentation at the A&E (accident and emergency) department (Bett, Tonkin, Thompson, & Aroney, 2005; Luepker et al., 2000).

"There is a discrepancy between theoretical stroke knowledge and the reaction in an acute situation. Help-seeking behaviour is more dependent on the perceived severity of symptoms than on symptom knowledge" (Teuschl & Brainin, 2010).

2.10.4 Care-seeking behaviour

"When the outcome is behaviour, end-points that are early in the causal chain, such as knowledge and attitudes, are insufficient, as even a strong effect on these cognitive outcomes will be attenuated as they are mediated through motivational and action-oriented processes to result in behaviour" (Michie & Johnston, 2012). Although there may be a disconnect between knowledge and behaviour, several educational campaigns and stroke studies have produced a significant change in the behavioural outcomes of affected individuals. For instance, Kim et al. (2011) showed that stroke awareness (in both patients and bystanders) was directly correlated with early presentation to hospital and was a major determinant of thrombolysis treatment. Although knowledge alone may not influence the initial response in the setting of an acute stroke, it "is a prerequisite for appropriate actions" (Mazor & Billings-Gagliardi, 2003).

Mellon et al. (2014) assessed the change in health service use by stroke patients following the first nationwide campaign in Ireland. The campaign used the FAST message and was broadcast through national television and local radio advertising. The authors noted a significant change ($p < 0.001$) in presentation to the emergency department by stroke patients.

Flynn et al. (2014) assessed the impact of three consecutive cycles of the FAST mass media campaign in the UK. The authors showed that views to the Stroke Association website, the number of calls to the Association’s helpline, and information material downloaded from their website increased significantly during the three cycles of the campaign. After phase 1, there was a significant increase in the number of emergency admissions and patients admitted via the A&E department. The rate of thrombolysis also increased drastically after the first and third cycles of the campaign.

Similarly, the TLL Temple Foundation Stroke Project (Morgenstern et al., 2002) showed that an aggressive stroke intervention programme can increase the delivery of acute stroke treatment in affected individuals. This outcome should be the end-point of any educational campaign, as this is what influences the morbidity and mortality from stroke and is therefore more important than simply measuring change in stroke knowledge. The authors showed that the rate of intravenous thrombolysis increased from 2% to 9% ($p = 0.02$) within the interventional group, while no significant changes were documented in the control group. Furthermore, the behavioural change in the intervention group was sustained in a follow-up study conducted by the same authors (Morgenstern et al., 2003).

Similarly, Alberts et al. (1992) showed how an educational campaign that targeted both the public and health professionals resulted in a significant reduction ($p < 0.00001$) in presentation delay following stroke. The campaign focused on stroke symptom recognition and was delivered via mass media.

Boden-Albala et al. (2015) carried out a randomised controlled trial to assess whether two different stroke preparedness educational strategies (interactive intervention (II) and enhanced educational (EE) materials) could reduce the time interval between stroke onset and presentation to the emergency department. The study included 1193 participants from different ethnic and socio-economic striata of the community. Although there was no significant difference in effectiveness between the two strategies, both resulted in a considerable increase in patients presenting within 3 hours of symptom onset. The main limitation of the study was that it lacked a placebo arm.

2.10.5 Long-term outcomes following stroke campaigns

Flynn et al. (2014) observed that outcomes decreased steadily during periods with no campaign activity. Despite this, the authors noted an enduring positive impact of the campaign on public behaviour in terms of stroke awareness and response to stroke symptoms.

Similarly, Wolters, Paul, Li, and Rothwell (2015) found that, following the FAST campaign, a larger percentage of individuals living in the UK presented directly to emergency services following stroke and arrived within a 3-hour window from symptom onset. The pre- and post-campaign differences were statistically significant (OR = 2.18, $p < 0{\cdot}0001$). Perhaps more importantly, the authors demonstrated a long-term benefit of the campaign since the outcomes were sustained between 2009 and 2013. The major limitation of this population-based study was that the authors assumed that any effects were directly related to the FAST campaign, but this cannot be ascertained.

The latter contrasts with the evaluation of other campaigns that failed to demonstrate a sustained benefit. Following a nationwide campaign in Ireland, Mellon et al. (2014) noted that the increased early presentation at the emergency departments was not sustained. The authors concluded that “accessing acute stroke services is a complex process with involvement of factors other than stroke knowledge and intention to call 911”. Hodgson et al. (2007) and Reeves et al. (2008b) have also highlighted the need for continuous advertising to sustain public stroke awareness. Similarly Mikulík et al. (2011) and Kleindorfer et al. (2009) also describe limited long-term success for stroke media campaigns in the Czech Republic and the US, respectively.

Hodgson et al. (2007) assessed the impact of a stroke educational campaign through television advertising in Ontario. A significant increase in stroke awareness and early presentation to the emergency department was observed within the study cohort. However, the authors reported a decline in these effects following a 5-month advertising blackout.

2.10.6 Variables affecting the success of the stroke campaigns

Large-scale multimedia campaigns are expensive and short-lived, and may not achieve the desired outcomes (Jurkowski et al., 2010; Tadros et al., 2009). The costs of these campaigns may be balanced against savings from the debilitating effects of stroke and the costs of long-term rehabilitation and nursing homes. Stroke campaigns therefore retain the potential to be cost-effective.

Several factors may explain why certain campaigns have reported a long-term sustained benefit while others have not. Trobbiani et al. (2013) postulate that the choice of key messages, media mix, and advertising saturation may influence the effectiveness of such campaigns. The authors stress that “it is critical to ensure that campaigns provide the clear and bold message that prompt action is an essential ingredient to reduce death and disability following stroke”. The choice of language used was also shown to have a significant impact on campaign effectiveness (Bray et al., 2010). In fact, the authors concluded that “some symptom descriptions used in the campaign were not reflective of the symptom experience. The content and language of these campaigns could be improved to portray stroke symptoms more realistically” (Bray et al., 2010). Campaigns may also be more effective if they focus on how affected individuals may overcome barriers to reacting appropriately to stroke (Flynn et al., 2014). It is therefore paramount that the planning of such campaigns considers all of these factors to ensure cost-effectiveness.

Mellon et al. (2011) postulated that although stroke patients may be aware that a fast response is required, they fail to understand why speed is so critical. They therefore conclude that “campaigns should convey that treatments for stroke are time dependent and perhaps emphasise the ‘time is brain’ imperative in order to reinforce the need for rapid action in combination with EMS activation”.

Rasura et al. (2014) stressed the importance of including the message ‘call an ambulance’ in every stroke educational campaign. Stroke campaigns should also aim to minimise barriers to stroke treatment and deal with fear and misconceptions surrounding the onset and treatment of stroke (Skolarus et al., 2011). Such an approach may directly target the disconnect between stroke knowledge and appropriate action and hence reduce pre-hospital delay.

Apart from the content of the campaign, Rasura et al. (2014) highlighted the importance of the campaign's 'dose', which is crucial for reaching the desired level of saturation and optimal outcomes.

2.10.7 Conclusion

Improvements in stroke knowledge and preparedness should not be taken for granted following a stroke educational campaign. Neither can it be assumed that any benefits will be sustained in the long term. In order to be cost-effective, a health educational campaign has to achieve an overall reduction in patient mortality and morbidity. Stroke knowledge does not translate directly into prompt action, and this complex behavioural process is affected by a multitude of interacting factors. It is therefore critical for stakeholders to understand these interactions before embarking on large-scale stroke educational campaigns.

2.11 Stroke in Malta

2.11.1 Introduction

Stroke is a leading cause of acquired disability and death worldwide. "Cardiovascular disease causes more deaths among Europeans than any other condition, and in many countries still causes more than twice as many deaths as cancer" (Nichols, Townsend, Scarborough, & Rayner, 2014). In Europe, stroke accounts for almost 1.1 million deaths per year (Vasiliadis, 2013), which translates into 10% and 15% of deaths in male and female Europeans, respectively (Nichols et al., 2014).

The World Health Organization estimates that in Europe, stroke incidence “is likely to increase from 1.1 million per year in 2000 to more than 1.5 million per year in 2025 solely because of (the) demographic changes” (Truelsen et al., 2006). This estimate is partly attributable to an aging population in Europe. In fact, the percentage of people in Europe aged over 65 years who are at increased risk of cerebrovascular disease is expected to increase from 20% to 35% between 2000 and 2050 (Truelsen et al., 2006).

Considerable differences in mortality rates and trends following stroke are observed between European countries. Western European countries have relatively low and decreasing mortality rates compared with Eastern European counties, where stroke mortality rates are on the increase (Sarti, Rastenyte, Cepaitis, & Tuomilehto, 2000). For example, stroke incidence in Latvia is double that in France and Switzerland (Truelsen et al., 2006). Similarly, northern European countries have a higher incidence of stroke compared with the south (Bejot, Benatru, & Rouaud, 2007).

As a result of the Europe 2020 strategy, several country-specific recommendations were issued in recent years. With regards to Malta, the main recommendation in relation to healthcare (CSR 2b) encompassed the need to reform the public health system with a focus on cost effectiveness and sustainability, especially in relation to the strengthening of primary healthcare (European Commission, 2014).

The publication of the National Health Systems Strategy (2014–2020) was one of the measures implemented to address this recommendation and in the launching report of this document, the main pressures on health systems in Europe are clearly delineated (Ministry for Health, 2014). The first of these pressures is the need for enhanced efficiency, productivity, and cost management in relation to healthcare systems. This is followed by the concept of an ageing population as well as the demand for more healthcare choices that are easily accessible in a shorter time frame. Finally, the management of chronic diseases is listed as one of the contemporary challenges that European healthcare systems face. Stroke education and awareness are intricately linked to all of these challenging issues as they may enhance the timely management of the condition in a way that affects treatment efficacy and cost effectiveness.

This research study helps to address the four main objectives of the National Health Systems Strategy, particularly objectives 1 and 2, which focus on the response to the challenges brought about by demographic changes by increasing the accessibility, availability, and timeliness of healthcare. Moreover, the aim of the current study was in line with the fourth objective forward in the strategy, that is, the sustainability of the Maltese healthcare system. This aim was brought about by the fact that greater awareness has the potential to result in earlier detection of the condition and hence a possible reduction in morbidity related to stroke. The most recent (Maltese) country report with regards to the Europe 2020 strategy was issued in April 2015 and indicates that the progress made in addressing the recommendation in relation to health is still limited (Ministry for Finance, 2015).

2.11.2 Local setting

Malta is a southern European country consisting of an archipelago of islands in the Mediterranean Sea. The country covers an area of 316 km^2 and is densely populated, with just under 450,000 inhabitants.

“The health profile is that of a developed country with low infant mortality and a long life expectancy” (Agius, 1990). This translates into a high incidence and prevalence of stroke as well as of non-communicable diseases secondary to an aging population. Estimates of the burden of stroke in Malta (Truelsen et al., 2006) show an incidence of 746 and a prevalence of 4288 per 100,000 inhabitants between the ages of 25–85+ years. The incidence and prevalence of stroke in Malta increases exponentially with age and is more common in men. In Malta, cerebrovascular diseases are responsible for 107.3 and 83.4 deaths per 100,000 inhabitants in males and females, respectively (Eurostat, 2015).

“One clear advantage resulting from small geographical size is easier access to the health care system” (Agius, 1990). This factor is especially true in the setting of acute stroke, where emergent treatments are time-dependent. Mater Dei Hospital is the main acute general hospital in Malta and is located in Msida, a central Maltese town with an excellent road network to neighbouring towns and villages. The hospital has 1000 in-patient beds and provides a vast range of specialist services including neurology, neuroradiology, and neurosurgery. All acute stroke patients are diagnosed, treated, and managed at Mater Dei until they are stable or fit enough to be discharged home or referred for further management in a rehabilitation facility.

Acute stroke treatment is also offered in Gozo General Hospital, which caters to the sister island of Gozo. Both institutions follow local guidelines for the treatment and management of acute stroke and are equipped to perform CT scanning of the brain and to administer intravenous thrombolytic therapy to eligible patients. Mechanical thrombectomy is performed only in Mater Dei Hospital, which also caters for patients presenting acutely to Gozo General Hospital who are then transferred via an air ambulance service.

2.11.3 Cultural aspects and genetics

In a prospective study of acute stroke patients who presented to Mater Dei Hospital, Mallia et al. (2015) found that 85.7% had at least one previously diagnosed risk factor for stroke. Hypertension was the most common risk factor, present in 73.2% of patients, followed by previous cerebrovascular accident and diabetes mellitus, which accounted for 43.9% and 39% of patients, respectively. Although certain risk factors display a genetic predisposition, they can potentially be controlled to drastically reduce the risk of stroke. Failure to control risk factors may be related to poor stroke knowledge and health literacy, which may also explain the high rate of stroke recurrence in the cohort. The main limitations of this study were the small number of participants (n = 42), which may have skewed the results in the sub-group analysis.

In 2014, the World Health Organization published data on the prevalence of risk factors for stroke in Maltese adults. These risk factors included insufficient physical activity (42.9%), tobacco smoking (26.6%), hypertension (25.4%), obesity (26.6%), and diabetes (7.3%) (World Health Organisation, 2014). "Hypertension remains the main risk factor for both ischemic and haemorrhagic strokes, followed by diabetes mellitus" (Vasiliadis, 2013).

2.11.4 Stroke knowledge and health literacy in Malta

Studies and data regarding public stroke knowledge in Malta are limited. Caruana et al. (2013) recruited 500 volunteers using a probability quota sample. Overall stroke knowledge in this cohort, which was representative of the Maltese population, was limited. The authors found that although 70% of participants were able to list a stroke symptom, only 3% could name the three stroke symptoms described in FAST. Only 43% of participants related unilateral weakness or numbness to stroke. As described in previous chapters, poor stroke knowledge in patients and bystanders is associated with increased long-term disability and mortality.

2.11.5 Local management and treatment of stroke

Local acute stroke guidelines were developed by a team of local experts and introduced at Mater Dei Hospital in October 2010. These guidelines summarised the recommended workflow for the assessment, management, and treatment of stroke. The guidelines also ensured that stroke patients who were eligible for thrombolysis were identified at triage and fast-tracked through the necessary radiological examinations.

Stroke patients who present to Mater Dei Hospital are automatically triaged as a medical emergency in order to reduce in-hospital delays. They are assessed by an emergency physician upon their arrival at the Emergency Department and transferred to the Medical Imaging Department for a CT brain scan. Upon their return to the Emergency Department, they are assessed again by a neurologist who decides on their eligibility for emergent treatment. Inclusion and exclusion criteria are summarised within the local guidelines. The major contra-indication to intra-venous thrombolysis in Malta remains presentation outside the treatment window, as reported in 73.7% of cases (Micallef et al., 2015). Similar findings were found in the study by Mallia et al. (2015), in which late presentation (52.4%) was potentially the most common contra-indication to thrombolysis.

Intravenous thrombolytic therapy for acute stroke was introduced in Malta in October 2010 (Micallef et al., 2015) following the publication of a randomised controlled study (National Institute of Neurological Disorders and Stroke & rt-PA Stroke Study Group, 1995) which showed that acute stroke patients treated with t-PA were at least 30% less likely to suffer long-term disability than patients treated with placebo. Micallef et al. (2015) found that only 1.59% of acute stroke patients presenting to hospital were eligible for (and received) t-PA. In July 2013, the treatment window for t-PA was increased from 3 hours to 4.5 hours to reflect international guidelines.

The local guidelines were revised in early 2015, following the publication of five randomised controlled trials (Berkhemer et al., 2015; Campbell et al., 2015; Goyal et al., 2015; Jovin et al., 2015; Saver et al., 2015), to include intra-arterial mechanical clot retrieval which aims to re-establish cerebral circulation. Mechanical thrombectomy for acute stroke was introduced in July 2015 and is currently offered either as a sole treatment or in combination with intravenous thrombolysis, with the latter acting as ‘bridging therapy’.

Patients who receive either of the two emergent stroke treatments are admitted to a dedicated stroke unit under the care of a consultant neurologist and their management includes input from other professionals including speech therapists, physiotherapists, specialist nurses, and social workers. A dedicated multi-disciplinary team was established to assist stroke patients following a local audit on stroke care practice (Mallia et al., 2015).

Medical imaging is also performed routinely on stroke patients, both in the acute and sub-acute phases. CT scanning at admission is crucial to identify intra-cerebral haemorrhage, as this is the main contra-indication to emergent stroke therapies. Finally, imaging is performed to assess the extent of (irreversible) infarction in order to provide a reliable prognosis and to assess whether the patient is at risk of another stroke, and is often repeated after 24 hours to check for potential treatment complications.

2.11.6 Stroke campaigns and comparison to foreign institutions

Prospective data collected in a local audit by Mallia et al. (2015) were compared with those from phase 2 of the UK National Sentinel Stroke Audit in 2008. Comparisons of the nine key indicators in the management of acute stroke patients identified serious lacunae in local stroke management. The authors concluded that "local results compared well to the RCP 2008 results in initiation of aspirin, imaging, and nutrition. However, we noted need for improvement in the assessment of swallowing, mood and cognitive function as well as involvement of a multidisciplinary team". The necessity for a dedicated stroke unit was also highlighted in this audit as randomised trials have shown that such units effectively decrease long-term disability and mortality rates (Stroke Unit Trialists Collaboration, 1997). Mallia et al. (2015) found that acute stroke patients were not provided with tailor-made rehabilitation goals set by a multidisciplinary team. This finding contrasted sharply with UK data showing that 86% of stroke in-patients had set goals. Mallia et al. (2015) also noted that lifestyle modification advice (which is a keystone of secondary stroke prevention) was not documented in any of the patient files.

2.11.7 Conclusion

Although Malta is no exception with respect to stroke-related morbidity and mortality, stroke knowledge and education have been limited until recent years. Since the introduction of new treatment locally, awareness of the condition may be on the increase, although this may not necessarily reflect readiness for prompt action in the face of stroke symptoms. This situation highlights the need for research such as the current study in order to understand the local picture and to address the population’s needs in a comprehensive manner.

2.12 Conclusion

Following this review of the literature related to stroke knowledge and education, it can be concluded that education does not simply consist of the reiteration of facts related to stroke but involves a plethora of other considerations regarding the variables that characterise the target population.

While the literature is abundant in this aspect, the process of undertaking this review has also identified a number of gaps. One area which may be neglected is research based on longer-term outcomes of stroke education initiatives. This topic is particularly important in the evaluation of campaign effectiveness. Perhaps the most striking gap is that which relates to local research and stroke awareness initiatives, which in itself serves as a sound rationale for the current study. This gap is both surprising and alarming, since – as described in this chapter – a lack of knowledge is often related to inaction or ineffective action, which increases the risk of detrimental effects of stroke. It is envisaged that the current study, using the existing literature as guidance, will unearth the untapped information that lies within the Maltese population in order to provide a better picture of the status quo with regards to stroke educational needs.

Chapter 3 – Method

3.1 Introduction

The aim of this chapter is to present the process that was followed during the conduct of this study. Having established the research questions, the most suitable paradigm to address these queries was selected. Consequently, the specific type of research method to be used was considered, as explored in this chapter. Other decision trails regarding design, data collection, analysis, quality assurance, and ethical considerations are also explored here.

3.2 Purpose statement and research questions

3.2.1 Purpose statement

The main aim of this study was to explore stroke knowledge and educational needs in Malta. An exploratory sequential mixed methods design was used, which primarily involves the collection of qualitative data which is subsequently used to inform the gathering of quantitative data. During the first phase, an interviewing technique was used to collect in-depth qualitative data from stroke sufferers and bystanders in order to explore their reflections on their management of stroke onset. The second phase involved the construction of a survey tool that was developed from the qualitative Stage 1 findings. The third and final stage consisted of the implementation of the tool among a population sample composed of a sub-group of healthcare professionals and another of the general public. The use of a mixed methods design was intended to facilitate the exploration of the topic while allowing for triangulation and generalisability.

3.2.2 Research questions

In order to address the aim of the study, the following research questions were set:

1. **What are the reflections of stroke sufferers and bystanders on the way that they managed stroke onset?**

   This was addressed using qualitative methods.

2. **How much knowledge does the Maltese population have with regards to stroke recognition and management?**

   This was addressed using quantitative methods.

3. **What findings emerge from comparing and merging data from the reflections of stroke sufferers and bystanders to quantitative instrument data on the Maltese population's knowledge?**

4. **Which educational lacunae are present in relation to the Maltese population's knowledge about stroke recognition and management?**

   The latter two questions were addressed using mixed methods, drawing on survey and interview data.

3.3 The research philosophy, method, and design

When carrying out social sciences research, it is crucial to reflect on the concepts of ontology and epistemology as well as the different approaches to research, since this sets the path towards an appropriately constructed investigation of the area of interest.

3.3.1 Research philosophy

3.3.1.1 Epistemology

The concern of epistemology is the nature of knowledge and the ways of exploring social reality. In addressing the epistemological basis of a particular area of study, Bryman and Bell (2007) recommend reflection upon that which can or should be regarded as acceptable knowledge within a particular discipline. In this view, knowledge parameters can be established and the sources and limits of such knowledge may be identified. Two pillars are often described in terms of epistemology, these being interpretivism and positivism. While the concern of positivism is mostly related to the testing and proving of a hypothesis, the focus of interpretivism is typically dedicated to acknowledging that there are different worldviews and interpretations rather than one truth. Thus, when engaging in interpretivist research, the researcher attempts to explore how individuals interpret their reality and adjust meaning and actions accordingly (Saunders, Lewis, & Thornhill, 2012).

According to Bodenreider, Smith, and Burgun (2004), "epistemology in the strict sense is the study of how cognitive subjects come to know the truth about given phenomena in reality" and for the purposes of the current study may be thought of as the study of stroke knowledge. It encompasses the ways in which physicians and the public come to know about the existence, aetiology, symptomatology, and outcomes of stroke.

3.3.1.2 Ontology

From an ontological perspective, there is an imperative need to acknowledge and understand the things that exist in social reality and assumptions about the form and nature of such reality.

In broad terms, the ontological positions of realism, idealism, and materialism are prominent in this concept (Snape & Spencer, 2003). Advocates of realism claim that there is a reality which is independent of human understanding, whereas, by contrast, idealists argue that reality is socially constructed and subjective. Alternatively, materialism only considers that which is material or physical to be real while other phenomena such as beliefs or values do not have a prominent role in shaping a material real world that is common across societies.

Bodenreider et al. (2004) state that ontology "starts out from the idea that there are invariants in reality … which are captured in the general terms used in the textbooks of biological science and which are instantiated by particular examples or cases of such classes, whether these be organisms or organism parts, qualities, functions, processes, diseases or symptoms". The study of such classes and the inter-class relationships with respect to stroke knowledge form the basis of the current study.

The epistemological and ontological applications and contributions to this study shall be explored in more depth in the forthcoming section.

3.3.2 Selection of research method

The selection of a suitable research method is a process that can be undertaken after gaining an in-depth understanding of the problem that is being addressed. Following a review of the available literature and the research questions posed, it may be noted that from an epistemological viewpoint, my research investigation could lend itself to both the interpretivist and positivist paradigms. To this extent, Creswell (2014) articulated the fact that qualitative and quantitative worldviews are not to be perceived as residing at opposite poles. In fact, he postulated that it may be more accurate to state that a study has a major qualitative (or quantitative) component in it – that is, residing upon a continuum – rather than describing it as being purely and exclusively qualitative (or quantitative). In this light, it may be beneficial to briefly engage in an exploration of both approaches and their potential application to the current study.

On looking at the research area with a postpositivist lens, the need to assess cause and effect in stroke knowledge and the late arrival to hospital emerges. This points towards the appropriateness of using a reductionist approach to measure an objective reality. In this stance, it is paramount to include numerical measures and to follow the scientific method in order to support or refute the hypothesis that guides the research process. This approach leads to what is often perceived as being a major pillar of quantitative research, namely, the ‘strength in numbers’ factor, academically termed as ‘generalisability’. Arguably, Keele (2011) (p. 4) posited that generalisability is not necessarily the metaphorical gold medal in research endeavours. Unfortunately, this notion often detracts from exploring the depth of a problem by instead prompting assumptions to be made based on investigating the width of the research topic at hand. To this extent, a social constructivist or interpretivist perspective envelops the richness of experiential subjective meaning in combination with multiple and varied views of a phenomenon. This perspective shuns the practice of sorting out ideas in narrow numerical categories in preference of allowing the complexity of data to lead to broad and general understandings (Creswell, 2014). When reflecting on the nature of my research study, the interpretivist undertones underlying the topic of interest can be detected. This is especially so because the study was based in one specific location with the intention of gaining a good understanding of the perceptions and attitudes of its constituents. Thus, it is particularly important to understand the historic, cultural, and personal backdrop to knowledge and perspectives regarding stroke – a tangent which can be brought about by the introduction of a qualitative dimension. This would necessitate the researcher’s complete immersion in the research endeavour, typically by interacting with participants and listening to them in an open-ended questioning approach (Bricki & Green, 2007). During this process, patterns of meanings can be inductively generated. While a qualitative paradigm is likely to facilitate a focused and intense inquiry leading to a comprehensive exploration of the phenomenon being addressed, factors such as representativeness and generalisability may pose a challenge in answering the set research questions (Polit & Beck, 2010). Additionally, the measurement of impact distribution and magnitude in terms of knowledge and behaviours related to stroke might have been difficult to address with the use of a research method that is solely based on an interpretivist philosophy.

Although the current study could lend itself to both qualitative and quantitative methods, this reflection upon the two major paradigms in research highlights the dilemma encountered since it seems as if neither may have been adequate as a standalone approach in providing the answers required. Subsequently, it seemed imperative to steer away from a monomethod investigation and to instead consider an eclectic paradigm – one that occupies the third chair in the research methods array, namely, mixed methods research. As postulated by Creswell (2015), the main strength of this multi-lens focus is that it enables the weaving of qualitative and quantitative data in order to address both the depth and the width of the problem at hand. This liberal use of assumptions arising from either stance may facilitate a pragmatic approach that is targeted towards application and problem solving. This approach is congruent with the objectives of the current study since stroke knowledge, attitudes, and the related educational needs are mirrored in the main descriptors of the mixed-method approach: action-focused, situation-dependant, and consequence-centred (Creswell, 2014). Based on constructivism, one of the tenets of mixed methods work is the awareness that there are many realities which, when explored in categorised demographics, may be connoted to common understandings (Morrow, 2007). As viewed within the remit of stroke knowledge and education in Malta, it is likely that the cultural aspect may result in a number of shared beliefs and attitudes; thus, singular and multiple realities had to be considered, as dictated by a pragmatic ontology. Since the data elicited had a numerical and a textual component, both the width and the depth of the research area could be addressed in an attempt to provide a holistic view of a local challenge that is, as yet, poorly understood and unexplored. Indeed, it is this opportunity of data source and methodology triangulation that enhanced the attractiveness factor of a mixed methods design for use in this study.

Although this approach may be regarded as the best fit for this study, it has to be realised that it is not good practice to idealise or shun any of the research paradigms explored since every method is characterised by strengths and limitations. Mixed methods research is not an exception to this and while the benefits of this position have been described, a number of limitations may characterise such studies. The main challenges to this approach are typified by data management, processing, and analysis as constrained by skill, time, and other resources required (Driscoll, Appiah-Yeboah, Salib, & Rupert, 2007; Lieber & Weisner, 2010). Unequal sample sizes in the quantitative and qualitative arms may also pose a difficulty in the merging of results (Creswell, 2015). Finally, there is the risk of undertaking a multiple methods study rather than a mixed methods one if the researcher does not ensure that quantitative and qualitative data are successfully combined. These and other threats to validity will be duly identified and described in the concluding part of the thesis. While these detractions inevitably featured in the current research process, various attempts were made to overcome them. Primarily, the mixed methods process guidance of Creswell (2015) acted as the backbone to the study since it offered a logical and clear way of keeping on track – this guidance will be described in more detail in the next section. Moreover, adherence to such specific guidelines is encouraged since it prompts the researcher to regard mixed methods as a separate third entity rather than a haphazard combination of two methods and their respective protocols.

3.3.3 Selection of the type of mixed methods approach

The introduction of a research method that diverges from a monomethod approach has prompted many researchers to put forth different enquiry strategies and their respective elaborate procedures as well as mixed methods research nomenclature and classification.

One prominent mixed methods typology was that presented by Caracelli and Greene (1997). This included two broad categories, namely, a **component design** and an **integrated design**, which, in combination, have a total of seven sub-categories. In component mixed methods research, quantitative and qualitative data are collected separately and remain so throughout the study. By contrast, in integrated mixed method research, the data collected within the quantitative and the qualitative arms are integrated throughout the process. A more recent interpretation and adaptation of these different designs that features in the literature presents the distinction between **basic** and **advanced** approaches (Creswell, 2015). The types of **basic** approaches are **convergent design** and a **sequential strategy**. The **advanced** designs consist of the **intervention**

approach, social justice design, and **multistage evaluation design**. Upon reviewing these different methods, the intervention design was not seen as representing a feasible framework for this study since it would require an intervention or experiment to be conducted and subsequently combined with qualitative data. Although this design could have been adapted to fit the study's aims, it was felt that an experiment or intervention would not be the best way to explore the topic of stroke knowledge and education in the local setting. A social justice strategy was initially considered since this requires the overarching influence and guidance of a theoretical lens, most commonly in addressing underrepresented or marginalised populations with a focus on prompting change. However, on further evaluation, it was concluded that such a strategy is more appropriate for exploring power and social relationships through an advocative, transformative lens (Sweetman, Badiee, & Creswell, 2010) and so would not fully capture the essence of the current study. Similarly, a multistage evaluation design was perceived as not being the best match since this design is mostly suited to evaluating the success of a programme which, once again, is not congruent with what was addressed in the current research study. Since the advanced designs were therefore eliminated, the basic designs were taken into consideration, the first of these being the convergent design. If a convergent technique is employed, a study is characterised by one data collection phase during which qualitative and quantitative data are collected simultaneously but separately. This phase is followed by data interpretation, during which the results are merged or compared. When reflecting on the application of this method to the current study, it is important to focus the lens again on the research intent, which highlights the need to initially gain a considerably deep understanding of the relatively unexplored area of stroke knowledge and educational needs in Malta. This focus ignites a controversial spark since, in a convergent approach, one does not have the opportunity to first explore the qualitative aspect of the problem which then feeds the quantitative part (or vice versa). In the context of this study, the lack of such an opportunity would have been undesirable since it was deemed more fruitful to collect and interpret important information during the first stage of data collection and consequently use this gained knowledge to construct the second phase. Such a process characterises the second type of basic mixed methods approaches which presents a sequential journey during which "the researcher seeks to elaborate on or expand on the findings of one method with another method" (Terrell, 2012).

A sequential mixed methods strategy may be of the **explanatory type**, which involves an initial quantitative part to test a theory or concept followed by a qualitative aspect to facilitate further deeper exploration. Alternatively, a **sequential *exploratory* mixed methods approach** necessitates commencing with qualitative data collection for an exploratory intent followed by a quantitative stage so as to allow for generalisability (Creswell, 2015).

Following their experiences of using different types of mixed method designs, Cronholm and Hjalmarsson (2011) advocate for the use of an exploratory approach in situations where the topic of interest is complex, relatively unknown, or understudied or when one needs guidance to ask the right question. Creswell and Plano Clark (2011) add that this type of research is also useful when data collection instruments or measures do not exist and when the variables are not known. Since this was considered to be the status quo of the current study and the situation regarding stroke knowledge in Malta, a sequential exploratory design was therefore deemed as being more likely to act as an effective guide to the research process and to yield rich results. Utilising this framework offered the opportunity to test the qualitative categories in the quantitative part. Moreover, it is a design which is known to be easy to implement, despite being time-consuming. Conversely, unless the initial qualitative stage provides findings which can be easily translated into a quantitative measure, proceeding into the second stage may pose difficulties (Creswell & Plano Clark, 2011).

The data collection strategy in the mixed methods paradigm that formed the framework of this study involved both constructivism and objectivity, as is commonly practiced in the mix of epistemologies that characterise such an approach. Constructivism was applied during the qualitative phase, which involved a direct meeting and discussion with the informants. During this phase, meanings associated with interactions between experiences and ideas were explored – this is congruent with Piaget's constructivist views (Ozer, 2004). Objectivity was more visibly employed during the second stage of the study with a focus on quantitative data collection. The issue of researcher objectivity may be questionable since it is somewhat impossible to approach a research study with a 'tabula rasa' due to the tendency for human nature to have an opinion about even relatively unknown situations (Heydebrand, 1994). In the case of my study, objectivity was an even greater challenge since my field of work is closely related to the topic under study and so my experiences and opinions may have introduced an element of bias in all phases of the research process, especially in the interpretation of results. However, the risk of bias was limited by cross-checking actions and interpretations with another researcher during the journey. Although this process was carried out throughout the study, it was increasingly necessary during the qualitative part since quantitative data collection and interpretation tends to be more objective whereas in qualitative research, the researcher may be more personally immersed in the process. On a more positive note, it should be acknowledged that this potential limitation proved to be a strength since my experience and previous knowledge of stroke facilitated the understanding of attitudes in the local scenario.

3.3.4 Research design

Although the research process followed in this study was based on an exploratory sequential mixed methods design, it should be noted that since the introduction of the mixed methods paradigm, many academics have put forward their understanding and presentation of different designs that fall under this kind of research. In this regard, an overview of the available literature shows that consensus is not always reached and while this leads to healthy critical discussions, it also highlights the need for a researcher to select one particular approach and use it as guidance. Thus, in this study, the exploratory sequential mixed methods design was that proposed by Creswell and Plano Clark (2011) because of the clear explanation provided and apparent effectiveness and simplicity to implement. As an overview, this framework involves three stages. The first stage is the qualitative phase, during which the problem is explored in depth and subsequently analysed. This leads to the second stage, which involves an examination of the qualitative analysis in order to use the information to construct an instrument or measure to be used for quantitative data collection. In this stage, conversion from the qualitative aspect to a quantitative one may be challenging since it involves the conversion of themes into scales, codes into variables, and quotes into items. While this process invariably has an element of complexity, existing sources for instrument construction, such as the guidance provided by Creswell (2015), may be of assistance.

The main strength in this process is that the quantitative tool that results is based on the informants' experiences, thus enhancing the pragmatic aspect of the study. The final and third stage is the application of the tool to a large sample – this can subsequently provide insight into the generalisability of the initial qualitative findings. While the exploratory sequential design is the most complex and time consuming of the basic designs, its rigor characterises it with a sophistication that the other methods do not exhibit (Creswell, 2015).

In the following section, the model proposed by Creswell and Plano Clark (2011) is described as applied to the current study.

3.4 Study phases and data integration

As depicted in Figure 3.1, three research stages were adopted during the study, each of which aimed to use a different source, method, and data collection tool to attempt the collection of data that is both comprehensive and holistic.

As described by Creswell (2015), one of the most important aspects of mixed methods research is the integration of data. While this process simply refers to the mixing of quantitative and qualitative data that should occur within such research, it should be acknowledged that the process merits particular attention since it is what actually characterises the mixed methods paradigm. Consequently, Creswell (2015) identified four types of data integration according to the type of research design being followed. For application to the current exploratory sequential design, the main integration type that featured was ‘Building of the Data’ which is actuated by using qualitative data in one phase to build the quantitative part, such as the construction of a new tool as seen in this study.

Thus, in this case, quantitative and qualitative data were connected (mixed) at the analysis phase using a matrix system to construct the tool in phase 2 and at the interpretation phase through a discussion.

Each study stage is explored in more detail in the following sections.

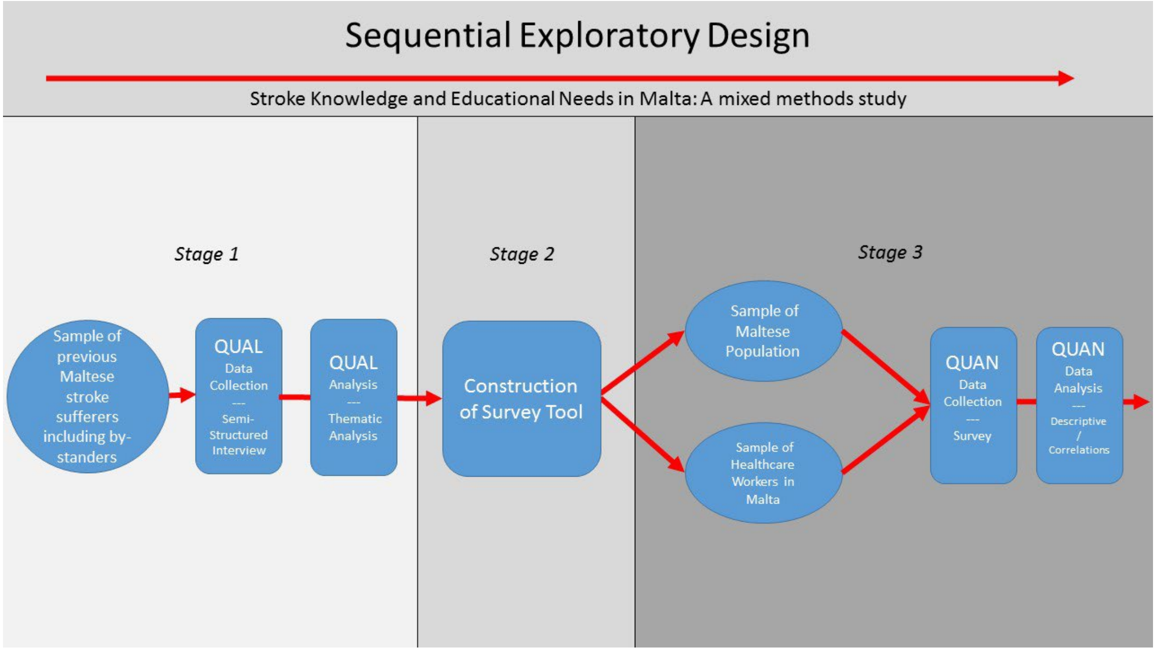


Figure 3.1: Research Plan

3.4.1 Stage 1: Qualitative data collection and analysis

3.4.1.1 Purpose

The first part of the study comprised qualitative data collection. The main purpose of this phase was to gain insight into the reflections of stroke sufferers and bystanders on the way that they managed the onset of stroke. Areas explored included attitudes and perceived knowledge about stroke prior to and after onset, the events leading up to stroke onset, and the immediate aftermath, as well as a critical evaluation of the way that the participants managed the onset (see Appendix 13: Interview guidelines). The findings generated informed the development of the data collection tool in the second phase of the study.

3.4.1.2 Method

Qualitative data collection can be undertaken using a myriad of methods and participant types. This study utilised an exploratory multiple case study design following the guidance and framework provided by Yin (2009). Although the major qualitative research paradigms were considered, a case study design was ultimately chosen because of its potential to explore a phenomenon in depth in its naturally occurring context in a situation where the boundaries between the phenomenon and its context are not clear (Yin, 2009). This description was considered to accurately portray the status quo regarding stroke knowledge in Malta, since the effect of the cultural norms and values on the stroke knowledge and attitudes in Malta is relatively unexplored and thus unclear.

In contrast to some other forms of research, this research method situates the researcher directly in the field so that he or she can record what is happening in an objective manner while simultaneously exploring its meaning (Stake, 1995) (p. 9). The emphasis on interpretation is imperative and involves analysis of the collected data as well as the researcher's ability to offer meaning and understanding to his or her experience so as to conclude with a constructive understanding of the cases involved. As suggested by Yin (2009), the type of case study to be employed is first and foremost determined by the type of research question that has been posited. In the case of 'what' questions, such as that leading the qualitative part of this study, exploratory studies are considered appropriate and necessitate the development of propositions that will be explored during the study process.

A multiple case study design was used in this study, as opposed to a single case study. The aim of this decision was to allow for literal replication (similar results) and theoretical replication (contrasting results for anticipatable reasons) (Yin, 2009) (p. 54).

One of the most common complaints regarding case study research is a potential lack of rigor. While such an issue may affect any research method, the application of quality assurance criteria may limit this challenge. Quality assurance pertaining to the case study stage of this study shall be explored in detail in a later section. Moreover, case study research has been characterised by the concern that it provides limited basis for generalisation. As noted by Yin (2009), the selection of a theory or theories allows for the generalisation of the results of a case study. This does not refer to statistical generalisation but to analytic generalisation, which refers to the fact that an existing theory is used as a template for comparison of the results of the case study (p. 38).

A suggested initial step in the implementation of the case study method is the establishment of propositions, which are statements derived from theory, literature, or past experience that help the researcher to focus on specific aspects that should be explored within the scope of research. However, Yin (2009) elaborates on the fact that in the case of exploratory research, such as the current study, propositions may be hard to set because the area of interest is of yet unexplored. Instead, the study should have a clearly defined purpose and criteria which define the exploration as successful – these objectives have been addressed by the compilation of multiple research questions and a detailed explanation of the quality assurance process characterising the process.

In view of the purpose of Stage 1, it was concluded that a semi-structured interview should be used to collect data from individuals who had suffered from a stroke during the previous 2 years as well as from any bystanders who accompanied the patient. The rationale behind this data collection method lies in the knowledge that the area under study has not been researched and so this merits a detailed and comprehensive inquiry which can be afforded by one-to-one interviews (Barroso, 2009) (p. 100). The fact that a semi-structured format was used (as opposed to a structured one) transcends other methods in that the researcher has a degree of flexibility and can adapt the direction of data collection based on emerging data during the discussion with the participant. Additionally, answers can be probed and clarifications or elaborations can be demanded instantly (Creswell, 2003) (p. 190). Perhaps the major drawback of using this data collection method is the time consumption that characterises one-to-one interviews and their transcription and analysis (Gillam, 2000) (p. 9). The semi-structured interview schedule was based on the research questions guiding the study and on prominent themes emerging from literature on the topic. Before commencement of the actual study, two pilot interviews were carried out in order to evaluate the feasibility and overall clarity of the interview guide and process as well as to practice interviewing techniques. Following the pilot interviews, the participants involved were asked for general feedback, which was then addressed accordingly. No changes were suggested to the interview format and structure. Interestingly, both stroke sufferers who took part in the pilot study opted to bring an individual who had been the bystander during stroke onset. The presence of the bystanders turned out to be invaluable as they offered important information in addition to supporting the stroke patient. As a result, it was decided to include bystanders in the study, and participants were asked to invite the bystanders to accompany them for a joint interview.

3.4.1.3 Case/sample selection

The reason for selecting stroke sufferers as the participant group in Stage 1 emerged from the realisation that these individuals are likely in a very strong position to provide rich data since they have first-hand experience of stroke and its consequences. Thus, capturing the voice of this group can add to the pragmatic and humanistic dimensions of the study.

Similarly, the rationale for including bystanders emerged from the pilot study since it was realised that they frequently prompted or reminded the stroke sufferer of certain details during the interview and so represented good sources of information as well as serving as a support for the patient. Most often, the stroke sufferer would not have actually forgotten what had happened during stroke onset, but the ‘pressure’ of the interview may make him or her temporarily forget certain details. This is a common occurrence, and in fact when a patient presents to hospital with a stroke, the medical team should interview both him or her and any bystander as otherwise important data is missed and the history taken may not be so accurate. Although a separate interview for each bystander was initially considered, it was eventually felt that this would be a problematic approach since it is the two individuals together who have the capacity to generate the most accurate data. Thus, it was decided to implement joint interviews.

The determination of the sample size is influenced by a consideration of available resources. Although a large sample may enhance representativeness and generalisability, these factors are not congruent with the underlying philosophy of qualitative research, which prioritises quality over quantity. Moreover, a large sample size may be difficult to manage, especially in view of the fact that this data collection procedure forms just one part of this mixed methods study. A large sample size may thus distract the researcher from being thoroughly immersed in the data, which may lead to inadequate understanding and interpretation. By contrast, a sample that is too small may result in an inability to answer the research questions set. Creswell's input to this argument revolves around the recommendation to opt for a small sample in order to allow for a comprehensive exploration of the subject and the study scenario (Creswell, 2003) (p. 222). In light of these reflections, it was decided to recruit eight to ten stroke sufferers and their bystanders (if any) for the first stage of this research study.

Sampling was carried out using a purposeful random sampling technique. This is a technique that draws upon the strengths of purposive sampling and random sampling while avoiding the lack of rigour and credibility that is associated with convenience sampling (Offredy & Vickers, 2010) (p. 139). In this stage of the study, using pure random sampling was not ideal since this technique is more appropriate for use in positivist studies, in populations which are relatively known, and where trends are normally distributed. However, an element of randomness can still be introduced by first selecting a purposeful sample, which is a common technique used in qualitative research, followed by random selection of individuals from that particular sample (Teddlie & Yu, 2007) (p. 90).

Thus, the sample was selected as follows:

- Selection of participants who had been admitted to a state hospital due to a stroke during the previous 2 years (to allow for accurate memory recall) but not earlier than 3 months prior to data collection (to allow for recovery following the acute period).

- Construction of a list of potential participants by liaising with multidisciplinary healthcare team members to assess whether the participants satisfy the inclusion/exclusion criteria.

- Random selection of twelve participants from the list that resulted. During the pilot phase of the study, two of the participants selected were interviewed. The other ten participated in the actual study.

- Bystanders were recruited by asking each stroke sufferer if he or she could bring their bystander(s) to the interview (only if he or she felt comfortable to do so).

- During recruitment, individuals who met the following criteria were excluded from participation:

    (i) Individuals younger than 18 years

    (ii) Individuals who had been subjected to legal incapacitation

    (iii) Individuals unable to consent to participation in the study

    (iv) Individuals who were not Maltese nationals and/or were not currently residing in Malta.

3.4.1.4 Data collection

Eligible individuals were contacted by a third party to invite them to take part in the study. The recruiter was provided with instructions on how to approach each potential participant. Emphasis was made on the need to provide the relevant information and on abiding to ethical guidelines during and after the interactions with each individual. Subsequently, the intermediary contacted each potential participant and provided the main details of the study while also presenting an information sheet. I was notified by the recruiter about individuals who agreed to participate, and I then proceeded to make contact with the subject. Upon contacting him or her, I described the study process and offered to clarify any pending queries prior to carrying out the interview. Furthermore, I asked each participant if he or she could bring the bystander(s) to the interview so that a joint interview could take place. Each participant was given the opportunity to select the location, date, and time of the interview. All participants and their bystanders opted to have the interview in a hospital setting. At the beginning of each interview, the consent form was presented and the participant was asked to sign it. The interview was then carried out. Prior to each interview, the participants were provided with a list of questions that they would be asked. Although the interviews were audio-recorded, no documentation took place during the discussion since this could have interrupted the process or resulted in missing information or cues (Smith, 2009). However, a journal was kept to record my thoughts and personal reactions in between interviews as part of the analytical and reflective journey that I undertook through the implementation of the study.

3.4.1.5 Data analysis

The first step of data analysis was the creation of documents from each interview, including transcripts of the interview as well as the notes and the recordings of the personal reactions to the interviews. The qualitative analysis software *Atlas.ti (Scientific*

Software Development GmbH) was used to facilitate data management and presentation. Yin's models of data analysis were used as guidance (Yin, 2009).

A preliminary analysis was initially conducted during which the documents were thoroughly reviewed and initial codes were extracted. During this process, the research questions were not given prominence, and the focus was instead on the respondents' perspective. Thus, an inductive coding technique was applied. The second step was to form themes for each case.

The themes were subsequently compared across the cases so that similarities and differences could be analysed and interpreted. This process followed Yin's analytic technique of cross synthesis. These similarities were then interpreted and contrasts performed. Interpretation involved both 'direct interpretation', which involved the process of deriving meaning from a single incident, as well as the developing of naturalistic generalisations, which consisted of the application of the findings from one case to the other cases (Creswell, 2003) (p. 245). This necessitated a review of each case to establish its uniqueness as well as its similarities to the other cases. Another coder was involved in this process to enhance the validity of the themes. Any discrepancies were explored, and amendments carried out accordingly.

3.4.1.6 Quality assurance

Since the current study used a mixed methods design, quality assurance was used to address both the quantitative and the qualitative aspects of the study. As this section describes the qualitative part of the study, quality assurance related to the qualitative process shall be explored whereas quantitative quality assurance shall be presented in the next section.

Trustworthiness was a fundamental principle during the design and implementation of Stage 1 of the study. Among others, Lincoln and Guba (1985), Shenton (2004), Yin (2009), and DeVault (2017) have described the main factors that characterise the trustworthiness of qualitative methods. These are credibility, dependability, transferability, and confirmability. In order to ensure trustworthiness during the current study, several measures were taken as summarised in Table 3.1.

Quality assurance measures	**Strategies suggested by Shenton (2004, p. 73) and Yin (2009, p. 41)**	**Provisions taken in the current study**
Credibility	Adoption of appropriate, well-recognised research methods	Mixed methods research: exploratory sequential
	Familiarisation with cultural aspects of participants	Researcher's experience as a medical professional who works with such a patient group
	Methodological triangulation and the use of different types of informants and sites	Two study stages with a different research paradigm and different participant types
	Measures to enhance honesty among informants	Iterated ethical right to refuse participation or withdraw from the study Participants informed about use of pseudonyms in report Emphasise on the main scope of the interview as

		not assessing for ‘correct’ or ‘wrong’ actions
	An iterative questioning style during data collection	Rephrasing of questions and probing was used when needed
	Negative case analysis	Interview data were analysed thoroughly and repeatedly to detect possible errors, especially in the process of coding and theme development
	Debriefing meetings with superiors and peers to allow for scrutiny and promote constructive feedback	Colleagues were asked to scrutinise the analysed data Contact maintained with supervisor throughout the study and continuous feedback obtained
	Use of ‘reflective commentary’	A reflective diary was maintained during the study process
	Disclosure of the researcher’s background and experience	Provided in Chapter 1 of this thesis
	Respondent validation of data collected, interpretation, and theories formed	Collected data were re-checked with participants for correctness

	Detailed description of the subject under scrutiny Assessment of relevant literature to frame findings and address contrasting explanations	An attempt to describe the phenomenon and previous research is given in Chapter 2 of this thesis
Transferability	Provision of background data to establish the study context and detailed description of phenomena in question to allow comparisons to be made	Addressed in Chapters 1, 2, and 4 of this thesis
Dependability	The use of ‘overlapping methods’	Taken into consideration by using a mixed methods approach
	Detailed description of the methodology used, allowing the study to be repeated	Addressed in Chapter 3 of this thesis
Confirmability	Triangulation to limit the effects of investigator bias	Taken into consideration using a mixed methods approach and different participant types
	Recognition and admission of researcher's beliefs	Addressed in Chapters 1 and 4 of this thesis
	Identification of limitations and shortcomings in the method used and understanding their impact	Addressed in Chapters 3, 6, and 7 of this thesis

	Detailed description of the method and decisions made during the study to enhance integrity and allow scrutiny of results	Addressed in Chapter 3 of this thesis
	Keeping an 'audit trail' by the use of diagrams in order to demonstrate a chain of evidence	Addressed in Chapter 4 of this thesis

Table 3.1: Quality Assurance Measures

3.4.2 Stage 2: Instrument compilation

3.4.2.1 Purpose and method

The second stage of the study consisted of the construction of a quantitative survey tool to be used in the survey during the third and final stage of the study, which involved a sample of the general public and a sample of healthcare professionals.

Development of framework for data interchange

The content of the tool was predominantly guided by the qualitative Stage 1 data. The other source for tool construction was the information that emerged from the literature review part of the current research study.

In order to facilitate and portray the conversion of qualitative data (Stage 1 + literature review) to quantitative (Stage 3) survey questions, a framework was constructed. This type of system ensures that all important qualitative themes are addressed in the quantitative stage, a necessary process because neglecting to address the comprehensive interchange of data between the stages is often a major pitfall of the mixed methods approach. Adequate mixing of the data is what renders a study truly mixed methods in design, since otherwise it would simply be a case of using multiple methods within the same research process. Moreover, the development and use of such a framework was also aimed at enhancing transparency.

A template of the framework used can be viewed in Figure 3.2, and the complete version can be found in Appendix 19.

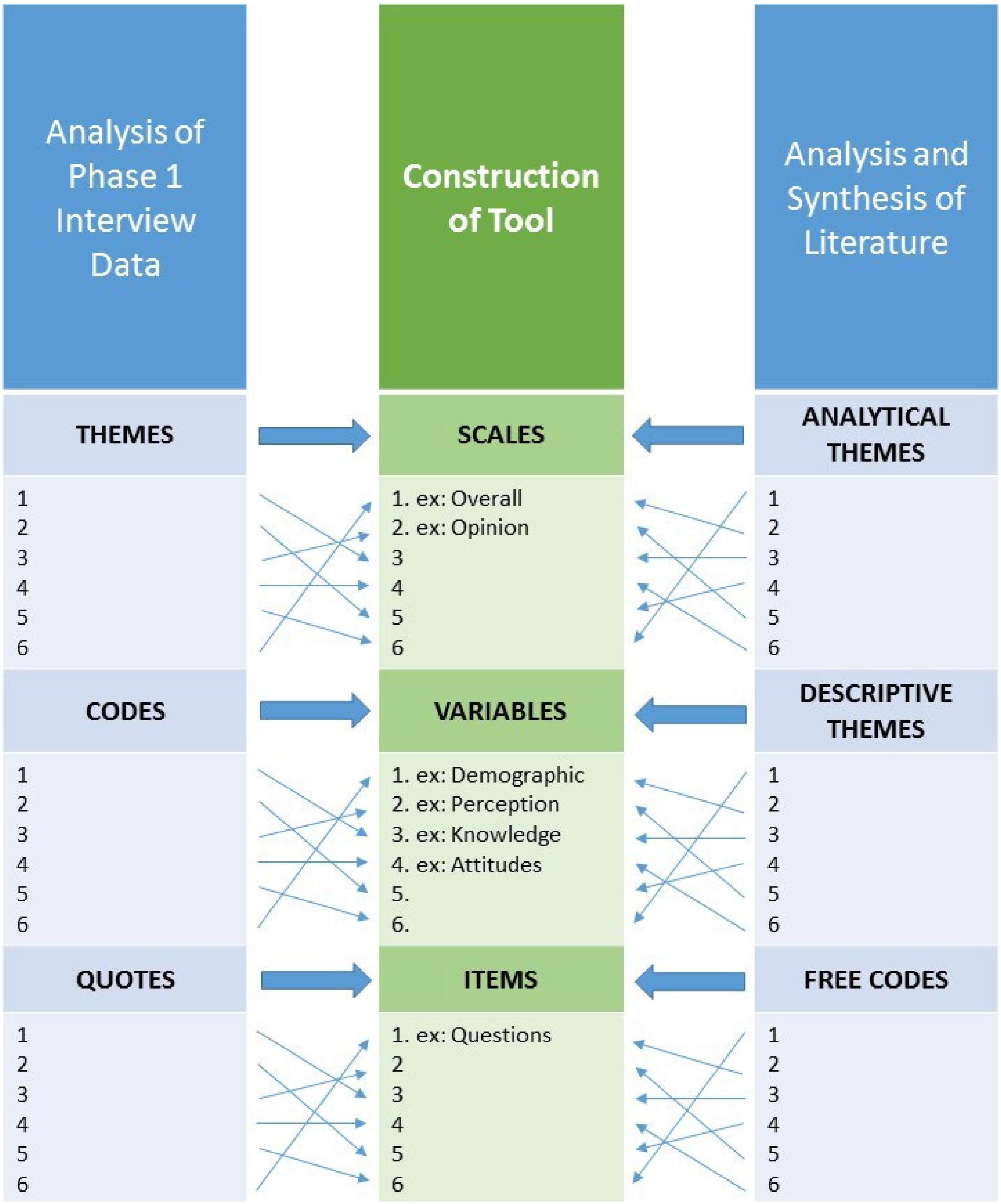


Figure 3.2: Framework used to facilitate conversion of qualitative data into a quantitative tool

The framework was constructed based on guidance offered separately by Braun and Clarke (2006), Thomas and Harden (2008), DeVellis (2012), Creswell (2015), and Tay and

Jebb (2017). In his guidance on tool construction, Creswell (2015) described the process of translating qualitative results into a quantitative instrument. To this extent, he referred to qualitative results which have already been analysed thematically into quotes, codes, and themes. At this stage, he recommended the conversion of quotes into the new instrument's items, the codes into variables, and the themes into scales. This guidance was followed during the construction of the instrument in the current study. However, rather than using the interview results only in the construction of the tool, it was decided to also include certain aspects from the existing body of the literature on the subject. The reason behind using both of these sources was to construct a tool that has local relevance but which is also informed by the existing evidence base on the topic. The construction process of the framework is described below.

3.4.2.2 Analysis of Phase 1 interview data (Figure 3.2 Column 1)

As described earlier, the thematic analysis of the data that emerged from the interview was carried out as guided by Braun and Clarke (2006). In particular, this involved a process during which selected quotes led to the extraction of codes which were then grouped into overarching themes.

3.4.2.3 Analysis and synthesis of the literature (Figure 3.2 Column 3)

In an article by Thomas and Harden (2008), the authors presented a process of thematic analysis as applied to a body of literature rather than to raw qualitative data as per the norm. The rationale for this application was to explore and promote the use of a more structured and rigorous process when attempting to integrate the results of qualitative studies in systematic reviews. The authors exhibited the use of such an approach, which they termed 'thematic synthesis', in a group of qualitative studies on health promotion research. The guidance on the process of thematic analysis offered by Braun and Clarke

(2006) was followed. However, instead of selecting quotes for coding, the authors reviewed the results of each qualitative study and highlighted the main points which they described as ‘free codes’ rather than quotes. The free codes were subsequently grouped into ‘descriptive themes’ which were further reduced to ‘analytical themes’. While the descriptive themes were essentially a summary of the results of the primary studies, the analytical themes went a step further by providing an element of interpretation in an addition to grouping the descriptive themes. This approach enabled the generation of novel constructs, explanations, and hypotheses (Thomas & Harden, 2008).

In the current study, the thematic synthesis process described by Thomas and Harden (2008) was applied to the integration of the studies included in the literature review. This facilitated the structuring of the literature review chapter into different sections and subsections. Additionally, this process allowed for the transparent integration of the literature into the new tool during Stage 2 of the study.

3.4.2.4 Construction of the tool (Figure 3.2 Column 2)

The outcome of the parallel analysis of the interview data and the literature was next used to inform the construction of the tool. Thus, quotes (column 1) and free codes (column 3) became items within the tool (column 2). Similarly, codes (column 1) and descriptive themes (column 3) were translated into variables (column 2). Finally, themes (column 1) and analytical themes (column 3) were used to form scales (column 2). This part of the process of the construction of the tool was informed by Creswell (2015). Moreover, guidance provided by DeVellis (2012) and Tay and Jebb (2017) on the different approaches to scale creation, principles of item creation, and psychometric properties was followed.

In addition to items assessing stroke knowledge, a section aimed at eliciting the participants’ demographic profile was included at the beginning of the tool and addressed the gender, age, educational level, and occupation (if any) of the participants. The following diagram presents the layout of the tool and the type of data that each of its sections was intended to collect.

Section	Description	Structure
Section A: **Demographics**	9 questions gathering socio-demographic information (gender, nationality, ethnicity, region of Malta, level of education, income, risk factors and healthcare worker status) about the participants.	Choice from multiple answers.
Section B: **Stroke Knowledge**	17 questions (K1 - K17) assessing stroke knowledge of participants.	5-point Likert scale. Possible answers included 'strongly agree', 'agree', 'undecided', 'disagree' and 'strongly disagree'.
Section C: **Stroke Response**	17 questions (R1 - R17) assessing stroke response of participants.	5-point Likert scale. Possible answers included 'strongly agree', 'agree', 'undecided', 'disagree' and 'strongly disagree'.

Table 3.2: Information about the data collected from the questionnaire

3.4.2.5 Quality assurance

Following its construction, the tool was subjected to a number of tests in order to assure its quality. This was primarily done using a critical appraisal framework developed by Hou et al. (2017) in their endeavour to assess the quality of stroke knowledge assessment tools included in their systematic review. The authors developed this framework by consulting with professionals and by synthesising three already-established criteria and checklists.

The resulting appraisal framework consisted of three sections: (1) conceptual framework, (2) psychometric properties (e.g. validity and reliability), and (3) feasibility (Hou et al., 2017).

These three sections of the critical appraisal framework were applied to the stroke knowledge assessment tool developed for use in the current study, as described below.

(1) Conceptual framework

As described earlier, the tool used in the current study was developed using existing evidence on the area of interest as well as the Stage 1 findings of this study. Thus, it seems acceptable to state that the tool has a sound conceptual framework.

(2) Psychometric properties

(2A) Validity testing

2A (i) Face validity

Test: *Does the instrument appear to subjectively measure what it is supposed to be measuring? (Thanasegaran, 2009)*

2A (ii) Content validity

Test: *Is the content of the tool representative?*

Method:

To ensure face validity, the questionnaire was scrutinised by a panel of experts in the field of stroke and later discussed within a focus group on the subject consisting of six lay persons. The experts were specifically asked to assess the questionnaire in terms of the (i) clarity of wording, (ii) style and formatting, (iii) feasibility, and (iv) readability (Haladyna, 2004; Trochim, 2001). They were also asked whether they thought the questionnaire could adequately assess stroke knowledge and to provide feedback that could enhance the representativeness of the instrument. Their experience and judgement were crucial assets here, and helped to identify potential flaws prior to starting data collection. The effect of literacy on reading comprehension was subsequently assessed within the focus group, and there was good agreement between the two samples (experts and lay persons).

Since the panel of stroke experts were familiar with the construct of interest, they were also asked to assess the degree of relevancy and representativeness of each item within the questionnaire (Haynes, Richard, & Kubany, 1995).

Outcome:

			Consensus outcome
i)	*Face validity*	Does the test appear to assess what it is supposed to?	Yes
ii)	*Content validity*	Are intended concepts clearly stated?	Yes

Table 3.3 Appraisal Criteria for Validity [adapted from Hou et al. (2017)]

(2B) Reliability testing

In order to explore the reliability of the instrument, a pilot study was carried out. Since the plan was to use an online version of the tool in the subsequent stage of the study, it was decided to use the same format for the pilot study. Thus, the new instrument was converted into an online version and uploaded to an online platform. The pilot study was then employed, and involved data collection at two instances from a sample of individuals with similar characteristics to the actual study sample. Individuals who participated in the pilot study were provided with a three-digit code to allow the comparison of answers from one point to another while safeguarding anonymity. One of the challenges faced was the dilemma between allowing for too large a time lapse between one data collection point and another, thus risking the answers being affected by intervening circumstances and, conversely, retesting immediately with the risk of the participants recalling the answers given during the first session (Polit & Beck, 2010). As advised by Parahoo (2014), a minimum time lapse of 2 weeks is needed to prevent the recall of material by participants. Thus, in the current study, I opted to allow for a 1-month period prior to retesting. Consequently, the following reliability tests were conducted:

2B (i) Test-retest (stability) reliability

Test: Will similar results be achieved following repeated administration of the tool?

Method: Administer tool twice to a number of participants

Outcome:

The Statistical Package for Social Sciences (SPSS) ® (Version 24.0) was used to assess the reliability of the tool. This was achieved by counting the participants' answers separately for each of the two data collection points and analysing them using the intra-class correlation (ICC) test. The results obtained are shown in Table 3.4.

Number of participants	**Time lapse between the two data collection points**	**Method used for identification of participants**	**Intra-class correlation coefficient**
118 (out of 308 who participated in the pilot study)	30 days	3-digit code	**0.79**

Table 3.4: Intra-class correlation table

With reference to Cicchetti's commonly used guidelines for interpreting the ICC test (Cicchetti, 1994):

Less than 0.40: poor.

Between 0.40 and 0.59: fair.

Between 0.60 and 0.74: good.

Between 0.75 and 1.00: excellent.

2B (ii) Internal consistency

Test: Do similar questions give similar answers?

Method: Include similar questions in the tool and administer the tool to a number of participants

Outcome:

Internal consistency was assessed in SPSS by measuring Cronbach's alpha, which ranges from a result of 0 (no correlation between items) to 1 (perfect correlation). The reliability analysis of the tool yielded a Cronbach's alpha of 0.832 for the Stroke Knowledge section and 0.775 for the Response section (see Section 5.2.1).

(3) Feasibility

In addition to the tests described, the conduction of the pilot study allowed other issues related to the tool to be explored, such as its feasibility, ease of comprehension, and other practical matters. Thus, following the pilot study, a focus group that included six of the participants was carried out to obtain feedback on these issues. The results of the feasibility testing can be viewed in Table 3.5.

		n (%)		
		Yes	Unsure	No
1	*Time and effort needed*	5 (83.3)	1 (16.7)	0
2	*Ease of scoring*	4 (66.7)	1 (16.7)	1 (16.7)
3	*Number of items*	5 (83.3)	0	1 (16.7)
4	*Accessibility*	6 (100)	0	0

Table 3.5: Feasibility table.

3.4.3 Stage 3: Quantitative phase – instrument implementation

3.4.3.1 Purpose

The final part of the study consisted of quantitative data collection. The main purpose of this phase was to explore the Maltese population's knowledge in relation to stroke recognition and management.

3.4.3.2 Method

An online survey design was selected due to its potential to quickly reach a large number of participants with minimal financial and human resources required. Furthermore, the absence of an interviewer may have encouraged the respondents to feel more comfortable and be truthful in their replies. Conversely, this data collection method is often limited by a low response rate and by access problems such as low literacy (Kelley, Clark, Brown, & Sitzia, 2003). Furthermore, replies cannot be probed since there is no direct contact between the participant and the researcher. The fact that this stage comprised only one part of the study may have helped to minimise some of these limitations, which again highlights the importance and benefit of the methodological triangulation that is afforded by engaging in mixed methods research.

3.4.3.3 Sample selection

In mixed methods research, it is common practice to include the same participants from the first stage of the study during the subsequent stages. However, this does not necessarily apply to exploratory designs since the recruitment of different participants may enhance and broaden the exploratory process as well as allowing generalisability (Creswell & Plano Clark, 2011). Therefore, in the current study, the participants in the quantitative phase were not the same as those in the qualitative phase. The decision to use the general public as one group of the target population in Stage 3 was based on the aim of the study, which was to explore stroke knowledge and education needs in Malta. Since stroke onset does not discriminate with regards to location, person, and time, it is highly likely that when a stroke occurs, the person is alone or with others in a non-healthcare setting and so symptom management depends on his or her knowledge and that of those around him or her. Nevertheless, and particularly if the symptoms are not overly alarming, the next step is typically to contact a GP or relative/friend who is also a healthcare professional. As discussed in the literature review section, it is therefore also important to explore the stroke knowledge and educational needs of healthcare professionals as they can find themselves in the position to provide good advice and to refer the person to emergency services in a timely manner. This background information led to the decision to recruit healthcare professionals as the second participant group in the third stage of the study.

The power analysis and sample size calculation were determined by statistical tests (Section 5.3.1), resulting in a sample size of 1872. A stratified probability sampling technique was employed to allow for adequate representation of sub-groups (strata) within the whole population (Crossman, 2016), as listed in the general electoral register.

The same exclusion criteria that were listed in the description of Stage 1 were applied during participant recruitment for the final stage of the study.

3.4.3.4 Data collection

Eligible individuals were contacted by email to invite them to participate in the study. The email contained information about the study as well as a link to the online survey. In a similar manner to the Stage 1 interviews, each potential participant was informed of his or her right to refuse participation and to withdraw from the study at any point. Moreover, reassurances regarding confidentiality, anonymity, and other ethical issues were provided. The consent form was not attached to the email but placed on the first page of the online survey so that unless the respondent completed this page, he or she would not be able to access the survey. The potential participants were given a deadline for survey completion and informed that a reminder email would be sent in 2 weeks' time.

3.4.3.5 Data analysis

Following data collection, descriptive statistics and correlations were performed as part of the data analysis process.

3.4.3.6 Quality assurance

While quality assurance in relation to the construction of the survey tool has previously been explored, the actual implementation of the online survey was characterised with its own quality checks. These are explored in the following paragraphs.

Accessibility and support

The pilot study carried out in Stage 2 explored the accessibility of the tool content to ensure that respondents understood the questions and did not encounter methodological difficulties that would interfere with the completion of the survey. This was even more important when considering the use of an online interface since, when using this method, responses were given 'alone' with no interviewer physically present in the room who could immediately resolve any difficulties. Nonetheless, in the introductory email, respondents were provided with a contact number which they could use if they needed to clarify anything.

When considering the use of an online platform, it was important to acknowledge that the survey could be accessed and completed even by individuals who were less experienced internet users. In view of this, specific technical features such as visually highlighted buttons, clear instructions, the option to save part of the survey and continue its completion later, and the possibility to change answers can enhance access and ease of use of the survey. To this extent, a commercial web survey tool was used since such platforms offer various survey templates, assistance, and anonymity assurance (Schaeffer, Dykema, Elver, & Stevenson, 2010). Furthermore, access to the tool was verified using the most common types of browsers and computer operating systems.

Monitoring

During the data collection period, regular checks of the process were performed to ensure that data collection was proceeding as expected. In particular, any completed surveys were backed up and stored on a password-protected computer to avoid the risk of data loss.

3.5 Mixed methods quality assurance

For each of the three stages of the study, specific quality assurance strategies pertaining to each phase were described. However, in keeping with the ethos of the mixed method approach, it was also deemed necessary to consider general quality assurance in relation to the three stages as one unit rather than as separate units. With reference to Creswell's advice on the matter, the primary concern of this type was to ensure that appropriate steps were used to make full use of the qualitative data when constructing the survey tool. As described previously, the framework for the transfer of qualitative data to the quantitative tool contents, as developed specifically for this study, was targeted at addressing this issue. Similarly, the conversion process was discussed with the supervisor and other colleagues to confirm that all qualitative data were included. Creswell (2014) has emphasised the inclusion of different participants within the qualitative and quantitative parts of the study when using an exploratory sequential mixed methods approach so as to avoid duplication of data. This advice was applied in the present study, and the Stage 3 participants were therefore not the same as those who participated in Stage 1. Finally, Creswell (2014) has strongly emphasised the need for quality assurance in each of the stages of a mixed methods approach since the resulting overall findings are ultimately the synthesis of each of its parts, so a lack of quality in any of the stages will inevitably lead to poor outcomes.

3.5.1 Further merging of the data

Following completion of the three stages of the study, the qualitative findings and quantitative results were merged, compared, and interpreted by discussing the themes, codes, and variables in a collective and integrated manner.

3.6 Ethical considerations

3.6.1 Ethical approval

Before starting the study, a research proposal was submitted for review and approval by the ethics committees of the University of Sheffield and the University of Malta. As part of this process, the relevant authorities were contacted for permission to collect data.

3.6.2 Informed consent

Subjects were invited to participate in the study without the involvement of the researcher in an attempt to avoid influencing or pressuring potential respondents. Thus, a third party was provided with information about the study and asked to approach potential subjects to explain the study, provide the individual with an information sheet, and invite him or her to participate. If the reply was positive, the researcher contacted the individual directly, confirmed the study details, clarified any difficulties, and obtained signed consent.

Prior to the interview, each stroke sufferer was asked if he or she could bring their bystander along, only if he or she felt comfortable in doing so. Moreover, the patient was asked to provide consent for the bystander to be interviewed jointly about the events that took place during stroke onset. Upon acceptance by both the stroke sufferer and the bystander, I proceeded to speak to the bystander directly to provide the study details and obtain consent.

Although the procedure for obtaining written consent was followed in an oral fashion during the Stage 1 recruitment process, an online process was applied for the online survey in Stage 3 with all information provided in the email that contained the survey link. In a similar manner to that used in the interviews, potential participants were informed that they were free to not answer any of the questions and to exit the survey at any point. To this extent, ‘pop up’ windows or other techniques that discourage participants from leaving were not used. Consent was addressed by placing it on the first page of the survey and setting up the page so that consent had to be endorsed before subsequent pages could be accessed (British Psychological Society, 2017).

3.6.3 Anonymity and confidentiality

Given that I was the person who carried out the Stage 1 interviews, anonymity could not be achieved. However, the use of pseudonyms instead of actual names in the report protected the identity of the respondents. The report was also scrutinised to remove any direct cues that may unintentionally reveal identities.

During the survey phase, anonymity was protected by switching off the option to collect computer IP addresses. A specific Google Forms account was created for use during the study, and only I had access to this account.

All data were handled in a sensitive manner by securing it in a locked location or by using computer password protection, and all records were destroyed upon completion of the study and after agreed and appropriate dissemination of results.

3.6.4 Protection from discomfort and harm

During the study, the researcher sought to prioritise the well-being of participants. To this extent, the interview guide and survey questions were thoroughly screened by the researcher and supervisor for any items that could potentially evoke negative emotions. Nevertheless, and with specific reference to the interviews, if a respondent were to communicate any discomfort during data collection, the process would have been terminated and support would have been provided. A mental health professional was informed about the study and asked to intervene if any of the participants required such support.

3.6.5 Incentives

Since participants used resources such as their time and personal internet connection to participate in the study, it was considered appropriate to use an incentive as an inducement to participate.

Thus, all participants in the study were eligible to win a 75-euro voucher that could be redeemed at a local bookstore. This feature was intended to serve as an incentive to participate as well as a small token of gratitude.

Chapter 4 – Qualitative Analysis

4.1 Introduction

This chapter presents the qualitative analysis of interviews with ten individuals who experienced a stroke (as described in Chapter 3) and with any others who were present during the stroke onset and chose to participate in the study.

Following transcription of the interviews, each of the cases was coded and themes were developed for each specific case to facilitate the in-depth exploration of each case and its uniqueness. Following this process, the themes were compared across the cases so that *literal replication* (similarities) and differences could be explored (Yin, 2009). This necessitated direct interpretation from issues encountered in single cases as well as naturalistic generalisation from the findings that emerged from one case to the other cases (Creswell, 2014). *Theoretical replication* (contrasting results for anticipatable reasons) could subsequently be undertaken as guided by Yin (2009).

This chapter consists of two main sections. The first section addresses the cases on an individual basis by presenting a general description of each case followed by the themes that emerged from that particular case. This allows for the process of 'Within Case Analysis' (Ayres, Kavanaugh, & Knafl, 2003; Goertz & Mahoney, 2012).

The second part of the chapter involves the merging of the cases by identifying common themes and discrepancies among the cases – a process called 'Cross-Case Synthesis' (Ayres et al., 2003; Goertz & Mahoney, 2012), which presents a more detailed analysis and discussion with interview excerpts.

4.1.1 Characteristics of the participants

The following table summarises the characteristics of the stroke sufferers who were interviewed during phase 1 of the study.

Case Number	**Age (Years)**	**Gender**	**Bystander Present**	**Notes**	**Acute Treatment**	**Interview Date**
1	**82**	**M**	Yes	Started with expressive aphasia; poor insight.	MT	*13/06/2017*
2	**67**	**M**	Yes	Woke up late in morning; GP delay.	None	*28/06/2017*
3	**71**	**F**	Yes	Wake-up stroke.	t-PA	*29/12/2017*
4	**59**	**M**	No	Farmer; late diagnosis.	None	*22/01/2018*
5	**65**	**F**	No	Husband accompanied her to Floriana polyclinic.	None	*23/01/2018*
6	**62**	**M**	No	Was at the bar with friends.	None	*09/02/2018*
7	**74**	**M**	Yes	Was watching TV; aphasia and hemiplegia.	t-PA	*09/02/2018*
8	**60**	**F**	Yes	Was at aquarium with grandchildren.	None	*14/02/2018*
9	**64**	**M**	No	Four previous TIAs/strokes.	None	*14/02/2018*
10	**60**	**F**	No	Was in bathroom; lost consciousness.	t-PA	*09/03/2018*

Table 4.1: Summary of Participants in Phase 1 of the Study

MT = Mechanical Thrombectomy; t-PA = Tissue Plasminogen Activator

4.2 Case descriptions and within case analysis

In this section of the chapter, the description and analysis of the ten cases are presented. The descriptive codes that emerged from the analysis of the transcripts were used to form vignettes in order to introduce the reader to each case. The key points emerging from each case follow each vignette.

4.2.1 Case 1

The participants in the first case of this study were an elderly couple who were both willing to share their experience of stroke in considerable detail. The stroke sufferer was the man and from the beginning of the interview, it was clear that his wife was exhibiting a protective attitude towards him, particularly due to the fact that she seemed to be the more health-conscious of the two while he seemed to be the less anxious, carefree partner. As a result, throughout the interview, she regularly chided him in a good-natured manner with regards to the fact that he should be more concerned and knowledgeable about stroke. The interview started off with a description of the stroke onset. The patient narrated how he had been in the kitchen while his wife was on the phone to their daughter. At one point he decided to speak to his wife but it seemed as if he could not manage to express himself, despite repeated attempts to do so. His wife immediately realised that he was suffering from a stroke and asked her daughter, who was still on the phone, to call for an ambulance. Soon after, the ambulance arrived and the patient was immediately taken to hospital. He insisted that he had no insight whatsoever of the seriousness of his condition and even showed a preference to walk to the ambulance rather than being transported by a stretcher. Thus, it never crossed his mind that the symptoms could be attributed to a stroke. Since the arrival to hospital was so quick, the patient was able to benefit from an intervention called mechanical thrombectomy, which his relatives had to consent to. The intervention was successful and the patient recovered quickly, managing to regain his full functionality. Following the incident, his knowledge about stroke has improved considerably and although he did not seek further information about this condition, he read the leaflets which were provided to him during his hospital stay. His wife seemed to be more active in her intent to seek further information and to help the patient to carry out life changes that may prevent another stroke.

Key Points (4.2.1.1 – 4.2.1.4)

4.2.1.1 “You don’t notice that it’s happening, unfortunately”

The first theme that emerged from this case was the patient’s complete lack of insight regarding the fact that he was experiencing a stroke. His only reported symptom was the fact that he could not express himself properly when he tried to speak to his wife. However, he lacked insight so much that he thought he could walk to the ambulance instead of being carried by a stretcher. He also remembered that during the onset, he felt completely calm and even tried to joke with his grandson, who presented himself upon arrival of the ambulance. This lack of insight terrifies the patient since he stated that while he is now aware of the symptoms of stroke, it does not mean that he will necessarily realise that he is suffering from the condition during its onset.

4.2.1.2 “She’s an expert when it comes to medical care”

In this case, the wife seemed very knowledgeable and practical. The fact that she was health literate and had received previous guidance from her son (a pharmacist) on how to manage a stroke equipped her with the right tools to help her husband. In fact, she quickly released that he was suffering from a stroke and knew that emergency services had to be activated immediately.

4.2.1.3 Anxiety as a barrier to action

Despite her knowledge, the terror and anxiety that the wife felt at the time of onset acted as a barrier as she could not remember the contact number for emergency services. Luckily, she was on the phone to her daughter at the time, and her daughter called for an ambulance. The wife recounted that she managed to present a calm façade in front of her husband so as not to cause any undue stress.

4.2.1.4 The way forward

Although the patient now seems more knowledgeable about stroke symptoms and management, it is the wife who is leading the recovery process. She seems to have a clear plan to access information other than the leaflets provided to them during the hospital stay. The patient stated that while he intends to refer to the leaflets provided, he prefers visual information as it is easier to understand.

4.2.2 Case 2

Another couple were the prominent actors in the second case. Once again, the stroke sufferer was the male, who was accompanied by his wife. They narrated how the stroke onset happened at 9 am, at which time the patient appeared to be slower, weaker, and lacking power in his limbs. He also seemed to be choking – a symptom that confused his wife and prevented her from realising that he was suffering from a stroke. Speech problems soon ensued. Interestingly, this was his second stroke in a year but it seemed as if neither the patient nor his wife thought that this could be a repeated episode. The wife was not really sure what to do but decided to contact their GP, who informed her that he would be visiting the patient at home later that day. As the morning went by and the GP had not yet paid a visit, the wife felt confused as to what would be the best action to take in the circumstances. One of their sons visited them at home and asked his father whether he wished to be taken to hospital. However, the patient refused and stated that he would rather wait for the GP to visit. Reluctant to ignore her husband’s plea, the wife decided to continue to wait for the doctor to visit. By 2.30 pm, she asked her son to phone the GP to remind him about the situation. The GP seemed surprised that an ambulance had not been called for and urged for an immediate transfer to hospital by ambulance. At hospital, the patient received the necessary treatment and managed to regain some of his former functionality. Following the stroke incident, it appears that the patient did not initiate any preventative lifestyle changes and is experiencing chronic stress due to his disabled condition. The wife seems to have gained some knowledge about stroke symptoms and management and showed a preference to accessing visual information rather than leaflets. The patient stated that he would like to receive more information about stroke.

Key points (4.2.2.1 – 4.2.2.3)

4.2.2.1 Uncertainly about the best action to take

One theme that was prominent in the case study was the wife's uncertainty about the best course of action in the circumstances. This may seem surprising, given that this was her husband's second stroke incident in a year. She faced two main barriers which led to a considerable delay. The first was based on her decision to contact the GP first rather than to activate emergency services. Second, her husband refused to go to hospital without being visited by the GP first. Upon this insistence, she felt uncomfortable to override his wishes and opted to wait.

4.2.2.2 "So I called our GP …"

The role of the GP is important in this case study. When contacted by the wife, the GP informed her that he would pay a visit later during the day. Unfortunately, he may not have realised that the symptoms were attributable to a stroke and so failed to refer the patient to hospital immediately. Although hours passed, the family, especially the patient himself, remained reluctant to bypass the GP and opted to wait further, thus wasting precious time during which treatment could have been administered with a higher chance of a good outcome.

4.2.2.3 The aftermath of stroke

It seems that after his first stroke, the patient started to experience chronic stress due to his condition. After the first and second stroke incidents, he did not attempt to carry out any lifestyle changes as preventative measures. It seemed that the patient's attitude as well as that of his wife was somewhat passive, especially as this was his second stroke in a year. However, both showed willingness to receive further information about stroke.

4.2.3 Case 3

This case presented with another couple, with the wife being the one who had experienced the stroke. The wife described how she had experienced the stroke onset while she was in the bathroom. Luckily, she had her mobile phone nearby and managed to call her husband, who was downstairs. The husband described how he immediately realised that she was suffering from a stroke and tried to help her to toile down on the bed. After he managed to do this, with difficulty, he contacted his GP. When the GP did not answer, he phoned his son to inform him about the situation and then called for an ambulance. The patient stated that during the stroke onset, she did not feel any pain but instead felt as if someone was continuously pushing her from behind. To this extent, she did not realise that she was suffering from a stroke. After arriving at hospital very quickly, she was administered the appropriate treatment and thus recovered fully. It seems that the couple did not attempt to seek further information about stroke following the incident. However, they seem to be aware of the main symptoms of stroke, some of the treatments available, and the lifestyle changes that are required. They did not wish to receive further information about stroke because they gained knowledge through their discussions with the different therapists that they encountered during the rehabilitation process.

Key points (4.2.3.1 – 4.2.3.3)

4.2.3.1 "Why are you calling for an ambulance?"

During stroke onset, it was clear that the patient did not have any idea that she was experiencing a stroke to the extent that she could not understand why she needed to go to hospital for treatment. This may have been because the symptoms that she experienced were not typical stroke symptoms.

4.2.3.2 Contacting others prior to activating emergency services

Although the patient's husband realised immediately that his wife was suffering from a stroke and knew that he needed to call for an ambulance, he chose to contact others for reassurance first. Thus, he first attempted to phone their GP. When the GP did not answer, he called their son to inform him about the patient's condition and that he was going to call for an ambulance. Finally, the ambulance was called for. Fortunately, this chain of calls did not lead to extensive delays. However, as per medical recommendations, activating emergency services should always be the first action so as to avoid wasting precious time during which treatment can be successfully delivered.

4.2.3.3 Unwillingness to receive further information

Both the patient and her husband seemed to have some knowledge in relation to stroke. However when probed further, such as when asked about the different types of stroke treatment available, their knowledge seemed to be lacking. This finding was at odds with their perception since they stated that they felt as if they had gained enough knowledge during the rehabilitation process and so did not need to access further information.

4.2.4 Case 4

The fourth case involved a farmer who was not accompanied by anyone else during the interview. His case was unique in that the stroke symptoms were very gradual and it ultimately took him several days to make the decision to go to hospital. He described how, on a particular Thursday morning, he was working in the fields with others when he suddenly started to feel unwell and eventually fainted. After around 30 minutes, he came around and went home to tell his wife about it. By the evening, he was still not feeling completely recovered. Having suffered from vertigo problems in the past, he simply put it down to another episode but decided to go to the GP for a visit. The GP reassured him that everything was fine even though the patient had another dizziness episode in front of him. That evening, the patient continued to feel unwell but woke up the next day feeling completely recovered. On Friday and Saturday he continued to feel well and managed to carry out his duties on the farm as usual. However, on Sunday he woke up feeling so dizzy and unwell that he could not get out of bed. In view of his symptoms, his brother called the patient's daughter, who came around to discuss options for the best action to take. Their conclusion was to call for an ambulance, which quickly transported the patient to hospital where he was administered appropriate treatment during a one-week stay. Although he did not recover completely, he has regained much of his functionality. The patient described how it never crossed his mind during onset that he was suffering from a stroke. Moreover, he did not wish to discuss his symptoms with his wife in great detail because he did not want to worry her. Notably, the patient explained that this was his first time in 60 years that he had ever been admitted to hospital, and this may have played a role in his decision to monitor the symptoms rather than to call for an ambulance immediately. Following the stroke incident, it seems as if the patient did not really seek information and as a result, his knowledge remains limited. The little knowledge that he has was obtained from having witnessed his own father experience a stroke and from a radio programme. He was also aware about dietary changes that he has to make as a preventative measure. He was not sure how he would manage another stroke onset and showed willingness to receive more information, in visual rather than written form.

Key points (4.2.4.1 – 4.2.4.3)

4.2.4.1 "I had fully recovered … then … couldn't get out of bed"

The prominent feature in this case is the gradual nature of the symptoms, in that it took days for the patient to deteriorate to a condition that merited the activation of emergency services. In fact, throughout these days, the patient had periods during which he felt completely normal and managed to continue working on his farm.

4.2.4.2 Ambulance call as a last resort

During this long delay in seeking emergency help, the patient took several self-treating measures. Whenever he felt sick, he attempted to sleep it off, and this sometimes did help him to feel better. On the first day, he also paid a visit to the GP who unfortunately may have misdiagnosed him and seemingly did not relate the symptoms to a stroke or attempt to provide advice regarding seeking urgent help. Two days later, upon sudden worsening of the symptoms, neither the patient nor his brother called for an ambulance immediately. Instead, the brother asked the patient's daughter to join them at the farm so that they could discuss the options. Finally, after so many steps, the call for an ambulance was made.

4.2.4.3 “Nothing! I don’t know anything”

It is surprising that even though the patient’s father had suffered two strokes, one of which was fatal, the patient’s information about the condition was very limited even after he experienced a stroke himself. Although he was aware of some of the stroke symptoms, he did not seem confident in explaining how he would manage the situation if he ever faced another stroke.

4.2.5 Case 5

The female in the fifth case was alone during the interview and also when she experienced the stroke onset. She described how she woke up from her afternoon nap feeling confused and dizzy. Her husband soon arrived home and urged his wife to go to the health centre immediately. He drove her there himself, and she was referred directly to hospital after being examined by a doctor. The patient mentioned that at no point did she or her husband suspect that she was suffering from a stroke because she looked completely normal. She was treated at the hospital and has since then made a good recovery. Importantly, near the end of the interview, the patient pointed out that the dizziness had actually started a day before and this had prompted her to go to the GP, who did not seem to relate the dizziness to a potential stroke. Following the stroke, the participant tried to follow a healthier diet. Her knowledge about stroke was limited and she did not wish to receive further information about the condition as she felt that this would precipitate anxiety. Moreover, she was adamant that there was nothing one could do when faced with a stroke.

Key points (4.2.5.1 – 4.2.5.2)

4.2.5.1 The winding road to the right action

In this case, it seemed as if there were a number of barriers to taking the right action. First, both the patient and her husband seem to have had limited knowledge about stroke. This led to an inability to recognise the stroke symptoms and the urgency associated with them. Consequently, they used their private car to go to the health centre instead of phoning for an ambulance. Another barrier was the fact that a GP visit on the day before the stroke did not result in an accurate diagnosis and so the required treatment was not delivered as early as possible.

4.2.5.2 "There's nothing much to do!"

It seemed as though one of the crucial findings of this study was the patient's helplessness with regard to stroke. Her attitude seemed to be somewhat passive as evidenced by her very limited knowledge-seeking activities following the incident and her unwillingness to receive further information. However, the underlying reason behind this attitude seems to be her belief that nothing could be done to manage a stroke.

4.2.6 Case 6

This interview was abrupt and the patient who participated did not share much information about his experience, likely because his overall knowledge about stroke as well as his insight during the onset were very limited. He described how on one particular evening, he had been at the pub with his friends. On his way home, while crossing the street, he suddenly lost his balance and fell over. His friends accompanied him to his home and apparently called for an ambulance as he then woke up in the ward. He does not recall anything that happened after his fall and did not seem to know anything about stroke symptoms or treatment. However, he at least showed that he had the knowledge to activate emergency services should he face another stroke again. The patient stated that he was willing to change his lifestyle but did not have the knowledge to do so. He seemed willing to receive more information, preferably visual material.

Key points (4.2.6.1 – 4.2.6.2)

4.2.6.1 “I don’t have a clue about what happened”

This case is particularly striking in that the patient had complete lack of insight during the stroke onset. The patient’s lack of knowledge, in addition to the abrupt onset and deterioration of his symptoms, may have been the main factors that contributed to this lack of insight. Luckily, he was accompanied by friends who seem to have managed the stroke onset appropriately by activating emergency services.

4.2.6.2 Limited knowledge

In this case, stroke knowledge was very limited to the extent that the patient could not list any stroke symptoms and stated that he would not realise that someone was experiencing a stroke. The one thing that he seemed to be aware of was the need to call for an ambulance, which is indeed positive. However, it is doubtful whether he would actually call for an ambulance if he cannot recognise that the presenting symptoms are attributable to a stroke. His lack of knowledge was also related to his wish to change his lifestyle but without really knowing what he needed to change. It was heartening to note that the patient showed willingness to receive more information about the condition.

4.2.7 Case 7

In this case, stroke onset happened in the evening while the participant was watching the television. He recalled how he suddenly felt his right arm go numb and weak. At this point in the interview, his wife added that she found him on the floor and was unable to communicate with him since he could not speak clearly. Consequently, she phoned their son to ask him to come over. The son noted that his father was also suffering from mobility problems and phoned for an ambulance. Both the wife and the patient noted that the patient was alert throughout the whole incident and could even communicate with the ambulance crew during the transfer to hospital. Once admitted to hospital, the patient was treated and made a good recovery. The wife stated that during the incident, she realised immediately that her husband was experiencing a stroke. She attributed this knowledge to previously reading, hearing, and watching programmes about stroke. By contrast, the patient did not realise that his condition was symptomatic of a stroke but understood that he needed to go to hospital immediately. When reflecting on her actions, the wife stated that if such a situation were to happen again, she would probably phone for the ambulance herself rather than phoning her son first. The couple did not seem to have engaged in accessing further information about stroke, and one reason provided for this was a lack of time. Preference for receiving further information was shown, and visual material was again deemed the most effective mode.

Key points (4.2.7.1 – 4.2.7.2)

4.2.7.1 “I immediately realised it was a stroke”

The couple who featured in this case were among those who were already equipped with some knowledge prior to the stroke incident. The wife seemed to be the most knowledgeable of the two, and realised immediately that her husband was experiencing a stroke. Although the husband did not have this insight, he seemed to realise that urgent care was required. Although the couple did not access further information during the aftermath of the incident, they admitted to having acquired experiential knowledge such as, for instance, the wife's reflection that in the eventuality of another stroke, she would call an ambulance immediately.

4.2.7.2 And then the ambulance call was made …

Despite the fact that both the patient and his wife seemed to have some knowledge about stroke, this knowledge did not automatically translate to the right action. During onset, the husband realised that he needed to call for an ambulance but he could not speak to communicate this. Meanwhile, his wife decided to call their son first and it was only after the son came around to their house that an ambulance was called for. Since the son lived just around the corner and the couple live near the hospital, the patient was still transferred to hospital with minimal delay. Notably, the couple stated that they were subscribed to an emergency support system whereby they can just press a button on a mobile alarm pendant to contact a specialised operator for support. However, the wife added that at the time, she did not even think about pressing the button.

4.2.8 Case 8

The woman in Case 8 was having coffee with her daughter and grandchildren when she suddenly started to feel dizzy. Her daughter thought that she was suffering from a hypotensive episode and provided her with some food to try to alleviate the symptoms. In fact, this led to a temporary improvement of the patient's condition. Soon after, they took the children for an outing even though the patient was still feeling slightly weak. At one point, she realised that she could not lift her legs to go up the stairs and this made her realise that she was suffering from a stroke. She asked her daughter to accompany her to hospital. However, she first wished to allow her grandchildren to finish their lunch so as to avoid worrying them and disturbing their outing. The woman added that she did not wish to involve her GP as he would anyway have referred her to hospital. After a considerable delay of 4 hours, the woman's daughter took her to hospital where she was treated with a good recovery. Strikingly, the patient in this case seemed highly knowledgeable about stroke and its symptoms as well as the need to call for an ambulance immediately. She was also knowledgeable about the lifestyle changes that she needed to maintain for prevention of stroke. She had acquired this knowledge by watching television programmes about the condition and wished to receive further information through television programmes as these were easier for her to follow.

Key points (4.2.8.1 – 4.2.8.2)

4.2.8.1 Knowledge may not translate into action

The woman in this case came across as one of the most knowledgeable among all of the interviewees. This knowledge enabled her to immediately realise that she was suffering from a stroke and to make the decision to go to hospital. Although she knew that she should have called for an ambulance right away, she opted to wait and to go to hospital in her daughter's car. This appears to be an example of how having the necessary knowledge does not always translate to taking the appropriate actions.

4.2.8.2 Self-sacrificing attitude

The reason for the patient's delay in going to hospital was that she did not wish to make a fuss or disrupt her grandchildren's outing, despite the fact that she was equipped with the necessary knowledge on the appropriate action required. Her father had also suffered from a stroke so she had acquired additional personal experience in relation to this condition. Although her actions are understandable, they did lead to unnecessary delays in seeking care.

4.2.9 Case 9

The elderly man who featured in this case was at home alone during the stroke onset. He described having just woken up from his afternoon nap and deciding to have a shower when he suddenly realised that his arm and half of his face were numb. Such symptoms had happened to him four times previously, and this seems to have provided him with the insight and knowledge on how to recognise stroke symptoms as well as the confidence to take the right action. Additionally, his GP had always advised him to call for an ambulance immediately should he ever experience such symptoms. Thus, he activated the alarm button on his emergency support pendant and the specialised operator called for an ambulance. He was transferred to hospital within 30 minutes. Although, subjectively, the patient in this case seemed very knowledgeable about stroke symptoms and the actions that needed to be taken, he did not perceive himself as being sufficiently informed about stroke. He stated that the little knowledge that he possessed had been obtained by watching television programmes on stroke. To this extent, he seemed willing to receive more information, ideally as leaflets.

Key points (4.2.9.1 – 4.2.9.3)

4.2.9.1 Self-confidence in action taking

During the interview, it was immediately noticeable that the participant was one who enjoyed a good level of self-confidence. This and the fact that he had suffered from previous stroke symptoms led to his making the right decision to activate emergency services without unnecessary deliberating and delays. Upon reflecting on the stroke incident, he expressed satisfaction that he had made the right decisions during onset.

4.2.9.2 “The GP always warns me to go straight to hospital”

In this case, the GP had a crucial role since he was the one who had previously informed the patient that in the case of a stroke, the only action needed is to immediately call for an ambulance. This shows the importance of providing good advice, especially by healthcare professionals who are close to the community and who may be the first point of contact and the primary source of health-related guidance.

4.2.9.3 Different routes to acquiring knowledge

Surprisingly, the patient in this case did not perceive himself as being knowledgeable about stroke even though he was one of the most informed patients encountered during the interviews. This perception may be due to the fact that he admitted that he had never actively searched for information related to stroke. This points towards the fact that knowledge can be acquired through different ways, not least through guidance offered by community experts such as GPs or via television shows that feature experts discussing the subject.

4.2.10 Case 10

The final case involved an elderly female who had experienced a stroke whist she was accompanied by her husband. During the interview, she was not accompanied by her husband but could clearly recall the events that occurred on the day of the stroke onset. She described how one morning, just before breakfast, she suddenly realised that her left arm had gone weak. This was soon followed by one-sided bodily weakness, speech problems, and loss of consciousness. Luckily, upon experiencing the symptoms, she managed to sit down on the sofa and so avoided a fall. Her husband immediately called their daughter who then phoned her husband to ask whether he knew the emergency services contact number. In less than half an hour, the patient was transported to hospital by ambulance in good time to receive adequate treatment. At the A&E department, the speech problems made it impossible for the patient to communicate with the medical team, and she found this frustrating. Although neither the patient nor her husband or daughter realised that the symptoms were characteristic of a stroke, it seemed as if the patient was quite knowledgeable about the symptoms of stroke, stroke management, and lifestyle changes that needed to be taken as preventative measures. To this extent, she has since stopped smoking. She seems to have received this information from the healthcare professionals that she encountered during the hospital stay. When asked whether she would like to receive more information about stroke, she answered that she did not know how to read or write and did not enjoying watching the television or listening to the radio.

Key points (4.2.10.1 – 4.2.10.3)

4.2.10.1 Lack of insight during onset

It appeared that during stroke onset, neither the patient nor her family realised that the symptoms were characteristic of a stroke. This led to deliberation about the best action to take. Luckily, upon the daughter’s husband’s insistence, the right conclusion to call for an ambulance was soon reached. It is good to note that the woman’s knowledge has improved considerably following her personal experience of a stroke.

4.2.10.2 Communication issues

A unique finding in this case was the woman's description of her frustration when she could hear healthcare professionals speaking to her and about her while her speech problems did not allow her to speak back. It would be beneficial for this type of finding to be communicated to healthcare professionals for consideration during their interactions with stroke patients and other patients who may be experiencing communication difficulties.

4.2.10.3 Information provision by healthcare professionals

In this particular case, it was encouraging to note that crucial information about stroke was provided by the healthcare professionals encountered during the hospital stay. Thus, the patient reported that one of the nurses had reinforced her knowledge about the need to call an ambulance when experiencing stroke symptoms. Similarly, the patient's neurologist provided her with information about the mechanism of stroke and the lifestyle changes that need to be undertaken. Such findings are encouraging, especially in the view that locally, healthcare professionals are typically perceived as being experts and so the value of their words may be greater than those coming from other sources or other types of educational attempts.

4.2.11 Conclusion

The aim of presenting the individual case studies and their emerging key points was to gain a thorough understanding of the prominent features of each case. In addition to understanding the uniqueness of each case, this exercise is preparation for transverse exploration across the cases, which shall be presented in the next section.

4.3 Cross-case synthesis and discussion

Multiple case studies give rise to the opportunity to explore similarities and differences related to stroke knowledge among different individuals and various contexts. The process of cross-case analysis necessitated the determination of common themes across the case studies. This resulted in four themes that were consistent across the cases, as depicted in Table 4.2.

Themes	**Description**	**Quotes**
Theme 1: Knowledge before the stroke incident	Any previous stroke knowledge that the patients or bystanders had before stroke was experienced.	P: The visual signs – yes, I knew … but otherwise I didn't know. (C1) P: No I don't know anything about the condition. Still I don't know anything now! Now, since I was a victim of stroke, I might find out more about it. (C6)
Theme 2: Stroke onset	This theme addresses the events that took place during stroke onset, including the signs and symptoms felt/observed and the actions taken.	P: I was terrified … as I realised I was suffering from an acute stroke … I feared half of my body would remain like that. (C8) P: Then in the morning … I was planning to pick strawberries on that day … But I just couldn't get out of

		my bed! I had this severe vertigo … (C4)
Theme 3: Reflections on the stroke incident	Following the stroke incident, some of the patients and bystanders reflected on the incident and actions taken – their shared thoughts make up this theme.	B: Had I brought him to hospital … there is a drug they told me … (C2) B: I think I did the right thing … not to be proud of myself … but I was aware of it. (C1)
Theme 4: New knowledge obtained after the stroke incident	The last theme presents the aftermath of the stroke incident, particularly the acquisition of new knowledge and lifestyle changes.	P: I would go straight to hospital … I mean I would call for an ambulance to go to hospital. (C10) P: Well … I know I should cut down on food … especially certain type of food, try to exercise myself … (C9)

Table 4.2: Cross-Case Analysis Themes

Once the themes were identified, word tables were formed according to the different issues/sub-topics within each theme. This method, suggested by Yin (2009), involves the creation of such tables to display data on a uniform topic (or code) from each individual case, thus facilitating the drawing of cross-case conclusions. As an example, Table 4.3 presents one of the word tables that was constructed.

Topic: Signs and Symptoms (Patients' Version)	
Case Number	**Summary**
1	Only realised something was wrong when he arrived at hospital and could not raise his arm. Not aware that it was a stroke. Had episodes of amnesia.
2	Realised that something bad was happening but did not think of a stroke.
3	Did not realise it was a stroke. Could recall all that happened.
4	Did not suspect what was going on. Thought he would feel better after a good night's sleep.
5	Felt something was wrong but did not realise that it was a stroke. Realised she had to somehow seek care.
6	Did not realise that something was wrong as he passed out immediately
7	Realised that something really bad was happening but attributed it to a heart problem instead of stroke.
8	Realised that she was experiencing a stroke and expressed the need to go to hospital after her grandchildren had finished their lunch.

9	Realised that it was a stroke as had experienced a previous episode. Called for help immediately.
10	No idea of what was happening.

Table 4.3: Word Table for the Topic 'Signs and Symptoms (Patients' Version)'

This chapter has been structured according to the four themes. Quotes and examples from individual case studies have been included in order to explore each theme in an in-depth manner. In the quotes provided, 'P' refers to the words of the patient, 'B' indicates the bystander's words, and 'I' presents a statement uttered by the interviewer.

4.3.1 Theme 1: Knowledge before the stroke incident

4.3.1.1 Patient knowledge

One of the topics that was explored with the patients who participated in the study was whether they had any previous knowledge about stroke prior to the incident. The findings showed that many of the patients were not really confident in their knowledge, with most of them admitting that they had limited previous knowledge, if any:

P: No I am not very knowledgeable … I only learnt basic things through television. (C9)

B: I can assure you - when it comes to healthcare - he just doesn't care, he doesn't know anything … in fact I tease him that he's not like a medical doctor's son! because his father was a general practitioner. (C1)

In a local study by Caruana et al. (2013), which included a sample representative of the Maltese population, local stroke knowledge was found to be limited. In fact, only 3% of participants could recall the three stroke symptoms incorporated in FAST. Similarly, only 43% of the same cohort could relate unilateral weakness or numbness to stroke.

Lack of local stroke knowledge reflects the information published in the literature. For example, in a very large population-based survey, Pancioli et al. (1998) found that only 57% of participants could at least identify one of the five major stroke signs. More negative results were found in a review by Nicol and Thrift (2005), who found that 10%–60% of participants could not list a single stroke sign.

Interestingly, certain stroke signs such as weakness and numbness were found to be more easily related to stroke than others (Jones et al., 2010; Kothari et al., 1997). On the other hand, "minor symptoms like headache, dizziness or unilateral numbness" were not readily associated with stroke, and patients were less likely to seek medical help in these instances (Das et al., 2007).

Lack of public stroke knowledge is thought to represent the main contributor to a delay in seeking urgent stroke treatment (Evenson et al., 2001; Yoon et al., 2001b). Williams et al. (1997) showed how failure to recognise the seriousness of stroke symptoms was the main reason for pre-hospital delays in stroke.

Notably, some of the patients stated that they had obtained some previous knowledge about stroke through the media, namely via television or radio:

P: The more one knows the better. I often follow health related programmes on TV … that's why I realised I was suffering a stroke. (C8)

Interestingly, the patient in Case 4 said that he did not really relate to printed information and consequently discarded any material that he received:

P: Let me tell you … I believe we might have received some material, but I just throw everything away! I am a simple farmer and I don’t enjoy reading. (C4)

However, he then said that he did listen to the radio and that was the source which had provided him with information about stroke treatment:

P: I am always listening to the radio during my free time, even when I am having dinner. Yes, I heard about it [treatment for stroke] … if it is performed quickly enough, it will completely cure the patient … it’s up to six hours if I’m not mistaken. In my case it was too late. (C4)

P: Sometimes there’s a medical doctor speaking on TV and I stay listening to him. They advise regarding diet, excess alcohol and so on. (C9)

Patient knowledge about stroke treatment is equally important, not only because such treatment is time-sensitive but also because it may promote an appropriate emergency response. This is better understood in the light of the ‘Theory of Reasoned Action’ (Fishbein, 1975). Unfortunately, Kleindorfer et al. (2009) found that less than 4% of participants within their study were aware of rtPA or an approximation of it.

4.3.1.2 Bystander knowledge

Some of the bystanders who accompanied the patients also offered information regarding their knowledge about stroke prior to the incident. Bystander knowledge is arguably as important as that of the affected individuals. It is often bystanders who need to recognise stroke warning signs and appropriately activate emergency services. This role is crucial when the stroke patient lacks either insight or the physical and mental ability to react.

Wein et al. (2000) found that over 95% of emergency stroke calls came from relatives or bystanders rather than from the affected individuals.

In Case 1, the bystander, who was the patient’s wife, discussed how she had always been interested in accessing medical literature and so was already equipped with some knowledge before her husband fell ill. She pointed out that stress could have been one of the precipitators of her husband’s stroke as exacerbated by the political situation in the country as well as their impeding house move:

B: There was a period where we were really stressed out this last month … because of political reasons … to be fair … we were stressed

P: and the house

B: the house … since we are going to move house … that's at the back of our minds … its traumatic …

P: at our age … (C1)

Apart from the information that she had accessed on her own, she added that their son is a pharmacist by profession and had always advised them that if symptoms of a stroke were to present themselves, they should immediately phone for an ambulance without consulting with anyone else:

B: Well my father had a stroke and I love reading medical stuff … and my son - well he's a pharmacist but he also tries to keep up to date. He used to tell me “mum if dad develops any symptoms do not call the GP or uncle Pete or anyone but rather call an ambulance straight away. Straight to emergency”. And that I kept in mind!” (C1).

Fussman et al. (2010) found that only 14% of participants within a large population-based study chose the correct response when presented with three different case scenarios. Interestingly, the same study revealed a disconnect between stroke knowledge and response. As previously discussed, the process of generating an appropriate response is highly complex, and although a degree of background knowledge is a pre-requisite, it is heavily influenced by other factors. This lack of association between stroke knowledge and appropriate response was also shown in the studies by Williams et al. (1997) and Ritter et al. (2007). In a study by Travis et al. (2003), only 42% of participants said that they would call 911 should they suffer a stroke.

Similarly Yoon et al. (2001b) showed that calling for an ambulance represented just 1.1%–20% of the initial responses among individuals who had suffered from stroke.

The provision of information by relatives and health professionals was also discussed in a review by Jones et al. (2010), which showed that these are the most common sources of public stroke knowledge. Similarly, in Case 7, the patient’s wife seemed to have had previous knowledge in relation to stroke symptoms and the action that must be taken in such circumstances. She attributed her knowledge to reading and hearing about stroke, especially from television programmes:

I: How come you were already familiar with the symptoms of stroke?

B: Well you know, you read, hear, watch TV … I knew it straight away when I touched his arm. (C7)

The participants who featured in Cases 8 and 9 also pointed out that any knowledge that they had was obtained by watching TV programmes on stroke.

Along similar lines, radio played an equally important role in knowledge acquisition for participants in Cases 2 and 4. This may highlight the importance of the media in the distribution of stroke-related information. In the review by Jones et al. (2010), the importance and efficacy of media in conveying important health-related information was also explored. In fact, television was mentioned by up to 82% of participants as a useful source of information. Similarly, television and the internet were the most important sources of stroke knowledge in the survey by Travis et al. (2003). By contrast, in a study based in India, Das et al. (2007) found that the most important source of information was leaflets – this differs from the finding in the current study, whereby leaflets did not seem to be a priority source of information according to the participants.

The bystander in Case 3 did not mention whether he had any previous knowledge but stated that upon the presentation of his wife's symptoms, he immediately realised that she was suffering from a stroke. This points towards the fact that he probably had some previous knowledge about the condition.

4.3.1.3 Previous symptoms

During the interviews, some of the patients disclosed that prior to the stroke incident, they had already experienced symptoms which could be possibly stroke-related. For instance, the wife of the patient in Case 1 recalled how 8 months prior to the onset of stroke, the patient had been at his brother's house when he suddenly experienced confusion and arm numbness. Although he did not relate these symptoms to a potential stroke incident at that time, they now realise that these symptoms may potentially have been the first warning signs of what was to come:

B: He experienced numbness in his arm and then his brother told him to sit down and after some time he gave him a glass of water and then he improved all of a sudden – but coming to think of it – this must have been a minor stroke … because he still occasionally gets pins and needles in his arm. (C1)

Previous stroke or TIA significantly increases the risk of a future cerebrovascular event. Despite this, most studies have shown that individuals who have previously experienced a stroke do not necessarily have increased stroke knowledge. Kothari et al. (1997) showed that up to a third of previously affected stroke patients were not familiar with any of the stroke warning signs. Jones et al. (2010) showed that stroke patients did not have increased stroke knowledge compared with their unaffected peers. Similarly, Bellolio et al. (2007) found that only 51.4% of patients with recurrent stroke realised that they were suffering from another cerebrovascular event. These findings contrast with those of Williams et al. (1997), who showed that previously affected patients had better knowledge about stroke compared with a demographically comparable control group.

Previous arm numbness was also experienced by the patient in Case 9 – this was accompanied by facial numbness and occurred on four different occasions prior to the stroke incident.

Certain stroke symptoms or warning signs may not be as noticeable or characteristic of stroke as others may. Such “minor symptoms like headache, dizziness” (Das et al., 2007) may be easily overlooked or attributed to something else both by the patient/bystander and medical doctors, leading to a delayed diagnosis or even a misdiagnosis. Affected individuals may perceive such symptoms as not particularly dramatic or life-endangering. The ‘Health Belief Model’ (Rosenstock, 1966) explains how individuals are more likely to engage in a desired behaviour with increased perceived severity of their condition/situation. Similarly, the ‘Theory of Reasoned Action’ (Fishbein, 1975) states that people’s attitude and behaviour is dependent upon perceived consequences. If the sequelae of these ‘minor symptoms’ are deemed insufficiently severe, it is highly unlikely that the affected individuals will display the necessary behaviour.

Dizziness was another symptom experienced by the patient in Case 5. In this case, the symptom appeared just one day before stroke onset:

P: I did go to the GP before this happened to me. I went to him the day before … but he found nothing wrong! He told me “Your lungs are clear, the heart also looks fine” … he checked my blood pressure and that was fine too.

I: Why did you go to your GP the day before? Was it a routine check-up?

P: No, since I felt dizzy … I usually take Stemetil. (C5)

The fact that the patient went to the GP on the evening of stroke onset points towards the possibility of a misdiagnosis. Of course, information regarding the severity of the dizziness is insufficient. Moreover, the fact that the patient reported that she tends to suffer from this symptom may have acted as a confounding factor, thus making it harder for the GP to suspect a stroke. However, it is felt that in such cases the GP needs to be equipped with the knowledge to advise the person to monitor their symptoms and to call for an ambulance immediately should they worsen. Unfortunately this did not seem to happen in this case since, when the symptoms did worsen, the patient lost precious time by going to the health centre instead of calling for an ambulance.

Collectively, despite these potential warning signs, the participants did not have the previous knowledge to realise that they could be symptomatic of a stroke.

It should be noted that the patient in Case 2 had already suffered from another stroke 4 months before the second onset. When he was asked whether he had made any changes to his lifestyle after the first attack, he vehemently declared that there had been no changes whatsoever and that he had even started to drive his car again. In fact, both he and his wife reflected on the fact that after the first onset, he still smoked, consumed alcohol, and experienced uncontrolled anxiety related to his struggle to cope with the fact that he had had a stroke. It should be noted that in this case, failure to carry out lifestyle changes was not a result of lack of knowledge since it was clear that the patient and his wife did know that these habits were stroke precipitators.

The reluctance to change health habits can potentially be explained by a number of health promotion models. Environmental factors may play an important role when an individual is considering a lifestyle change or plans to discontinue certain habits. The role of such factors in behaviour modification is highlighted in the 'Social Ecological Model' (McLeroy et al., 1988). For example, one can understand how stopping smoking can be extremely difficult if an individual’s partner/family continue with this habit. In fact, the ‘Social Learning Theory’ (Bandura, 1963) also stresses the importance of positive reinforcement when it comes to such behavioural changes. Before embarking on these lifestyle changes, it is crucial that the individual understands the sensitivity and susceptibility of his or her situation. Unless an individual considers him- or herself to be at risk it will be very unlikely for him or her to embark on such lifestyle changes (Rosenstock, 1966). It is also important to consider the stages of change mentioned in the ‘Transtheoretical Model’ (Prochaska et al., 1992). An individual’s willingness to change a particular health-related behaviour varies within the same individual over time, and hence such individuals may require some time before they embark on lifestyle changes.

However, the issue of uncontrolled anxiety – which was brought in Case 2 – may merit further exploration and research due to the fact that such psychological states may act as major barriers to change. In fact, it may be the case that, as a medical emergency, the physical symptoms of stroke take precedence – especially during the acute presentation of the condition. This may lead to unintentional neglect of the patient’s emotional state – a state which, as some of the patients in this study described, is usually one of sadness and terror and that may linger even months and years after the onset:

P: I have been feeling very down lately. It is worse after 5 pm, as it is getting dark. I start feeling very sad … actually it is more like anxiety. (C10)

During and especially in the aftermath of stroke, it is thus important to address these feelings as they may result in further morbidity and additional risk factors for another stroke or other illnesses.

This information about failure to address risk factors is a critical finding, and one that has already been presented in a publication by the World Health Organization addressing the prevalence of risk factors for stroke in Maltese adults. Insufficient physical activity (42.9%), tobacco smoking (26.6%), hypertension (25.4%), obesity (26.6%), and diabetes

(7.3%) were among the most prominent findings (World Health Organisation, 2014). Moreover, in a local study by Mallia et al. (2015), it was found that 85.7% of acute stroke patients who presented to the local hospital had at least one previously diagnosed stroke risk factor. Hypertension was the most common risk factor present, followed by previous cerebrovascular accident and diabetes mellitus. Although certain risk factors are linked to a genetic predisposition, they can potentially be controlled, thus reducing the risk of stroke.

4.3.2 Theme 2: Stroke onset

4.3.2.1 Signs and symptoms

Many of the patients who were interviewed were able to recall some of the events that occurred during the stroke incident. The patient in Case 1 discussed how, at that time, he was not really aware of the seriousness of his condition since the only symptom that he was experiencing was speech problems, followed by a headache at a later point. In fact, when the ambulance arrived, he wanted to walk from his house to the ambulance instead of being transported by stretcher. He admitted that he does not recall the journey to hospital but has vague memories, particularly of the treatment that he was administered and the medical intervention that he underwent (mechanical thrombectomy):

P: Well I tried to tell her [his wife] but couldn't express myself, well I couldn't express myself ok. Then I tried again but couldn't manage.

P: I thought I was talking in a normal way at that point, but I still felt that I couldn't express myself well.

P: … when the ambulance people came I asked them whether I should go to the ambulance myself. But they told me that they were going to use a stretcher. (C1)

Notably, the patient stated that he did not realise that he was suffering from a stroke – this finding was common to eight of the other patients who were interviewed.

The patients in Cases 3, 5, and 9 experienced the onset of stroke during their afternoon nap, and woke up to find themselves to be experiencing stroke symptoms. The patient in Case 3 described how she woke up to find that she could not walk properly. In a similar manner to the patient in Case 1, she did not realise that her condition was so serious and consequently could not understand why her husband was insisting on calling for an ambulance. Although she remembers parts of the treatment that she received, she has memory gaps of the events that occurred:

P: At one point I woke up and found myself covered in sweat. That's all I recall from that otherwise uneventful night. When I woke up, I went to the bathroom, but couldn't walk properly as if my foot kept slipping …

P: I told him [her husband] why are you calling for an ambulance, but he told me "your mouth is deviated!" (C3).

In Case 5, the patient woke up from her nap feeling confused and dizzy. Unfortunately, she did not feel as if her condition was serious enough to merit immediate transportation to hospital by ambulance but opted to wait for 3 hours before going to a health centre in a private car driven by her husband:

P: I went to have a nap in the afternoon and when I woke up I was 'confused' … As if … I didn't know what I wanted … and then I thought to myself … how come I still feel dizzy?

I: What was the time lapse between waking up confused and going to the polyclinic?

P: Around three hours … perhaps not even 3 hours. He [her husband] drove me there. (C5)

This finding is not surprising, as it seems that most studies on the subject show that the public are unaware of the benefits of ambulance transfer to hospital as opposed to private transportation during stroke onset (Deng et al., 2006; Morris et al., 2000; Moser et al., 2006; Williams et al., 1997).

The patient who featured in Case 9 also woke up from her afternoon nap experiencing stroke symptoms, namely complete right arm numbness and facial paralysis:

P: This hand and half of my face went numb … however, I was otherwise completely fine. I was not nauseated or dizzy. This had already happened to me on several occasions … it is always the same side that is affected. (C9)

It was noticed that in some of the cases, stroke onset was sudden and without any warning signs. Thus, the patient in Case 7 was watching the television when he suddenly experienced arm numbness and mobility problems:

P: I was watching TV, and at one point, I could not feel this arm any longer. It was completely numb. I was afraid, actually terrified that I could not feel my arm. I was sitting in my armchair, waiting for the programme to start … I tried to grab something with my hand, but I did not manage. (C7)

Similarly, the patient in Case 8 was having coffee when she felt a tingling sensation affecting half of her body. This was accompanied by dizziness and mobility problems. This patient was the only one who immediately realised that she was suffering a stroke, and to her, the obvious indicator was that she could not move half of her body:

P: However, at one point, I could not go up the stairs. I could not lift my leg. Therefore, we stopped to eat something at the aquarium. Then, I asked my daughter to accompany me to the Emergency department once the children had finished eating, as I told her “I have a stroke!”. She asked me “How do you know that?”. I answered that I could not move half of my body; I could not even lift the fork. (C8)

The patient in Case 10 experienced similar symptoms to those mentioned by the others. She recalled three main symptoms, arm weakness, leg numbness, and speech problems. An interesting point raised by this patient was that throughout the event, she remained fully conscious and so upon arrival to the A&E department, she could hear the healthcare professionals speaking to her and about her but could not answer them back. This was the source of intense frustration for this individual. By contrast, the patient in Case 6 can barely recall any of the event proceedings. He remembered that he was at a local pub having a beer with his friends. When he was on his way back home, he felt dizzy and lost his balance, which led to him falling over and hitting his face as he was crossing the street. When he came around, he found himself at the hospital with no recollection of what had happened to him. However, not all individuals experience such sudden onsets – the narrative that emerged in Case 4 portrays this clearly. In this case, the interviewee was a farmer who spent most of his time tending to his crops and livestock. In his account, he described how one day, he was working in the fields when he started to feel unwell. This soon led to a fainting episode. Since he had previously suffered from vertigo, he attributed this to be the cause of the presenting symptoms. Since his symptoms persisted, he decided to seek the advice of his GP, who assured him that everything was fine – even though the patient had another dizziness attack in front of him. Despite this reassurance, the patient continued feeling unwell and decided to go to bed to rest. It was at this point that he started to feel very nauseated but then woke up the day after, feeling fully recovered, and went to work in the fields. Two uneventful days later, he could not get out of bed in the morning due to severe vertigo and general weakness. This prompted his daughter to call for an ambulance. In this case in particular, it is not surprising that neither the patient nor his relatives considered stroke to be the possible cause of the symptoms since the onset was very gradual with vague symptoms. This issue was also brought up by Das et al. (2007), whose study showed that most stroke survivors and members of the general public were not ready to seek medical help for "minor symptoms like headache, dizziness or unilateral numbness". Moreover, a GP visit resulted in false reassurance and a misdiagnosis which increased the time lapse from stroke onset to receiving adequate medical treatment:

P: So we went to the GP … he examined me and told me it was due to a problem with my semi-circular canals. He checked my blood pressure and other stuff … he told me everything was absolutely fine. All of a sudden, I felt dizzy again, in front of him, but he instructed me to take deep breaths. I followed his instructions and felt much better in no time. He told me that he was not going to prescribe anything to me. After that, we went home, my wife and I. My wife asked me "are you going to eat something?". But I told her I didn't feel like. Instead, I told her that I was going straight to sleep. (C4)

Most of the bystanders who were present during the interviews mentioned that there were several signs which could be observed during stroke onset. In Case 1, the patient's wife noted that he seemed to be very confused and was also experiencing facial symptoms and arm weakness. To her, these were clear symptoms of a stroke:

B: I knew what was going on from the very start as though I was a medical doctor myself. Because it was very obvious. I though he was kidding me initially but when I saw his eyes staring like that … I knew straight away. (C1)

In Case 2, the visible signs observed by the bystander were those of limb stiffness, a general slowing down in movement, and choking. In this case, the patient appeared to have speech problems – a sign which was also noted by the bystanders in Cases 3 and 7:

B: I immediately realised it was a stroke. When I lifted his arm … it was so floppy … I knew it straight away. Even his speech was slurred … and he was like stuttering. (C7)

The wife of the patient in Case 7 found her husband lying on the floor. Although she tried to place him in an armchair, she did not succeed because he had weakness on the right side of his body. She recalled how continuous vomiting was another sign that her husband presented with. Surprisingly, the patient in Case 5 stated that her husband had not noticed any signs indicative of a stroke or medical emergency:

I: Did your husband notice anything different?

P: No he didn't … I looked completely normal … (C5)

However, this statement has to be treated with caution and as secondary information, since the husband himself chose to not be present for the interview.

Through these narratives, it became clear that during stroke onset, most of the patients exhibited symptoms of being medically unwell. Although most of the bystanders were aware of this fact, not all of them realised that the cause of the symptoms was a stroke. To this extent, the wife of the patient in Case 2 thought that her husband was choking rather than suffering from a stroke:

B: No, I thought … I don’t even know what I thought … even when he couldn’t cough, I thought he was going to suffocate. I don’t know what I thought at that time … the fact that he couldn’t even move his legs – I was astonished … (C2)

Similarly, the daughter of the patient in Case 8 assumed that her mother’s symptoms were to the result of a hypotensive episode and so provided her with some food to attempt to correct the drop in blood pressure. In Case 5, the husband seemed equally unaware that his wife was experiencing a stroke, while the relatives of the patient in Case 4 lacked insight to the extent that they did not call an ambulance until days had passed after the initial symptoms. By contrast, as previously indicated, the wife of the patient in Case 1 stated that she realised that her husband was experiencing a stroke. Such insight was also present in Cases 3, 7, and 10, in which all the relatives stated that during onset, they were positive that the symptoms were being caused by a stroke:

P: My husband realised immediately from the way I was speaking to him. (C10)

I: Did you realise she had suffered a stroke?

B: The way she was talking to me … yes I immediately did! (C3)

Unlike the bystanders, the majority of the stroke sufferers who participated in the study did not realise that the symptoms that they were experiencing were characteristic of a stroke. In fact, only the patients in Cases 8 and 9 stated that they realised that they were experiencing a stroke during its onset. In Case 9, the patient stated that this acute insight was a result of the fact that he had experienced a previous stroke with similar symptoms. This contradicts with findings that emerged from a study by Williams et al. (1997) in which stroke symptom knowledge in patients who had already suffered a stroke was explored. Only a quarter of the cohort managed to correctly identify the symptoms as being attributable to a stroke, with 29% believing that the symptoms were caused by something else. Consequently, in this same study, the main reason for late arrival to hospital was a failure to recognise the seriousness of the symptoms. However, the scenario presented in Case 2 of the current study replicates the findings by Williams et al. (1997) in that neither the patient nor the relatives seemed to be aware that a stroke was being experienced, despite that fact that this was the patient's second stroke in a year.

In the remaining cases, the patients recalled that although they were aware that something bad was happening to them, they did not relate the symptoms to stroke. For instance, the patient in Case 7 thought that she was having a cardiac incident. Similar findings were presented in studies by Mikulík et al. (2008) and Hsia et al. (2011) in which some patients attributed their symptoms to other illnesses such as muscular problems or ageing, especially when these symptoms did not fit their stereotype of stroke. Alarmingly, the patient in Case 4 disclosed that he had simply assumed that the symptoms would improve after a good sleep. This behaviour has previously been documented in the literature, and Moser et al. (2007) described this waiting as a "natural coping response to indecision". In their study, Moloczij et al. (2008) also found that patients had different thresholds for considering the seriousness of their symptoms, with a number of participants stating that they had monitored their symptoms "to see if they worsened, how long they lasted, and gauge how serious they perceived them to be". This emerged as a major contributing factor in pre-hospital delay.

The initial reaction of monitoring and seeking self-treatment was also apparent in a study by Mandelzweig et al. (2006), and echoing other literature on the topic, this behaviour was correlated positively with delays in seeking help and arriving at hospital. Interestingly, however, the authors mentioned that some of their participants perceived control over their symptoms such that they felt able to control the symptoms to an extent. This was another factor that led to delays, and one which was not mentioned by any of the participants in the current study. By contrast, it seems as if most of the cases described in the current study feature feelings of helplessness and lack of insight or awareness that urgent care is required, with none of the participants reporting that they felt that the symptoms were under control.

The delay in activating emergency services secondary to a failure to recognise the seriousness of stroke symptoms has also been noted in similar studies (Hsia et al., 2011; Mikulík et al., 2008). Surprisingly, the patient in Case 1 lacked insight so completely that he only realised that something was wrong when he arrived at hospital – this could be due to the fact that he had moments of amnesia during stroke onset. This lack of insight may be challenging, as studies have highlighted that the type of action taken is associated with the presenting symptom. For example, Yoon et al. (2001b) found that 89.9% of participants in their study claimed that they would call an ambulance or visit the emergency department if they were certain that they were experiencing a stroke. By contrast, only 3%–42% of the same participants responded in the same way when asked about their immediate reaction should they experience stroke warning signs (without knowing directly or with certainty that their symptoms were attributable to a stroke). This finding is concerning, since one needs to have sufficient knowledge and self-confidence to alert medical services without first seeking extensive reassurance that the symptoms are indeed attributed to a stroke.

One of the questions that was put forward to patients during the interviews was whether they recalled any emotions that were experienced during stroke onset. It seems as if common feelings that were – understandably – experienced were those of fear and sadness. Another common feeling was that of helplessness. Such feelings are extremely important in the light of the 'Theory of Panned Behaviour' (Ajzen, 1985), which states that behavioural intent depends on an individual's perceived control of the situation. Hence, unless a stroke patient believes that his or her condition could be ameliorated, it is very unlikely that he or she will perform the correct action.

Anxiety also plays an important role in help-seeking. Mandelzweig et al. (2006) showed that stroke patients with high anxiety levels were less likely to seek immediate medical help. The patients in Cases 8 and 9 were terrified of permanent paralysis and death, respectively:

P: I was terrified … as I realised I was suffering from an acute stroke … I feared half of my body would remain like that … it’s like being paralysed … yes I was really afraid … and I did panic a little bit too. (C8)

P: I was sad … as it was happening to me yet again. I was actually terrified … no one wants to die … and one can die of a stroke. Previously, all my symptoms would vanish completely in less than 10 minutes … this time around I did not recover completely. (C9)

However, the patient in Case 4 was worried about the work that needed to be done at the farm which he was unable to attend to. Only the patient in Case 1 stated that he felt very calm during the whole episode – this could be due to the fact that he had previously claimed that he did not have any insight of what was going on.

4.3.2.2 Actions taken

One of the points of interest explored during the interviews was the patient’s course of action upon the onset of symptoms. Logically, most of the patients opted to inform someone else that she or he was feeling unwell. This was noted in Cases 1, 3, 5, 7, 8, and 10, in which the person who was contacted was a spouse or daughter/son.

As the patient in Case 1 explained, it may be rather challenging to notify relatives if speech difficulties are present. However, as noted earlier by some of the bystanders, this may actually be one of the prominent signs that alerts the bystander that there is something medically wrong with the person. It is understandable that patients who were physically accompanied by another person during stroke onset chose to confide in that person and allow him or her to take the lead. Along the same lines, the literature shows that individuals who are affected by stroke are often influenced by others in the decision-making process. This applies not only to those who are physically accompanied by someone else during stroke onset but also to those who are alone and decide to contact another individual before calling for an ambulance. Thus, stroke sufferers may rely on others “for a sense of safety, to validate their experience in some way, or to seek advice” (Moloczij et al., 2008). Such interactions may help to hasten or delay help-seeking.

However, in certain cases, such as in Case 2, the patient chose not to follow the advice of his wife and son to go to hospital and instead opted to wait for the GP. The wife stated that she had noticed this type of behaviour in the past, due to the fact that the patient goes to great lengths to avoid being admitted to hospital:

B: And my son told him as well “Dad isn’t it better to get an ambulance and take you to hospital?” But he insisted he wanted the GP to check whether he should go to hospital. But he didn’t tell me that he had a headache. Sometimes he doesn’t tell the whole truth to avoid being admitted to hospital. (C2)

This aversion to hospital admission, which certainly acted as a psychological barrier to seeking help, was in fact later mentioned by the patient himself, who stated:

P: It was a big fright initially to go to hospital again. Then I thought that something really bad was happening to me. (C2)

By contrast, the patient in Case 8 asked her daughter to accompany her to A&E as she knew that she was experiencing a stroke. She was adamant that the GP should not be called as she reasoned that it would waste precious time. However, since at that time they were out on a family outing, she wanted to wait for her grandchildren to finish their lunch first:

P: Then, I asked my daughter to accompany me to the Emergency department once the children had finished eating, as I told her “I have a stroke!”. (C8)

P: Yes. I thought it was better to go to hospital straight away rather than calling the GP first. In addition, the GP would still have sent me to a polyclinic or hospital … and that would have wasted even more time. Whereas, I knew that at A&E department they would deal with my condition straight away. (C8)

This may be a clear example of the fact that stroke knowledge and awareness that one is experiencing a stroke may not necessarily translate to adequate action. Similar findings were reported in the study by Fussman et al. (2010), in which the initial response to stroke symptoms was assessed. To this extent, participants' knowledge and response were assessed when they were presented with three different stroke scenarios. Interestingly, the study revealed a poor association between stroke warning signs and appropriate response. In fact, although 72%–87% of participants realised that the affected patient in each scenario needed to be transferred to hospital, only 17.6% of those with adequate stroke knowledge reported calling 911 as their initial response for all three scenarios.

When reflecting on the results of their qualitative study, Moloczij et al. (2008) described how during stroke onset, the decision-making process of their participants, who were stroke survivors, involved three crucial steps: 'recognition', 'interpretation', and 'negotiation'. Each of these steps was influenced by a number of factors, such as the period during which participants tried to make sense of their symptoms and normalise them. It was felt that in the current study, the patient in Case 8 was in fact trying to maintain this described 'sense of normality' by choosing to not seek immediate help as this would have disrupted her family outing. This echoes findings that emerged from other studies showing that patients often prioritised commitments or duties over their own health, especially if they felt that their state was not severe enough to require medical help (Moloczij et al., 2008). The authors also found that patients had different thresholds for considering their symptoms as pertaining to a serious condition and frequently reverted to monitoring their condition rather than calling for an ambulance immediately. This was even more prominent when the individual could continue to function and did not experience pain (Moloczij et al., 2008). This finding is somewhat different from the situation described by the patient in Case 8, who realised that her condition merited immediate transfer to hospital yet decided to wait until her grandchildren finished their lunch. Similar reasoning was described by participants in a study by Grady et al. (2014) in which some of the respondents said that that they would not call an ambulance if they experience a stroke because they "did not want to trouble anyone". These findings indicate that stroke knowledge does not always translate to the right response, as also demonstrated in the studies by Williams et al. (1997), Ritter et al. (2007), and Schroeder et al. (2000).

It is disheartening to encounter situations such as that in Case 4 in which the patient's GP failed to realise that urgent medical care was required:

P: So we went to the GP … he told me everything was absolutely fine. (C4)

A similar problem was described by the bystander in Case 2 who called the GP and asked him to carry out a house visit. Unfortunately, after a time lapse of 5 hours, the doctor had still not visited the patient, so the patient's son phoned the doctor again. At this point, the doctor advised the son to phone for an ambulance to take the patient to hospital. Of course, this led to unnecessary time wastage during a crucial period where treatment could have possibly been administered effectively. Healthcare professionals' stroke knowledge has been explored in previous studies. For instance, Sangeeta et al. (2013) found that only half of the healthcare providers who participated in a study that included physicians, nurses, residents, and medical students knew the therapeutic window of the stroke treatment rt-PA, and that 62% of the same cohort were unfamiliar with the eligibility criteria of this treatment and the National Institute of Health's Stroke Scale (NIHSS). These studies and the two cases in the current study clearly highlight the need for professionals at the frontline of care to receive ongoing stroke education and to be acutely aware that the provision of good advice to their patients is not just important, but may save lives. The patient in Case 9 provided pragmatic evidence to this point when he stated that his GP had always warned him that if he ever experienced such symptoms, he should go straight to hospital rather than calling his GP. Thus, during stroke onset, the patient activated his emergency assistance device and the operators called the ambulance for him:

P: I called for an ambulance straight away as my GP had told me to do that in case I ever felt these symptoms again. Actually, I pressed my telecare button and they called for the ambulance themselves. (C9)

As discussed earlier, the role of the bystanders during stroke onset is an extremely important one because they are often the ones who take action on behalf of the patient. Thus, it was felt necessary to explore the bystanders' actions in addition to the actions taken by the patients themselves when experiencing stroke symptoms. When raising this subject during the interviews, it became apparent that the participating bystanders approached the situation in one of three main ways. Primarily, some of the bystanders chose to call a relative first rather than an ambulance. Thus in Cases 1, 4, 7, and 10, sons and daughters were contacted for advice, and they in turn phoned for an ambulance.

P: My brother called my daughter and told her that I was feeling unwell. She came to our farm. We discussed the options, but then she called an ambulance. (C4).

P: My husband then called our daughter as she was going to visit us that day. My daughter called her husband to ask him whether he knew the ambulance's phone number … and after a short while an ambulance was at our house … it only took them a couple of minutes! (C10)

B: I called our son straight away. He then called for an ambulance. (C7)

Although this arguably introduced an extra step in the help-seeking chain, it has to be realised that at times during stroke onset, feelings of anxiety and terror may paralyse bystanders, preventing them from taking the appropriate action. This may affect even the most knowledgeable of bystanders, such as the wife of the patient in Case 1 who, despite all the previous knowledge that she had, could not remember the emergency services contact number as she felt so distraught.

B: I asked my daughter to call for an ambulance herself as I couldn't remember the telephone number … the 112 … I couldn't recall this number. That I left to my daughter.

B: … but otherwise I kept very calm … I didn't show him that I was terrified … I was acting really … because I was utterly terrified about what had happened – I knew exactly what was going on … (C1)

The bystanders in Cases 2, 3, and 5 opted to seek the advice of their GP prior to contacting anyone else. In two of these cases, this led to unnecessary delays in receiving adequate treatment at hospital, with Case 3 luckily opting to call for an ambulance after he did not manage to get through to his GP:

B: I immediately called our GP … twice … but he didn’t answer. So I called for an ambulance. They answered immediately … and it [the ambulance] was there in no time. It definitely took them less than fifteen minutes. (C3)

P: I was alone when it started, but after some time my husband came home and told me to go to the polyclinic … he drove me there. Moreover, he told me to leave straight away: “Let’s leave now because we won’t find a doctor otherwise”. (C5)

B: So I called our GP, and he told me that he would try to come over to our house once he was available. Since he hadn't turned up at 2:30 pm, I called my son and asked him if he could phone our GP to remind him. Then my son called me back and told me that our doctor was going to call me. He called and told me to call 112 and take him to hospital. (C2)

It is surprising that, when faced with her husband's second stroke, the wife of the patient in Case 2 called the GP and waited for so long before transferring the patient to hospital. One would expect that following a previous stroke episode, the patient and his relatives would be more knowledgeable and assertive with regards to the right course of action to take. Equally unexpected was the long delay in phoning for an ambulance described by the patient in Case 4 in view of the fact that his own father had suffered from two strokes, one of which was fatal. Grady et al. (2014) substantiates the hypothesis that such individuals should fare better as they found that response awareness among participants in their study was positively correlated with a history of stroke in a first-degree relative. Thus, one may speculate why the relatives in Cases 2 and 4 did not call for an ambulance immediately. Although a myriad of psychological factors may have been in play, it also should be noted that in Malta, the GP has a very important cultural role and has often a close link to his or her patients following long years of service. Thus patients and their relatives may feel obliged to include their GP in all health-related decision-making and consequently may feel uneasy in bypass him or her or taking any decisions without consulting the GP. Although calling for an ambulance is the best action to take when faced with stroke symptoms, contacting the GP may seem to be an acceptable compromise. However, this may not be the case if the GP fails to recognise the stroke symptoms and consequently does not refer the patient to hospital urgently, as happened in some of the cases, particularly Cases 2 and 4. In Case 8, the patient was aware of a history of stroke in a relative, her father:

P: Yes, my dad had suffered a stroke at the age of 56. He ended up hemiplegic … but he used to smoke and drink alcohol. (C8)

However, in her case, the delay in seeking emergency care was not related to lack of knowledge or to the GP but to the fact that she did not want to make a fuss in front of her grandchildren, despite having first-hand experience of the serious consequences of a stroke.

The daughter of the patient in Case 8 stood out from the rest of the bystanders in the other cases in that she did not opt to contact medical services or any medical professional upon the initial presentation of the symptoms. Instead, she assumed that her mother's malaise was related to a drop in blood pressure, and so provided the patient with some food to try to alleviate the symptoms:

P: My daughter thought it must have been related to my blood pressure. Therefore, she bought a packet of crisps for me and we went out for some fresh air. I felt better straight away. We then took her children to the aquarium … I was still feeling my leg heavy and tired. (C8)

In view of these actions taken by the bystanders, the American Heart Association recommends that activating EMS should be the first and only action during stroke onset (American Stroke Association, 2016). In addition to reducing hospital arrival times, this action is also directly correlated with faster triage, imaging, and administration of intravenous thrombolytic therapy (Deng et al., 2006; Maestroni et al., 2008; Morris et al., 2000). However, it is not only in the current study that the correct response was not always sought – for instance, as mentioned previously, in the study by Fussman et al. (2010), the correct response (calling 911) was only provided by 20.4%–51.5% of participants for different scenarios.

4.3.2.3 Barriers encountered

Barriers to action may not only involve the patients themselves, but also their relatives/bystanders. These barriers may sometimes override an adequate level of knowledge. In fact, Skolarus et al. (2011) found that “in addition to knowledge of stroke warning signs, behavioural interventions … may be useful for helping people make appropriate 911 calls for stroke”.

In a study by Hsia et al. (2011), the major barrier to appropriate action in stroke was a failure to recognise the seriousness of the presenting symptoms. Another important barrier to action in that study was a feeling of hopelessness and that the situation could not be reversed. The latter accounted for up to 25% of late hospital presentations. As highlighted in the ‘Theory of Reasoned Action’ (Fishbein, 1975), people’s behaviours are affected by the perceived outcomes. Hence, unless they believe that early arrival at hospital is beneficial, their response is likely to be delayed.

Another important barrier is mistrust in the healthcare system. Jurkowski et al. (2008) demonstrated that individuals who had previously experienced delays in medical care were less likely to call 911 in the event of stroke. Similarly, Moloczij et al. (2008) showed that previous experiences and interactions with the healthcare system influenced help-seeking behaviour.

Further social and demographic factors may also play a role in behaviour intent. These factors are even more pronounced in Malta, where most people live in small towns and villages.

Having explored the actions taken by the patients and bystanders, the subject was explored in a deeper manner by examining whether any barriers were encountered during the process of seeking help. While the patients and bystanders in Cases 1, 3, and 9 readily stated that there were no barriers, others described some of the challenges that they were subjected to. The barriers mentioned were mostly psychological rather than physical or logistical. Thus, the wife of the patient in Case 2 mentioned that during stroke onset, she did not wish to take decisions on behalf of her husband with regards to calling for an ambulance and transferring him to hospital:

B: No, as I usually let him take decisions, I don’t want to decide for him! (C2)

This proved to be a problem for her, as while she knew that her husband required urgent medical attention, he kept refusing to go to hospital. Moreover, she was faced with the challenge of physically managing him as he had developed mobility problems. Similarly, the wife of the patient in Case 7 could not call an ambulance because she was hesitant to leave him lying alone on the floor. She also admitted that at that time, she felt terrified and that this impeded her from acting as fast as she would have liked to:

B: I was terrified! Secondly, I was making sure he was fine, as he was still lying on the floor. I did not panic but I was terrified. (C7)

At the time of stroke, the patient in Case 8 was out on a family outing. Although she realised that the symptoms that she was experiencing were typical of a stroke, she was reluctant to seek immediate help and she did not wish to make a fuss by disrupting her grandchildren’s lunch or making them go to hospital with her:

P: I didn’t want the children to know what was happening or to come to A&E with us. (C8)

While such altruism is commendable, in this case it led to unnecessary delays in the administration of treatment and so also acted as a barrier to seeking help.

Notably, some of the cases showed that the symptoms of stroke may also act as a barrier, particularly if there is no pain or major deterioration in functioning. As the patient in Case 3 described:

P: It was as if someone kept pushing me from behind. I did not experience any pain though. (C3)

Such unconventional symptoms may confuse sufferers and make it difficult for them or the bystanders to realise that they are actually symptomatic of a stroke.

As already discussed, time from stroke onset to administration of adequate treatment is a crucial issue and an imperative factor in the patient's prognosis. Some of the patients who participated in the study managed to make it to hospital in a matter of minutes. Thus, in Cases 1, 3, 7, 9, and 10, a time lapse of less than 45 minutes was recorded:

B: Certainly not more than 30 or 35 minutes. We do not live far from hospital so the ambulance was there immediately. (C7)

P: It took me less than half an hour. By 2:30pm, I was definitely in A&E. (C9)

Unfortunately, in the remaining cases, long delays of 4 hours to even longer than one day were apparent:

P: It happened in the morning. It was probably around 9:30 am. But we only got to hospital between 1:30 pm and 2:00 pm. (C8)

Lacy et al. (2001) explored arrival times to hospital following an acute stroke as well as any associated variables. They found that 46% and 61% of patients within their cohort arrived at the emergency department within 3 to 6 hours of symptom onset, respectively. These data are similar to those from previous studies performed both in the US and Europe which have shown ranges of 25%–59% and 35%–66% for the two time intervals (Alberts et al., 1990; Anderson et al., 1995; Jorgensen, 1996; Kay et al., 1992).

During a similar exploration of delays in seeking treatment, Billings-Gagliardi and Mazor (2005) developed the STAT, a tool that assesses participant reaction to several stroke and non-stroke symptoms. On average, only 34.1% of participants within their study said that they would activate emergency services if they or a family member experienced stroke symptoms. Incorrect answers in this study included ‘call doctor's office’, ‘wait 1 hour and then decide’, or ‘wait 1 day and then decide’. These actions are similar to those taken by some of the participants in the current study. Unfortunately, ample studies show that it is this hesitation to take the decision to seek emergency care that represents the most significant contribution to pre-hospital delay in acute stroke (Alberts et al., 1990; Bratina et al., 1995; Chang et al., 2004; Faiz et al., 2013; Yang, Shih, Chang, Huang, & Chien, 2011).

4.3.2.4 Interactions with healthcare professionals

During the interviews, some of the participants described the interactions that they had had with a number of healthcare professionals during stroke onset. It was clear that some of the interchanges described were positive. For instance, the patient in Case 10 explained that the neurologist explained the cause of the symptoms to her and also advised her to quit smoking, to exercise and to follow a balanced diet. Similarly, an A&E nurse informed her that when a stroke is experienced, she should call for an ambulance immediately rather than being driven to the hospital by relatives:

P: A nurse in casualty told us that when something like this happens one should always call for an ambulance as opposed to being driven to hospital by his relatives.

P: The neurologist told me to quit smoking immediately. He also advised me to exercise myself regularly and eat in a healthy fashion. (C10)

By contrast, in his study, Harper (2007) found a knowledge deficit in acute stroke care among emergency nurses whereby only 15% of this cohort had participated in CPD programmes on stroke during the previous year. The authors also found that nurses who had read stroke literature during the same period demonstrated better stroke knowledge compared with those who had not accessed any literature. Similarly, in a pre- and post-intervention study by Kirchoff-Torres et al. (2011), more than 50% of emergency department nurses incorrectly identified the maximum dose of rt-PA and the goal door-to-thrombolysis time.

Alarmingly, it was noted that not all healthcare professionals involved in the current study cases were aware of the urgency of stroke symptoms. Thus, while the GP involved in Case 5 immediately referred the patient to hospital, the GP that featured in Case 4 reassured the patient that everything was fine and simply sent him back home:

P: At the polyclinic … I think she knew what was happening to me as she asked me some questions and then told me “No, you should go to hospital instead”. (C5)

P: So we went to the GP … he examined me and told me it was due to a problem with my semi-circular canals. He checked my blood pressure and other stuff … he told me everything was absolutely fine. (C4)

The situation in Case 2 was perhaps even more concerning, as the relatives called the GP and he told them that he would visit the patient at home but failed to do so. This led to a delay of more than 5 hours because the patient and his relatives decided to wait for the GP's visit and only phoned him again when he had not turned up by the afternoon. Such findings highlight the importance of education and the necessity for healthcare professionals to keep up to date with the recognition and management of stroke.

The cases presented in the current study also represent examples of the support – or lack of – provided by the various health professionals that they encountered. For instance, in Case 1, it seemed as if the patient's relatives were unsure of whether they would consent to the interventional treatment that the patient required. In the face of their anxiety and uncertainty, the doctor told them that if this happened to her father, she would consent to the treatment. This statement seemed to be perceived as very helpful by the relatives as it somewhat alleviated their anxiety and helped them to make a decision:

B: … and there was a very nice doctor called Jane who told me that if this had happened to her dad, she would agree to this treatment. So, I told her that we would follow her advice … (C1)

The participants' narratives also elicited possible communication issues between professionals and patients or their relatives. As an example, the daughter of the patient in Case 1 was informed by the doctor that her father's condition was 'stable' – a word whose meaning was not really understood by the women and left the daughter with further questions:

B: And he told us "he's stable" … my elder daughter told me "mum what does that mean?". My son told her "It's the opposite of unstable!" … but she was so anxious that stable didn't mean anything to her! (C1)

Similarly, the patient in Case 10 described how, during stroke onset and at the hospital, she could hear healthcare professionals speaking to her and about her but could not reply back – this was extremely frustrating for her:

P: The ambulance brought me straight to casualty and I could hear the doctors talking … I could perfectly understand what they were saying but I could not reply. It is a very frustrating experience … not being able to answer the questions they are asking you! I was fully conscious as soon as I arrived in hospital. (C10)

Although the link between the interaction with professionals and seeking help may not be so obvious or direct, it is an important factor in the decision-making process related to activating emergency services. In fact, Hsia et al. (2011) postulated that a potential barrier to seeking urgent medical help may be an attitudinal barrier, due to a mistrust in the healthcare system and its providers. Along similar lines, Jurkowski et al. (2008) found that study participants who had previously experienced a delay in medical care were less likely to call for an ambulance if they were to experience stroke symptoms. These findings were echoed in another study by Moloczij et al. (2008) who found that help-seeking behaviour in stroke was influenced by the individual’s perception of medical services, particularly previous interactions with such services.

4.3.3 Theme 3: Reflections on the stroke incident

4.3.3.1 Reflections on actions taken during stroke onset

During the interviews, some of the patients engaged in self-reflection about the actions that they had taken during stroke onset. It was noted that patients who had chosen the right course of action, that is, to immediately call for an ambulance, stated that they would not change anything in the way that they or their bystanders had managed the stroke onset:

P: As you can see, I have recovered completely. We were in hospital in no time. (C10)

On the other hand, the patient in Case 4, who had waited for days prior to going to hospital, showed his disappointment in trusting his GP who had reassured him that all was fine. To this extent, he realised that he should not have waited for so long to seek appropriate treatment:

P: I think I am not able to answer this question. I have no clue what I should have done then! If I had known this was a stroke … I would have gone to hospital on Friday not waited until Sunday. My GP told me it was my semi-circular canals and I trusted him! (C4)

Unfortunately, the patient in Case 5 who opted to go to the health centre during stroke onset did not seem to realise that her stroke management was not optimal. To this extent, she stated that if such an incident was to happen again, she would not change anything as, in her opinion, there was nothing much that could be done in such situations:

I: Would you do something different should this happen again?

P: Not really, there’s nothing much to do! … (C5)

This is quite surprising, since one would expect that following her first stroke episode, the patient would have at least gained the basic but crucial knowledge that emergency medical help must be sought. The acquisition of new knowledge following the stroke incident is further explored in the next section.

Along the same lines, some of the bystanders who were interviewed chose to answer the question regarding whether they had any reflections on the actions taken during stroke onset. The wife of the patient in Case 1 stated that she felt good about the actions that she had taken as they were the appropriate ones as recommended by her son:

B: I think I did the right thing … not to be proud of myself … but I was aware of it … my son used to tell me to go straight to hospital if something like this ever happened … without asking our GP or Uncle Pete first. I called the GP after two days and told him ‘just to let you know … my husband has suffered a stroke bla bla bla’ … (C1)

Similarly, the husband of the patient in Case 3, who had also taken his wife to hospital by ambulance, said that if this were to happen again, he would act in the same way. When reflecting on her actions, the wife of the patient in Case 7 decided that she would call an ambulance herself instead of asking her son to do this in the eventuality of another stroke. Finally, the wife of the patient in Case 2 showed her regret at not having taken her husband to hospital earlier as she feels that he would have benefitted more from the treatment provided:

B: Had I brought him to hospital … there is a drug they told me … (C2)

4.3.3.2 Perception of effectiveness of treatment

Consensus was reached by all participants who discussed the effectiveness of the treatment administered at hospital. In this aspect, there was no hesitation in their reply, and bystanders who were present were equally adamant that the medications and/or interventions that their relatives received helped them to start recovering from the stroke:

P: Whatever was done to him was done to perfection … (C1)

P: Moreover, at hospital they did an excellent job as well. (C7)

I: Do you feel as if this treatment helped you?

P: A lot! I could already make it to the bathroom on my own later that night in hospital! (C8)

P: Sure it did! I am back to my normal life. I can perform all my errands on my own. (C10)

It is felt that the dissemination of excerpts such as the above may be particularly powerful since they may serve as a motivational factor for individuals to take the right course of action to enhance outcomes in the face of a stroke. The clear message that these statements deliver is that as terrifying as a hospital admission may seem, it may offer a stroke sufferer treatment benefits that cannot be obtained elsewhere.

Knowledge that something can be done about stroke in the acute phase is crucial. In fact, the patient/bystander needs to believe that his or her actions may improve the patient's condition and long-term outcomes. This psychological process determines which and when an action is taken. The perceived outcome is central to the 'Theory of Reasoned Action' (Fishbein, 1975). Stroke education should also aim to enrol previously affected patients who have made a good recovery to act as role models. An individual's behaviour is moulded through observation and imitation. Likewise, positive reinforcement is another pillar within the 'Social Learning Theory' (Bandura, 1963).

While those individuals who make it to hospital as quickly as possible typically have the highest chance of a good recovery, care can be given even to those who present to the A&E department after a considerable delay, such as the situation in Case 4 in the current study:

P: The first two days of my hospital stay … I felt terrible … I had so many wires and pipes attached to me. I had visitors all the time but I just wasn't myself. I could barely recognise the visitors. Then, they started some treatment for me and I improved quickly. My daughter and wife couldn't believe I was so much better after 2 days! (C4)

4.3.4 Theme 4: New knowledge obtained after the stroke incident

4.3.4.1 Patient knowledge

An issue that was brought up during the interviews was whether the patients had actively sought to gain more knowledge about stroke following the stroke incident. Surprisingly, a highly passive attitude was noted in this regard, to the extent that all patients who discussed this were in agreement that they did not attempt to seek stroke-related knowledge:

I: Did you search for further information on your own?

B: So far, I have not. I have been very busy since this happened. (C7)

P: No, I never bothered. (C9)

The patient in Case 4 added that if there was a stroke-related programme on the radio, he would be willing to listen to it:

P: No, I don't enjoy reading. But if there's a discussion on the radio, I open my ears widely and follow what is being said! (C4)

The patient in Case 1 was the only one who may be considered somewhat of an exception, as he stated that he had read the leaflets provided at the hospital and planned to read them again. Nevertheless, he did not seem to consider any other sources of obtaining stroke-related information.

These attitudes may be viewed against the backdrop provided by the Health Belief Model whereby individuals will only take action if they understand and believe the perceived seriousness of stroke. This may subsequently lead the individual to conclude that the benefits of action outweigh the perceived barriers, thus resulting in the desired behaviour.

In this light, application of the Health Belief Model involves educating the target population about stroke prevalence, incidence, and risk as well as the potentially serious consequences of the condition. Additionally, stroke educational strategies and campaigns need to focus on the potential benefits of early stroke treatment as this may alter an individual's immediate actions. Moreover, the act of accessing information needs to be portrayed as a crucial and potentially life-saving 'need' rather than an activity that patients can describe as 'not bothering' or 'not enjoying' to partake in.

Interestingly, however, some of the participants tried to access stroke-related information during the interview by asking me, the researcher, certain questions. During these moments, I was aware that I was experiencing confusion between the role of a researcher and that of a clinician – while I answered the questions posed, I realised that these participants had various burning questions but seemed to prefer to wait for 'information to make it to them' rather than to actively seek it:

P: I only want to ask one question … could this happen again to me? (C10)

I: Do you want to add something else to this interview?

P: Yes – can I continue with my normal life? (C1)

P: What are the chances that I will suffer another stroke? (C1)

In view of this lack of knowledge-seeking, it seemed surprising that upon further probing, most of the patients stated that they had become more aware of important facts related to stroke. A possible reason for this discrepancy may be that the patients had gained experiential knowledge as a result of suffering an actual stroke. Thus, it may be the case that the patients had obtained information passively, for instance, by hearing healthcare professionals or relatives speak about stroke in the aftermath of the experience. This situation was also addressed by Jones et al. (2010), who reported that in addition to personal experience, relatives, friends, and health professionals were the most common sources of public stroke knowledge in their study. As a result, the patient in Case 1 in the current study stated that he now knows what symptoms to look out for and is also aware that he has to call for an ambulance if stroke symptoms are experienced:

P: I would look for facial asymmetry and drooping, upper limb weakness … they asked me to raise my hand (C1)

However, his main worry was that during stroke onset, he might not have the insight to recognise the stroke symptoms – this had happened in his case and, as described previously, he was not even aware of the seriousness of his condition until he arrived at hospital. This issue was highlighted by Yoon et al. (2001b), who found that just 3%–42% of their study sample would call an ambulance or visit the emergency department only if they had full insight and certainty that they were experiencing a stroke.

It was heartening to listen to the patients in Cases 2, 6, 9, and 10 insisting that when experiencing stroke symptoms, the immediate action was to call for an ambulance. Importantly, the patient in Case 9 added that one should avoid contacting the GP as that introduces an unnecessary step because the GP would inevitably refer the patient to hospital:

P: Call for an ambulance … if there is someone else with him he should ask them to call for an ambulance. Your GP will still refer you to hospital … and in doing so you are only losing time. I did call my GP once they had me sorted in hospital and she agreed that was the appropriate action to take. (C9)

P: I would go straight to hospital … I mean I would call for an ambulance to go to hospital. (C10)

Unfortunately, in addition to stating that he would call for an ambulance, the patient in Case 6 added:

P: … [he doesn't] think [he] would realise that someone is having a stroke. (C6)

While the positivity of this new knowledge acquired by some of the participants cannot be negated, it can only be hoped that it will translate to the correct actions if a stroke is experienced. As discussed previously, this may not always be the case – Fussman et al. (2010) showed that improved stroke knowledge may not necessarily translate into appropriate action and that a 'disconnection' exists between the two. Marx et al. (2008) also showed that increased knowledge following a multimedia campaign failed to trigger a change in intended behaviour for stroke. Similarly, Hsia et al. (2011) found a large discrepancy between behavioural intent to call 911 and actual behaviour following a stroke. Thus, within a population of predominantly urban African Americans, 89% reported that their initial response to stroke would be to call 911. However, only 12% of affected patients had called 911 first. In this aspect, the application of the Theory of Reasoned Action may be useful. This theory postulates that an individual's behavioural intention is determined by his or her intrinsic behavioural intentions, which are based on his or her 'attitude' towards the behaviour in question and beliefs on whether others ('subjective norms') would support such behaviour (Fishbein, 1975). In other words, people consider the consequences of their behaviour before engaging in such behaviour and their attitude is moulded by their outcome expectations and the values of such expectations.

Importantly, this theory may introduce the cautionary aspect that improved knowledge may not necessarily alter behavioural intent. Thus, individuals affected by stroke will likely consider all factors – including 'subjective norms' – before making the call to activate emergency services during onset. If, for instance, in a given culture, activating emergency services is viewed as a personal weakness, individuals may show reluctance to engage in this desired behaviour. In such situations, role models may be helpful as they may cause an individual to approve the behaviour in question. The theory also highlights the importance of any stroke education strategy to emphasise the benefits of early treatment as this may modify an individual's 'attitude' towards that behaviour.

Unfortunately, not all of the patients interviewed during the current study were armed with the basic yet crucial knowledge regarding the need to activate emergency services. For instance, the patient in Case 4 stated that he did not have any idea of how to manage stroke onset. As an afterthought, he added that he would lay the person on the floor and call his or her relatives. However, he believed that he would not realise that a person was having a stroke:

P: I am not sure I can answer this. If it happened to someone else, I would lie him down on the floor … I think I can't do anything else, myself … the first thing I would do is to inform his relatives – that I will certainly do first! As this is not something personal that I can deal with! It would be unfair on his family otherwise. (C4)

Conversely, the patient in Case 5 stated that he did not know why someone had to be taken quickly to hospital when suffering from a stroke. He reasoned that nothing could be done in the face of stroke symptoms:

P: God protect us! You can’t do anything … can you? You can’t do anything. (C5)

When asked whether he would call his GP or go to the health centre or hospital, he said that he would call his GP. Unfortunately, this reasoning may lead to unnecessary delays in receiving adequate treatment as discussed previously. This feeling that nothing can be done once a stroke occurs is an important barrier and one that was responsible for up to 25% of patients presenting late to the emergency department in the study by Hsia et al. (2011).

This attitude may be adequately explained by the Theory of Planned Behaviour, which introduces the concept of an individual’s perceived behavioural control such that behavioural intention is reliant on a person’s perceived control of opportunities and resources in addition to the skills needed to perform such behaviour. Thus, individuals may fail to carry out a behaviour due to lack of confidence and control in addition to or apart from lack of knowledge – this was clearly demonstrated by some of the participants in the study, as exemplified by the helplessness that echoes in the quote above from the patient in Case 5.

In stroke education, application of the Theory of Planned Behaviour may help to predict a person’s action in risk-conducive situations, in this case, the decision whether or not to call an ambulance during stroke onset. This prediction is possible due to the identification of factors that may influence the individual’s decision and volitional control. Thus, it is beneficial to consider that individuals are more likely to change their behaviour and engage in the correct actions if they believe that these actions lead to health benefits such as limiting negative stroke consequences by seeking early help, and having the approval of others such as a spouse who supports the decision to call for an ambulance. Moreover, individuals need to have appropriate skills such as the ability to identify stroke symptoms and the necessary resources for action, such as accessible emergency services (Ajzen, 1991). The need for approval from others was highly prominent in the current study, with most of the participants opting to inform their relatives about their situation in order to involve them in the decision-making process or else to rely totally on their relatives regarding the appropriate course of action to take. This finding may partly be attributable to a lack of self-confidence and assertiveness to call for an ambulance directly. However, it may also be due to local cultural values which the family hold close to heart. Thus, in many families, members are in close contact and support each other intensively during problematic situations. As also postulated in the Theory of Reasoned Action, seeking approval from others may therefore be crucial. Additionally, in the local setting, it is typically not only family members who look out for each other and keep track of each other's activities, but also neighbours and other town/village inhabitants. Once again, this refers to the issue of 'subjective norms' – doing what may be deemed as acceptable by others. Independent of the reason for involving others in the decision-making process, these findings point towards the importance of educating the general public about improved outcomes expected from an appropriate response in the hope that this will serve as motivation to take the right actions. Such knowledge may also equip individuals with a more assertive attitude that may prompt them to make the ambulance call immediately rather than wasting time discussing and deliberating with others. Most campaigns to date have stressed the recognition of stroke symptoms and the need to activate emergency services as the initial response but have failed to emphasise the actual benefit of these actions.

Perceptual barriers are also related to lack of knowledge about stroke and the treatment available. Hsia et al. (2011) referred to this relationship as "informational barriers".

In a population-based study, Fussman et al. (2010) assessed the initial response to stroke symptoms by assessing participants' responses when presented with three different scenarios featuring symptoms typical of a stroke. The correct response (calling 911) was given by just 20.4%–51.5% of participants for the different scenarios – this may in part have been secondary to a failure of participants to recognise these warning signs of stroke. Similarly, in the current study, only half of the participants stated that the right action was to call for an ambulance. In the integrative review by Jones et al. (2010), the range of participants in the different studies who would call emergency services if they suspected that a stroke was being experienced was 27%–100%. On the other hand, Travis et al. (2003) found that only 42% of participants would call 911 if experiencing a stroke. Lower figures than this were reported in a study based in Australia, where calling for an ambulance was the initial response of just 1.1%–20% of participants when presented with individual stroke warning signs (Yoon et al., 2001b). Similar to the study by Fussman et al. (2010), this may have been partly due to the inability to recognise stroke symptoms. In fact, the majority of the same participants said that they would call an ambulance if they specifically knew that a stroke was being experienced.

The importance of recognising stroke symptoms also emerged in the current study. The patients in Cases 1, 3, 8, 9, and 10 showed that they were aware of certain stroke symptoms, while those who featured in Cases 2, 3, and 8 had some insight regarding the stroke treatment that they received:

P: I know that with a stroke, half of your body may become paralysed … well that did not happen to me. In others, their face turns to one side. This had also happened to me a long time ago … I used to go for therapy … but after a month, it was back to normal. It was shifted like this, all the way to the left side. (C10)

P: A doctor examined me in the emergency department, and then they performed an ECG and an X-ray. Once all the results were out, they started a drip and gave me some pills. (C8)

However, some of the patients interviewed (namely those in Cases 4 and 5) had very limited or no knowledge about potential stroke symptoms and/or treatment:

I: Why is it important that someone who suffers a stroke is quickly taken to hospital?

P: No, I don’t have a clue … I don’t know why! (C5)

I: Can you describe what you know about stroke treatment?

P: Nothing! I don't know anything. I just take the pills they prescribed before I left hospital. (C4)

This finding was not surprising, given that these were the same patients who had previously stated that they did not know how to manage stroke onset and thus it seems as if their lack of knowledge may be related to any aspect related to stroke. It was noted that limited knowledge about treatment was a common theme among all cases in the current study. Similarly, in a survey by Pancioli et al. (1998), only 21% of participants were aware of 'clot-buster' or 'blood thinning' drugs as appropriate treatment for stroke, and in a study by Kleindorfer et al. (2009), only 3.6% of participants were aware of rtPA.

4.3.4.2 Bystander knowledge

The bystanders who were present during the interviews were also asked about any new knowledge that they had acquired after their relative had suffered from a stroke. The relatives of the patients in Cases 3 and 7 were ready to discuss some of the symptoms of stroke as well as the treatment options:

B: Yes I know about the injection that they gave her at A&E, that is supposed to work in most cases … it only fails in 1 case out of 20 … (C3)

B: Weakness of the upper and lower limbs, slurring of speech … I know these are symptoms of stroke. (C7)

The relative of the patient in Case 7 insisted that it was important to call for an ambulance when faced with stroke symptoms. By contrast, the wife of the patient in Case 2 believed that calling the GP should precede the need to go to hospital. In fact, she contradicted herself by first stating that she would immediately call for an ambulance but then corrected herself by adding that she would first phone the GP:

B: Next time I will call the ambulance straight away … I definitely will … because I didn't know … I didn't know … and I didn't want to take him to hospital. But if I see something I need to ask him whether he's feeling well, for example, whether he is suffering from a headache. And then he will have to go to hospital. (C2)

B: I will call my GP to see what he thinks … if he says he can't make it quickly I will tell him "let me call an ambulance then". (C2)

Although she could name some stroke symptoms and describe the cause of stroke, she was not aware of any treatment options. The other bystanders did not disclose any new information that they had obtained following the incident. These findings are in line with the literature on the subject. In a survey by Pancioli et al. (1998), only half of the sample population could identify at least one of the warning signs of stroke, and the most common signs mentioned were dizziness and numbness. Weakness and paralysis were also listed as common stroke signs in an integrative review by Jones et al. (2010), while numbness was an additional commonly mentioned symptom in the studies by Schneider et al. (2003) and Hickey et al. (2009).

Although there may be a disconnect between knowledge and behaviour, several educational campaigns and stroke studies have shown a significant change in the behavioural outcomes of affected individuals. For instance, Kim et al. (2011) showed that stroke awareness (in both patients and bystanders) was directly correlated with early presentation to hospital and was a major determinant of thrombolysis treatment. While knowledge alone may not influence the initial response in the setting of an acute stroke, it "is a prerequisite for appropriate actions" (Mazor & Billings-Gagliardi, 2003).

The exploration of stroke knowledge during the current study has provided further evidence that prompting individuals to take the right decisions is a highly complex task since underlying reasons for behaviour and reluctance to change are as many as they are intriguing. Perhaps, in addition to the other health-promotion models mentioned, the Social Ecological Model may provide a more comprehensive view and guidance on how to understand and address this issue. Thus, the specific Social Ecological Model by McLeroy et al. (1988) presents multiple levels of influence including ‘individual/intrapersonal’, ‘interpersonal’, ‘organisational/institutional’, ‘community’, and ‘public policy’. Since all of these levels affect an individual’s decision-making and behaviour, they should be taken into account in order to create a holistic environment that is conducive to adherence to the desired behaviour. While this may sound like a relatively simple process in theory, in reality it can be quite daunting, especially when it comes to changing norms. One example that springs to mind on a local level is the need to ‘normalise’ the use of an ambulance as a mode of transportation. This is because the arrival of an ambulance is often a cause of alarm and activity in the neighbourhood, with people typically gathering near the scene to observe, offer support, or speculate on the reason for the ambulance’s arrival. This may be unacceptable, overwhelming, and extremely stressful for individuals who are more private and do not wish to be part of, or even worse, the cause of a big scene.

4.3.4.3 Information provision by health professionals

One of the areas explored during the interviews was the provision of stroke-related information during the patient’s hospital stay. It was clear from the patient’s responses that the provision of information by healthcare professionals was limited and inconsistent. Thus, the patient in Case 1 stated that he had been provided with stroke-related leaflets, which he had read. The patient in Case 2 was also provided with a leaflet, but it was specifically related to smoking cessation. It seems as if these were the only two patients who were provided with leaflets:

I: Has someone described to you how you can reduce the risk of stroke in the future?

P: Yes, they gave me a bunch of papers.

B: Not really, but they gave us some leaflets … in my own time I will read them over and over again. (C1)

The patient in Case 4 discussed how he was provided with dietary advice, while the patient in Case 10 explained that the neurologist had provided him with information about the pathophysiology of stroke:

P: My neurologist later explained to me that I had a blood clot in my brain, which was causing these symptoms. He also explained that a clot on the right side of the brain affects the contralateral side of the body. (C10)

He added that a nurse at the A&E department had also advised him to call for an ambulance should he experience stroke symptoms in the future. In Cases 5, 6, and 7, it was stated that no information was provided by healthcare professionals apart from the advice to adhere to medication:

P: They gave me some pills, but honestly, I do not know why they gave me such medicine … they tell you to have these pills … and you have to take them! (C5)

P: Yes, I have to change something. I don’t know what exactly I have to change though! No one explained to me regarding life style changes! (C6)

These findings leave one questioning why there seems to be a lack of consistency in the provision of information to the patients. Thus, while one of the patients received a leaflet about stroke, another was provided with a leaflet about smoking cessation only.

Moreover, none of the other patients or bystanders seem to have been given any leaflets, although some fortunately obtained advice from their healthcare professionals. However, a number of them were not provided with any information at all. There may be various reasons for such discrepancies, including recall bias on the part of the patients and bystanders. However, this also likely points to the need to provide patients with a structured and consistent package of information, not only during the hospitalisation period but also in the later stages of recovery. This need is further explored in the recommendations chapter.

As a conclusion to this exploration of knowledge acquisition following the stroke incident, patients who were interviewed were asked whether they would be willing to receive further information with regards to stroke. In most cases, the answer was positive:

P: It is always better to have more knowledge, especially when it comes to healthcare. (C8)

I: Do you think you would benefit from more stroke education?

P: Yes I think so. (C2)

The only exceptions were the patients in Cases 3 and 5. In the former, it seemed as if the patient had already attained sufficient knowledge from the different therapists that she had been in contact with during her recovery process. Alarmingly, the patient in Case 5 stated that she preferred to remain uninformed about stroke since she felt that receiving knowledge about this condition would just precipitate her anxiety:

P: To tell you the truth … the less I know the better! Because otherwise I worry too much! If I read about something, I will start imaging that I have it! It’s better not to hear about these things. (C5)

Once again, the contentions of the Health Belief Model can be considered, whereby the perceived seriousness of the condition needs to be portrayed in order to overcome barriers such as the one described by the patient in Case 5 in the quote above.

Interestingly, the patients had different preferences with regards to the mode of receiving information. For instance, the patients in Cases 1, 6, and 7 explained that visual material was the preferred mode for receiving information as it was more practical and easier to comprehend:

P: Something visual is always better because it's more practical … especially to understand the symptoms and so on. (C1)

B: Visual. I do not understand certain medical jargon especially when I am reading. Once you see something, it is much easier to remember. (C7)

It should be noted that the patient in Case 1 also showed willingness to revert to the leaflets that were provided to him at the hospital, while the patient in Case 9 similarly showed a preference for leaflets as a way of accessing information about stroke:

P: I would say leaflets … perhaps sent at home … you know sometimes you have an extra five minutes and you may read the leaflet. Well I am a pensioner and widowed a couple of years ago … so I might read through such a leaflet once I am a bit free. (C9)

The patient in Case 7 added that it was important to use lay language rather than medical jargon to present the information. Information delivered during TV or radio programmes was specifically discussed by the patients in Cases 2, 4, and 8:

B: Someone speaking on TV … I love to listen … because last time I watched Dr. Pace on TV speaking about stroke. (C2)

P: No, I don’t enjoy reading. But if there’s a discussion on the radio, I open my ears widely and follow what is being said! (C4)

Additional insight provided by the patient in Case 8 highlighted that in the elderly, watching and hearing about stroke may be more effective than reading. The patient in Case 10 proved somewhat of a dilemma by stating that he could not read or write and did not like to listen to the radio or watch television. This may not be as problematic as one may expect since Hsia et al. (2011) found that participants with a lower level of education were more likely to use emergency services in cases of stroke. In fact, this observation rings true in this case because, when the patient was asked about how she would tackle a similar incident, she answered:

P: I would go straight to hospital … I mean I would call for an ambulance to go to hospital. A nurse in casualty told us that when something like this happens one should always call for an ambulance as opposed to being driven to hospital by his relatives. (C10)

Importantly, this shows that individuals may access information through ways that are less conventional than leaflets and the media. It also emphasises the need to consider the employment of different strategies in the distribution of health information. While the use of traditional methods such as leaflets and media channels is beneficial, it may also be fruitful to include other creative methods for people experiencing the difficulties presented by the patient in Case 10. While this issue is further discussed in the recommendations, it is worthwhile to revert to the stroke educational campaigns that have been described previously, which targeted pharmacies, churches, supermarkets, and beauty salons in order to increase accessibility to such education.

4.3.4.4 Prevention plans

Some of the patients who participated in the current study discussed their plans for stroke prevention. Patients in Cases 8, 9, and 10 seemed to be quite aware of beneficial strategies and mentioned their intention to follow a more balanced diet, the need for smoking cessation, and the introduction of an exercise routine into their lives:

P: I quit cigarette smoking … I used to smoke around 10 cigarettes a day! I take care about my dietary intake and try to avoid sugar containing foods. (C8)

P: One should try a diet … I have always loved eating though … habits are very difficult to change (C9)

P: The neurologist told me to quit smoking immediately. He also advised me to exercise myself regularly and eat in a healthy fashion. I have stopped smoking since then. Unfortunately, my husband and daughters are still smoking inside our house. I think I should put up a sign saying “No Smoking!” (C10)

Failure to adopt lifestyle changes may follow one of two patterns. Patients may either completely ignore or refuse medical advice, or else such changes may not be sustained in the long term. The first pattern may be explained by several health promotion theories that were previously discussed and are summarised in Figure 2.3. The latter pattern or failure to sustain a recommended lifestyle change echoes the literature on the subject, whereby long-term benefits following a stroke education campaign are not sustained. Both Mikulík et al. (2011) and Kleindorfer et al. (2009) showed failure of long term success in stroke prevention and education. On a similar note, Hodgson et al. (2007) highlighted the need for continuous stroke education.

The need to reduce alcohol intake and to follow a healthy diet was also mentioned by the patients in Cases 2 and 5, respectively. The patient in Case 5 also mentioned that it was important to adhere to the medication prescribed:

P: I am trying to reduce my food intake and to avoid certain food. And I am having the pills which they prescribed to me. (C5)

In view of the participants' responses, it appears that the Transtheoretical Model of Health Behaviour may be applicable here. This model describes six key stages of behaviour change that an individual may progress through when attempting to change. Thus, the patients in Cases 5 and 8 seemed to be already in the fourth step, the 'action' phase, as they had already stopped smoking. Similarly, it seems as if the patient in Case 5 had already taken action by reducing her food intake.

By contrast, the patients in Cases 6 and 7 seemed to be completely unaware or unwilling to change anything, which places them in the 'pre-contemplation' stage of the Transtheoretical Model of Health Behaviour:

P: Yes, I have to change something. I don't know what exactly I have to change though! No one explained to me regarding life style changes! (C6)

On the other hand, the patients in Cases 1, 3, and 4 may be in the 'contemplation' phase as they seemed to be aware of the changes required but had not yet committed themselves to a plan of action. Thus, in relation to stroke education, the Transtheoretical Model may serve as an aid for its ability to incorporate various strategies that target the different stages that individuals may be in. For instance, for those who are still in the pre-contemplation phase, educational efforts may be dedicated to enhancing awareness of the effects of the current behaviour and the potential benefits of a behaviour change. However, for those in the contemplation stage, it may be more effective to use healthy role models to give a vivid example of how a behavioural change may alter a person's identity in a positive way. Similarly, motivational messages from stroke survivors may be helpful for those who are in the action stage to further encourage them to maintain the change.

The use of motivational messages and positive reinforcement is also a prominent feature of the Social Learning Theory, which emphasises the important role of observational learning. This emphasis is based on the postulation that individuals learn not just through their past experiences but also by observing the actions of others and the resulting benefits. To this extent, fictional characters and movies may be used as stimuli to empower those who need to undergo a behaviour change. Along these lines, it may come as no surprise that the household situation described by the patient in Case 10 is not at all helpful. This is because, although the patient had stopped smoking, those who live with her still smoke. Thus it is not surprising that she finds it difficult to observe their actions while trying to maintain the desired behaviour change. To this extent, sometimes the most influential 'role models' may very well be the people who are closest to the individual, and it is thus crucial to focus educational initiatives not only on the affected person but also on those who are likely to accompany him or her along the way. This focus does not apply to preventative measures only but also to the right action to take in the face of an acute stroke since the important role of bystanders and their role in the decision-making process has previously been elaborated on.

Several of the bystanders also seemed to have plans for helping the patient regarding stress prevention. The bystanders in Cases 1, 2, and 3 were the only ones who mentioned specific measures, and they seemed to be in agreement that the four most important actions were smoking cessation, maintaining a balanced diet, limiting alcohol intake, and stress reduction:

B: He needs to change his lifestyle … he's always very busy … going up and down the stairs … why do you do this? You are abusing the situation … your body talks to you! You shouldn't over do it! Try to relax a bit! There's a limit. (C2)

B: You have to keep yourself active, exercise … like walking and so on. One should also reduce the food intake and smoking. (C3)

The importance of this knowledge was apparent in a local study by Mallia et al. (2015), who found that 85.7% of acute stroke patients who presented to the emergency department had at least one previously diagnosed risk factor for stroke. Hypertension was the most common risk factor, followed by previous cerebrovascular accident and diabetes mellitus.

In 2014, the World Health Organization published data on the prevalence of risk factors for stroke among Maltese adults, including insufficient physical activity (42.9%), tobacco smoking (26.6%), hypertension (25.4%), obesity (26.6%), and diabetes. Although certain risk factors are characterised by a genetic predisposition, they can potentially be controlled, thus reducing the risk of stroke. Unfortunately, failure to control risk factors may be partly caused by poor stroke knowledge and insufficient health literacy.

4.4 Conclusion

The findings that emerged from the qualitative analysis are crucial in understanding the experience of stroke, particularly regarding the knowledge and behaviour of individuals who had suffered from a stroke and any others who were present during stroke onset. While each of the cases were analysed linearly, the use of a multiple case study design made it possible to engage in a transverse analysis process across the cases to compare and contrast the findings emerging from each case. This allowed for literal replication (similar results) and theoretical replication (contrasting results for anticipatable reasons) across the cases. It was also possible to apply analytic generalisation (comparing the results of the case study to existing theories) using prominent health promotion theories and models as a backdrop to the findings.

Moreover, in a true mixed methods design, the process of qualitative analysis in the current study was important in informing the quantitative part of the study as well as constituting the framework on which the questionnaire to be used for quantitative data collection was constructed. The forthcoming section focuses on the quantitative results and their discussion, followed by a narrative dedicated to the consolidation of the main points that emerged from the qualitative and quantitative analysis and discussion, respectively.

Chapter 5 – Quantitative Analysis

5.1 Introduction

A pilot study was initially carried out to assess the fundamental elements of the questionnaire, including its validity and reliability. Validity is the ability of the tool to measure what it is intended to measure whereas reliability assesses whether the tool is able to measure consistently (Tavakol, Mohagheghi, & Dennick, 2008). Although reliability is directly related to the tool's validity, the opposite is not true. In fact, an instrument's reliability is independent of its validity (Nunnally, 1994). A total of 308 responses were gathered during this phase of the study over a span of 2 weeks.

5.2 Pilot study

5.2.1 Internal consistency of the questionnaire

Cronbach's alpha is the most widely used objective measure of a tool's reliability (Tavakol & Dennick, 2011). Since it depends on a single test administration, it is relatively easy to calculate compared with other tests of reliability (Cohen & Swerdlik, 2010).

Cronbach's alpha measures the internal consistency between a number of related items by measuring a latent dimension (for example, Knowledge and Response). Cronbach's alpha has an upper limit of 1, and any value larger than 0.7 indicates good internal consistency between the items.

To measure stroke knowledge, 17 items were generated, which yielded a Cronbach's alpha of 0.804. However, it was noted that items K9 and K17 were weakly related to the other items and were therefore removed, resulting in an increase in Cronbach's alpha to 0.832. As shown in the correlation table 5.1, all pairwise relationships between the remaining 15 items were positive.

	k1	k2	k3	k4	k5	k6	k7	k8	k10	k11	k12	k13	k14	k15	k16
k1	1.000	.361	.125	.233	.386	.119	.270	.223	.381	.212	.212	.166	.200	.171	.252
k2	.361	1.000	.069	.256	.372	.026	.197	.200	.334	.090	.146	.140	.136	.120	.210
k3	.125	.069	1.000	.256	.362	.498	.279	.310	.341	.254	.370	.237	.346	.256	.376
k4	.233	.256	.256	1.000	.476	.182	.434	.219	.401	.287	.305	.298	.243	.172	.332
k5	.386	.372	.362	.476	1.000	.199	.490	.390	.547	.272	.335	.321	.244	.309	.450
k6	.119	.026	.498	.182	.199	1.000	.180	.260	.155	.100	.278	.190	.240	.145	.253
k7	.270	.197	.279	.434	.490	.180	1.000	.179	.362	.308	.324	.148	.336	.412	.318
k8	.223	.200	.310	.219	.390	.260	.179	1.000	.290	.161	.320	.273	.284	.104	.342
k10	.381	.334	.341	.401	.547	.155	.362	.290	1.000	.321	.311	.254	.261	.226	.304
k11	.212	.090	.254	.287	.272	.100	.308	.161	.321	1.000	.354	.194	.174	.233	.199
k12	.212	.146	.370	.305	.335	.278	.324	.320	.311	.354	1.000	.381	.505	.156	.372
k13	.166	.140	.237	.298	.321	.190	.148	.273	.254	.194	.381	1.000	.241	.020	.303
k14	.200	.136	.346	.243	.244	.240	.336	.284	.261	.174	.505	.241	1.000	.195	.366
k15	.171	.120	.256	.172	.309	.145	.412	.104	.226	.233	.156	.020	.195	1.000	.248
k16	.252	.210	.376	.332	.450	.253	.318	.342	.304	.199	.372	.303	.366	.248	1.000

Table 5.1: Inter-Item Correlation Matrix (Knowledge)

Cronbach's Alpha	Cronbach's Alpha Based on Standardised Items	Number of Items
0.832	0.845	15

Table 5.2: Cronbach's Alpha (Knowledge)

Seventeen items were also generated to measure response, which yielded a Cronbach's alpha of 0.729. R2, R14, and R15 were removed as correlations were close to 0 or negative. Cronbach's alpha between the remaining 14 items subsequently improved to 0.775.

	r1	r3	r4	r5	r6	r7	r8	r9	r10	r11	r12	r13	r16	r17
r1	1.000	.219	.305	.152	.300	.471	.276	.199	.213	.346	.193	.218	.116	.448
r3	.219	1.000	.142	.212	.273	.199	.193	.097	.204	.158	.238	.254	.066	.130
r4	.305	.142	1.000	.167	.185	.243	.320	.111	.152	.234	.167	.094	.063	.266
r5	.152	.212	.167	1.000	.226	.211	.196	.124	.137	.092	.212	.233	.101	.105
r6	.300	.273	.185	.226	1.000	.459	.286	.186	.185	.342	.129	.284	.243	.270
r7	.471	.199	.243	.211	.459	1.000	.351	.347	.319	.535	.099	.288	.145	.337
r8	.276	.193	.320	.196	.286	.351	1.000	.079	.171	.357	.171	.214	.074	.301
r9	.199	.097	.111	.124	.186	.347	.079	1.000	.256	.247	-.031	.160	.051	.180
r10	.213	.204	.152	.137	.185	.319	.171	.256	1.000	.263	.134	.235	.133	.227
r11	.346	.158	.234	.092	.342	.535	.357	.247	.263	1.000	.094	.255	.084	.395
r12	.193	.238	.167	.212	.129	.099	.171	-.031	.134	.094	1.000	.205	.086	.096
r13	.218	.254	.094	.233	.284	.288	.214	.160	.235	.255	.205	1.000	.211	.262
r16	.116	.066	.063	.101	.243	.145	.074	.051	.133	.084	.086	.211	1.000	.070
r17	.448	.130	.266	.105	.270	.337	.301	.180	.227	.395	.096	.262	.070	1.000

Table 5.3: Inter-Item Correlation Matrix (Response)

Cronbach's Alpha	Cronbach's Alpha Based on Standardised Items	Number of Items
0.775	0.787	14

Table 5.4: Cronbach’s Alpha (Response)

Assessment of the internal consistency of the questionnaire during the pilot phase of the study was crucial to identify and remove items that demonstrated poor inter-item correlation. It was also crucial to enhance the validity and accuracy of data interpretation (Tavakol & Dennick, 2011).

5.2.2 Distribution of data

‘Normal’ data refers to data that emerges from a population that exhibits a normal distribution. Such distribution is the most commonly used in both theoretical and applied statistics (NIST/SEMATECH, 2013) because “Normally distributed data exhibit predictable traits and probabilities” (Conduent, 2018).

The shape of normal distribution is unimodal and symmetrical about the mean. It has a characteristic bell-shape and is often referred to as ‘Gaussian distribution’. In the real world, it is extremely rare to come across a characteristic that exactly fits a normal distribution.

Statistically, it is possible to transform non-normal data into ‘approximately normal’ data using a transformation. A multitude of possible transformations is available, but the choice of the most suitable transformation may not be an obvious one (NIST/SEMATECH, 2013).

Dealing with normal data is only indispensable when a researcher needs to utilise a specific statistical test, such as the *paired t-test*. Hence, normal distribution should be regarded as “a means to an end, not the end itself” (Buthmann, 2018). In fact, the researcher may opt to use a statistical tool that does not require normally distributed data, such as the *one-sample sign test*.

In order to evaluate data distribution in this study, knowledge and response scores (x-axis) were plotted against their frequencies (y-axis). The distribution curves for both scores (figures 5.1 and 5.2) were flatter and left-skewed (i.e. negatively skewed) compared with the normal curve.

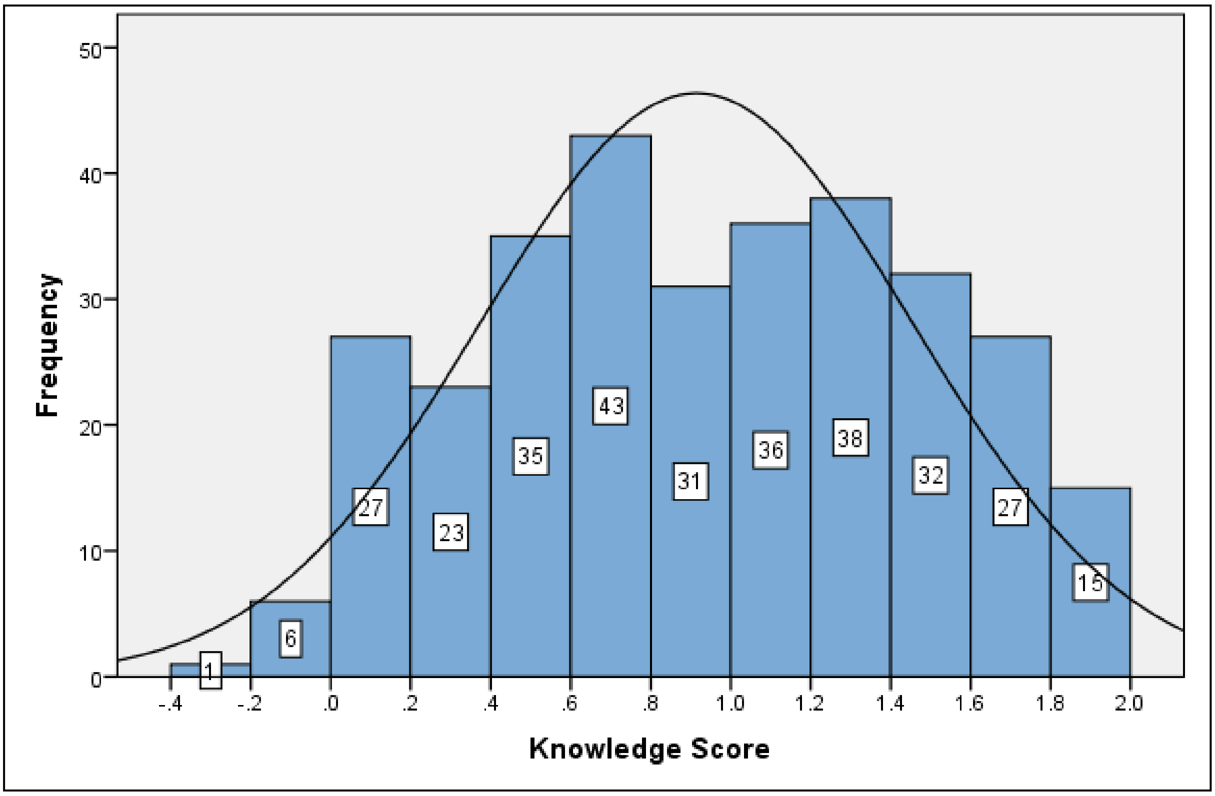


Figure 5.1: Data Distribution (Knowledge)

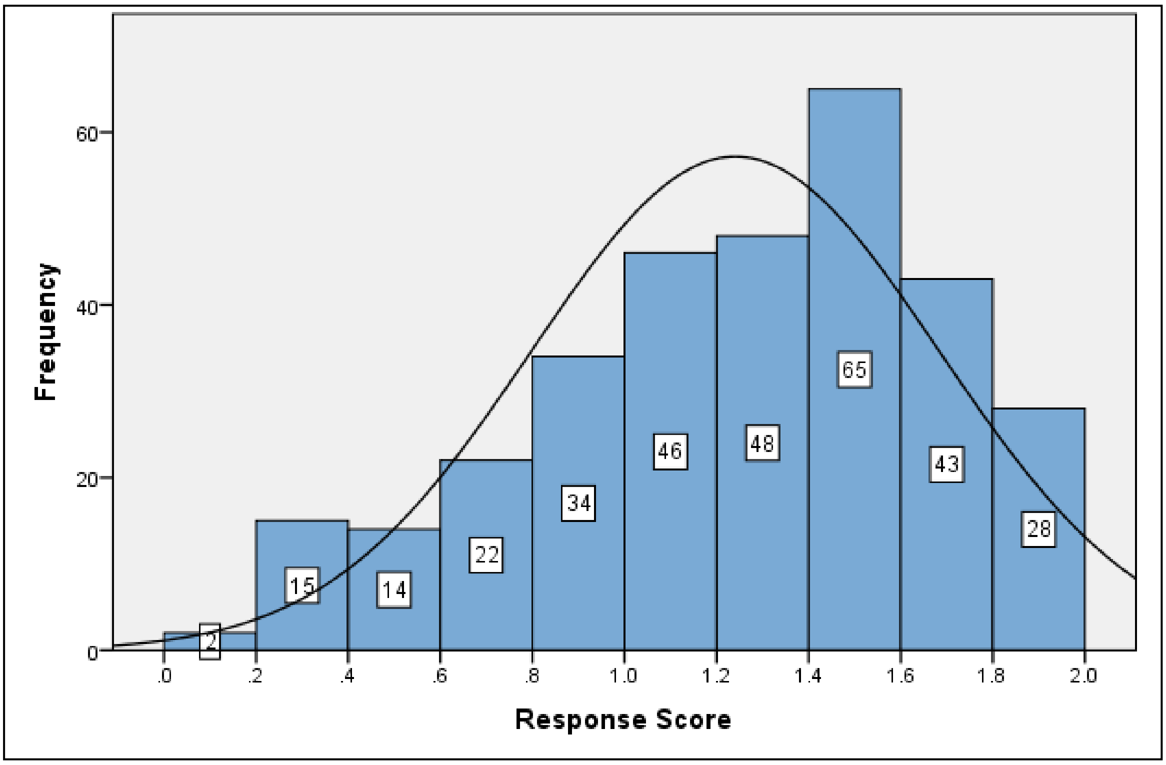


Figure 5.2: Data Distribution (Response)

5.2.3 Tests of normality

Since the data were not normalised, the Shapiro–Wilk test was used to test for normality. This test evaluates the null hypothesis that the population is normally distributed (Wikipaedia, 2018b) and is accepted if the p-value exceeds the 0.05 level of significance. Alternatively, the alternate hypothesis is accepted if the p-value is lower than the 0.05 level of significance, and specifies that the score distribution is skewed.

	Shapiro–Wilk Statistic	df	P-value
Knowledge Score	.978	308	.000
Response Score	.970	308	.000

Table 5.5: Shapiro–Wilk Test (Pilot Study)

Since the p-value (0.000) was less than the chosen alpha level (0.05), the null hypothesis was rejected.

5.3 Sample size

In total, 1872 responses were collected via the online survey over a 2-month period. The target sample size was reached after 41 days. Google Forms was used for the online administration of the questionnaire, which could be accessed through the following link: https://goo.gl/forms/SA5tDlMuXqHKuLkC3.

5.3.1 Sample margin of error calculation

The required sample size to achieve the study's objectives was calculated during the design stage of the study.

Responses collected from the questionnaire represent only a sample of the target population, that is, the Maltese population. Since calculation of the appropriate sample size relies "on a subjective choice of certain factors and sometimes crude estimates of others" (Whitley & Ball, 2002), it is important to understand what is meant by the terms 'confidence interval' (i.e. margin of error) 'and confidence level'. The former represents the range of values in which the true value lies and is expressed as a plus or minus figure. The confidence level, is a measure of certainty, and most researchers use a confidence level of 95% (CRS, 2017). The two terms are inter-related as the wider the confidence interval that the researcher is ready to accept, the higher is the confidence level that can be employed.

The Maltese population was taken to be 450,000 and the following mathematical calculation was used to determine the confidence interval of this sample size:

Margin of error $= z\sigma_{\bar{p}}$

For a 95% confidence level, $z = 1.96$

σ_p is the standard error (standard deviation of the sampling distribution of proportion), which is given by:

$$\sigma_p = \sqrt{\frac{p(1-p)}{n}\left(\frac{N-n}{N-1}\right)}$$

The proportion *p* is unknown, however σ_p is maximised when $p = 0.5$.

When the sample size is $n = 1872$ and population size is $N = 450000$, the maximum value of the standard error σ_p is:

$$\sigma_p = \sqrt{\frac{p(1-p)}{n}\left(\frac{N-n}{N-1}\right)} = \sqrt{\frac{(0.5)(0.5)}{1872}\left(\frac{450000-1872}{450000-1}\right)} = 0.0115$$

$$\text{Maximum margin of error} = z\sigma_{\overline{p}} = (1.96)(0.0115) = 0.0226 = 2.26\%$$

A sample size of 1872 participants selected from the entire Maltese population guarantees a maximum margin of error of 2.26%, assuming a 95% degree of confidence.

5.4 Descriptive statistics

The demographics section of the questionnaire contained nine questions. The following table summarises the number of valid responses per item within this section.

		Age	Gender	Nationality	Ethnicity	Region	Education	Income	Risk Factors	Risk Factors Coded	Healthcare worker?
N	Valid	1872	1869	1864	1866	1866	1863	1835	1869	1869	1863
	Missing	0	3	8	6	6	9	37	3	3	9

Table 5.6: Number of Responses According to Demographic Variables

5.4.1 Demographic data

The demographic variables (age, gender, nationality, ethnicity, geographical region, education, income, risk factors, and whether participant is/is not a healthcare worker) of the respondents are summarised in appendix 22.

5.4.2 Coding responses

The answers were coded to allow statistical analyses using the following scheme:

D1	**Age**	1 = 18–25 years 2 = 25–40 years 3 = 41–60 years 4 = 61–80 years	1 = 18–25 years 2 = 25–40 years 3 = 41–60 years 4 = 61–80 years
D2	**Gender**	1 = Male 2 = Female 3 = Other	1 = Male 2 = Female
D3	**Nationality**	1 = Maltese 2 = Other	1 = Maltese 2 = Other
D4	**Ethnicity**	1 = White 2 = Black 3 = Mixed/Multiple 4 = Asian 5 = Other	1 = White 2 = Other
D5	**Region of Malta**	1 = Gozo 2 = North 3 = Central 4 = South	1 = Gozo 2 = North 3 = Central 4 = South

D6	**Education**	1 = Primary 2 = Secondary 3 = Tertiary	1 = Primary 2 = Secondary 3 = Tertiary
D7	**Income**	1 = < 10,000 euro p/a 2 = 10,000–30,000 euro p/a 3 = 30,000–60,000 euro p/a 4 = > 60,000 euro p/a	1 = < 10,000 euro p/a 2 = 10,000–30,000 euro p/a 3 = 30,000–60,000 euro p/a 4 = > 60,000 euro p/a
D8	**Risk Factors**	1 = Hypertension 2 = Diabetes 3 = Smoking 4 = Heart disease 5 = Previous stroke/TIA 6 = Multiple risk factors 7 = None	1 = Hypertension 2 = Diabetes 3 = Smoking 4 = Heart disease/stroke 6 = Multiple risk factors 7 = None
D9	**Healthcare Worker Status**	1 = Yes 2 = No	1 = Yes 2 = No

Table 5.7: Scheme for Coding Responses

A 5-point Likert scale was used for the Knowledge and Response sections of the questionnaire. Data were coded (scored) as follows:

	Correct Answer	**Incorrect Answer**
Strongly Agree	+2	−2
Agree	+1	−1
Undecided	0	0

Disagree	−1	+1
Strongly Disagree	−2	+2

Table 5.8: Scheme for Scoring Responses

There were 15 questions in the Knowledge section and 14 questions in the Response section. The responses for each item are summarised in appendix 23.

The scores for all variables within each section were added together to calculate the Knowledge and Response scores. The total score was divided by the number of questions within each section to derive a mean score for each item. A total score for the participant was also generated by adding the Knowledge and Response scores.

5.4.3 Knowledge scores and means

The mean score for each item in the Knowledge section (K1-K17) was calculated by dividing the total score by the number of participants (n = 1872). As a result, relative low mean scores indicate that participants struggled to answer those particular questions. This therefore provides crucial information on the knowledge gap with regards to stroke knowledge in the Maltese population. Such information is also invaluable should one try to address the major educational lacunae in a national stroke campaign.

	Sample Size	Range	Minimum	Maximum	**Sum**	**Mean**
k1	1872	3	−1	2	**3136**	**1.68**
k2	1872	4	−2	2	**1505**	**0.80**
k3	1872	4	−2	2	**704**	**0.38**
k4	1872	3	−1	2	**2063**	**1.10**

k5	1872	3	−1	2	**2367**	**1.26**
k6	1872	4	−2	2	**-212**	**-0.11**
k7	1872	3	−1	2	**3117**	**1.67**
k8	1872	4	−2	2	**1181**	**0.63**
k10	1872	4	−2	2	**1894**	**1.01**
k11	1872	4	−2	2	**1611**	**0.86**
k12	1872	4	−2	2	**1378**	**0.74**
k13	1872	4	−2	2	**195**	**0.10**
k14	1872	4	−2	2	**2445**	**1.31**
k15	1872	4	−2	2	**2072**	**1.11**
k16	1872	4	−2	2	**2041**	**1.09**

Table 5.9: Knowledge Scores and Means

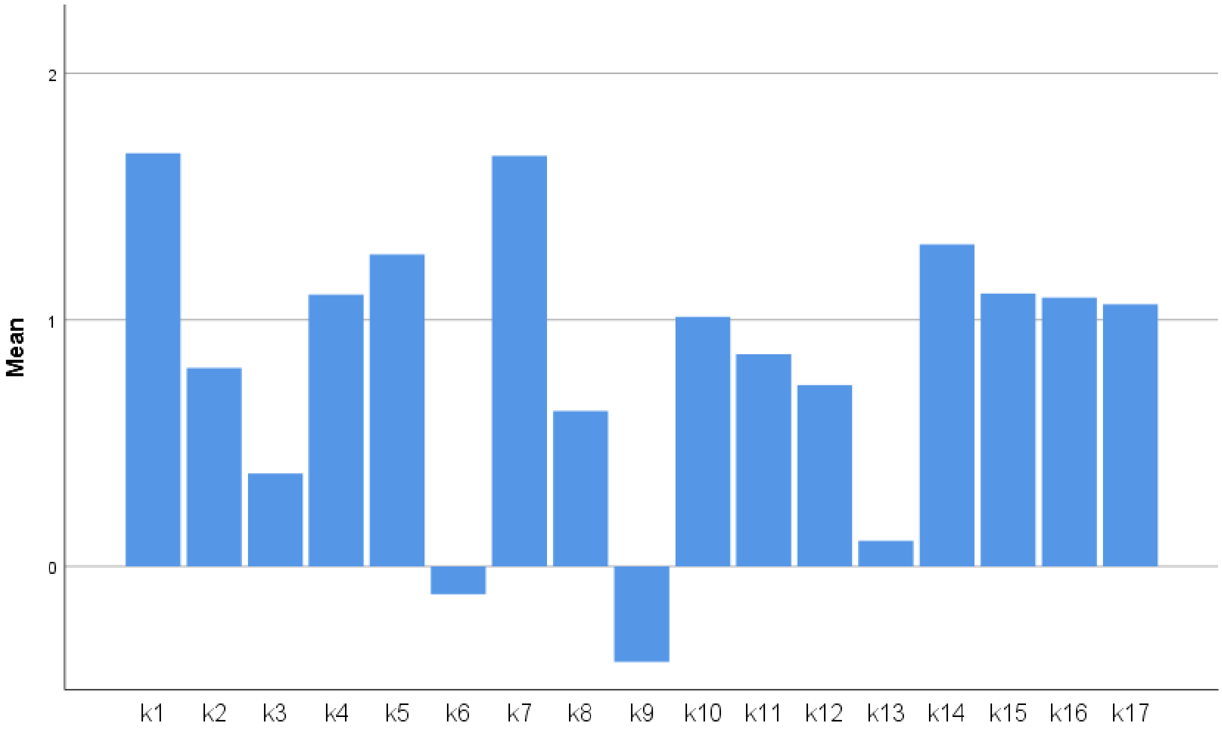


Figure 5.3: Mean Scores for Knowledge Questions

5.4.4 Response scores and means

In a similar manner as to what was done in the Knowledge section, mean scores for all the items in the Response section (R1-R17) were calculated. The following table demonstrates whether participants were knowledgeable and whether they struggled to answer a specific question by displaying the range, sums and mean scores.

	Sample Size	Range	Minimum	Maximum	**Sum**	**Mean**
r1	1872	4	−2	2	**1973**	**1.05**
r3	1872	4	−2	2	**3502**	**1.87**
r4	1872	4	−2	2	**1414**	**0.76**
r5	1872	4	−2	2	**3381**	**1.81**
r6	1872	4	−2	2	**3152**	**1.68**
r7	1872	4	−2	2	**1803**	**0.96**
r8	1872	4	−2	2	**2758**	**1.47**
r9	1872	4	−2	2	**514**	**0.27**
r10	1872	4	−2	2	**1579**	**0.84**
r11	1872	4	−2	2	**2257**	**1.21**
r12	1872	4	−2	2	**3272**	**1.75**
r13	1872	4	−2	2	**2655**	**1.42**
r16	1872	4	−2	2	**1787**	**0.95**
r17	1872	4	−2	2	**2476**	**1.32**

Table 5.10: Response Scores and Means

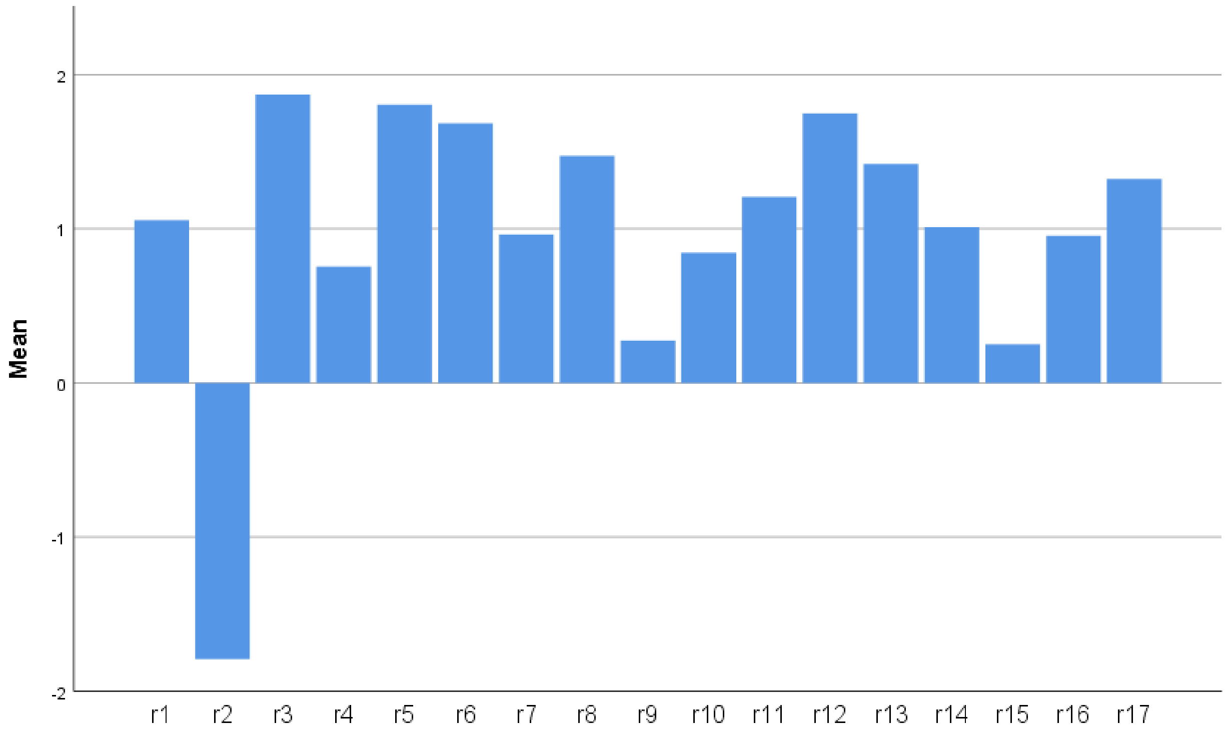


Figure 5.4: Mean Scores for Response Questions

5.4.5 Correct answers in the knowledge and response sections

The results emerging from the Knowledge section of the questionnaire were categorised into four groups, namely Symptoms (seven questions), Risk factors (three questions), Aetiology (four questions) and Campaigns/Education (three questions). The scope of this exercise was to obtain a more representative idea of educational lacunae which could have been present. Hence, total scores for the four groups were also calculated. Scores were further subdivided into two participant groups namely public and healthcare workers. Such division was deemed crucial to provide a true picture of public stroke knowledge and it also allowed comparisons with previous studies assessing stroke knowledge. Questions K9 and K17 were removed from the analysis as they demonstrated poor inter-variable correlation when assessing for internal consistency of the tool (during the pilot phase). This breakdown may prove invaluable when devising a national stroke campaign as it provides a more detailed assessment of stroke knowledge and may therefore indicate which areas should be stressed upon in a campaign.

KNOWLEDGE

A. Symptoms

	K3	K4	K7	K11	K12	K13	K14	Total
	Chest pain	*Vision loss/vertigo*	*Speech*	*Headaches*	*Sensation*	*Silent*	*Muscle power*	
HCW	74.4%	89.0%	99.3%	86.3%	77.0%	57.7%	94.1%	82.5%
Public	33.3%	64.6%	93.3%	59.2%	49.2%	32.2%	78.4%	58.6%
Total	57.4%	78.9%	96.6%	75.2%	65.4%	47.1%	87.6%	72.6%

B. Risk Factors

	K1	K5	K10	Total
	Smoking	*Previous TIA/stroke*	*Diabetes*	
HCW	98.6%	95.4%	84.2%	92.7%
Public	91.9%	53.4%	53.1%	66.1%
Total	95.8%	78.5%	71.5%	81.9%

C. Aetiology

	K2	K6	K8	K9*	Total
	vs Breast cancer	*Affects heart*	*Rare cause of disability*	*More common in females*	
HCW	73.4%	48.2%	78.8%	14.8%	53.8%
Public	55.3%	26.3%	48.4%	9.2%	34.8%
Total	66.0%	39.1%	66.3%	12.5%	46.0%

D. Campaigns/Education

	K15	K16	K17*	Total
	FAST	*Lifestyle changes*	*Mass media*	
HCW	78.6%	89.7%	82.4%	83.6%
Public	61.1%	67.5%	76.4%	68.3%
Total	71.5%	80.5%	80.0%	77.3%

E. Questions Removed

K9*	K17*
More common in females	*Mass media*

Table 5.11: Summary Tables of Stroke Knowledge showing Percentages of Correct Answers (Answers 1+2). HCW = Healthcare Worker.

Similarly, the Response scores were categorised into the following groups: Response (nine questions), Reasons (five questions), Treatment (two questions) and Miscellaneous (one question). The participants were further subdivided into the general public and healthcare worker group. Questions R2, R14 and R15 were removed from the response sections as described in section 5.2.1 as they were weakly related to the other items.

RESPONSE

A. Response

	R1	R2*	R3	R4	R5
	Wait for symptoms to improve	*Patient should attend a polyclinic*	*Act fast*	*Discuss with relatives*	*Phone number = 112*
HCW	85.8%	1.2%	99.3%	69.8%	98.7%
Public	72.2%	0.4%	100%	67.3%	95.2%
Total	80.2%	0.9%	99.4%	68.8%	97.1%

	R8	R12	R14*	R17	Total
	'Wait and See' approach	*Call ambulance immediately*	*Patient should drive him- or herself to hospital*	*Patient should call for help him- or herself*	
HCW	95.2%	97.8%	79.2%	91.7%	79.8%
Public	86.5%	97.2%	75.2%	84.8%	75.4%
Total	91.5%	97.4%	77.6%	88.8%	78.0%

B. Reasons

	R6	R7	R11	R15*	R16	Total
	Outcome may improve with treatment	*Prognosis is invariably poor*	*Stroke will invariably progress*	*t-PA time window*	*Time-dependent irreversible brain damage*	
HCW	99.1%	91.0%	94.6%	41.7%	79.3%	81.1%
Public	91.9%	47.3%	76.4%	15.0%	63.5%	58.8%
Total	96.0%	73.1%	87.1%	30.9%	72.6%	71.9%

C. Treatment

	R9	R10	Total
	Elevate legs	*Paracetamol as treatment*	
HCW	48.9%	74.6%	61.8%
Public	13.7%	46.3%	30.0%
Total	34.4%	63.1%	48.8%

D. Miscellaneous

	R13	Total
	Patient may lack insight	
HCW	96.7%	96.7%
Public	96.4%	96.4%
Total	94.0%	94.0%

E. Removed		
R2*	R14*	R15*
Patient should attend a polyclinic	*Patient should drive him- or herself to hospital*	*t-PA time window*

Table 5.12: Summary Tables of Stroke Response showing Percentages of Correct Answers (Answers 1+2). HCW = Healthcare Worker.

5.5 Inferential statistics

The Shapiro–Wilk test was repeated on the total sample of 1872 responses to determine whether the Knowledge, Response, and Total score distribution was normal or skewed (not normal).

	Shapiro–Wilk Statistic	df	P-value
Knowledge Score	0.981	1872	0.000
Response Score	0.975	1872	0.000
Total Score	0.981	1872	0.000

Table 5.13: Shapiro–Wilk test

All p-values (approximately 0) of the Shapiro–Wilk test were below the 0.05 level of significance, indicating that all three distributions (Knowledge Score, Response Score, and Total Score) are skewed and do not satisfy the normality assumption. For this reason, non-parametric tests were used to analyse the data.

5.5.1 Comparing mean scores

The Kruskal–Wallis test is a non-parametric test that determines whether the mean ranks are similar in all groups. It is used when the measurement variable fails to meet the normality assumption, and hence one-way ANOVA cannot be utilised (McDonald, 2014).

The Kruskal–Wallis test was used to compare mean scores between several independent groups clustered by age, gender, ethnicity, geographical region, education, income, risk factors, and whether the participant is/is not a healthcare worker. The null hypothesis (which is accepted if the p-value is larger than the 0.05 level of significance) specifies that the mean scores vary marginally between the groups. By contrast, the alternative hypothesis specifies that there is a significant variation in the mean scores between different groups and is accepted when the p-value is below the 0.05 criterion.

5.5.1.1 Age

	Age	Sample Size	Mean	Std. Deviation	P-value
Knowledge Score	18–25 years	104	1.01	0.528	0.000
	26–40 years	981	1.01	0.515	
	41–60 years	621	0.81	0.449	
	61–80 years	166	0.60	0.454	
Response Score	18–25 years	104	1.31	0.374	0.000
	26–40 years	981	1.31	0.423	
	41–60 years	621	1.18	0.405	
	61–80 years	166	1.01	0.449	
Total Score	18–25 years	104	1.16	0.428	0.000
	26–40 years	981	1.16	0.442	
	41–60 years	621	0.99	0.394	
	61–80 years	166	0.79	0.412	

Table 5.14: Comparison of Mean Scores by Age

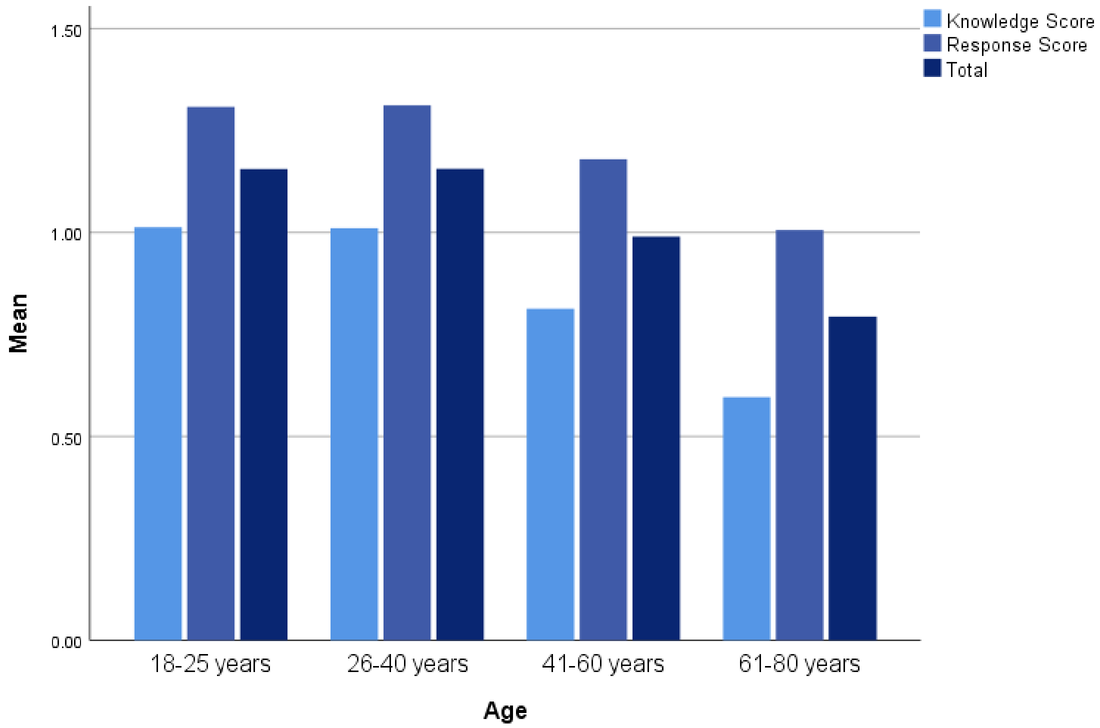


Figure 5.5: Column Chart of Mean Scores Clustered by Age

The mean knowledge score, mean response score, and mean total score decrease monotonically with an increase in age. This reduction in mean scores is significant since all the p-values (approximately 0) are below the 0.05 level of significance. Hence, we can generalise that younger Maltese participants have a higher knowledge, higher response, and higher overall score than their older counterparts.

These findings echo those described in the review by Jones et al. (2010), where both stroke symptom knowledge and risk factor awareness decreased with increasing participant age. Similarly, Yoon et al. (2001a) showed an indirect correlation between age and stroke knowledge. Apart from the apparent decrease in stroke knowledge with age, Jurkowski et al. (2010) showed that elderly patients were less likely to call for help in the event of a stroke. This is rather unfortunate, since the elderly population is at the highest risk of stroke. Elderly patients seemingly lack knowledge on identifying stroke symptoms and on how to activate emergency services. These are crucial factors in decreasing pre-hospital delay and are therefore closely related to long-term outcome.

This decrease in knowledge may be attributable to a combination of lack of education on the subject as well as potential memory limitations that are significantly more common with increasing age.

It is therefore imperative that stroke education campaigns not only reach the elderly but specifically target this demographic group. It is also crucial to remember that the latter group may not be as receptive to stroke education as their younger counterparts. This was shown to be the case in studies by Silver et al. (2003) and Reeves, Mullard, and Wehner (2008a).

5.5.1.2 Gender

	Gender	Sample Size	Mean	Std. Deviation	P-value
Knowledge Score	Male	716	0.97	0.541	0.000
	Female	1153	0.87	0.481	
Response Score	Male	716	1.26	0.443	0.039
	Female	1153	1.23	0.413	
Total Score	Male	716	1.11	0.462	0.001
	Female	1153	1.05	0.419	

Table 5.15: Comparison of Mean Scores by Gender

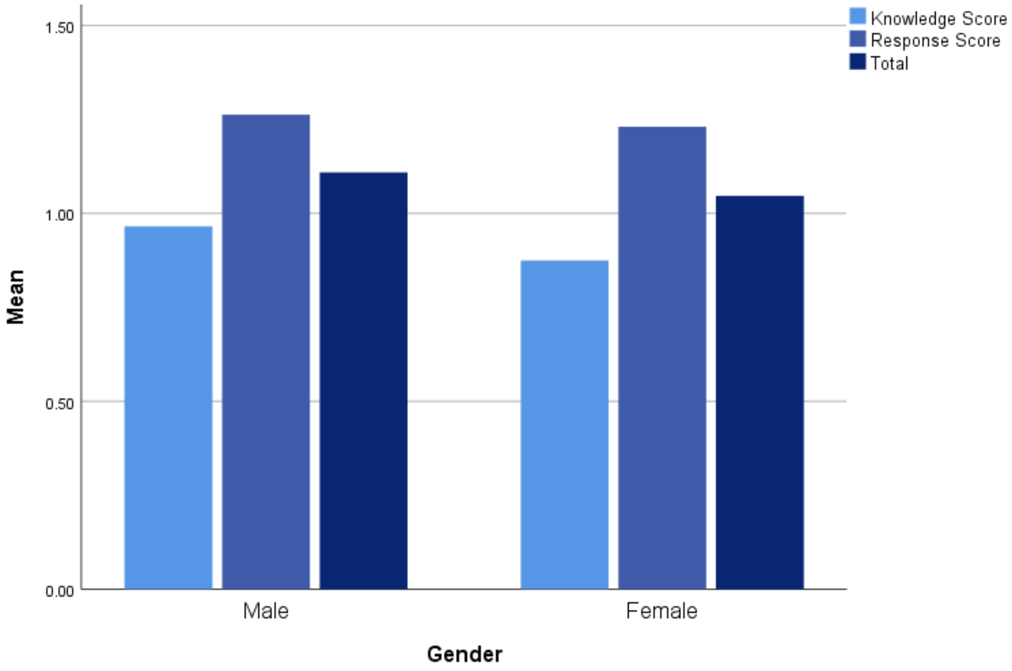


Figure 5.6: Column Chart of Mean Scores Clustered by Gender

Males were found to have a significantly higher mean knowledge score and mean total score compared with females ($p \leq 0.001$). Although the mean response score was also higher in males, the correlation was less significant ($p = 0.039$).

By contrast, in a study in Western Germany, females performed better than males when asked to name stroke symptoms and regarding the actions that should be taken in the event of a stroke (Marx et al., 2010). Similarly, females were found to have better stroke knowledge compared with males in the studies by Yoon et al. (2001a) and Müller-Nordhorn et al. (2006).

5.5.1.3 Ethnicity

	Ethnicity	Sample Size	Mean	Std. Deviation	P-value
Knowledge Score	White	1854	0.90	0.505	0.170
	Other	12	0.98	0.518	
Response Score	White	1854	1.24	0.424	0.014
	Other	12	1.28	0.455	
Total	White	1854	1.06	0.436	0.076
	Other	12	1.13	0.481	

Table 5.16: Comparison of Mean Scores by Ethnicity

As described previously, ethnicities were grouped into White and Other. The latter category accounted for only 0.64% of respondents. This finding may be explained by the fact that 95% of the Maltese population is composed of native Maltese (World Population Review, 2018). Although the mean Knowledge, Response, and Total scores were lower for Whites, the difference in the mean Total score between the two groups was not significant (p-value = 0.076). Since the ‘Other’ sub-group consisted of just 12 individuals, no further extrapolations were attempted.

5.5.1.4 Region of Malta

	Region	Sample Size	Mean	Std. Deviation	P-value
Knowledge Score	Gozo	434	0.91	0.531	0.698
	North	444	0.91	0.499	
	Central	489	0.92	0.489	
	South	499	0.88	0.507	

Response Score	Gozo	434	1.23	0.435	0.572
	North	444	1.22	0.434	
	Central	489	1.27	0.403	
	South	499	1.22	0.424	
Total	Gozo	434	1.07	0.458	0.536
	North	444	1.06	0.437	
	Central	489	1.09	0.414	
	South	499	1.05	0.437	

Table 5.17: Comparison of Mean Scores by Residential Region

No significant correlations were found between the four regions of Malta and the mean knowledge (p = 0.698), mean response (p = 0.572), and mean total scores (p = 0.536). All p-values were above the 0.05 level of significance.

This finding may initially be surprising, as discrepancies in stroke knowledge between different geographical regions have been extensively documented in the literature. For example, Marx et al. (2008) found better stroke knowledge in Germany compared with neighbouring European countries, Australia, and the US. Such discrepancies were also found to exist in different regions within India (Das et al., 2007; Pandian et al., 2005) and Ireland (Hickey et al., 2009).

There are several factors that may explain why such differences were not found to be as pronounced in Malta. First, the country is very small, covering only 316 km^2 (Wikipaedia, 2018a), and inter-regional differences are therefore likely to be less relevant in this context. Furthermore, the entire population is exposed to similar television and radio programmes and therefore mass media educational campaigns are not expected to influence any geographical region more than another. No significant cultural, ethnic, or religious differences are generally found between the different localities. Although social and educational events may be organised on a smaller scale by local councils, the entire population is exposed to the same educational curricula and national campaigns.

5.5.1.5 Education

	Education	Sample Size	Mean	Std. Deviation	P-value
Knowledge Score	Primary	9	0.8889	0.63070	0.000
	Secondary	203	0.4125	0.35067	
	Tertiary	1651	0.9710	0.48828	
Response Score	Primary	9	1.2460	0.64197	0.000
	Secondary	203	0.8638	0.39888	
	Tertiary	1651	1.2895	0.40341	
Total	Primary	9	1.0613	0.62350	0.000
	Secondary	203	0.6304	0.33481	
	Tertiary	1651	1.1248	0.41609	

Table 5.18: Comparison of Mean Scores by Education

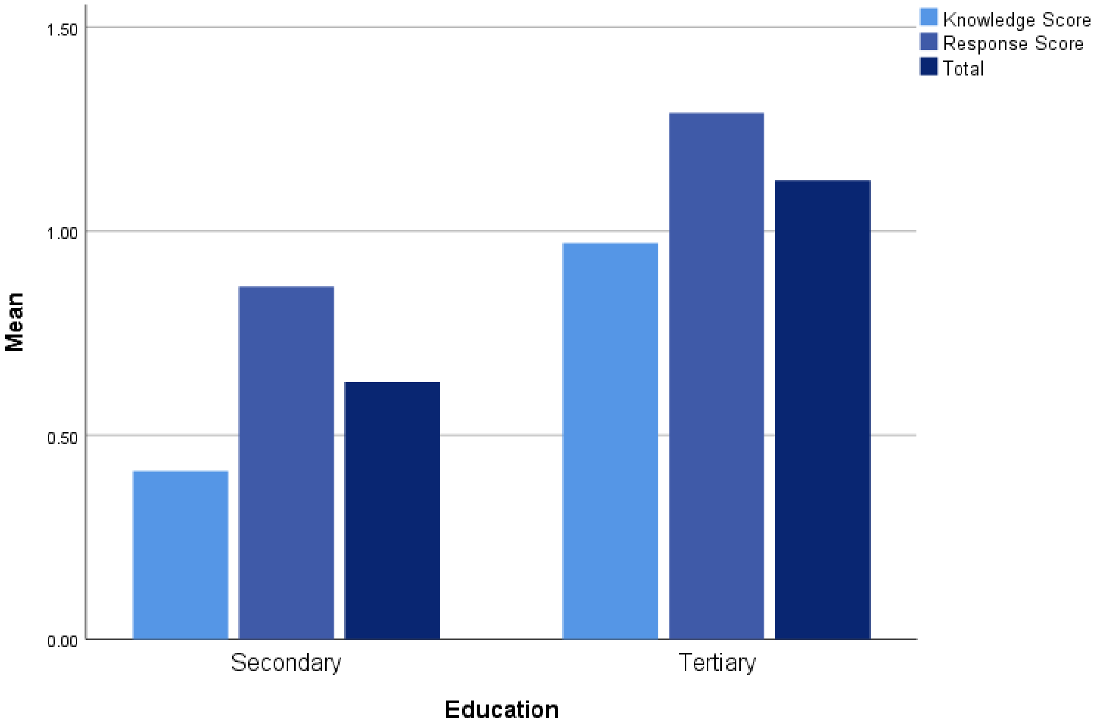


Figure 5.7: Column Chart of Mean Scores Clustered by Level of Education

Only 0.5% of participants who filled the questionnaire had a primary level of education. The mean knowledge score, mean response score, and mean total score were higher in participants with tertiary education compared with those having a secondary level of education. This increase in the mean scores is significant because all p-values (approximately 0) were below the 0.05 level of significance. We can therefore generalise that participants with a tertiary level of education have higher knowledge, higher response, and higher overall scores.

The very low rate of participants with a primary level of education results from the fact that secondary school has been obligatory in Malta for a number of decades. Participants with a tertiary level of education may be over-represented, since the sample included a large number of healthcare workers (who typically have a tertiary level of education).

The direct relationship between education and stroke knowledge is also reflected in the literature. This relationship has been demonstrated in studies by Pancioli et al. (1998) and Marx et al. (2010). Similarly, Reeves et al. (2002) and Alkadry et al. (2006) showed major deficiencies in stroke knowledge among participants with a low educational background.

Williams et al. (1998) showed how poor literacy was a key factor in limiting the efficacy of health educational campaigns. Apart from having a lower baseline knowledge, this demographic sub-group is therefore less likely to benefit from stroke educational campaigns.

5.5.1.6 Income

		Sample Size	Mean	Std. Deviation	P-value
Knowledge Score	< 10000 Euro	127	0.67	0.427	0.000
	10000–30000 Euro	1033	0.80	0.462	
	30000–60000 Euro	499	1.11	0.492	
	> 60000 Euro	176	1.26	0.435	

Response Score	< 10000 Euro	127	1.04	0.427	0.000
	10000–30000 Euro	1033	1.17	0.412	
	30000–60000 Euro	499	1.37	0.403	
	> 60000 Euro	176	1.48	0.363	
Total	< 10000 Euro	127	0.85	0.400	0.000
	10000–30000 Euro	1033	0.98	0.406	
	30000–60000 Euro	499	1.24	0.417	
	> 60000 Euro	176	1.37	0.369	

Table 5.19: Comparison of Mean Scores by Income

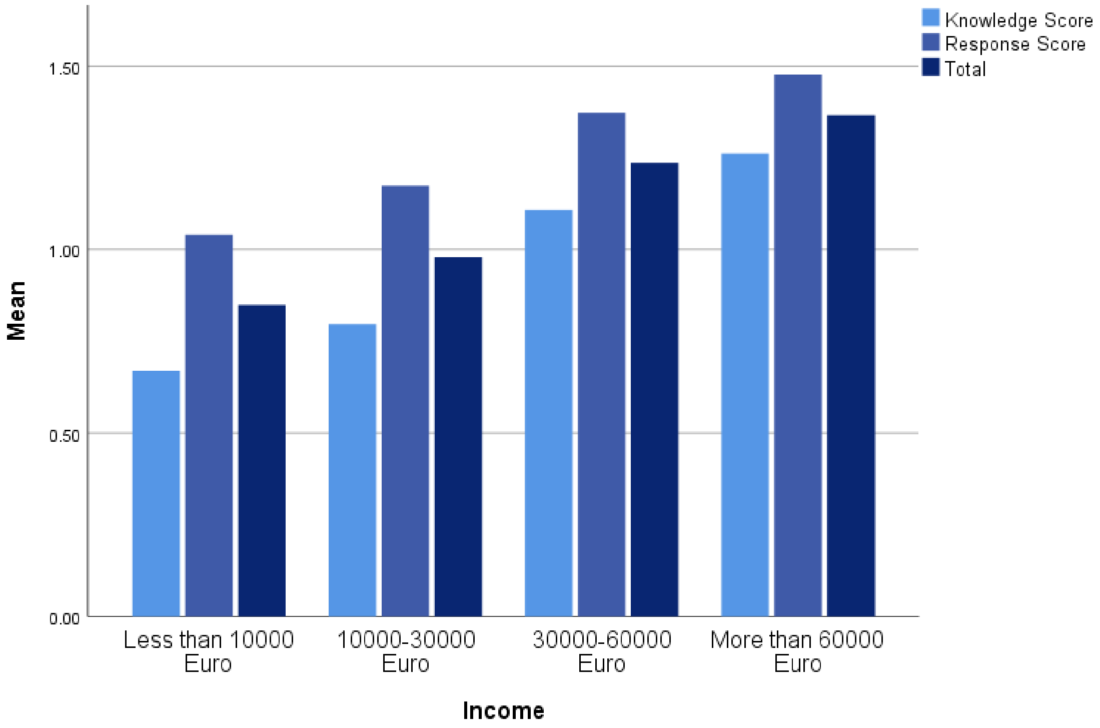


Figure 5.8: Column Chart of Mean Scores Clustered by Income

The three mean scores increase monotonically with an increase in annual income. This increase is significant because all the p-values were approximately 0. We can therefore conclude that people earning a higher salary have better stroke knowledge compared with those earning lower wages.

These results echo those reported in the literature. High income was found to be positively correlated to stroke knowledge in a study by Yoon et al. (2001a). This correlation may partly be explained by the fact that people who have a higher level of education generally tend to have better wages. However, the authors found that this correlation was independent of other demographic and social variables.

Similar findings were reported by Travis et al. (2003) and Lutfiyya et al. (2010). The latter found that financial implications, lack of health insurance, and lack of a heath care provider meant that individuals were more likely to suffer delays in their stroke care. Hence, individuals who earn a low salary are less likely to recognise stroke symptoms and are less likely to be treated in time. Although the latter may not be relevant in the local scenario because healthcare is provided for free, a special focus needs to be placed on this sub-set of the population during the planning and delivery of any national stroke education campaign.

5.5.1.7 Risk factors

	Risk Factor	Sample Size	Mean	Std. Deviation	P-value
Knowledge Score	High blood pressure	217	0.86	0.487	0.000
	Diabetes	27	1.04	0.478	
	Smoking	165	0.77	0.529	
	Heart disease/stroke	7	1.00	0.357	
	Multiple risk factors	73	0.77	0.454	
	None	1380	0.93	0.506	
Response Score	High blood pressure	217	1.16	0.465	0.000
	Diabetes	27	1.24	0.362	

	Smoking	165	1.17	0.445	
	Heart disease/stroke	7	1.24	0.217	
	Multiple risk factors	73	1.10	0.436	
	None	1380	1.27	0.413	
Total	High blood pressure	217	1.01	0.446	0.000
	Diabetes	27	1.14	0.382	
	Smoking	165	0.96	0.463	
	Heart disease/stroke	7	1.12	0.282	
	Multiple risk factors	73	0.93	0.409	
	None	1380	1.09	0.431	

Table 5.20: Comparison of Mean Scores by Risk Factors

	Risk Factors (Coded)	Sample Size	Mean	Std. Deviation	P-value
Knowledge Score	Single risk factor	416	0.84	0.506	0.000
	Multiple risk factors	73	0.77	0.454	
	No risk factors	1380	0.94	0.506	
Response Score	Single risk factor	416	1.18	0.448	0.000
	Multiple risk factors	73	1.10	0.437	
	No risk factors	1380	1.27	0.413	
Total	Single risk factor	416	1.00	0.448	0.000
	Multiple risk factors	73	0.93	0.409	
	No risk factors	1380	1.09	0.431	

Table 5.21: Comparison of Mean Scores by Risk Factors (Coded)

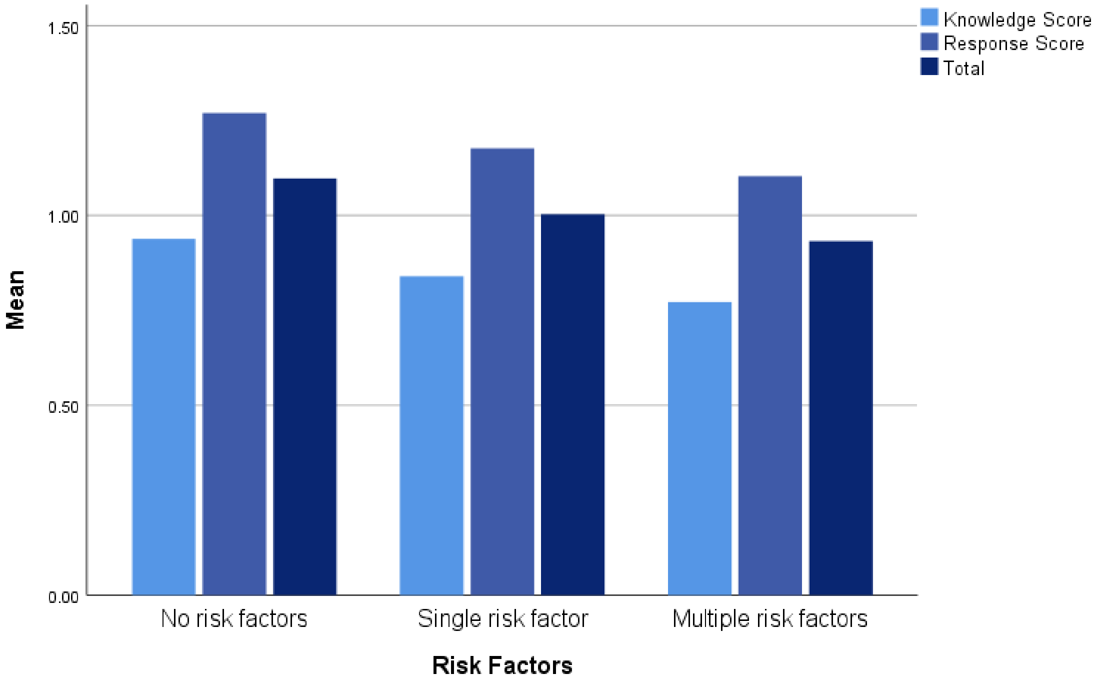


Figure 5.9: Column Chart of Mean Scores Clustered by Risk Factors

Participants were clustered into three groups: those who had no risk factors, those who had a single risk factor, and those who had multiple risk factors for stroke. Risk factors included hypertension, diabetes, smoking, heart disease, and previous TIA or stroke.

Paradoxically, as shown in the tables above, the group with no risk factors for stroke had the best mean knowledge, response, and total scores, followed by those with a single risk factor. All correlations were found to be significant as all p values (approximately 0) were below the chosen level of significance (0.05).

These findings reflect those found in multiple studies exploring stroke knowledge. For instance, Jones et al. (2010) showed that individuals who had either suffered from or had previous experience of stroke did not demonstrate improved stroke knowledge. This is surprising, as these individuals would be expected to read about the condition and make the necessary lifestyle changes in order to decrease their chances of a future event. Similarly, Bellolio et al. (2007) found that only 51% of patients who had previously suffered stroke realised that they were having another ischemic event when they presented to

A&E with stroke symptoms. Kothari et al. (1997) also found that 39% of patients who had suffered a stroke in the US were not familiar with any of the stroke signs or symptoms.

Weltermann et al. (2013) revealed a lack of stroke knowledge among patients with diabetes, who are also at higher risk of stroke. Affected patients in this study demonstrated a lack of knowledge in the symptomatology of stroke and were also unfamiliar with the necessary action in case of stroke.

Conversely, Williams et al. (1997) and Yoon et al. (2001a) showed that patients with a previous history of stroke and patients with heart disease, respectively, had increased stroke knowledge compared with their healthy peers.

5.5.1.8 Healthcare worker status

	Healthcare Worker	Sample Size	Mean	Std. Deviation	P-value
Knowledge Score	Yes	1103	1.14	0.434	0.000
	No	760	0.57	0.403	
Response Score	Yes	1103	1.39	0.379	0.000
	No	760	1.02	0.392	
Total	Yes	1103	1.26	0.375	0.000
	No	760	0.79	0.362	

Table 5.22: Comparison of Mean Scores of General Public vs Healthcare Workers

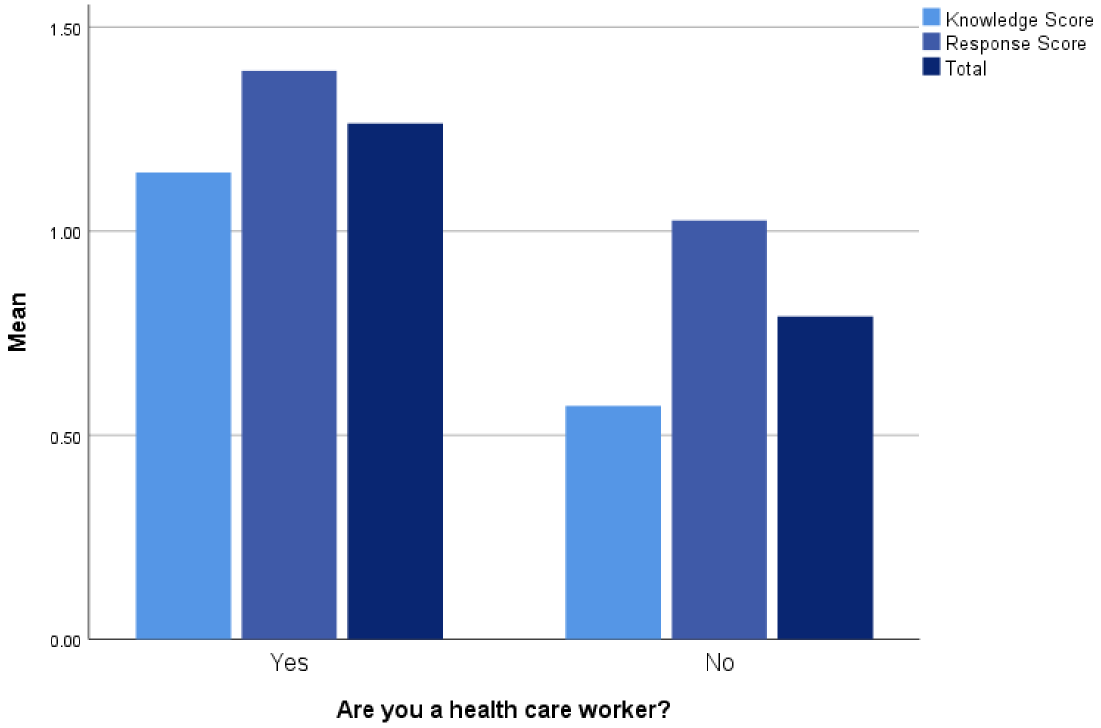


Figure 5.10: Clustered Column Chart of Mean Scores of General Public vs Healthcare Workers

Perhaps not surprisingly, participants who work in a healthcare setting were found to have better mean knowledge, mean response, and mean total scores. This correlation is significant, with all the three p values approximating 0. A marked difference in scores was observed for the Knowledge scores in particular, where healthcare workers achieved a mean score of 1.14 compared with non-healthcare workers, who only scored 0.57.

This correlation should, however, not be taken for granted. Sangeeta et al. (2013) found that only 56% of healthcare workers were familiar with the time window of intravenous thrombolysis. This finding has very serious implications. Healthcare workers are the people administering stroke treatment and unless they are familiar with its indications and contra-indications, they may be hesitant to administer it. Such hesitation in turn leads to in-hospital delay and a missed chance to administer emergent stroke treatment. Similarly, Harper (2007) and Kirchoff-Torres et al. (2011) identified serious deficits in stroke knowledge among emergency nurses. Park et al. (2015) showed that deficits in stroke knowledge among nurses was the primary cause of stroke mismanagement in nursing homes.

These findings highlight the importance of continuing medical education for all healthcare workers, particularly those working in emergency settings. Such initiatives have been shown to be effective in increasing stroke knowledge among healthcare workers (Kawano et al., 2014).

5.5.2 Correlation between knowledge and response

Spearman’s rho was calculated for the correlation between Knowledge and Response scores as the latter were both non-normalised data sets. The Spearman correlation coefficient measures the strength of the relationship between the knowledge and the response scores and ranges from −1 to 1. A correlation coefficient close to 1 demonstrates a strong positive relationship, a correlation coefficient close to −1 shows a strong negative relationship, and a correlation coefficient close to 0 indicates that there is no relationship.

The null hypothesis is accepted if the p-value is larger than the 0.05 level of significance and specifies that no relationship exists between the two variables. The alternative hypothesis, on the other hand, specifies that a significant relationship between the two variables is present and is accepted when the p-value is lower than the 0.05 criterion.

		Response Score
Knowledge Score	Correlation Coefficient	0.753
	P-value	0.000

Table 5.23: Spearman Correlations

The Spearman correlation coefficient (0.753) is positive and shows a strong positive relationship between the two variables. Moreover, this relationship is significant since the p-value (approximately 0) is less than the 0.05 level of significance. Hence, we can generalise that participants who have a high knowledge score also tend to achieve a high response score.

It is crucial, however, to understand that a high Response score does not necessarily translate into appropriate action in case of a stroke. Fussman et al. (2010) showed that better knowledge did not translate into appropriate action in the event of stroke. Similarly, Marx et al. (2008) demonstrated that an educational campaign failed to trigger the appropriate action in the event of a stroke.

Three main factors may cause a dissociation between knowledge and action. First, the affected individual may be physically or mentally unable to perform the necessary action following the onset of stroke. Second, certain patients may refrain from the correct action due to a number of perceived ‘barriers’. Finally, unless patients genuinely believe that they will benefit from the necessary actions, they may refrain from activating emergency services. The latter factor in addition to the process of health-seeking behaviour is dealt with in detail in ‘Health Promotion Theories and Models’ in Section 2.8.1. Action will also be determined by the perceived seriousness of the condition by the patient and his/her perceived control of the situation (Moser et al., 2007).

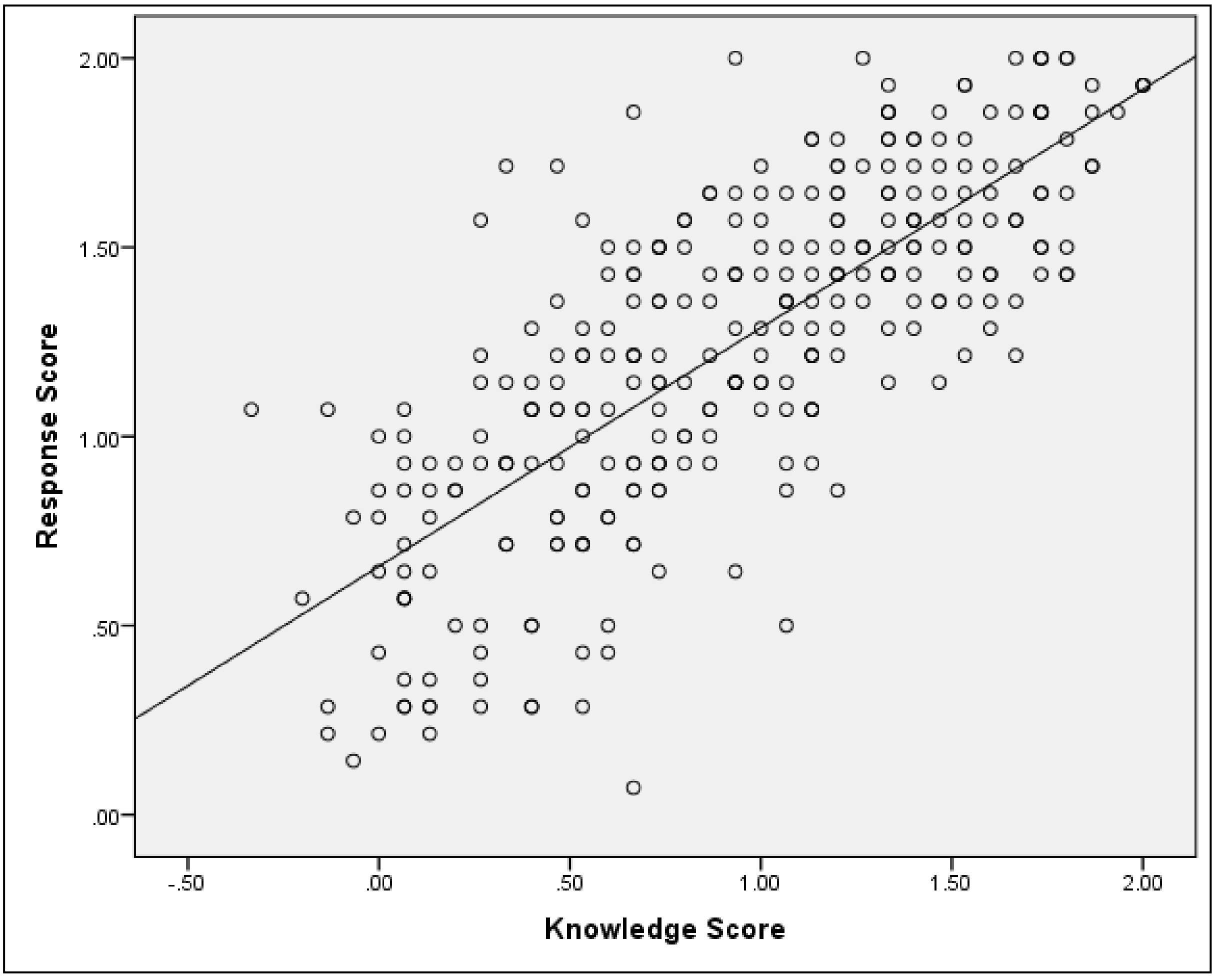


Figure 5.11: Scatter Plot of Response Score vs Knowledge Score

5.6 Conclusion

This chapter has dealt with the quantitative analysis of data collected following the distribution of the questionnaire. The required sample size was calculated in advance to ensure the possibility of generalisation of results. Hence, the findings and analyses regarding stroke knowledge and response, represented here, are reflective of the Maltese population in general.

As described in Chapter 3, the questionnaire was developed using qualitative data generated from the semi-structured interviews by the use of a matrix, which ensured transparency throughout the process.

The next chapter will further analyse and merge the findings presented in Chapters 4 and 5. It is suggested that this process of triangulation will further enhance the trustworthiness of this study and provide richer information about stroke in Malta.

Chapter 6 – General Discussion

6.1 Introduction

When reflecting on the qualitative and quantitative analysis of the data collected during the consecutive stages, a number of themes emerge that were worthy of further exploration in this penultimate chapter. Thus, the first part of the chapter involves a reflection on the main themes that emerged, particularly in cases where the quantitative findings contrasted with or corroborated the qualitative ones. Literature on the topic shall be interspersed in order to shed further light on these prominent issues. This general discussion consequently leads to the generation of recommendations, which are presented in the second part of the chapter.

6.2 Stroke knowledge variables in Malta

6.2.1 The link between increasing age and stroke knowledge

Increasing age is itself a risk factor for stroke, with cohort studies showing a mean age of 70 at stroke onset (Kissela et al., 2012). It is somewhat surprising, then, that the quantitative findings within the current study showed that the mean knowledge and response score decreased monotonically with increasing age (Table 5.14, Figure 5.5). These findings are similar to those reported in the review by Jones et al. (2010) which showed that stroke knowledge decreased with increasing age of participants. An indirect correlation between age and stroke knowledge was also demonstrated by Yoon et al. (2001a).

Stroke education should therefore focus on this elderly group, who may not only have decreased stroke knowledge but are also at increased risk of stroke. Unfortunately, this paradox was also observed when stroke knowledge was stratified according to the presence of risk factors for stroke. In this case, patients with no risk factors had better stroke knowledge compared with those having one or more risk factors (Table 5.21, Figure 5.9).

Additionally, Jurkowski et al. (2010) showed that elderly patients were less likely to call for help in case of a stroke, which may further aggravate pre-hospital delay. There may be several reasons for this finding, some of which have been described by participants in the qualitative stage of the current study. For instance, the patients in Cases 1–7 and 10 did not even realise that they were experiencing a stroke, and some were therefore surprised when their relatives attempted to call for help. Others, such as the patients in Cases 4 and 8, did not wish to make a big deal out of the symptoms or alarm others, and so decided to self-monitor and wait.

6.2.2 Link between academic education and stroke knowledge

In the current study, participants with a tertiary level of education were found to have higher stroke knowledge and response scores (Table 5.18, Figure 5.7). This is not surprising, since patients with a higher level of education are more likely to read about stroke and may also have better comprehension and retention of the information accessed. The wife of the patient in Case 1 in the qualitative part of the study represents a good example of this point since her eagerness to seek information and access medical literature prompted her to recognise her husband’s symptoms and take the right action. Although her level of academic education was not revealed, it was clearly higher than that of some of the other interviewees, who admitted that they were illiterate. Pancioli et al. (1998) and Marx et al. (2010) both showed a direct relationship between level of education and stroke knowledge. People with poor literacy may also struggle to understand and remember the messages conveyed by health educational campaigns. In fact, Williams et al. (1998) showed that poor literacy was responsible for limited efficacy in a number of campaigns.

6.2.3 The link between income and stroke knowledge

Yearly income and the level of education within a population have been shown to be directly correlated (Porter, 2014). A direct correlation between income and stroke knowledge could therefore be expected. In fact, the current study showed that stroke knowledge increased monotonically with an increase in annual income (Table 5.19, Figure 5.8). This finding was echoed in the study by Yoon et al. (2001a), which demonstrated a positive correlation between a higher salary and stroke knowledge. This correlation was independent on other demographic and social variables and was therefore attributed solely to the participants' salaries.

6.2.4 Risk factors and stroke knowledge

Sub-group analysis within the current study showed that participants with a single or multiple risk factors had reduced stroke knowledge compared with their peers (Table 5.21, Figure 5.9). One non-modifiable risk factor for stroke is a previous history of stroke or TIA. History of the latter failed to increase stroke knowledge in previously affected individuals. This finding was also encountered in the qualitative side of the study – for instance, although the patient in Case 2 had experienced a stroke previously, he and his wife both failed to recognise the symptoms and take the right action when stroke was re-experienced. Similarly, the patient in case 9, who had suffered from four previous TIAs/strokes failed to demonstrate improved stroke knowledge.

People with modifiable risk factors (such as smoking and hypertension) were found to have poorer stroke and response knowledge compared with their peers. This finding is particularly concerning, as this subset of the population is at a higher risk of stroke. Deficiency in stroke knowledge in at-risk individuals is well documented, as shown in previous studies including those by Jones et al. (2010) and Bellolio et al. (2007). This finding contrasts to other studies where stroke knowledge was better within the at-risk group (Gupta & Thomas, 2002; Pancioli et al., 1997; Schneider et al., 2003).

6.2.5 Healthcare workers and stroke knowledge

Stroke knowledge scores were found to be higher among healthcare workers compared with the general public (Table 5.22, Figure 5.10). This is to be expected, as most of these workers would have been exposed to stroke education during their studies. Furthermore, they may potentially have worked with patients presenting with or being treated for stroke. This positive correlation should not be taken for granted, however. In a study by Sangeeta et al. (2013), only 56% of healthcare workers were familiar with the time window for intravenous thrombolysis. Similarly, the current study showed how a misdiagnosis or delayed diagnosis by a GP could have serious long-term implications. Such a scenario was described in Cases 4 and 5 in the qualitative part of the study, where it was evident that inappropriate action by the GP led to delays in treatment delivery. Since healthcare workers remain the first point of reference in cases of stroke, it is crucial that they are familiar with the symptomatology, recommended action, and latest guidelines for stroke. This topic is further discussed in Section 6.6.2.5.

6.3 Link between knowledge and response

As described in the Methodology chapter, the questionnaire generated separate scores for stroke knowledge and stroke response for each participant. A strong positive correlation (Spearman correlation coefficient = 0.753) was found between stroke knowledge and response, and the relationship was significant (p-value approximately 0). Hence, we can generalise that Maltese participants who had a high knowledge score also achieved a high response score (Figure 5.11).

However, several authors including Marx et al. (2008b) and Fussman et al. (2010) have shown that increased stroke knowledge does not necessarily translate into appropriate action in case of a stroke. Thus, the patient's action might not be modified, even if a stroke educational campaign proves to be successful in improving stroke knowledge (Ho et al., 1989). Similarly, Cheung (2000), Becker et al. (2001), and Carroll et al. (2004) failed to demonstrate a direct correlation between stroke knowledge and hospital arrival time. One of the reasons for this observation, as described in Section 2.4.3.2, may be that certain beliefs and 'barriers' can overcome any gains achieved during educational campaigns. Thus, certain individuals will attempt to avoid admission to hospital at all costs, as seen with the patient in Case 2. A multitude of social and cultural aspects may apply when a patient is faced with an acute condition. Similarly, the patient in Case 8 decided to wait and to not alarm her relatives, even though she knew that she had suffered a stroke. In fact, she was prepared to put her relatives before her own wellbeing.

Such scenarios are concerning, as the ultimate goal of stroke educational campaigns is to reduce pre-hospital delay and therefore improve stroke outcome.

However, an improvement in stroke response cannot be achieved without education. In fact, knowledge and awareness are pre-requisites for a change in behaviour (Prochaska et al., 2008). Additionally, education may help to overcome certain barriers and may promote the appropriate response by demonstrating the advantages of early appropriate action. This issue has been discussed extensively in the section on health models and theories (2.8.1), and is further discussed in Section 6.7.

Another aspect that emerged during the interviews was the behaviour exhibited by patients when faced with minor stroke symptoms. Such symptoms are not only difficult to correlate to stroke but are routinely overlooked by patients, as they are perceived as not being severe. Another important aspect that emerged during the qualitative phase of the study was that although some patients/bystanders were familiar with certain signs and symptoms of stroke, they failed to recognise stroke in the acute situation. Patients and bystanders alike may attribute signs and symptoms to other conditions than stroke. Sometimes they may even have a sense of disbelief and may struggle to accept the fact that they or their relatives may be affected by stroke. Bystanders may not notice certain symptoms – such as numbness – unless the affected patient discloses the symptom. Additionally, the anxiety faced by patients and relatives during such an acute event should be considered, and one can therefore easily understand how stroke response may be affected.

6.4 The adaptation of health promotion theories and models in stroke

A number of health promotion theories can be directly or indirectly applied to behaviour in relation to stroke, both in the acute phase as well as during rehabilitation and the patient's return to the community. The action taken after a stroke is highly complex and is not only dependent on one's knowledge of the subject but is also influenced by a number of psychological processes as well as social and cultural barriers. The use of such theories and models facilitates an understanding of such complex decision making and may also clarify how the effectiveness of stroke education can be increased. These aspects of health behaviour emerged in the literature review and were also encountered throughout the qualitative phase of this study.

6.4.1 Feeling of helplessness

A common feeling that emerged from the interviews with stroke sufferers was that of helplessness. These feelings were particularly prominent during the interview with the individual in case 5. This may be expected, as these patients have experienced devastating physical and psychological stressors with potential long-term sequelae. Such feelings may also deter a patient from taking appropriate action in the event of another stroke. This finding is better understood in the context of the 'Theory of Planned Behaviour' (Ajzen, 1985), which demonstrates how behavioural intent is dependent on an individual's perceived control of the situation, meaning that adequate stroke knowledge may not be sufficient in these instances as action will ultimately be determined by the patient's behaviour. It also highlights the importance of showing how stroke may be treated, particularly in the acute phase. The feeling of helplessness may be less prominent if affected individuals believe that something can be done to ameliorate their condition. In fact, behaviour may be affected by the perceived outcomes or consequences of actions taken as outlined in the Theory of Reasoned Action (Fishbein, 1975).

6.4.2 Stressing the benefits of treatment

Following their study, Morgenstern et al. (2007) concluded that "rather than fear, encouragement and motivation in the form of improved outcome expectations were key" to that intervention's success. Unless affected individuals truly believe that something can be done about their condition, it is highly unlikely that they would take the desired stroke action. On the other hand, patients/bystanders who are aware of potential stroke treatment are less likely to feel helpless and therefore more likely to alert emergency services. In the qualitative stage of the study, this was evident in the first case – during this scenario, the relative's previous knowledge gave her the insight and confidence required to take the right action since she was well aware of the potential benefits of treatment. In contrast, in Case 4, lack of knowledge regarding stroke and its treatment led to a long delay in activating emergency services. Thus, it may be necessary (as with stroke knowledge in general) to also educate the population regarding the benefits of stroke treatment on a regular basis. This is not only necessary to refresh one's memory, but also to reach people passing through different 'stages of change' as described by Prochaska et al. (1992).

6.5 Reasons for an inappropriate stroke response

6.5.1 Anxiety

Suffering from a stroke can be quite a stressful experience, especially so when the patient is aware of the seriousness of the situation and has just experienced devastating immediate effects such as aphasia or hemiparesis. Most patients will therefore suffer from anxiety during the onset of stroke and also as a long-term aftereffect. In fact, McCoy (2006) found that 31% of stroke patients had post-traumatic stress disorder (PTSD) at one year following stroke onset.

Anxiety during stroke onset may impair one's ability to think rationally and elicit the appropriate action. For instance, in Case 1 of the qualitative stage of the current study, the wife of the patient called her daughter instead of the ambulance as she could not remember the emergency telephone number in her anxiety.

Anxiety also has a crucial role in help-seeking behaviour. In fact, Mandelzweig et al. (2006) showed that high anxiety levels in stroke patients led to a decreased intent to seek immediate medical help.

6.5.2 Lack of insight

One of the main reasons behind delays in stroke treatment is failure by the patient to recognise that he or she is suffering from a stroke. This may happen when a patient fails to recognise the importance and relevance of certain signs and symptoms. Depending on which part of the brain is affected by the stroke, there are certain instances in which the patient may be completely unaware of his or her situation. This lack of insight emerged in a number of cases during the semi-structured interviews. For instance, in Case 1, the patient presented with an acute paralysis of half of his body yet offered to walk to the ambulance himself as opposed to being transferred by stretcher. The patient was unable to walk on his own at that time, but was completely unaware of his current situation. This fact is particularly concerning, as an affected individual does not understand that he or she lacks the physical and mental capability to perform routine actions. Similarly, during the acute onset of stroke, the patient in case 6 was not aware of what was happening to him and only woke up to find himself in hospital. Thus, stroke patients may suffer from accidental falls or be involved in motor vehicle accidents. A lack of insight will almost certainly compromise an appropriate stroke action. In fact, failure to recognise the seriousness of an individual’s situation was the main reason for delayed arrival to hospital in a study by Williams et al. (1997). This finding may be explained by considering one of the core constructs of the ‘Health Belief Model’, namely ‘perceived severity’ (Rosenstock, 1966). Unless a patient is aware of his or her imminent risk to well-being, it is highly unlikely that he or she would alert emergency health services.

6.5.3 Failure to recognise stroke symptoms

A common phenomenon displayed by both patients and doctors is the failure to recognise the symptoms of stroke and may simply result from a lack of stroke knowledge and therefore an inherent inability to associate certain signs and symptoms with stroke. The second major problem is the difficulty associated with minor or subtle symptoms or other non-specific symptoms (such as headaches) which are not readily attributable solely to stroke. This situation was encountered twice during the semi-structured interviews, with vertigo attributed to other conditions in favour of stroke (Cases 4 and 5). Das et al. (2007) showed how “minor symptoms like headache, dizziness or unilateral numbness” were not readily associated with stroke.

Such a failure may have devastating consequences and may compromise the delivery of acute stroke treatment. Again, this highlights the importance of continued stroke education, particularly for GPs, who are often contacted by their patients with such complaints.

6.5.4 Significant others

It was evident during the semi-structured interviews that despite suffering from a very serious condition, stroke patients considered the wishes and well-being of others before taking any action. This is probably more prominent in the local setting, where the family retains a strong cultural significance. It was clear that stroke patients would not want to upset their relatives by rushing into decisions without their consent. It was also obvious that in certain instances, patients were looking for support/approval for their actions. This was also apparent within the patient–GP relationship. In fact, the patients in Cases 2 and 4 refused to go to hospital without the approval of their GP. This indicates that some patients were willing to place trust in and loyalty to their GP ahead of their well-being.

Similarly, the patient in Case 8 who realised that she was suffering from a stroke refused to take immediate action so as not to spoil her family's outing. This type of sacrificing attitude again shows that certain values are still extremely prominent in the local scenario and may sometimes represent potential barriers to action.

6.6 Recommendations

6.6.1 Research

6.6.1.1 Local research and record keeping

Following an intensive literature search, it became apparent that stroke in Malta is under-studied. The majority of local data have been gathered and published by the World Health Organization and the European Stroke Association. This is unfortunate, as the local scenario is crucial to understanding the aetiology, response, and outcome of stroke.

Thus, the importance of data gathering and the publication of stroke-related research in the local setting is clear, as it will shed light on current local practices as well as being crucial to the auditing of different aspects of this important healthcare issue.

An up-to-date stroke register should also be maintained. "Organised services are vital to reduce the burden of stroke, and stroke registers are recognised as an invaluable tool in planning and monitoring the performance of stroke services" (Brunyee, Bamford, Wardman, & Fear, 2000). This is of utmost importance for assessing the incidence and prevalence of the disease in Malta as well as for offering a demographic stratification of the disease. Such data also allow more accurate outcome assessment and facilitate the long-term follow-up of stroke patients.

6.6.1.2 Importance of stroke questionnaire

Following an extensive literature review, it was immediately apparent that the majority of stroke knowledge questionnaires had been developed for the purpose of a particular trial and were rarely used in other populations.

The questionnaire used in the current study has been informed by in-depth qualitative interviews and was validated prior to use. Thus, it may be easily deployed again within the Maltese population to interrogate any temporal trends in stroke knowledge and response. The use of a standard questionnaire makes data analysis and interpretation much easier and more reliable. To this extent, Sudlow and Warlow (1996) stress that “comparisons are only meaningful if they are based on studies that use similar definitions, methods, and data presentation”. Direct comparisons with previous local studies were in fact limited as different methodologies and questionnaires had been used.

Another issue that surfaced during the literature review was the difficulty in comparing stroke knowledge between different countries as published studies of such knowledge utilised different questions. Although the questionnaire was developed with consideration to the social and cultural aspects of the Maltese population, it could also be utilised (following minor alterations) across different populations abroad. This may permit interesting comparisons between different geographical and ethnical populations.

6.6.2 Stroke education in Malta

It is justifiable to say that stroke education in Malta is insufficient. There has never been a national campaign to address stroke symptomatology and the necessary action needed in such instances. Mass media adverts are virtually non-existent locally. This contrasts with the massive 'Act FAST' campaign launched in the UK in recent years, which included regular TV adverts, educational leaflets, billboards, and several other adverts on ambulances and in hospitals.

Formal education about stroke is not incorporated in the Maltese school curricula, including those pertaining to science subjects. The only exposure to stroke education is through sporadic television or radio programmes in which stroke experts have the opportunity to discuss certain aspects of stroke and answer questions. Unfortunately, this does not follow a specific educational programme, meaning that important information related to stroke education may be completely ignored.

This situation contrasts with other medical campaigns in Malta such as the breast cancer campaign and campaigns regarding heart disease. For example, an entire month is dedicated to the former, during which social activities, mass media adverts, and billboards raise awareness of breast cancer during 'Pink October'.

World Stroke day has only recently been recognised locally, meaning that at least a number of local news stories (followed by a large number of Maltese people) are dedicated to stroke on the 29th of October each year.

Although – as described in previous chapters – there have been massive financial investments in the treatment of stroke in Malta (including the installation of a dedicated neuro-interventional angiosuite, the introduction of a stroke unit, and a new stroke rehabilitation unit), focusing on prevention and stroke education is probably as important.

The role of a stroke nurse has also been recently introduced at the main acute hospital. Although stroke education (both in hospitals as well as in the community) is within his or her portfolio, the stroke nurse is frequently overwhelmed due to the fact that he or she has to attend to a large number of stroke admissions. As discussed during the qualitative stage of the study (Chapter 4), stroke education remains severely lacking and is not standardised, even during the hospital stay.

6.6.2.1 Symptom knowledge

There is a significant discrepancy in stroke symptom knowledge between healthcare workers and the general public, who scored 82.5% and 58.6%, respectively, in the total symptom score in this study. The general public group scored less in each of the knowledge questions (K1–K17) compared with the healthcare worker group. This finding is perhaps not unexpected, since healthcare workers have been educated about stroke and deal with stroke cases on a daily basis. It was quite encouraging to note that 99.3% and 94.1% of healthcare workers knew that stroke could affect speech and muscle power, respectively. This group performed worse on the question regarding sensory symptoms, as only 77.0% of participants chose the correct answer. This could be due to the fact that sensation is not included in the 'FAST' acronym, and also because sensory loss is a less obvious sign. It was also encouraging to see that healthcare workers performed well in terms of less obvious symptoms, namely vision loss (89.0%) and headaches (86.3%). In spite of this, two stroke sufferers who participated in the semi-structured interviews experienced a misdiagnosis or a delayed diagnosis by their GP. Thus, although these scores are promising, the outcome can be devastating when a healthcare worker fails to recognise stroke symptoms.

Both sub-groups performed worst in question K13, which investigated whether a stroke could be clinically silent. Only 57.7% and 32.3% of healthcare workers and the general public, respectively, knew that a stroke could be completely asymptomatic.

The general public was mostly familiar with disorders of speech (93.3%) and muscle weakness (78.4%) as potential indicators of stroke. A lower percentage of the general public cohort knew the other symptoms of stroke, namely vision loss (64.6%), altered sensation (49.2), and headaches (59.2%). Similar findings were found by Das et al. (2007), who reported that most people did not readily associate 'minor symptoms' with stroke and were less likely to seek medical assistance if they experienced such symptoms. This may be explained by the phenomenon of perceived severity of their symptoms and the severity of one's situation, as explained in the Health Belief Model (Rosenstock, 1966). In fact, an affected patient may completely ignore headaches or altered sensation as he or she might feel that such symptoms are tolerable. Among the Maltese public, 63.8% could relate muscle weakness or numbness to stroke. This percentage is much higher than that found by Caruana et al. (2013), who showed that only 43% of individuals could make such an association when they investigated public stroke knowledge in Malta. This discrepancy could be secondary to certain biases in the studies but may also reflect an improvement in local knowledge over time. This temporal trend was also found by Kleindorfer et al. (2009), who demonstrated that stroke knowledge improved steadily over a 10-year period within the same population.

Another interesting finding was that 66.7% of the general public would incorrectly expect to experience chest pain during stroke onset. This situation may be somewhat misleading, and may result in pre-hospital delays.

It was also interesting to note that the options ‘strongly agree’ and ‘strongly disagree’ were rarely chosen by the general public compared with healthcare workers throughout the questionnaire, indicating a lack of confidence in the answers of the former group.

Education regarding stroke symptomatology is crucial, as the recognition of these symptoms is necessary to trigger an appropriate response. As shown previously, repeated exposure and education regarding these symptoms is necessary for both the general public and healthcare workers. The current data highlight the need to focus more on symptoms that are perceived to be less severe or less characteristic of stroke.

6.6.2.2 Time window for treatment

Acute stroke treatment is limited by a time-window, that is, the time between the onset of stroke and presentation to hospital. As discussed previously in more detail, there are two types of treatment that may be provided in the acute setting, namely intravenous thrombolysis and mechanical thrombectomy. The former has a time window of 4.5 hours, as established following the ECASS 3 trial, after which this treatment was found to be potentially deleterious (Hacke et al., 2008). Following the recent DAWN (Nogueira et al., 2018) and DEFUSE-3 (Albers et al., 2018) trials, the time window for mechanical thrombectomy has been extended to up to 24 hours if imaging results meet certain criteria.

Unfortunately, although this extended time window means that more patients may benefit from this procedure, there is a real risk that both patients and doctors may procrastinate when considering this treatment option. It is well established that the quicker the treatment is provided, the better the expected clinical outcome. In fact “Time Is Brain—Quantified” estimated that 1.9 million neurons are permanently lost every minute following a stroke (Saver, 2006). Hence, although the treatment window for mechanical thrombectomy has been extended, pre- and in-hospital delays can still have severe implications.

It is crucial that both the general public and emergency physicians are aware of the available treatments and that such treatments are especially effective if administered early on. Unless a stroke sufferer is aware that something may be done in the acute phase, it is very unlikely that he or she will activate emergency services. This forms the bases of the “Theory of Reasoned Action” (Fishbein 1975), which states that people’s attitudes are affected by the perceived outcome of their behaviour. Similarly, physicians need to treat stroke patients as priority cases and should follow hospital guidelines to avoid unnecessary delays. It is also their obligation to keep abreast of treatment advances and updates to stroke guidelines.

6.6.2.3 Use of different modes of education

It became apparent during the semi-structured interviews that different individuals have different preferences when it comes to receiving stroke education. The literature search revealed a whole spectrum of methods that have been employed as a medium to stroke education. These included grassroots approaches, formal education (Section 2.6.10), audio-visual methods including mass media campaigns, and the exploitation of strategic locations (Section 2.6.9). It also highlighted the importance of tailoring education according to local social and cultural factors (Section 2.6.2).

In fact, certain successful programmes such as ‘Know Stroke in the Community’ (Emr, 2006) paid particular attention to cultural sensitivities and specifically asked participants about cultural appropriateness. Similarly, Boden-Albala et al. (2010) declared that “traditional information pamphlets along with public ad campaign demonstrate suboptimal success possibly due to inadequate attention to health literacy or cultural tailoring”. The authors devised a stroke educational programme culturally tailored to the target population which included the use of bilingual material and videos produced in familiar surroundings.

The current study attempted not only to explore lacunae related to stroke knowledge and needs but also to determine how certain demographic and social aspects correlate with such needs. This undertaking may be crucial when planning a national stroke educational campaign or when limited resources need to be focused on tackling such lacunae. As discussed previously, stroke knowledge (and lack of it) in Malta has been shown to echo that found in the literature, thus highlighting the necessity of urgent stroke education.

It was evident that the majority of stroke patients would prefer audio-visual aids to increase their stroke knowledge. Apart from being more appealing to the lay person, video interventions have previously been shown to be highly effective media types in health education and could also potentially influence behaviour (O'Donnell et al., 1995). Feigin (2007), Chan et al. (2008a), and He et al. (2014) have all demonstrated the effectiveness of video-based stroke educational campaigns.

Mass media communications are trusted by viewers and have proven to be a very effective means of community education. Several campaigns, including those by Becker et al. (2001), Silver et al. (2003), and Marx et al. (2008), have been shown to be successful in improving public stroke knowledge. When devising such campaigns, care is required to present accurate scientific content in a way that is attractive to the target audience (Miyamatsu et al., 2012). This requirement is crucial in terms of the cost-effectiveness of a campaign. In fact, the main drawback of such campaigns are their huge financial implications (Hodgson et al., 2007).

Stroke education is not included in any of the school curricula in Malta. KIDS (Morgenstern et al., 2007) utilised a formal curriculum spread over 3 years which taught children about stroke symptomatology and the necessary emergent action. Apart from formal teaching, the curriculum included role-play, audio-visual motivational messages, the launch of an interactive website, and the production of a stroke advert. Such activities may serve to encourage children to participate and learn more while ensuring that they get involved. Another aspect of school education is the ability to utilise children as educators because children can share their knowledge with the rest of their family, meaning that the target population of such an educational intervention would increase drastically. A similar approach was found to be effective in ‘Hip Hop Stroke’, which was designed for students in the fourth and fifth grades. Furthermore, an undergraduate curriculum in stroke education has been developed and introduced in the Philippines (Navarro et al., 2013), followed by the launch of a Master’s programme in 2003. Although the introduction of a dedicated stroke module in schools in Malta may be unrealistic due to an already full curriculum, stroke awareness and knowledge could be included in the basic sciences.

Less formal teaching about stroke has also been shown to be effective. This is especially so when educational strategies exploit strategic locations. The latter also allows a degree of flexibility so as to consider/incorporate cultural and social aspects of the population in question. Such fine-tuning may not only be more appealing but may also be more cost-effective. For instance, Kleindorfer et al. (2008) targeted beauty shops and successfully taught beauticians to ‘educate’ their clients about stroke. Beauticians could also hand out information brochures to their clients.

A strategic location in Malta could include churches, where a large number of Maltese people regularly attend Sunday mass. This would follow the same practice as described by Zahuranec et al. (2008), who explored the feasibility of a church-based stroke educational campaign. Similarly, Tadros et al. (2009) and Fogle et al. (2010) targeted churches and pharmacies. The advantage of this type of campaign is that it not only reaches a large number of the general public but does so when individuals are relaxed and more likely to engage in stroke education.

Another site where stroke education is likely to be highly effective is the waiting area of the emergency department and GP practices. Such programmes may target chronically ill patients who are at a higher risk of stroke. Similar approaches were successfully employed by Chan et al. (2008b) and He et al. (2014).

Another successful strategy employed by Inoue et al. (2015) was the distribution of flyers to cash points in supermarkets. Individuals queuing at cash points are likely to notice and read through such flyers. Again, cultural aspects were given the utmost importance in this campaign and the flyer was written in the local dialect "to attract attention, facilitate understanding, and psychologically imprint the process of calling EMS".

Apart from developing and distributing leaflets about stroke, there are more indirect methods available to deliver stroke education. These include the use of children's literature (Butler, 2007), comic books, and cartoons (Ohyama et al., 2015; Sakamoto et al., 2014; Shigehatake et al., 2014). Such strategies have been shown to successfully improve stroke knowledge, both immediately after the intervention and during follow up. Additionally, these methods of education have been shown to be more interactive and enjoyable, particularly for children. Other methods of alternative teaching include games. Again, these may prove to be more engaging to participants as opposed to standard methods of education. Another advantage of game-based education is that it allows for immediate feedback (Henry, 1997). Telner et al. (2010) and Williams et al. (2014) have used this approach to educate adults and children, respectively, about stroke. Apart from being an effective teaching method, game-based education has also been found to provide a more satisfying learning experience (Telner et al., 2010).

Music has also been shown to be an effective method of stroke education. 'Hip Hop Stroke' (Williams & Noble, 2008) showed how music and catchy phrases improved stroke knowledge and response.

Regardless of the strategy used, the most effective campaigns have focused on two aspects of behaviour modification: stroke prevention and stroke preparedness (Boden-Albala & Quarles, 2013).

6.6.2.4 Bystanders/significant others

Wein et al. (2000) found that 95% of emergency stroke calls were made by relatives or bystanders and not by the affected patients. As previously described, there are several reasons underlying this fact. Patients may not recognise the stroke signs/symptoms themselves or may not have the physical ability to do so. Another important barrier to making the emergency call is a socio-cultural one, whereby patients would prefer to wait and check whether their symptoms improve over time. This highlights the importance of bystanders in recognising stroke and in activating an emergency response without unnecessary delay. As discussed previously, such prompt action may save precious time and ultimately improve the long-term outcome of the affected individual.

Bystanders are typically non-healthcare workers and their knowledge regarding stroke and the necessary action thus reflects that of the general public.

Lack of knowledge has been shown to be the main contributor to pre-hospital delay in stroke treatment (Evenson et al., 2001; Yoon et al., 2001b). This further highlights the importance of educating the general public as opposed to limiting stroke education to people at risk.

6.6.2.5 Education

As indicated by the qualitative findings, there is a dire need to incorporate stroke knowledge within undergraduate and postgraduate healthcare courses.

Existing curricula and teaching material within such courses need to be revised and updated to reflect recent changes in stroke management. As described in Chapter 2, the treatment of stroke has changed dramatically in the last two decades with several treatment options becoming available for the acute phase of the disease. Stroke guidelines keep changing regularly and it is crucial that students are presented with the latest data and stroke pathways. This will ensure that unnecessary delays are prevented and may potentially result in improved patient outcomes.

However, it may not be enough for potential healthcare workers to be knowledgeable about stroke symptomatology as it is important for such students to receive training on how to educate the general public and engage in health promotion efforts. A review of healthcare courses offered by the University of Malta, such as those hosted by the Faculty of Health Sciences, Faculty of Medicine and Surgery and Faculty for Social Wellbeing shows that some of the courses feature a study unit regarding Health Promotion. Unfortunately, not all the courses on offer include this study unit and those which do, do not seem to have a consistent and uniform structure of how Health Promotion is taught. One recommendation would be to introduce a core Health Promotion study unit that is co-ordinated by one group of academics and that is compulsory within all undergraduate and postgraduate healthcare courses. Importantly, such a study unit would need to be based on a hands-on, pragmatic approach with assessments that include field-based projects rather than examinations or assignments that test theoretical knowledge only. Part of this study unit would be subject specific so as to target the main public health challenges in the 21st century, with stroke being one of them. This recommendation shall be actualised by presenting these research findings to the academic body at the University of Malta against a background of the severe socioeconomic consequences attributed to stroke in Malta and on a European level.

Although the stroke knowledge of healthcare workers was found in this study to be ‘adequate’, particularly for recognising signs and symptoms, the semi-structured interviews highlighted that a delayed diagnosis by a GP could lead to crucial delays. Repeated stroke education for GPs is necessary, not only to refresh knowledge but also to keep abreast with advances in the field. As previously discussed, international guidelines and recommendations are updated on a regular basis and it is very important for GPs to be aware of these changes. In fact, GPs may still be the first point of reference for their patients in cases of stroke. This finding can probably be explained by the fact that most patients have built trust in their GP and may often have a sense of loyalty towards him or her, as observed during the interviews conducted in this study. Morovic et al. (2012) stated that it is an 'ethical obligation' for all healthcare workers to keep themselves abreast of medical advances. Similarly, Carter et al. (2009) stressed the importance for medics to "keep up in a constantly changing knowledge based environment". The 'Temple Foundation Stroke Project' targeted physicians and paramedics (Morgenstern et al., 2002) and aimed at improving their stroke identification skills. It also updated these healthcare workers regarding stroke guidelines. These interventions led to a decrease in pre-hospital delays within the same community.

6.6.2.6 Consistent education package

Following the semi-structured interviews with stroke patients, it became apparent that no standard education package is provided during the acute phase or upon discharge from hospital. As discussed previously, a dedicated stroke outreach service is not currently available and therefore the only opportunity to educate these at-risk patients is during acute admission or at outpatient follow-up appointments. The latter are often over-booked, and the medical consultants inevitably focus on the medical issues experienced by patients while sacrificing prevention education. This issue could be addressed through the appointment of preventive medicine specialists whose role would be to advise and educate stroke patients (and their families) regarding risk factors, aetiology, and necessary response to stroke.

Patients often tend to postpone lifestyle changes following a stroke and provide a number of excuses for doing so, including personal-, family-, and work-related issues. These issues seem to be given priority over the prevention of another stroke in the future. Education therefore needs to start at the bedside during admission and should focus on the potential risks that can arise unless lifestyle modifications are embraced. As explained previously, several effective approaches may be employed, including efforts to increase patient motivation, the use of positive re-enforcement, and information on how long-term outcomes may be effectively improved.

Two aspects of stroke education emerge here. First, there is a need for a standard educational package which all patients are exposed to. This ensures that all patients will receive the same exposure, even if admitted under the care of different consultants. Such a package would need to be updated regularly to follow aspects emerging from stroke studies and to reflect updates to international guidelines. Second, dedicated personnel (such as stroke nurses) should ideally deliver these packages and regularly educate patients during their hospital stay. Patients often build a sense of trust in these professionals, meaning that they may be more effective in conveying educational messages.

6.6.2.7 Follow-up on education

Another important aspect of stroke education is the need for repeated exposure. Otherwise, the benefit of successful campaigns would likely last for only a couple of months. “The ultimate test of an educational intervention is the sustainability of the effect after the intervention ceases” (Morgenstern et al., 2003). This approach was successfully utilised by Tadros et al. (2009), who concluded that “staggered, repeated exposure to a message prevents memory decay and thus enhances long term retention of the message”. Similar findings have emerged from the study carried out by Hodgson et al. (2007), who showed that continuous advertising was not only necessary to increase stroke knowledge but also to sustain stroke awareness.

6.6.2.8 Need for local campaigns

As highlighted during the semi-structured interviews, stroke education in Malta has been limited to date, both for the general population as well as in the hospital setting. Most of the patients interviewed had never been exposed to stroke education before their acute admission.

A national stroke campaign has never been launched in Malta, despite the introduction of new stroke treatments to the island in the past decade. A huge investment by the government has also seen the installation of a new biplane angiosuite and the opening of a stroke unit. This contrasts with the lack of educational efforts aimed at reducing the risk and long-term effects of stroke in the community.

Although several national campaigns have been launched globally, none are specific to the Maltese context, and these campaigns cannot be simply modified for local use. First, a national campaign would ideally be in the Maltese language to reach even the minority of the general population who do not speak English. The campaign should also consider the specific social and cultural aspects of the local scenario. For example, the ways stroke education is delivered should reflect the lacunae identified from studies such as this one. As described in previous sections, a campaign that considers such aspects is more likely to be cost-effective. Although stroke education campaigns may seem excessively expensive to run, stroke often represents a huge financial and strategical burden on the health services budget. For example, it is estimated that “the treatment of and productivity loss arising from stroke results in total societal costs of £8.9 billion a year, with treatment costs accounting for approximately 5% of total UK NHS costs” (Saka, McGuire, & Wolfe, 2009). More timely and effective treatment, which is the ultimate goal of stroke education campaigns, may therefore not only reduce patient morbidity but also address these financial implications.

6.6.3 Post-stroke care

6.6.3.1 Lifestyle changes

Stroke patients are at a significantly higher risk of a second stroke compared with their peers, and especially so during the first year following the initial event. This is particularly true if the affected person fails to make certain lifestyle changes and fails to adhere to his or her medical regime. As discussed previously, in Chapter 4, lifestyle changes are not necessarily straightforward and often require significant motivation. It is crucial that patients understand the importance and potential benefits of such changes. Specifically, the individual needs to be aware of the sensitivity and susceptibility of his or her situation (Rosenstock, 1966).

Lifestyle changes need to be emphasised during the acute admission but also periodically following discharge form hospital. A patient's willingness to alter a health-related behaviour changes over time, as described in the stages of change within the 'Transtheoretical Model' (Prochaska et al., 1992). A community-based service should therefore be introduced whereby these patients are monitored and offered help should the need arise. Such help may include psychological support, advice on the necessary lifestyle changes, and a helpline through which patients may get their questions answered.

Ideally, the stroke nurse who has followed the patient's recovery should also continue supporting his or her needs in the community. During such visits, positive reinforcement methods should be employed to encourage the required behavioural alterations. Affected individuals should also be referred to support groups, which are proven to be effective for addressing certain bad habits (for example, smoking cessation).

Healthcare workers may tend to focus on medical treatment during the acute phase, meaning that lifestyle changes may be overlooked.

6.6.3.2 Motivation following stroke

The attitudes and beliefs of stroke patients are pivotal when it comes to rehabilitation. Maclean, Pound, Wolfe, and Rudd (2000) found significant differences in beliefs between stroke patients who had low versus high motivation for rehabilitation:

"Information from professionals about rehabilitation, favourable comparisons with other stroke patients, and the desire to leave hospital had a positive effect on motivation. Conversely, overprotection from family members and professionals, lack of information or the receipt of "mixed messages" from professionals, and unfavourable comparisons with other patients had a negative effect" (Maclean et al., 2000).

Again, this highlights the role of healthcare professionals in the holistic treatment of stroke. Information provided to patients needs to be consistent, evidence-based, and delivered in a way that patients can clearly understand. Once again, this emphasises the need for specialist stroke nurses who can follow stroke patients more closely, educate, and discuss any queries that patients may have. A potential flaw in the local setting is that stroke rehabilitation (following acute hospital admission) occurs in a different hospital than the setting to which patients are admitted under the care of a different consultant. This transfer of care may result in certain lacunae (predominantly educational) which are never dealt with, as the second consultant might assume that they had been previously dealt with in the acute setting. Such mishaps may be avoided if a stroke nurse follows the same patient throughout his or her recovery process until discharge.

Healthcare professionals themselves need to trust in the patient's ability to improve and gain a degree of function after a stroke. "Their behaviour can positively and negatively affect motivation" (Maclean et al., 2000).

This study also highlights the importance of patient motivation in rehabilitation, which may be stimulated by role models. Patients who make a good recovery may be highly influential to others who are still undergoing rehabilitation. Such motivational stimuli can mould behaviour, as described in the 'Social Learning Theory' (Bandura, 1963). As discussed previously, role models may also determine the initial response to stroke by patients and bystanders alike.

6.6.3.3 Psychological support to patients

Stroke may have devastating psychological effects. It is easy to understand how a previously independent person who has permanently lost his or her dependency, literally in a couple of seconds, may go through a complex and often lengthy psychological process. In fact, up to 31% of stroke patients will develop clinical depression within 5 years of the acute event (Robinson & Jorge, 2016). This risk may be even higher for patients who experience severe strokes (Robinson & Jorge, 2016). Although previously accepted as part of the long-term sequelae of stroke, it is crucial to recognise and treat depression in stroke patients as this will not only affect their quality of life but also affect the rehabilitation process. In fact, in their review, Robinson and Jorge (2016) found that “depression severity was an independent predictor of severity of impairment in activities of daily living”.

Secondarily, the stroke itself may directly affect certain areas in the brain that are responsible for emotions and thought processes.

6.6.3.4 Community support

Following discharge from hospital, patients may feel isolated and lack the motivation to read about stroke and embark on the necessary lifestyle changes. For this reason, it would be ideal to monitor stroke patients in the long term via community-based services. During such visits, healthcare workers may answer questions that patients bring up, increase patient motivation via positive reinforcement, and continue with stroke education. As previously shown, stroke education needs to be an ongoing process, and it therefore makes sense that certain aspects of it are updated periodically.

It may also be very helpful to establish stroke support groups in the community. This would be beneficial for affected individuals as it allows them to meet with other stroke sufferers and have the opportunity to discuss important coping mechanisms with them. Ideally, such groups would be led by stroke specialists or psychologists, who would also take the opportunity to educate patients regarding stroke. Group meetings might also represent the perfect occasion to meet 'role models', that is, previous stroke suffers who have recovered completely from stroke, as they may offer valuable motivation to patients still recovering from their acute event.

6.6.3.5 Incentives to increase stroke knowledge following stroke

Education about stroke knowledge should ideally start during acute admission, as these patients are at significantly increased risk of a second stroke. This may, however, be hindered by the fact that some of these patients will be physically and psychologically unwell during the admission. As discussed in previous sections, educational efforts should continue on an outreach basis. Stroke knowledge is of utmost importance, as these high-risk patients will otherwise fail to recognise subtle or non-characteristic signs and symptoms of stroke and therefore lose precious time. It also emerged from the current study that knowledge is directly correlated to response. Furthermore, we know that stroke education may affect an individual's behaviour. For example, behaviour and response may be altered by demonstrating the positive outcomes of early treatment (Ajzen, 1985), using 'role models' (Bandura, 1963), and explaining the situation in terms of potential risks and susceptibility to stroke (Rosenstock, 1966).

Such educational tactics may also increase the patient's willingness to learn more about stroke and may stimulate the patient to read, research, and discuss stroke-related literature. Similarly, psychological support is crucial as certain conditions such as depression can leave the patient feeling helpless and will invariably affect the willingness to increase stroke knowledge.

6.6.3.6 Patient-focused care

Following the semi-structured interviews, it became clear that the majority of stroke patients still had certain questions that remained unanswered. This could have been the result of clinicians focusing on medical issues as opposed to spending time hearing the patient’s concerns, or because certain questions may have arisen following discharge. Questions such as “Can I continue with my normal life?” and “What are the chances that I will suffer another stroke?” are highly pertinent as they affect the quality of life of stroke patients. Apart from this, patients may be willing to make certain behavioural changes to decrease future risks, but may fail to do so unless instructed by a professional. Spending time with patients and hearing their concerns not only increases patient satisfaction but helps to build trust in that professional. It would therefore be ideal to have dedicated healthcare workers such as stroke nurses who are trained in interacting with and educating stroke patients. These individuals could discuss the risk factors associated with stroke, describe the presenting signs and symptoms, and stress the importance of calling an ambulance immediately should a stroke happen again in the future.

6.6.4 Dissemination

6.6.4.1 Academic Endeavours

I plan to disseminate the salient findings and methodological aspects emerging from this study by participating in local and international conferences related to public health, stroke and health education. I also plan to publish papers in peer-reviewed journals regarding the following:

1. Presentation of local data regarding stroke knowledge and educational needs in Malta. This data will also be conveyed to the World Stroke Association and European

Stroke Organisation in order to present an up-to-date evaluation regarding stroke in Malta.

2. Description of the relationship between stroke knowledge and response and highlighting the importance of social and behavioural barriers particularly in the local setting.

3. Provision of a summary of health promotion theories and models in relation to stroke and their significance in education and health promotion.

4. A synthesis of different educational means used in stroke education and how these can be adapted to the local setting.

5. Description of the methodological development of a matrix in order to ensure appropriate merging of quantitative and qualitative data when employing mixed methods research.

6. Demonstration of the use of thematic synthesis of data gathered through a systematic search of the relevant literature.

6.6.4.2 Discussions with local policy makers and stakeholders

As highlighted in Chapter 2, stroke educational campaigns are often prohibitively expensive to run. Health budgets are already stretched and healthcare already accounts for a substantial percentage of the country's annual budget. It is therefore necessary to devise a way in which a proposed campaign will not only demonstrate its health benefits but will also prove to be economically feasible. This is crucial for the initial planning phases of a national stroke campaign and to convince the relevant policy makers and stakeholders, that such an investment would also make sense financially.

When considering this dilemma, one has to look into both the acute and chronic financial burdens of the disease. The acute treatment is often followed by a lengthy rehabilitation process whereby patients are helped to gain a degree of independence. Despite the best efforts, patient independence after a stroke is not always achieved. One can therefore imagine both the direct and indirect financial implications of this, the latter representing loss of workforce and a huge burden on social contributions.

A national campaign about stroke education should primarily aim at prevention with the identification of risk factors and effective ways on how one could reduce their effects. Secondly, it should focus on stroke preparedness. As discussed previously in Chapter 2, the earlier the presentation after stroke onset, the better would be the expected clinical outcomes.

It is also crucial to plan such a campaign effectively. As discussed in Section 2.9, the way the stroke message is devised and delivered is crucial to determine the cost-effectiveness of a campaign. Studies such as the current one, may help determine which sections of the population are most in need of stoke education and to identify certain educational lacunae which may be targeted specifically. Several methods of delivering the stroke message have also been reviewed extensively in the literature review section. The choice of such delivery may be crucial in limiting the expenses of a national campaign whilst increasing its effectiveness. Repeated exposure may be also required to maintain the required level of stroke education.

Finally, consideration of previous campaigns is necessary to discover ways of how these campaigns were planned and run successfully. The current study may help identify certain aspects, which are more relevant to the local scenario and may therefore help to tweak a national campaign in order to enhance its cost effectiveness.

Such health promotion efforts should not be solely viewed as a recommendation emerging out of this study, as they actually comprise the third sustainable development goal within the United Nations' 2030 Agenda for Sustainable Development. This goal focuses on improving health and well-being and so the suggested actions related to the findings from the study are viewed as being in line with broader targets set by governing bodies. The need to abide to the European Commission's targets may be an additional motivating factor when discussing the findings and recommendations with local policy makers and stakeholders.

6.7 Limitations of the study

Since this study used a mixed methods approach, the major limitations of the study are divided into those arising through the qualitative phase, the quantitative phase, and other miscellaneous limitations. The following subsections (6.7.1–6.7.3) focus on potential biases in this study. This process is crucial as "… a thorough understanding of bias and how it affects study results is essential for the practice of evidence-based medicine" (Pannucci & Wilkins, 2010). Since bias is inevitable, it is crucial to reflect on how it may influence the conclusions of a particular study (Pannucci & Wilkins, 2010).

6.7.1 Qualitative Phase

6.7.1.1 Interviewer bias

The semi-structured interviews were performed by myself, a consultant radiologist working in the same hospital where the interviews were held. This meant that I was sometimes aware of clinical and other data before the interview took place. This may have unintentionally led to a degree of interviewer bias which is defined as a "systematic difference between how information is solicited, recorded, or interpreted" (Pannucci & Wilkins, 2010). The use of a semi-structured design with a standard group of questions may have limited such bias as the interviewer will attempt to adhere to the pre-set questions.

6.7.1.2 Recall bias

Pannucci and Wilkins (2010) describe recall bias as the “phenomenon in which the outcomes of treatment (good or bad) may colour subjects' recollections of events prior to or during the treatment process”.

For this reason, it was decided to also interview bystanders (when present), as their recounting of the facts may not have been influenced by the patient’s outcome. It was in fact interesting to hear how certain details provided by patients differed from those provided by their bystanders. This may be attributable to the fact that stroke in itself may affect short- and long-term memory, particularly if certain areas of the brain such as the hippocampus and amygdala are affected.

During the design of this study, care was taken when recruiting patients so that the interview would not take place too soon after the stroke event (when the patient’s emotions could have influenced the recollection of events) nor too late (when crucial details regarding the onset and reaction to stroke could have been omitted). The time-frame was specified before the start of recruitment and was stated in the inclusion criteria of the study.

6.7.1.3 Selection bias

Acute stroke admissions to Mater Dei Hospital are categorised using two criteria. The first criterion is age, with patients under the age of 70 being admitted to a neurology ward whereas those older than 70 years are admitted to general medical wards. The second criterion depends on the treatment administered acutely. All patients who receive thrombolytic therapy or undergo mechanical thrombectomy are admitted under the care of a neurologist. Patients admitted under general medical consultants may be more difficult to identify and include in stroke databases. The cohort of patients included in this study was selected according to inclusion criteria set before the initiation of the study.

These criteria specified that participants should have recently suffered a stroke. It is possible that some of the patients admitted to general medical wards may either have not appeared or appeared late in the stroke register, resulting in a skewed sample of younger patients with potentially better outcomes.

6.7.1.4 Consent bias

Consent bias is also known as authorisation bias and has “potentially serious consequences for the quality of medical research, the use of public resources and the quality of patient care” (Junghans & Jones, 2007). In the current study, consent bias may have resulted from the fact that patients, particularly those who had received acute stroke treatment, may have felt obliged to participate in the study. This could have been further aggravated by power issues in the patient–doctor relationship. Thus, potential participants were approached by a third party in order to reduce this phenomenon. Participants were also offered the option to quit the interview at any point should they have second thoughts about participating or experience negative emotions. Patients who had been subjected to legal incapacitation were excluded from the study as specified in the exclusion criteria.

6.7.2 Quantitative Phase

6.7.2.1 Selection bias

The questionnaire was delivered via Google Forms and invitations to participate were sent via email, meaning that only people who were computer literate and had internet access received the invitation to participate. This resulted in selection bias during the quantitative phase of the study. Since the researcher was also interested in a sub-group of healthcare workers, there might have been further selection bias in terms of the educational level of the entire sample as most of these workers (including nurses, physiotherapists, occupational therapists, radiographers, and medical doctors) would have achieved a tertiary level of education. In fact, the healthcare worker group represented 59.2% of the entire cohort. However, the non-healthcare worker sub-group was representative of the Maltese population in terms of the demographic variables collected.

6.7.2.2 Questionnaire bias

In their comprehensive review, Choi and Pak (2004) identified 48 different types of bias in questionnaires and categorised them under three major headings: question design, questionnaire design, and administration of questionnaire. The authors have insisted that researchers should “understand and be able to prevent or at least minimize bias in the design of their questionnaires”. Their checklist was utilised during the design of the questionnaire used in Phase 2 of the current study in order to identify and reduce potential biases before being used as a survey instrument.

Questions were screened for ambiguity and unnecessary complexity and technical jargon were completely removed. Vague and uncommon words were similarly replaced. The Likert scale chosen for data collection consisted of a five-point scale to avoid forced choices and the phenomenon of ‘missing intervals’. Special attention was also paid during the design of the questionnaire to avoid formatting problems and to optimise its structure.

6.7.2.3 Acquiescence bias

Acquiescence bias may be particularly problematic in questionnaires that utilise agree-disagree questions as it can distort data collection. Acquiescence “describes the general tendency of a person to provide affirmative answers to items of a questionnaire, regardless of the content of the items" (Hinz, Michalski, Schwarz, & Herzberg, 2007). For this reason, a five-point Likert scale with a balanced proportion of positive and negative items was used. Similarly, a negative construct was utilised for a number of questions within the different sections of the questionnaire.

6.7.3 Miscellaneous

6.7.3.1 Confirmation bias

"Confirmation bias is deeply seated in the natural tendencies people use to understand and filter information" (Sarniak, 2015). Since the researcher has been actively involved in the area of study for a number of years, certain pre-existing beliefs or hypotheses may have unintentionally developed. Such beliefs may influence both data gathering (particularly during the interviews) and data interpretation. Although certain pre-existing beliefs are ingrained, the researcher was aware of these beliefs and their potential detriment on the execution and interpretation of the study. Such insight is crucial for minimising the effect of confirmation bias. The researcher also sought to continuously re-evaluate his impressions of participants and challenge any pre-existing assumptions throughout the study.

6.7.4 Conclusion

Although the list of potential biases within the current study may not be exhaustive, the author has tried to highlight the most salient points with respect to the study design and execution. An awareness of potential biases is crucial during a study to ensure accuracy in participants' perspectives and quality standards. As described in the previous sections, attempts were actively made throughout the study to reduce the deleterious effect of such biases.

6.8 Final thoughts

Chapter 6 was dedicated to the merging of separate and sequential methodological findings, namely the qualitative (Chapter 4) and quantitative (Chapter 5) results. Although tension exists between the two approaches (sometimes referred to as the ‘epistemological crises’) a third approach, mixed methods, emerges. This eclectic paradigm promises to combine the two in a manner that highlights the strength of each approach while dampening their relative weaknesses. This combination needs to follow strict criteria and the researcher must ensure trustworthiness throughout the process (as described in Chapter 3). The end result is data gathering which is both ‘deep’ and ‘wide’ and results which do not compromise on generalisability. The researcher may therefore produce work that promises to be more representative of the area studied.

Chapter 7 – Conclusion

7.1 Headline results

In this concluding chapter, it is useful to engage in a final reflective exercise in order to highlight and combine the main outcomes of the study in a succinct summary. Hence, I feel that the following points summarise the research that I have undertaken and require consideration if further studies related to the subject or a national strategy on stroke should be implemented in practice:

1. Stroke knowledge in Malta is limited but reflects that found in the literature.
2. Action in stroke is dependent on the degree of stroke knowledge. This direct correlation persists even when one considers potential social and cultural barriers to action.
3. New approaches to public education regarding stroke are needed and may include:
    a. culturally appropriate descriptions of stroke symptoms.
    b. educational campaigns targeted at broader audiences other than patients at risk.
    c. an emphasis on the fact that effective treatment now exists and may improve clinical outcomes.
    d. an emphasis on the fact that stroke symptoms (no matter how trivial) merit immediate medical attention.
    e. patients at risk or who have already suffered a stroke need support to modify potential risk factors and reduce the chances of a future event.
4. Stroke treatment and practice guidelines are continuously evolving and improving – medical doctors and healthcare workers need to keep abreast of such advances.

7.2 Review of the information generated in relation to the research questions

In this concluding part of the thesis, the four research questions posed at the start of this study are reviewed again and discussed in terms of the respective knowledge attained from this study.

7.2.1 The stroke experience

The most reliable experience of stroke was considered to have been provided by patients and bystanders who were present at the time of the acute event. Hence, the first research question focused on their experiences and reflections:

> **What are the reflections of stroke sufferers on the way that they managed their stroke onset?**

Most patients lacked insight of what truly happened during stroke onset. This became obvious in a number of interviews where the bystanders either filled in the gaps left by patients or recounted a different story from the one recalled by the patient. It also became clear that patients had never discussed with their bystanders what had truly happened on the day of the stroke.

It immediately became obvious during the interviews that previous stroke experience did not necessarily translate to improved stroke knowledge. It was almost shocking to discover that some of the patients interviewed were still unfamiliar with stroke symptomatology.

Despite suffering from such a devastating condition, a number of patients were either reluctant or lacked the motivation to make lifestyle changes in order to deal with modifiable risk factors. They similarly failed to read or learn about their condition, despite being aware of an increased risk for another stroke.

Although some patients knew what the appropriate stroke response should have been, they preferred to postpone or avoid this response so as not to be a burden on their families. These patients did not have any guilt feelings regarding the way they managed their stroke as they felt that the ‘well-being’ of their family was still their priority. Similarly, they seemed to prioritise the trust in and friendship with their GP, even when a misdiagnosis or a delayed visit by the GP led to exclusion from acute treatment. This finding contrasts with the exponential increase in medico-legal suits experienced in other countries and is reflective of the cultural and social values intrinsic to the Maltese population.

It was clear that certain emotions such as anxiety and fear are a very common occurrence in acute stroke whereas other emotions such as a low mood or other psychological difficulties are not uncommon in the long term. The need for psychological support and motivation cannot be understated.

Finally, it was perhaps unexpected to learn that the majority of patients interviewed still lacked a concrete plan on how to deal with the sequelae of stroke and how to reduce their future stroke risk.

7.2.2 Stroke knowledge in Malta

This section explores the knowledge attained in attempting to answer the following two research questions:

> **How much knowledge does the Maltese population have with regards to stroke recognition and management?**

What findings emerge from comparing and merging data from the reflections of stroke sufferers to quantitative instrument data on the Maltese population's knowledge?

The first question was addressed via the development and administration of a survey tool which generated a large volume of data representative of the Maltese public. This was the first time such information was collected on this scale in Malta. The second research question was answered following the integration of qualitative and quantitative data using a mixed methods approach.

7.2.2.1 Stroke knowledge and response

One of the challenges in recognising stroke is the presentation with mild or non-specific symptoms such as dizziness and headaches. This situation may be challenging for both patients and doctors, and irreversible consequences may result if these symptoms are overlooked or attributed to other disease processes. By contrast, speech problems and muscle weakness are more readily related to stroke. Overall, the level of public stroke knowledge in Malta was comparable to that found in the literature, and there was a suggestion of a positive temporal trend in knowledge over the last past decade. Although the public seems to be familiar with international stroke campaigns and the risk factors associated with stroke, a severe knowledge deficit regarding the aetiology of stroke exists. Although this may sound trivial, I firmly believe that basic knowledge of the condition is necessary for an understanding and appreciation of the benefits of certain lifestyle changes.

Although the majority of participants were aware of the appropriate response to stroke, it emerged that most opted to call their relatives, friends, or GP when faced with the condition. Although there may be a number of factors underlying this response, I believe that part of it is attributable to a lack of knowledge regarding the importance of such a response and an unfamiliarity with stroke treatment, as clearly emerged during the quantitative phase of the study.

Another point which requires consideration is the lack of insight that patients may experience during stroke. The patients who participated in the study were completely unaware that a stroke was happening and in such a situation, it seems as if emergency services will not be activated unless a bystander or relative realises what is happening. This situation highlights the importance of educating a broader audience.

7.2.2.2 Influence of demographic variables on stroke knowledge

Stroke knowledge was found to be related to age, income, and level of education attained. It was perhaps more unexpected to find that patients with established risk factors for stroke had poorer stroke knowledge compared with their peers. Some of the patients interviewed during the qualitative phase of the study were still unfamiliar with the symptomatology of stroke and the necessary lifestyle changes required. Others simply accepted that a stroke had happened and were reluctant to actively seek solutions.

Reassuringly, participants who worked in a healthcare setting in Malta out-scored members of the public in stroke knowledge and response assessment. The need for continuous medical education remains crucial for this sub-group, especially in a time when advances in stroke treatment are happening quickly.

7.2.2.3 Relationship between knowledge and response

A strong positive correlation was found between stroke knowledge and response. Although an awareness of the appropriate action does not guarantee that the appropriate action is taken during a stroke, it confirms that stroke knowledge is a pre-requisite for the correct response. Knowledge is also crucial to understand the benefits of stroke treatment and the importance of early arrival to hospital. As described in a number of health promotion theories, stroke knowledge may also overcome a number of social and cultural 'barriers' which may hinder the desired response. Knowledge also plays a vital role in overcoming the anxiety and feeling of helplessness commonly experienced by stroke patients.

7.2.2.4 Cultural influence

Another phenomenon which was encountered throughout the course of this study was the failure to respond in a timely fashion, even when the affected individuals were aware of the appropriate action that needed to be taken. This was partly mediated by the influence of others. Several participants and their bystanders sought 'approval' from their family members before calling emergency services. Similarly, the affected individuals also considered the burden on their relatives should they be transferred to hospital. The loyalty and friendship to the family doctor in Malta emerged repeatedly during several phases of this study. This highlights the importance of considering cultural aspects when attempting to enhance knowledge within a particular population since this is definitely a scenario where one size does not fit all.

7.2.3 Stroke educational needs in Malta

The following research question tackled the issue of identifying and quantifying stroke educational needs in Malta:

> **Which educational lacunae are present in relation to the Maltese population's knowledge about stroke recognition and management?**

Identifying stroke education deficiencies was a primary aim of the study and would not have been possible without a broad and thorough investigation. I believe that the use of mixed methods offered this opportunity without compromising on either the details or generalisability of the data.

Stroke educational campaigns in Malta need to be built around these deficiencies in order to increase their impact and become cost-effective. Educational campaigns should primarily target the symptoms of stroke and perhaps use more culturally appropriate descriptions of such symptoms. The target audience should not be limited to persons at risk but should also engage potential bystanders. The public needs to have a basic understanding of the aetiology of stroke, and the importance of a timely and appropriate action cannot be overstated. Campaigns need to emphasise the fact that effective treatments are now available and the clinical outcomes after stroke may be dramatically improved. Finally – but similarly important – is the role of stroke prevention. The public needs to be aware of the risk factors of stroke and must be provided with practical and effective solutions on how to modify them.

7.3 My contribution to knowledge

Throughout the course of this study, it became obvious that local studies regarding stroke knowledge were extremely limited. I consider the collection and analysis of the data undertaken during this study to represent a true picture of the current local situation regarding the studied aspects of stroke. Attempts will be made to disseminate the results of the study through publications, participation in local and international conferences, and media reports.

The study also serves as a baseline for future stroke studies in Malta and offers the possibility of checking for temporal trends in stroke knowledge.

The development of the stroke questionnaire was informed by both the experiences of previous stroke sufferers as well as the international literature. There is a lack of tools to assess stroke knowledge and previous studies on the subject have used different questions and scales, making international comparisons impossible. Future use of the questionnaire may serve as the basis of such comparisons and highlight local deficiencies in knowledge.

Additionally, the matrix specifically set up for this study to allow for the integration of qualitative and quantitative data may also be used as a template for other mixed methods studies.

The knowledge gained from this study may inform and guide future educational campaigns and national strategies on stroke management, potentially improving the outcomes of stroke sufferers.

7.4 Strengths, limitations, and final words

The main strength of this study lies in the meticulous use of a mixed methods paradigm which ultimately led to a comprehensive and reliable picture of the current situation in Malta. Throughout the study, several measures were taken in an attempt to enhance the trustworthiness of the study. Any decisions taken during the study process and other processes undertaken are clearly documented in the thesis. These efforts enhance the transparency of the study and serve as a guideline for future studies on the subject.

I acknowledge certain limitations in the study, the most relevant of which are thoroughly discussed in Chapter 6. Throughout the study, I sought to reduce the negative impact that my familiarity with the research setting and my own beliefs on the subject may have had. I believe that by following a strict methodology, these factors turned out to be invaluable assets and were used in a positive and constructive manner.

Many crucial lessons were learnt during the process of conducting this research study. Perhaps the most important of all was the realisation that each of the two approaches used led to the generation of different but equally valuable data that allowed me to gain an in-depth insight into stroke knowledge within the Maltese population. Since a thorough integration of the two different types of data was desired, I had to immerse myself in the findings that emerged from each stage in an extremely intensive manner, which led to further insight and appreciation of the topic. Still, ensuring proper integration of the data was not an easy process and required careful planning. Eventually a matrix was constructed, which is considered to have enhanced transparency and allowed for a structured approach to be used.

This journey has been a laborious and at times a difficult one. It was also one which was full of enjoyable moments that satisfied my research hunger. It was the intrinsic need to learn more about a subject at heart and my desire to contribute towards medical research that ultimately drove this study. Again, the words I uttered during my Hippocratic oath come to mind: “May I always act so as to preserve the finest traditions of my calling and may I long experience the joy of healing those who seek my help”.

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List of Appendices

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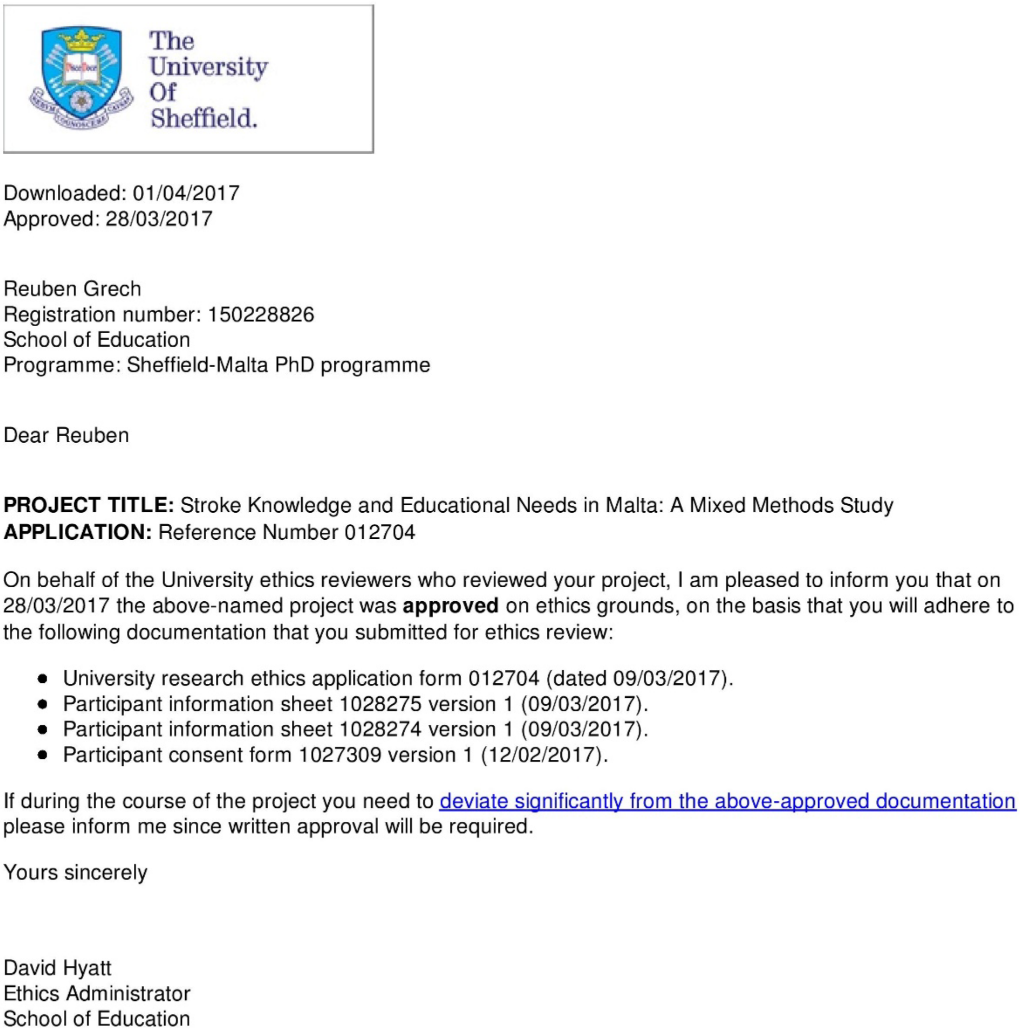
Appendix 1 - Ethics approval – University of Sheffield



The
University
Of
Sheffield.

Downloaded: 01/04/2017
Approved: 28/03/2017

Reuben Grech
Registration number: 150228826
School of Education
Programme: Sheffield-Malta PhD programme

Dear Reuben

PROJECT TITLE: Stroke Knowledge and Educational Needs in Malta: A Mixed Methods Study
APPLICATION: Reference Number 012704

On behalf of the University ethics reviewers who reviewed your project, I am pleased to inform you that on 28/03/2017 the above-named project was **approved** on ethics grounds, on the basis that you will adhere to the following documentation that you submitted for ethics review:

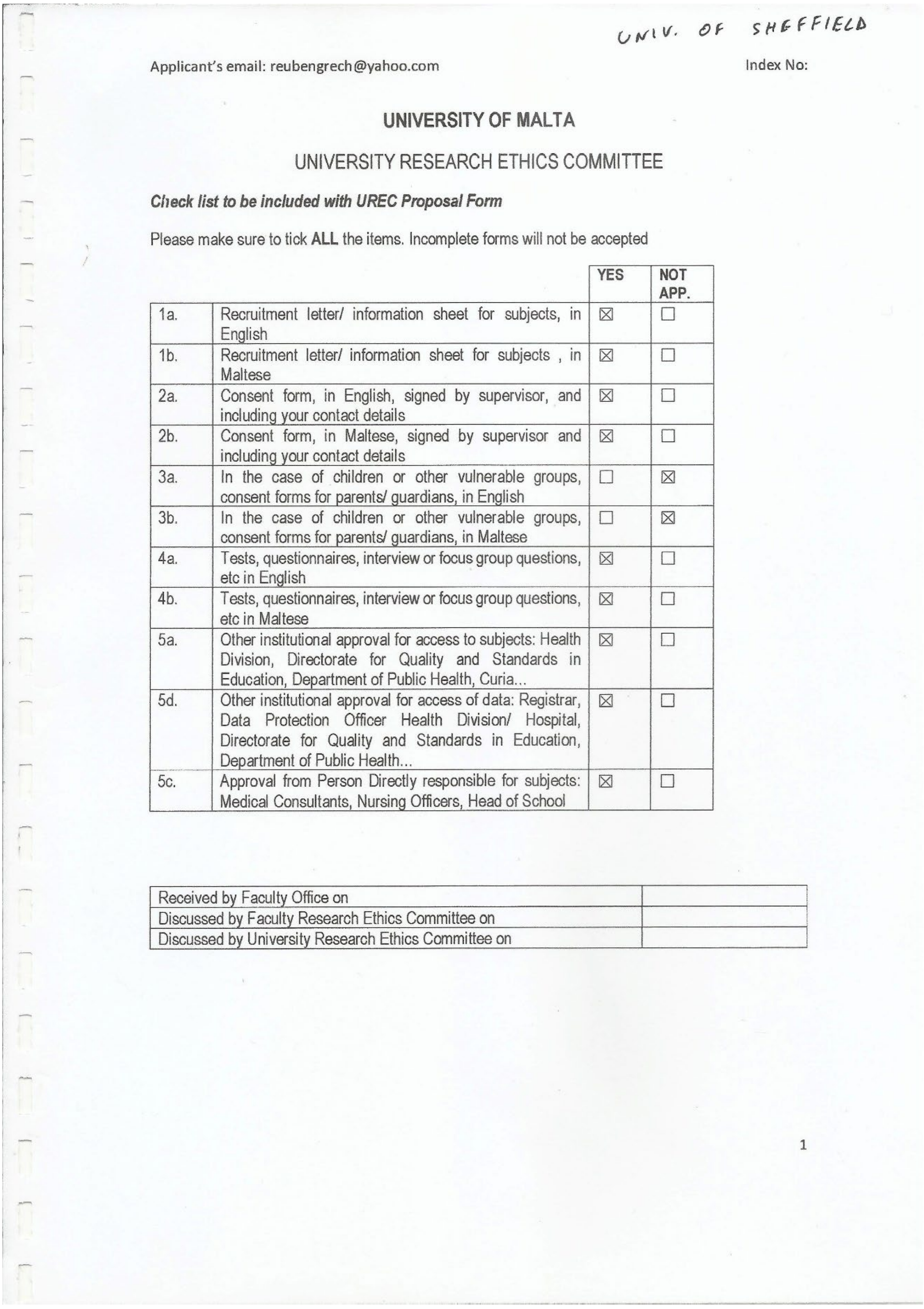
- University research ethics application form 012704 (dated 09/03/2017).
- Participant information sheet 1028275 version 1 (09/03/2017).
- Participant information sheet 1028274 version 1 (09/03/2017).
- Participant consent form 1027309 version 1 (12/02/2017).

If during the course of the project you need to deviate significantly from the above-approved documentation please inform me since written approval will be required.

Yours sincerely

David Hyatt
Ethics Administrator
School of Education

Appendix 2 - UREC approval - University of Malta



UNIV. OF SHEFFIELD

Applicant's email: reubengrech@yahoo.com

Index No:

UNIVERSITY OF MALTA

UNIVERSITY RESEARCH ETHICS COMMITTEE

Check list to be included with UREC Proposal Form

Please make sure to tick **ALL** the items. Incomplete forms will not be accepted

		YES	NOT APP.
1a.	Recruitment letter/ information sheet for subjects, in English	☒	☐
1b.	Recruitment letter/ information sheet for subjects , in Maltese	☒	☐
2a.	Consent form, in English, signed by supervisor, and including your contact details	☒	☐
2b.	Consent form, in Maltese, signed by supervisor and including your contact details	☒	☐
3a.	In the case of children or other vulnerable groups, consent forms for parents/ guardians, in English	☐	☒
3b.	In the case of children or other vulnerable groups, consent forms for parents/ guardians, in Maltese	☐	☒
4a.	Tests, questionnaires, interview or focus group questions, etc in English	☒	☐
4b.	Tests, questionnaires, interview or focus group questions, etc in Maltese	☒	☐
5a.	Other institutional approval for access to subjects: Health Division, Directorate for Quality and Standards in Education, Department of Public Health, Curia...	☒	☐
5d.	Other institutional approval for access of data: Registrar, Data Protection Officer Health Division/ Hospital, Directorate for Quality and Standards in Education, Department of Public Health...	☒	☐
5c.	Approval from Person Directly responsible for subjects: Medical Consultants, Nursing Officers, Head of School	☒	☐

Received by Faculty Office on	
Discussed by Faculty Research Ethics Committee on	
Discussed by University Research Ethics Committee on	

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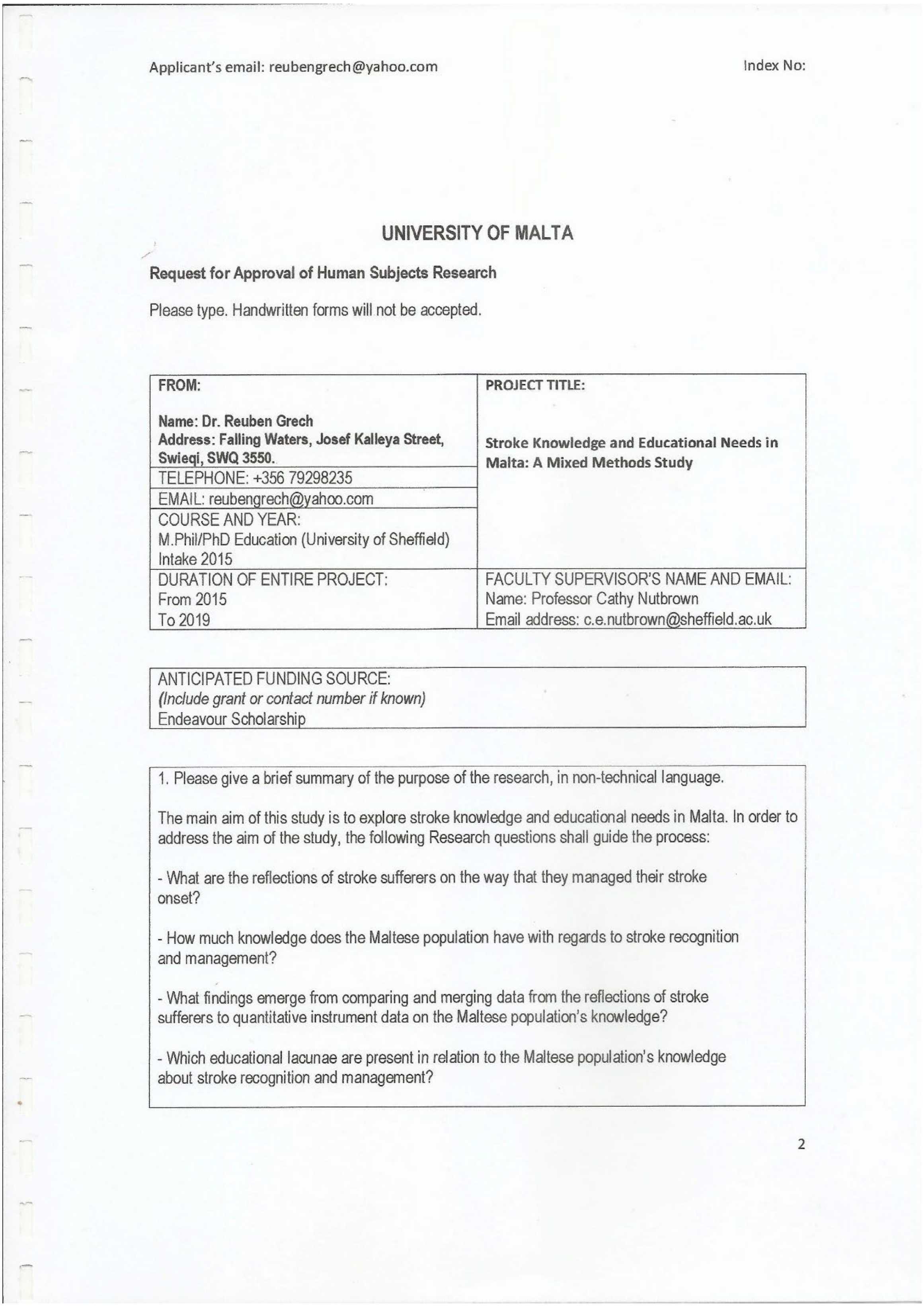


Applicant's email: reubengrech@yahoo.com Index No:

UNIVERSITY OF MALTA

Request for Approval of Human Subjects Research

Please type. Handwritten forms will not be accepted.

FROM: **Name: Dr. Reuben Grech** **Address: Falling Waters, Josef Kalleya Street, Swieqi, SWQ 3550.**	**PROJECT TITLE:** **Stroke Knowledge and Educational Needs in Malta: A Mixed Methods Study**
TELEPHONE: +356 79298235	
EMAIL: reubengrech@yahoo.com	
COURSE AND YEAR: M.Phil/PhD Education (University of Sheffield) Intake 2015	
DURATION OF ENTIRE PROJECT: From 2015 To 2019	FACULTY SUPERVISOR'S NAME AND EMAIL: Name: Professor Cathy Nutbrown Email address: c.e.nutbrown@sheffield.ac.uk

ANTICIPATED FUNDING SOURCE: *(Include grant or contact number if known)* Endeavour Scholarship

1. Please give a brief summary of the purpose of the research, in non-technical language.

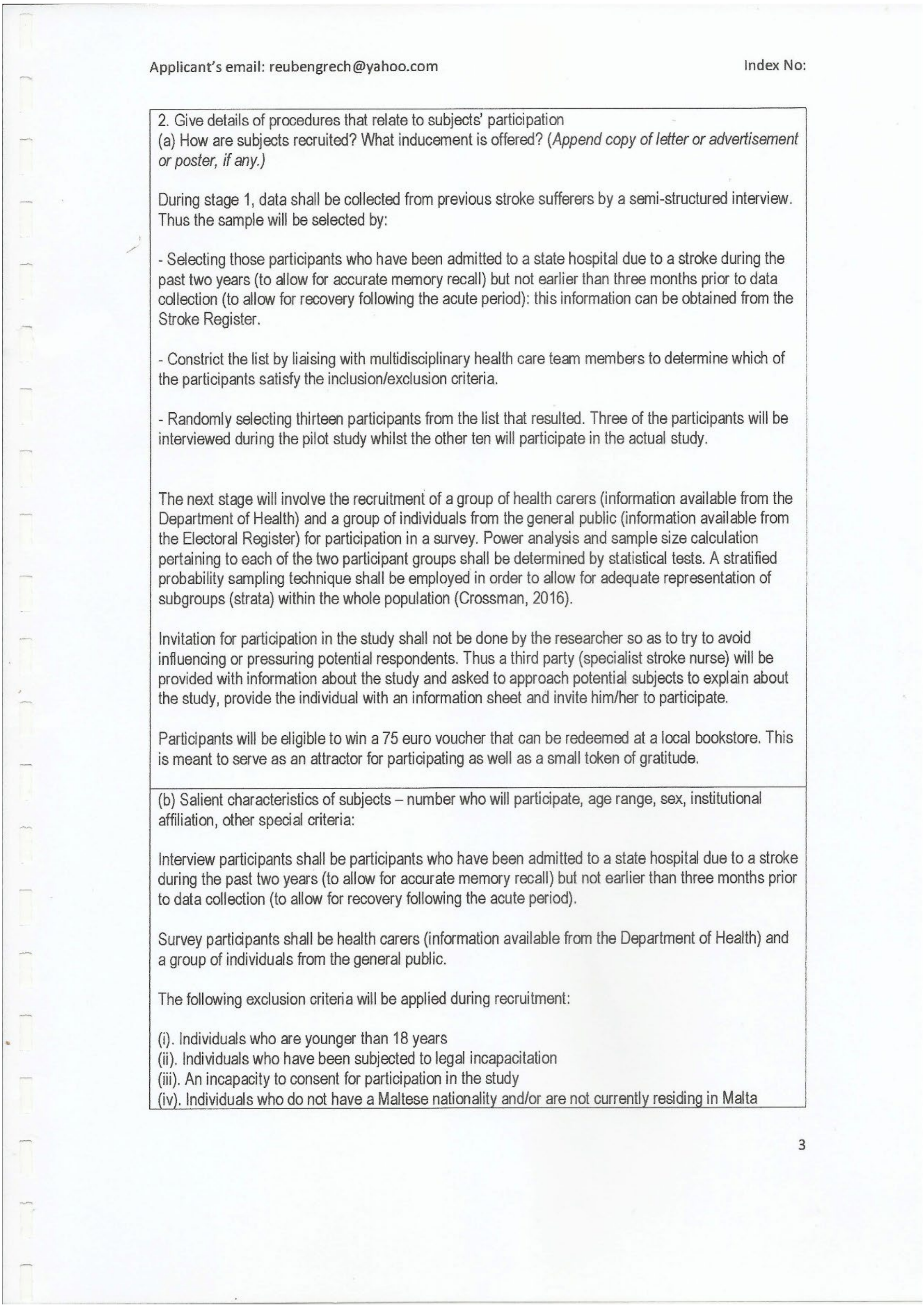
The main aim of this study is to explore stroke knowledge and educational needs in Malta. In order to address the aim of the study, the following Research questions shall guide the process:

- What are the reflections of stroke sufferers on the way that they managed their stroke onset?

- How much knowledge does the Maltese population have with regards to stroke recognition and management?

- What findings emerge from comparing and merging data from the reflections of stroke sufferers to quantitative instrument data on the Maltese population's knowledge?

- Which educational lacunae are present in relation to the Maltese population's knowledge about stroke recognition and management?



2. Give details of procedures that relate to subjects' participation

(a) How are subjects recruited? What inducement is offered? (*Append copy of letter or advertisement or poster, if any.)*

During stage 1, data shall be collected from previous stroke sufferers by a semi-structured interview. Thus the sample will be selected by:

- Selecting those participants who have been admitted to a state hospital due to a stroke during the past two years (to allow for accurate memory recall) but not earlier than three months prior to data collection (to allow for recovery following the acute period): this information can be obtained from the Stroke Register.

- Constrict the list by liaising with multidisciplinary health care team members to determine which of the participants satisfy the inclusion/exclusion criteria.

- Randomly selecting thirteen participants from the list that resulted. Three of the participants will be interviewed during the pilot study whilst the other ten will participate in the actual study.

The next stage will involve the recruitment of a group of health carers (information available from the Department of Health) and a group of individuals from the general public (information available from the Electoral Register) for participation in a survey. Power analysis and sample size calculation pertaining to each of the two participant groups shall be determined by statistical tests. A stratified probability sampling technique shall be employed in order to allow for adequate representation of subgroups (strata) within the whole population (Crossman, 2016).

Invitation for participation in the study shall not be done by the researcher so as to try to avoid influencing or pressuring potential respondents. Thus a third party (specialist stroke nurse) will be provided with information about the study and asked to approach potential subjects to explain about the study, provide the individual with an information sheet and invite him/her to participate.

Participants will be eligible to win a 75 euro voucher that can be redeemed at a local bookstore. This is meant to serve as an attractor for participating as well as a small token of gratitude.

(b) Salient characteristics of subjects – number who will participate, age range, sex, institutional affiliation, other special criteria:

Interview participants shall be participants who have been admitted to a state hospital due to a stroke during the past two years (to allow for accurate memory recall) but not earlier than three months prior to data collection (to allow for recovery following the acute period).

Survey participants shall be health carers (information available from the Department of Health) and a group of individuals from the general public.

The following exclusion criteria will be applied during recruitment:

(i). Individuals who are younger than 18 years
(ii). Individuals who have been subjected to legal incapacitation
(iii). An incapacity to consent for participation in the study
(iv). Individuals who do not have a Maltese nationality and/or are not currently residing in Malta

(c) Describe how permission has been obtained from cooperating institution(s) – school, hospital, organization, prison, or other relevant organization (*append letters).* Is the approval of another Research Ethics Committee required?

Permission from the Research Ethics Committee of the University of Sheffield has been obtained.

Additionally, permission from the following shall be requested:

Chief Executive Officer (Mater Dei Hospital)
Responsible Medical Consultants
Data Protection Officer (Mater Dei Hospital)

(d) What do subjects do, or what is done to them, or what information is gathered? (*Append copies of instructions or tests or questionnaires)* How many times will observations, test, etc., be conducted? How long will their participation take?

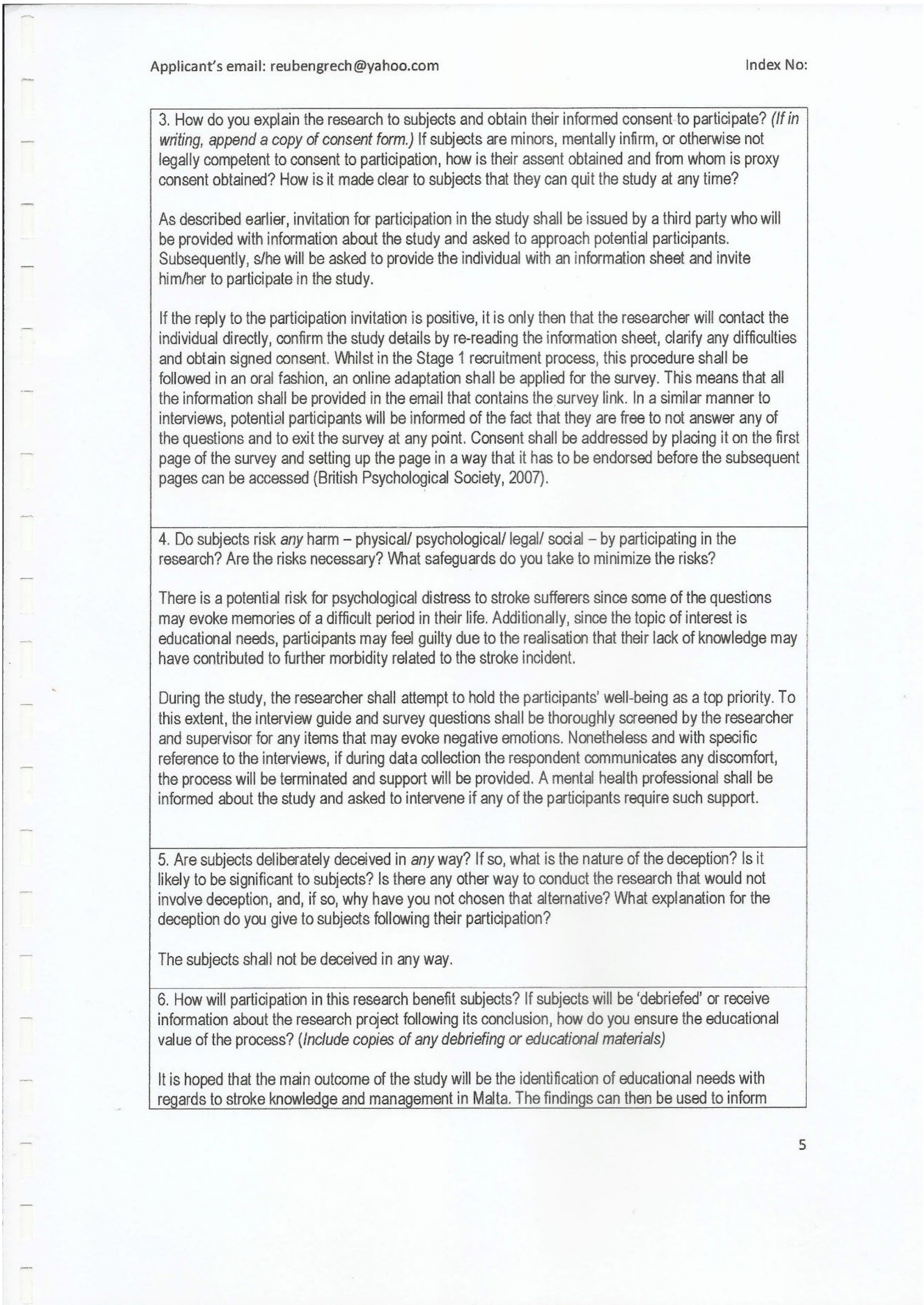
During the first phase, an interviewing technique shall be used to collect in-depth qualitative data from stroke sufferers in order to explore their reflections on their management of stroke onset. Each participant shall be interviewed once for an hour.

The following phase will involve the construction of a survey tool that will be developed from the qualitative stage 1 findings. The third and final stage will consist of the implementation of the tool amongst a population sample that consists of a sub-group of health carers and another of the general public. Each participant would need to complete one survey which would take around 15 minutes.

(e) Which of the following data categories are collected? Please tick where appropriate.

Data that reveals:

Race and ethnic origin	☐
Political opinions	☐
Religious and philosophical beliefs	☐
Trade union memberships	☐
Health	☒
Sex life	☐
Genetic information	☐



3. How do you explain the research to subjects and obtain their informed consent to participate? *(If in writing, append a copy of consent form.)* If subjects are minors, mentally infirm, or otherwise not legally competent to consent to participation, how is their assent obtained and from whom is proxy consent obtained? How is it made clear to subjects that they can quit the study at any time?

As described earlier, invitation for participation in the study shall be issued by a third party who will be provided with information about the study and asked to approach potential participants. Subsequently, s/he will be asked to provide the individual with an information sheet and invite him/her to participate in the study.

If the reply to the participation invitation is positive, it is only then that the researcher will contact the individual directly, confirm the study details by re-reading the information sheet, clarify any difficulties and obtain signed consent. Whilst in the Stage 1 recruitment process, this procedure shall be followed in an oral fashion, an online adaptation shall be applied for the survey. This means that all the information shall be provided in the email that contains the survey link. In a similar manner to interviews, potential participants will be informed of the fact that they are free to not answer any of the questions and to exit the survey at any point. Consent shall be addressed by placing it on the first page of the survey and setting up the page in a way that it has to be endorsed before the subsequent pages can be accessed (British Psychological Society, 2007).

4. Do subjects risk *any* harm – physical/ psychological/ legal/ social – by participating in the research? Are the risks necessary? What safeguards do you take to minimize the risks?

There is a potential risk for psychological distress to stroke sufferers since some of the questions may evoke memories of a difficult period in their life. Additionally, since the topic of interest is educational needs, participants may feel guilty due to the realisation that their lack of knowledge may have contributed to further morbidity related to the stroke incident.

During the study, the researcher shall attempt to hold the participants' well-being as a top priority. To this extent, the interview guide and survey questions shall be thoroughly screened by the researcher and supervisor for any items that may evoke negative emotions. Nonetheless and with specific reference to the interviews, if during data collection the respondent communicates any discomfort, the process will be terminated and support will be provided. A mental health professional shall be informed about the study and asked to intervene if any of the participants require such support.

5. Are subjects deliberately deceived in *any* way? If so, what is the nature of the deception? Is it likely to be significant to subjects? Is there any other way to conduct the research that would not involve deception, and, if so, why have you not chosen that alternative? What explanation for the deception do you give to subjects following their participation?

The subjects shall not be deceived in any way.

6. How will participation in this research benefit subjects? If subjects will be 'debriefed' or receive information about the research project following its conclusion, how do you ensure the educational value of the process? *(Include copies of any debriefing or educational materials)*

It is hoped that the main outcome of the study will be the identification of educational needs with regards to stroke knowledge and management in Malta. The findings can then be used to inform national stroke education campaigns which are, as yet, non-existing in Malta. Such campaigns will be addressed to enhance awareness which is of benefit to the general public including study participants. Following completion of the study, participants will be provided with an information sheet that outlines the main findings of the study.

TERMS AND CONDITIONS FOR APPROVAL IN TERMS OF THE DATA PROTECTION ACT

- Personal data shall only be collected and processed for the specific research purpose.
- The data shall be adequate, relevant and not excessive in relation to the processing purpose.
- All reasonable measures shall be taken to ensure the correctness of personal data
- Personal data shall not be disclosed to third parties and may only be required by the University or the Supervisor for verification purposes. All necessary measures shall be implemented to ensure confidentiality and where possible, data shall be anonymized.
- Unless otherwise authorized by the University Research Ethics Committee, the researcher shall obtain the consent from the data subject (respondent) and provide him with the following information: The researcher's identity and habitual residence, the purpose of processing and the recipients to whom personal data may be disclosed. The data subject shall also be informed about his rights to access, rectify, and where applicable erase the data concerning him.

I, the undersigned hereby undertake to abide by the terms and conditions for approval as attached to this application.

I, the undersigned, also give my consent to the University of Malta's Research Ethics Committee to process my personal data for the purpose of evaluating my request and other matters related to this application. I also understand that, I can request in writing a copy of my personal information. I shall also request rectification, blocking or erasure of such personal data that has not been processed in accordance with the Act.

Signature: [redacted]

APPLICANT'S SIGNATURE: *I hereby declare that I will not start my research on human subjects before UREC approval* [redacted] DATE 03.10.2017	FACULTY SUPERVISOR'S SIGNATURE *I have reviewed this completed application and I am satisfied with the adequacy of the proposed research design and the measures proposed for the protection of human subjects.* DATE

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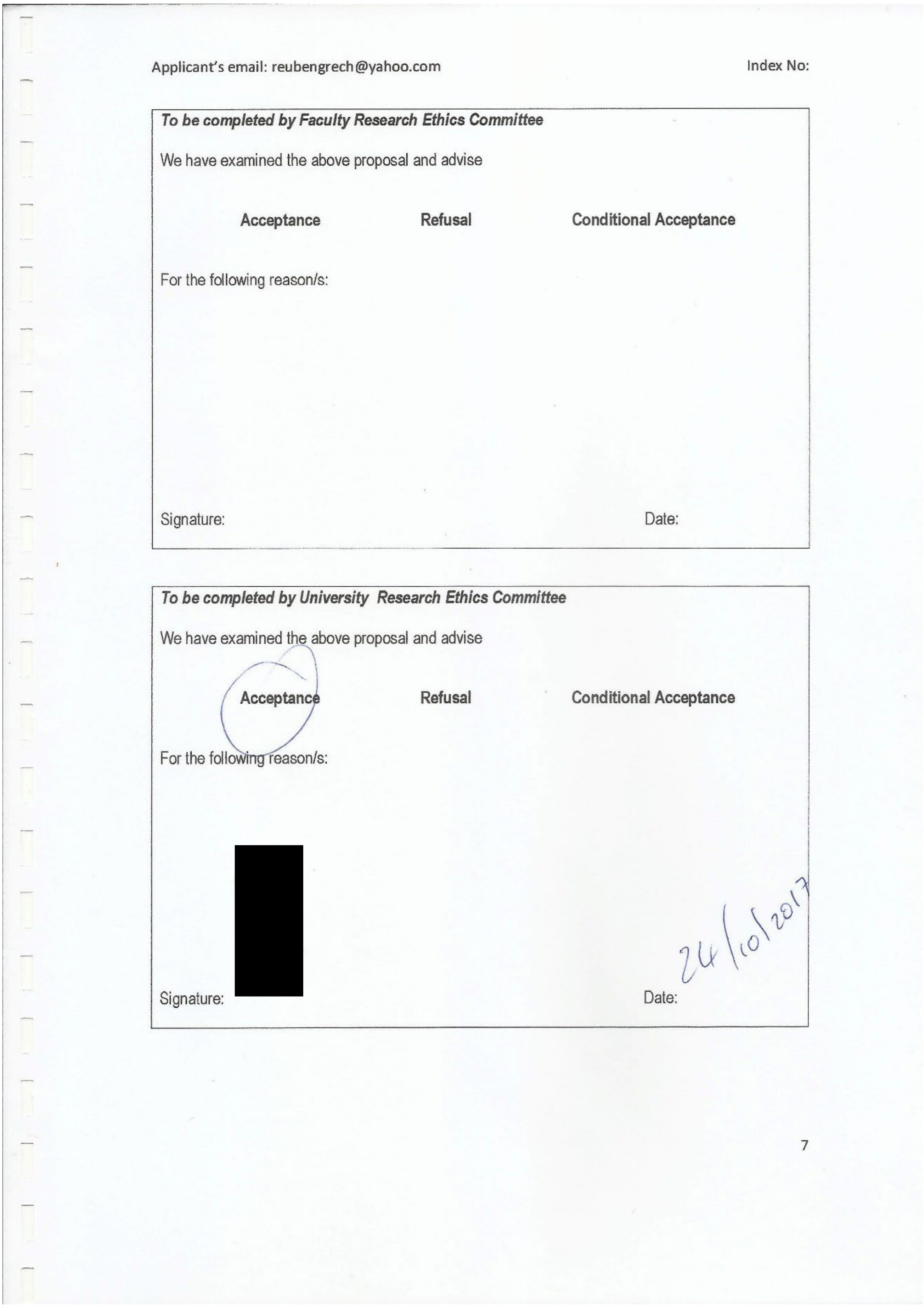


Applicant's email: reubengrech@yahoo.com

Index No:

To be completed by Faculty Research Ethics Committee

We have examined the above proposal and advise

Acceptance **Refusal** **Conditional Acceptance**

For the following reason/s:

Signature:

Date:

To be completed by University Research Ethics Committee

We have examined the above proposal and advise

[✓ **Acceptance**] **Refusal** **Conditional Acceptance**

For the following reason/s:

Signature: [redacted]

Date: 24/10/2017

Appendix 3 - Information letter - Stroke sufferers

15th February 2017

Information Letter

Stroke Knowledge and Educational Needs in Malta: A Mixed Methods Study

Dear Sir/ Madam,

I am following a PhD in Education which involves the undertaking of a research study. My chosen study is *Stroke Knowledge and Educational Needs in Malta: A Mixed Methods Study.*

I would like to invite you to take part in this research study. In order for you to decide, please take time to read this letter so that you understand the aim of this research and what it involves. You may wish to discuss with others who may help you to decide.

The aim and benefit of this study is to gain further understanding of stroke knowledge and educational needs in Malta. Furthermore, it is hoped that this in-depth exploration will identify the type of knowledge that is required by the main stakeholders in order for stroke onset to be managed in a manner that enhances therapeutic outcomes.

In order to gather information, I shall be carrying out interviews of stroke sufferers in order to explore their reflections on their management of stroke onset. Participation involves an interview with a duration of 45-60 minutes – these interviews shall be audio-recorded as this makes it easier for me to record information. The audio-recordings shall only be used to analyse the interview and no other use will be made of the recordings without requesting your written permission.

Your participation is voluntary and you are free to withdraw from the study at any time, without providing a reason. No one but myself shall have access to the information and the recordings so that anything that is said during the interviews remains strictly confidential. Your identity will not be revealed in the study report as pseudonyms will be used instead of names. Audio-recordings and transcriptions shall be stored securely and password protected. They shall be destroyed on successful completion of the study after agreed and appropriate dissemination.

Please note that the study proposal has been reviewed by the Research Ethics Committees of the University of Sheffield and the University of Malta. To the best of my knowledge, the interview questions should not evoke harmful emotions. However, if following the interview, psychological assistance is required, this shall be offered.

15th February 2017

Any queries or complaints regarding the study can be discussed by contacting me on 79298235 or reubengrech@yahoo.com or my supervisor at c.e.nutbrown@sheffield.ac.uk. If you feel that your query or complaint has not been addressed appropriately, you may wish to contact the chair of the School of Education ethical review panel Dr David Hyatt [d.hyatt@sheffield.ac.uk].

Please note that you will be provided with a copy of this information sheet and consent form. Thank you for your consideration.

With thanks and regards,

Reuben Grech
PhD student

The School of Education
University of Sheffield

Appendix 4 - Information letter - Health carers and public

15th February 2017

Information Letter

Stroke Knowledge and Educational Needs in Malta: A Mixed Methods Study

Dear Sir/ Madam,

I am following a PhD in Education, which involves the undertaking of a research study. My chosen study is *Stroke Knowledge and Educational Needs in Malta: A Mixed Methods Study.*

I would like to invite you to take part in this research study. In order for you to decide, please take time to read this letter so that you understand the aim of this research and what it involves. You may wish to discuss with others who may help you to decide.

The aim and benefit of this study is to gain further understanding of stroke knowledge and educational needs in Malta. Furthermore, it is hoped that this in-depth exploration will identify the type of knowledge that is required by the main stakeholders in order for stroke onset to be managed in a manner that enhances therapeutic outcomes.

In order to gather information, I shall be carrying out a survey on a group of health carers and another of the general public in order to explore stroke knowledge and related educational needs. Participation involves the completion of an online survey which should take around fifteen minutes.

Your participation is voluntary and you are free to withdraw from the study at any time, without providing a reason. No one but myself shall have access to the survey information so that this remains strictly confidential. Your identity will not be revealed in the study report, as pseudonyms will be used instead of names. Survey answers shall be stored securely and password protected. They shall be destroyed on successful completion of the study and after agreed and appropriate dissemination.

Please note that the study proposal has been reviewed by the Research Ethics Committees of the University of Sheffield and the University of Malta. To the best of my knowledge, the interview questions should not evoke harmful emotions. However, if following the interview, psychological assistance is required, this shall be offered.

Any queries or complaints regarding the study can be discussed by contacting me on 79298235 or reubengrech@yahoo.com or my supervisor at c.e.nutbrown@sheffield.ac.uk. If you feel that your query or complaint has not been addressed appropriately, you may wish to contact the chair of the School of Education ethical review panel Dr David Hyatt [d.hyatt@sheffield.ac.uk].

Please note that you will be provided with a copy of this information sheet and consent form. Thank you for your consideration.

With thanks and regards,

Reuben Grech
PhD student

The School of Education,
University of Sheffield

Appendix 5 - Information letter - Stroke sufferers (Maltese)

15 ta' Frar 2017

Ittra ta' Informazzjoni

'Stroke Knowledge and Educational Needs in Malta: A Mixed Methods Study'

Sinjur/a,

Jiena qed nagħmel PhD fl-edukazzjoni li tinvolvi proġett ta' riċerka. L-istudju tiegħi jismu '*Stroke Knowledge and Educational Needs in Malta: A Mixed Methods Study'*.

Nixtieq nistiednek biex tipparteċipa f'dan l-istudju. Jekk jogħġbok, aqra din l-ittra biex tifhem l-iskop u l-proċess ta' din ir-riċerka. Tista' wkoll tiddiskuti ma' xi nies oħra biex jgħinuk tiddeċiedi.

L-iskop ta' dan l-istudju huwa li jinkiseb għarfien fuq il-bżonn tal-edukazzjoni dwar il-puplesija f'Malta. Apparti minn hekk, nispera li dan l-eżerċizzju jidentifika x'tip ta' għarfien huwa meħtieg mill-partijiet interessati biex il-puplesija tiġi ġestita aħjar u jitjieb l-eżitu tal-puplesija.

Biex tinġabar din l-informazzjoni, se nkun qed nagħmel intervista ma' pazjenti li ġew milquta mill-puplesija biex nesplora r-riflessjonijiet tagħhom fuq kif irreaġixxew fil-bidu tal-puplesija. Din l-intervista mistennija ddum madwar 45-60 minuta u ser tiġi rrekordjata biex b'hekk tkun tista' tinġabar l-informazzjoni aħjar. Il-materjal irrekordjat se jintuża biss biex tiġi analizzata l-intervista u mhux se jintuża għal skopijiet oħra mingħajr il-kunsens miktub tiegħek.

Il-parteċipazzjoni tiegħek hija volontarja u għandek dritt toħroġ mill-istudju fi xħin tixtieq u mingħajr ma tagħti spjegazzjoni. Ħadd ħliefi mhu ser ikollu aċċess għall-informazzjoni miġbura u, għaldaqstant, kulma jintqal waqt l-intervista ser jibqa' strettament kunfidenzjali. L-identità tiegħek mhix ser tkun żvelata peress li fir-rapport tal-istudju ser jintużaw psewdonimi flok l-ismijiet tal-parteċipanti.

L-informazzjoni miġbura waqt l-intervisti ser tkun miġbura b'mod sigur u protetta b' użu ta' passwords. L-informazzjoni ser tiġi meqruda ladarba l-istudju jintemm u jiġi disseminat kif miftiehem.

Il-proposta għal dan l-istudju ġiet riveduta mill-kumitati tar-'Research Ethics' tal-Università ta' Sheffield u l-Universita ta' Malta. Safejn naf jien, id-domandi tal-intervista m'għandhomx iqanqlu emozzjonijiet negattivi. F'każ li wara l-intervista jkun hemm bżonn ta' assistenza psikoloġika, din ser tiġi pprovduta.

Jekk ikollok xi domandi jew ilmenti fuq dan l-istudju, tista' tiddiskutihom miegħi fuq 79298235 jew reubengrech@yahoo.com. Inkella tista' tikkuntattja lis-supervisor tiegħi fuq c.e.nutbrown@sheffield.ac.uk. F’każ illi taħseb li d-domandi jew ilmenti tiegħek ma ġewx indirizzati tajjeb, tista’ wkoll tikkuntattja lil Dr David Hyatt [d.hyatt@sheffield.ac.uk] li huwa ċ-chair ta’ ‘School of Education Ethical Review Panel’.

Inti ser tiġi pprovdut b’kopja ta’ din l-ittra ta’ informazzjoni u l-formola ta’ kunsens. Grazzi talli se tikkunsidra din l-offerta.

Nirringrazzjak bil-quddiem,

Reuben Grech
Student tal- PhD

The School of Education
University of Sheffield

Appendix 6 - Information letter - Health carers and public (Maltese)

15 ta' Frar 2017

Ittra ta' Informazzjoni

'Stroke Knowledge and Educational Needs in Malta: A Mixed Methods Study'

Sinjur/a,

Jiena qed nagħmel PhD fl-edukazzjoni li tinvolvi proġett ta' riċerka. L-istudju tiegħi jismu '*Stroke Knowledge and Educational Needs in Malta: A Mixed Methods Study'*.

Nixtieq nistiednek biex tipparteċipa f'dan l-istudju. Jekk jogħġbok, aqra din l-ittra biex tifhem l-iskop u l-proċess ta' din ir-riċerka. Tista' wkoll tiddiskuti ma' xi nies oħra biex jgħinuk tiddeċiedi.

L-iskop ta' dan l-istudju huwa li jinkiseb għarfien fuq il-bżonn tal-edukazzjoni dwar il-puplesija f'Malta. Apparti minn hekk, nispera li dan l-eżerċizzju jidentifika x'tip ta' għarfien huwa meħtieg mill-partijiet interessati biex il-puplesija tiġi ġestita aħjar u jitjieb l-eżitu tal-puplesija.

Biex niġbor l-informazzjoni neċessarja, ser nagħmel stħarriġ ma' grupp ta' nies li jaħdmu fis-settur tas-saħħa kif ukoll mal-pubbliku inġenerali biex nesplora l-għarfien fuq il-puplesija u l-bżonn ta' edukazzjoni f'dan ir-rigward. Il-parteċipazzjoni tiegħek tinvolvi li timla stħarriġ online li mistenni jeħodlok madwar ħmistax-il minuta.

Il-parteċipazzjoni tiegħek hija volontarja u għandek dritt toħroġ mill-istudju fi xħin tixtieq u mingħajr ma tagħti spjegazzjoni. Ħadd ħliefi mhu ser ikollu aċċess għall-informazzjoni miġbura u, għaldaqstant, kulma jintqal waqt l-intervista ser jibqa' strettament kunfidenzjali. L-identità tiegħek mhix ser tkun żvelata peress li fir-rapport tal-istudju ser jintużaw psewdonimi flok l-ismijiet tal-parteċipanti.

L-informazzjoni miġbura waqt l-intervisti ser tkun miġbura b'mod sigur u protetta b' użu ta' passwords. L-informazzjoni ser tiġi meqruda ladarba l-istudju jintemm u jiġi disseminat kif miftiehem.

Il-proposta għal dan l-istudju ġiet riveduta mill-kumitati tar-'Research Ethics' tal-Università ta' Sheffield u l-Universita ta' Malta. Safejn naf jien, id-domandi tal-intervista m'għandhomx iqanqlu emozzjonijiet negattivi. F'każ li wara l-intervista jkun hemm bżonn ta' assistenza psikoloġika, din ser tiġi pprovduta.

Jekk ikollok xi domandi jew ilmenti fuq dan l-istudju, tista' tiddiskutihom miegħi fuq 79298235 jew reubengrech@yahoo.com. Inkella tista' tikkuntattja lis-supervisor tiegħi fuq c.e.nutbrown@sheffield.ac.uk. F'każ illi taħseb li d-domandi jew ilmenti tiegħek ma ġewx indirizzati tajjeb, tista' wkoll tikkuntattja lil Dr David Hyatt [d.hyatt@sheffield.ac.uk] li huwa ċ-chair ta' 'School of Education Ethical Review Panel'.

Inti ser tiġi pprovdut b'kopja ta' din l-ittra ta' informazzjoni u l-formola ta' kunsens. Grazzi talli se tikkunsidra din l-offerta.

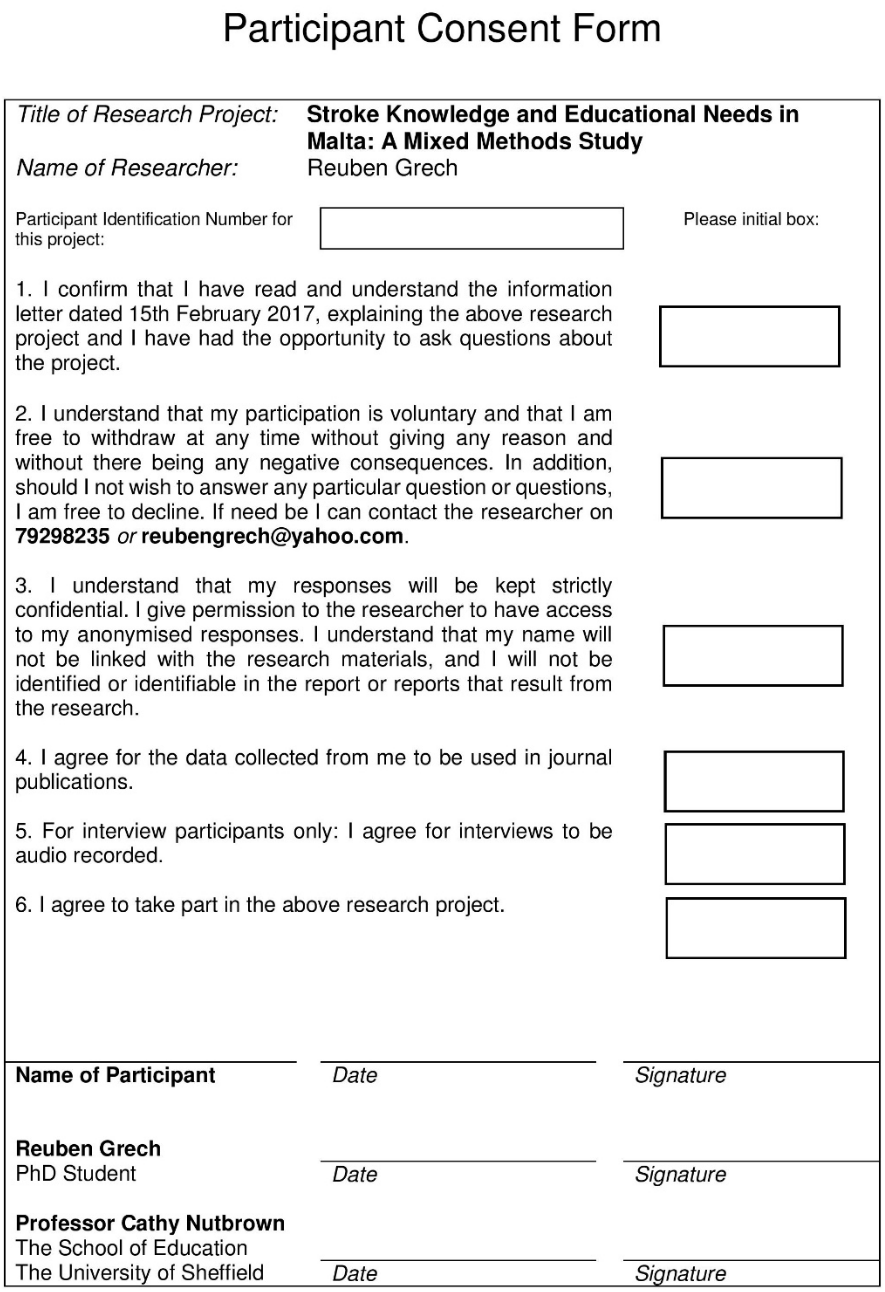
Nirringrazzjak bil-quddiem,

Reuben Grech
Student tal- PhD

The School of Education
University of Sheffield

Appendix 7 - Consent form

University of Sheffield



Participant Consent Form

Title of Research Project: **Stroke Knowledge and Educational Needs in Malta: A Mixed Methods Study**

Name of Researcher: Reuben Grech

Participant Identification Number for this project:

Please initial box:

1. I confirm that I have read and understand the information letter dated 15th February 2017, explaining the above research project and I have had the opportunity to ask questions about the project.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without there being any negative consequences. In addition, should I not wish to answer any particular question or questions, I am free to decline. If need be I can contact the researcher on **79298235** *or* **reubengrech@yahoo.com**.

3. I understand that my responses will be kept strictly confidential. I give permission to the researcher to have access to my anonymised responses. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research.

4. I agree for the data collected from me to be used in journal publications.

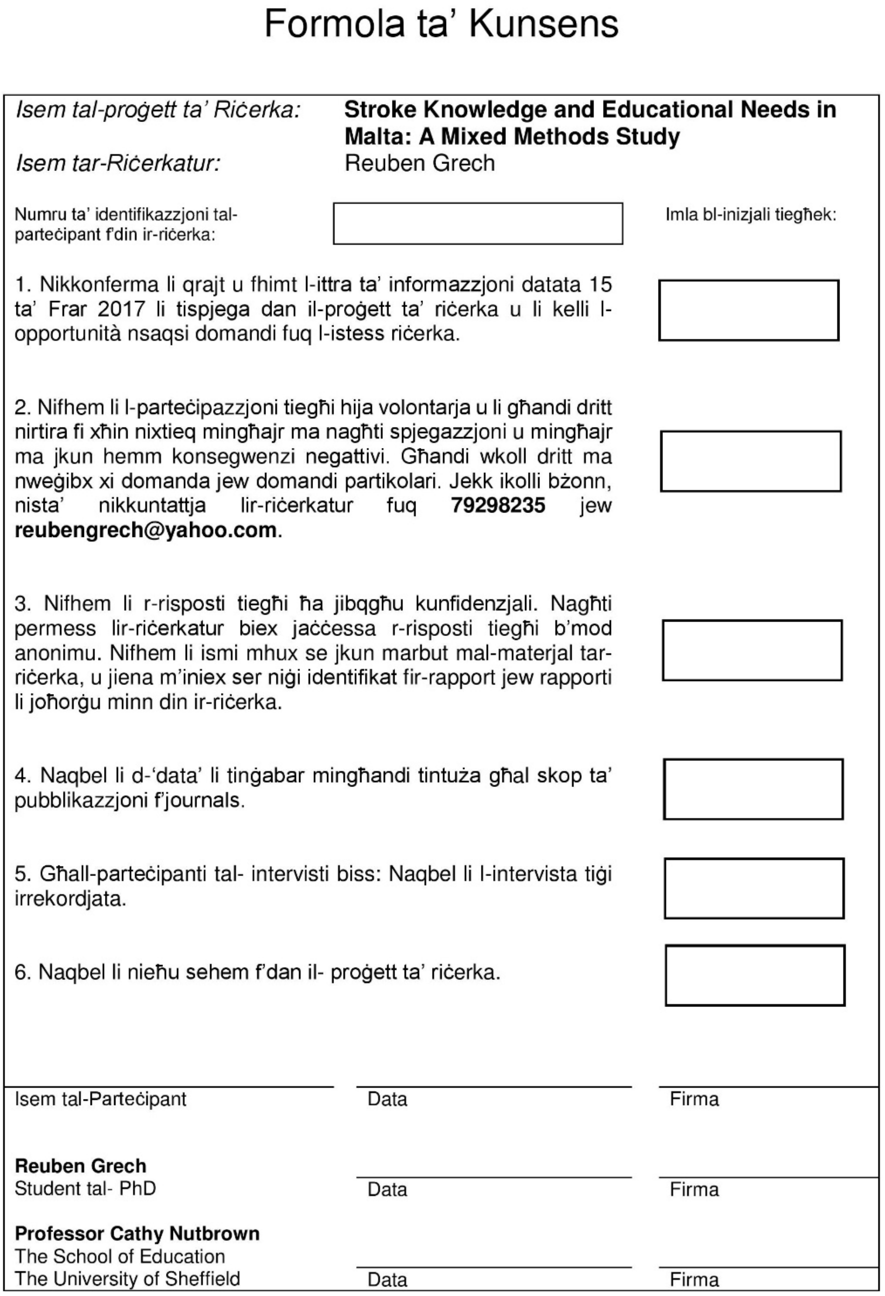
5. For interview participants only: I agree for interviews to be audio recorded.

6. I agree to take part in the above research project.

Name of Participant	*Date*	*Signature*
Reuben Grech PhD Student	*Date*	*Signature*
Professor Cathy Nutbrown The School of Education The University of Sheffield	*Date*	*Signature*

Appendix 8 - Consent form (Maltese)

University of Sheffield



Formola ta' Kunsens

Isem tal-proġett ta' Riċerka: **Stroke Knowledge and Educational Needs in Malta: A Mixed Methods Study**

Isem tar-Riċerkatur: Reuben Grech

Numru ta' identifikazzjoni tal-parteċipant f'din ir-riċerka: ☐

Imla bl-inizjali tiegħek:

1. Nikkonferma li qrajt u fhimt l-ittra ta' informazzjoni datata 15 ta' Frar 2017 li tispjega dan il-proġett ta' riċerka u li kelli l-opportunità nsaqsi domandi fuq l-istess riċerka. ☐

2. Nifhem li l-parteċipazzjoni tiegħi hija volontarja u li għandi dritt nirtira fi xħin nixtieq mingħajr ma nagħti spjegazzjoni u mingħajr ma jkun hemm konsegwenzi negattivi. Għandi wkoll dritt ma nweġibx xi domanda jew domandi partikolari. Jekk ikolli bżonn, nista' nikkuntattja lir-riċerkatur fuq **79298235** jew **reubengrech@yahoo.com**. ☐

3. Nifhem li r-risposti tiegħi ħa jibqgħu kunfidenzjali. Nagħti permess lir-riċerkatur biex jaċċessa r-risposti tiegħi b'mod anonimu. Nifhem li ismi mhux se jkun marbut mal-materjal tar-riċerka, u jiena m'iniex ser niġi identifikat fir-rapport jew rapporti li joħorġu minn din ir-riċerka. ☐

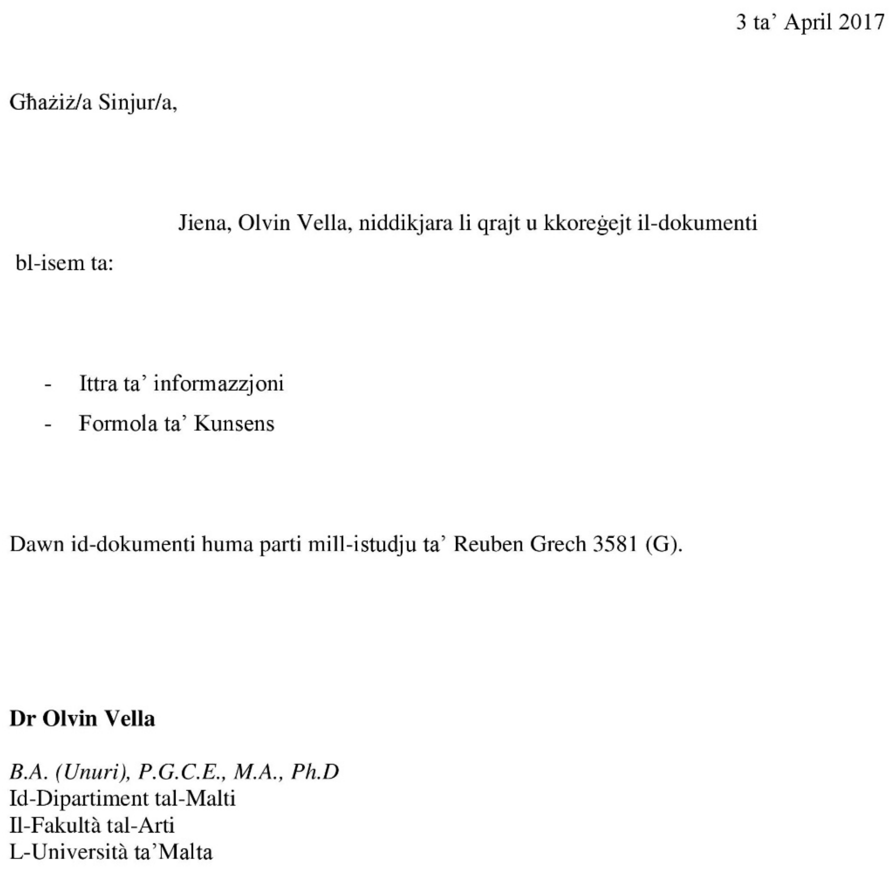
4. Naqbel li d-'data' li tinġabar mingħandi tintuża għal skop ta' pubblikazzjoni f'journals. ☐

5. Għall-parteċipanti tal- intervisti biss: Naqbel li l-intervista tiġi irrekordjata. ☐

6. Naqbel li nieħu sehem f'dan il- proġett ta' riċerka. ☐

Isem tal-Parteċipant	Data	Firma
Reuben Grech Student tal- PhD	Data	Firma
Professor Cathy Nutbrown The School of Education The University of Sheffield	Data	Firma

Appendix 9 - Declaration regarding Maltese translation



3 ta' April 2017

Għażiż/a Sinjur/a,

Jiena, Olvin Vella, niddikjara li qrajt u kkoreġejt il-dokumenti bl-isem ta:

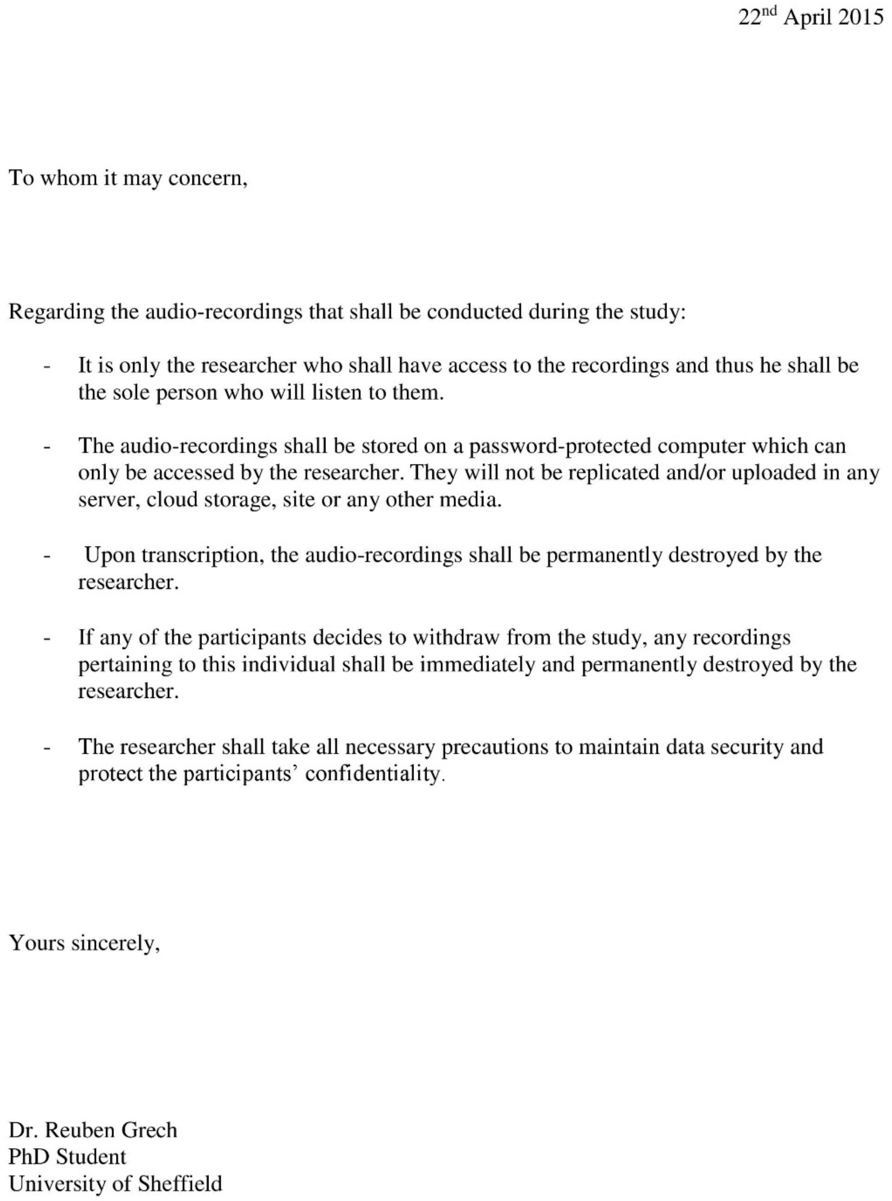
- Ittra ta' informazzjoni
- Formola ta' Kunsens

Dawn id-dokumenti huma parti mill-istudju ta' Reuben Grech 3581 (G).

Dr Olvin Vella

B.A. (Unuri), P.G.C.E., M.A., Ph.D
Id-Dipartiment tal-Malti
Il-Fakultà tal-Arti
L-Università ta'Malta

Appendix 10 - Declaration regarding audio recordings



22nd April 2015

To whom it may concern,

Regarding the audio-recordings that shall be conducted during the study:

- It is only the researcher who shall have access to the recordings and thus he shall be the sole person who will listen to them.
- The audio-recordings shall be stored on a password-protected computer which can only be accessed by the researcher. They will not be replicated and/or uploaded in any server, cloud storage, site or any other media.
- Upon transcription, the audio-recordings shall be permanently destroyed by the researcher.
- If any of the participants decides to withdraw from the study, any recordings pertaining to this individual shall be immediately and permanently destroyed by the researcher.
- The researcher shall take all necessary precautions to maintain data security and protect the participants' confidentiality.

Yours sincerely,

Dr. Reuben Grech
PhD Student
University of Sheffield

Appendix 11 - Search strategy – Ovid Medline

Ovid Medline Search Strategy

1 exp Stroke/ (100218)

2 exp Brain Ischemia/ (90351)

3 exp Cerebral Infarction/ or exp Brain Infarction/ (31888)

4 (cerebrovasc$ accident or cerebrovasc$ event).m_titl. (584)

5 occlusive cerebrovascular disease.m_titl. (117)

6 ((brain or cerebr$) adj5 (ischaemi$ or ischemi$ or infarct$ or hypoxia$)).m_titl. (27354)

7 AIS.m_titl. (196)

8 CVA.m_titl. (152)

9 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 (149804)

10 ($acute or sudden or wake-up).m_titl. (429372)

11 9 and 10 (13402)

12 (signs or symptoms or recognition or presentation).m_titl. (181227)

13 (intervention or management or outcome or act fast or treatment).m_titl. (1367859)

14 (pre-hospital delay or care or hospital arrival or late presentation or delayed presentation or timely presentation).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] (1636363)

15 12 or 13 or 14 (2969843)

16 (education$ or strategy or framework or culturally tailored or community engaged).m_titl. (180141)

17 (campaign or national framework or communication or management programme).m_titl. (45704)

18 16 or 17 (224632)

19 (awareness or perception or preparedness or self-identified or knowledge or public).m_titl. (163569)

20 15 or 18 or 19 (3263434)

21 11 and 20 (3942)

22 limit 21 to humans (3827)

23 limit 22 to last 10 years (2672)

****

Appendix 12 - Sample e-mail

From: Reuben Grech <reubengrech@yahoo.com>
Sent: 05 June 2018 18:07:40
To:
Subject: Stroke Knowledge Questionnaire

Dear Sir/Madam,

I am a consultant radiologist working at Mater Dei Hospital and I am currently reading for a PhD at the University of Sheffield. The research study that I am undertaking during my studies is entitled "Stroke Knowledge and Educational Needs in Malta: A Mixed Methods Study".

The main aim of this study is to explore the Maltese population's knowledge in relation to stroke recognition and management. A part of this study involves the completion of a questionnaire by health care professionals and the general public. Kindly refer to the attached information letter for further details.

I would like to invite you to participate in the study by completing the questionnaire. This should take no longer than 5 minutes. The questionnaire can be accessed via the following link:

https://docs.google.com/forms/d/e/1FAIpQLSfgucouPFpTMp4eeitPoYpRnznbWypz51WEACFoB2YCobH2RQ/viewform

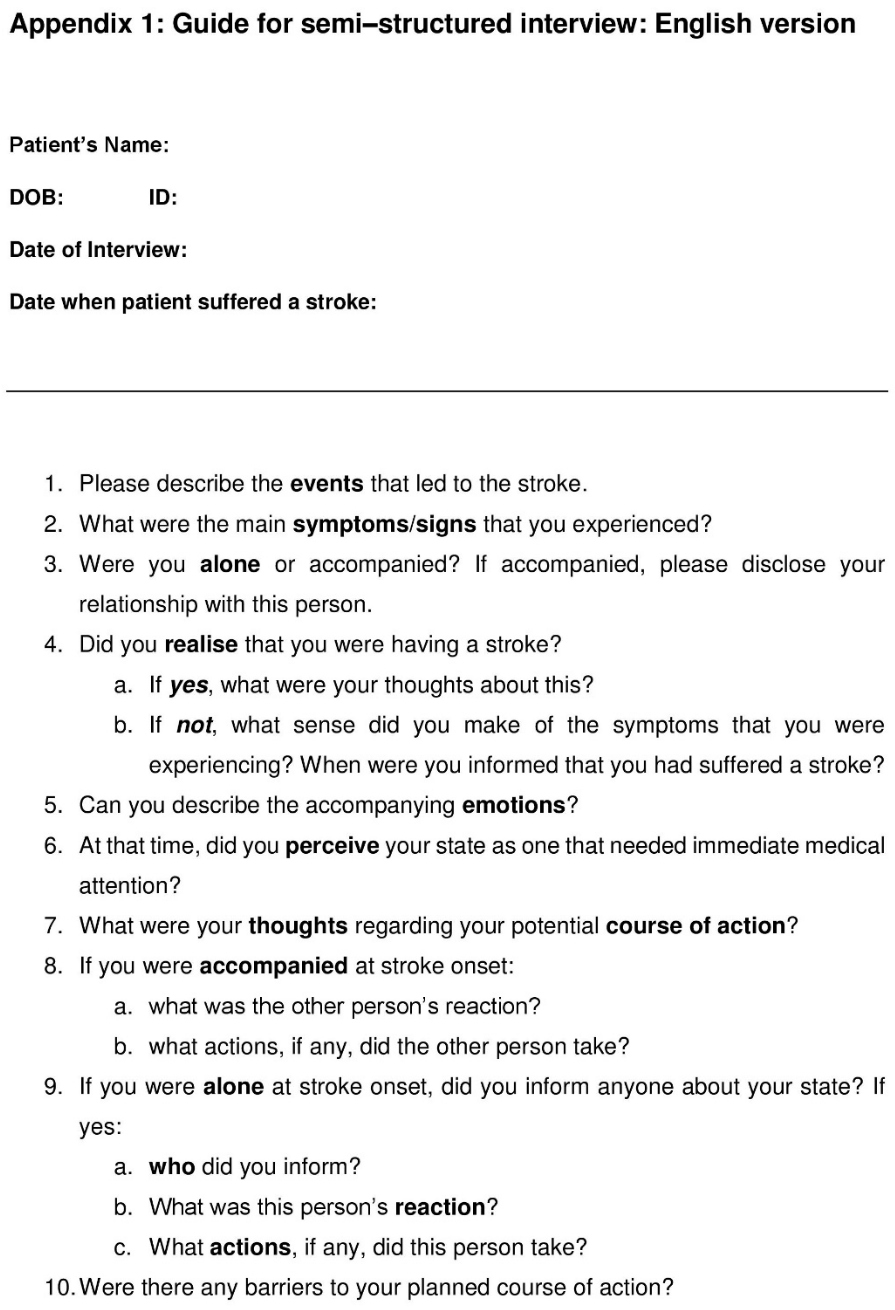
Kindly note that the act of completing the questionnaire automatically signifies your informed consent for participating in this part of the study.

Whilst thanking you for your time, I look forward to your participation.

Best wishes,

Reuben

Appendix 13 - Semi-structured interview guide



Appendix 1: Guide for semi–structured interview: English version

Patient's Name:

DOB: **ID:**

Date of Interview:

Date when patient suffered a stroke:

---

1. Please describe the **events** that led to the stroke.
2. What were the main **symptoms**/**signs** that you experienced?
3. Were you **alone** or accompanied? If accompanied, please disclose your relationship with this person.
4. Did you **realise** that you were having a stroke?
    a. If ***yes***, what were your thoughts about this?
    b. If ***not***, what sense did you make of the symptoms that you were experiencing? When were you informed that you had suffered a stroke?
5. Can you describe the accompanying **emotions**?
6. At that time, did you **perceive** your state as one that needed immediate medical attention?
7. What were your **thoughts** regarding your potential **course of action**?
8. If you were **accompanied** at stroke onset:
    a. what was the other person's reaction?
    b. what actions, if any, did the other person take?
9. If you were **alone** at stroke onset, did you inform anyone about your state? If yes:
    a. **who** did you inform?
    b. What was this person's **reaction**?
    c. What **actions**, if any, did this person take?
10. Were there any barriers to your planned course of action?

--- . ---

11. How **long** did it take from stroke onset to the point when medical care was provided?
12. What did **you do** during this period?
13. Did you decide that you needed medical help or was this decided by **someone else**? (Intro.) If this was decided by someone else: (Intro. and background)
    - How did you **feel**?
    - What did you **think**?
14. How do you feel about the way that you **managed** your stroke onset? ***OR*** How do you feel about the way that any other persons involved **managed** your stroke onset?
15. If you were to go back to that day, would you do something **differently**?
16. Do you feel as if back then you had **enough knowledge** and awareness on stroke?
17. Did you or someone you know suffer from a stroke **prior** to this incident? If yes, how did this present? How was this event managed?
18. Prior to this incident, had you ever come across any stroke **educational material**/ **campaigns**? If yes, please describe.
19. What kind of medical **treatment** were you provided with?
20. Do you feel as if this treatment **helped you**?

--- . ---

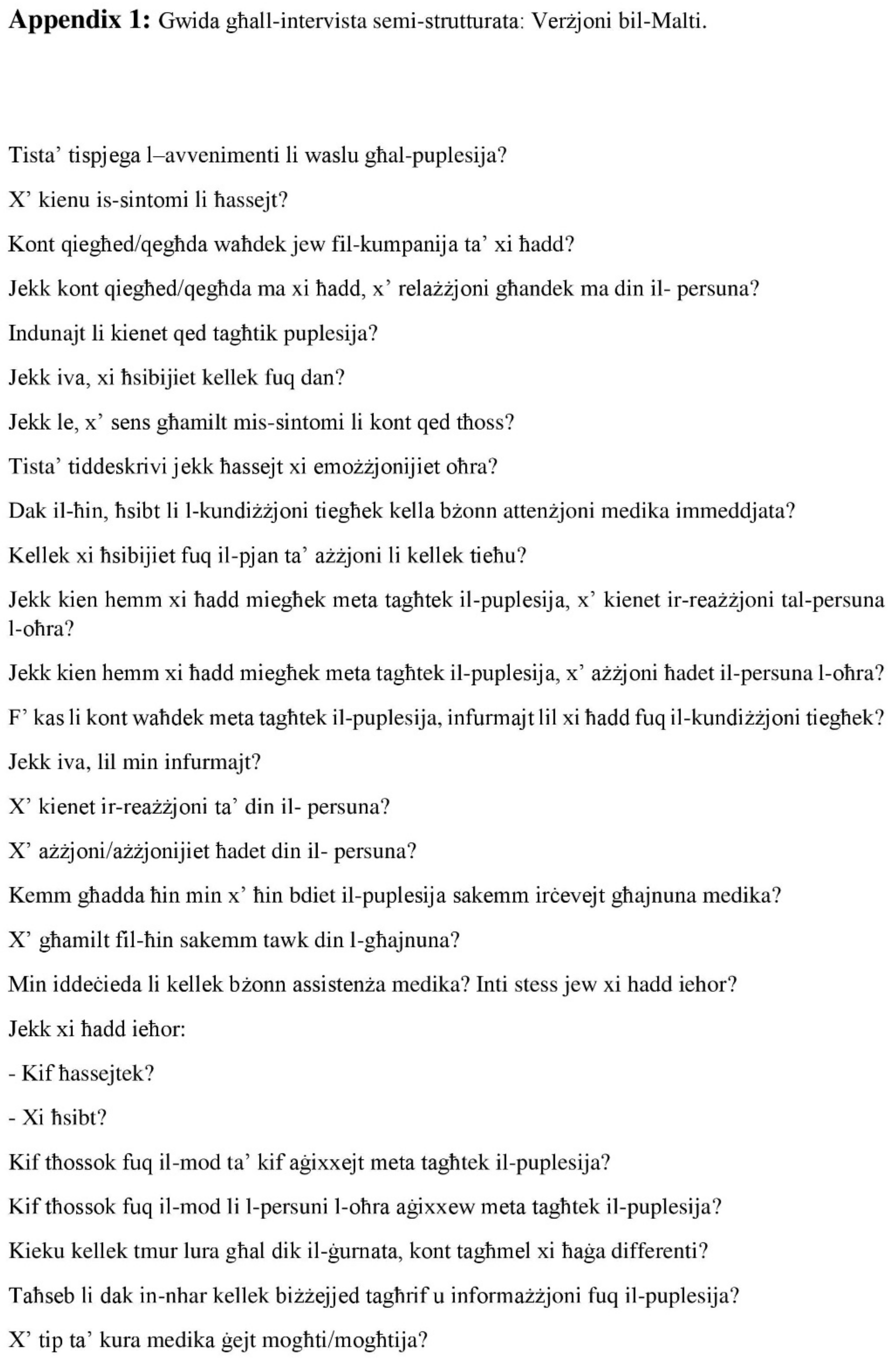
21. Can you name the **main symptoms** of stroke?
22. What should one do in the **eventuality** of a stroke?
23. **Nowadays** what course of action would you take if a stroke were to be experienced by yourself or others?
24. Can you describe what you know about stroke **treatment**?
25. Can you **summarise** what you know about stroke in addition to anything else that you may have already mentioned?
26. Following your stroke incidence, were you provided with advice on desirable **lifestyle adaptations**? Were you given **long-term medication**?

27. Did you **search** for any/further information on your own? If yes, where did you get the information **from**?
28. Following your stroke incidence, did you **change** anything in your life?
29. Do you feel as if you need **more** information about stroke?
30. If so, what **type** of information would you need?
31. Which would be the **best** way for you to access and understand this information?

--- . ---

32. Is there **anything else** that you would like to add?

Appendix 14 - Semi-structured interview guide (Maltese)



Appendix 1: Gwida għall-intervista semi-strutturata: Verżjoni bil-Malti.

Tista’ tispjega l–avvenimenti li waslu għal-puplesija?

X’ kienu is-sintomi li ħassejt?

Kont qiegħed/qegħda waħdek jew fil-kumpanija ta’ xi ħadd?

Jekk kont qiegħed/qegħda ma xi ħadd, x’ relażżjoni għandek ma din il- persuna?

Indunajt li kienet qed tagħtik puplesija?

Jekk iva, xi ħsibijiet kellek fuq dan?

Jekk le, x’ sens għamilt mis-sintomi li kont qed tħoss?

Tista’ tiddeskrivi jekk ħassejt xi emożżjonijiet oħra?

Dak il-ħin, ħsibt li l-kundiżżjoni tiegħek kella bżonn attenżjoni medika immeddjata?

Kellek xi ħsibijiet fuq il-pjan ta’ ażżjoni li kellek tieħu?

Jekk kien hemm xi ħadd miegħek meta tagħtek il-puplesija, x’ kienet ir-reażżjoni tal-persuna l-oħra?

Jekk kien hemm xi ħadd miegħek meta tagħtek il-puplesija, x’ ażżjoni ħadet il-persuna l-oħra?

F’ kas li kont waħdek meta tagħtek il-puplesija, infurmajt lil xi ħadd fuq il-kundiżżjoni tiegħek?

Jekk iva, lil min infurmajt?

X’ kienet ir-reażżjoni ta’ din il- persuna?

X’ ażżjoni/ażżjonijiet ħadet din il- persuna?

Kemm għadda ħin min x’ ħin bdiet il-puplesija sakemm irċevejt għajnuna medika?

X’ għamilt fil-ħin sakemm tawk din l-għajnuna?

Min iddeċieda li kellek bżonn assistenża medika? Inti stess jew xi hadd iehor?

Jekk xi ħadd ieħor:

- Kif ħassejtek?

- Xi ħsibt?

Kif tħossok fuq il-mod ta’ kif aġixxejt meta tagħtek il-puplesija?

Kif tħossok fuq il-mod li l-persuni l-oħra aġixxew meta tagħtek il-puplesija?

Kieku kellek tmur lura għal dik il-ġurnata, kont tagħmel xi ħaġa differenti?

Taħseb li dak in-nhar kellek biżżejjed tagħrif u informażżjoni fuq il-puplesija?

X’ tip ta’ kura medika ġejt mogħti/mogħtija?

Taħseb li t-trattament li ħadt għenek?

Tista issemmi s-sintomi prinċipali tal-puplesija?

Illum il-ġurnata kif tirrejaġixxi jekk int jew xi ħadd ieħor tagħtieh puplesija?

Tista’ tiddeskrivi x’ taf fuq it-trattament tal-puplesija?

Tista’ tgħidli fil-qosor x’ taf fuq il-puplesija apparti dak li diga’ għidtli?

Wara l-puplesija, ġejt provdut b’ informażżjoni u pariri fuq xi adattamenti ta’ l-istil ta’ ħajja tiegħek?

Fittixt għall-aktar informażżjoni min jeddek?

Jekk iva, min fejn sibt din l-informażżjoni?

Minn dak in-nhar bdilt xi ħaġa fl-istil ta’ ħajja tiegħek?

Tħossok li għandek iktar bżonn ta’ informażżjoni fuq il-puplesija?

Jekk iva, x’ tip ta’ informażżjoni għandek bżonn?

Kif ikun l-aħjar mod għalik sabiex taċċessa u tifhem din l–informażżjoni?

Hemm xi ħaga oħra li tixtieq iżżid?

Appendix 15 – Sample interview (Interview 1)

Interview No: 1

Patient's ID:

Date of Interview: 13/06/2017

I: Do you recall what happened when you suffered a stroke?
P: I was in the kitchen, and went to the bedroom where my wife was speaking to our daughter on the phone and I told her - well I tried to tell her but couldn't express myself, well I couldn't express myself ok. Then I tried again but couldn't manage. She told me "Stop kidding me", since I love playing jokes on other people. Then she asked me again to stop it as she thought I was making fun of her. But then she suddenly realised something was wrong with me.

I: Were you aware that something was wrong with you?
P: No I...I thought I was talking in a normal way at that point, but I still felt that I couldn't express myself well.

I: Were you aware that one side of the body was weak?
P: No, certainly not at that point. In fact, when the ambulance people came I asked them whether I should go to the ambulance myself. But they told me that they were going to use a stretcher.

I: Did you wait for the ambulance sitting down?
P: No, I was standing on my feet and walked towards my wife. "I was standing in front of you when I spoke to you and.."

I: Was it the first time that you experienced such symptoms?
P: Yes, it was my first time.
B: eh sorry can I add something? Eight months ago, he went to his brother, so he went and emmm what did you feel exactly on that occasion? Were you confused? When you went to Carol?
P: yes like...
B: He experienced numbness in his arm and then his brother told him to sit down
[2:00]
and after some time he gave him a glass of water and then he improved all of a sudden - but coming to think of it - this must have been a minor stroke...because he still occasionally gets pins and needles in his arm. Do you still get this?
P: Yes just a little bit, but Mr. Manche told me to ignore it.

I: So until you arrived to hospital, where you aware that your body was very weak?
P: No, no, no I wasn't. I only realised that something was wrong when I came to hospital and they told me to raise my arm

I: Oh!, that was at the end of the procedure to check whether it was successful.

P: No, I was a not aware that I had a stroke.

I: So who was there with you when your symptoms started?
B: Well I was there and my daughter was on the phone with me, I was with him all the way but he was very confused.
[3:00]

I: what was going through your mind?
B: No, I knew he was suffering a stroke - yes from the very start.
P: Yes she is an expert when it comes to medical care! (laughs)
B: No, like his face was like this and when I raised his arm - he just dropped it down.

I: Were you aware that these symptoms point to a stroke?
B: Well my father had a stroke and I love reading medical staff…and my son - well he's a pharmasist but he also tries to keep up to date. He used to tell me "mum if dad develops any symptoms do not call the GP or uncle Carol or anyone but rather call an ambulance straight away. Straight to emergency. And that I kept in mind!
P: Why did he only mention dad? Couldn't this have happened to mum as well?
B: That he should have told you I suppose… but I always thought somehow this would happen to you.

I: So, you were not aware that you had suffered a stroke right?
B: No
P: No not that I had suffered a stroke - I cannot recall many things that happened until I came to hospital.
P: They told me...because we live next door to my sister's...I don't recall there were people outside our house
B: Yes, there were many people there...but as he was being transferred to the ambulance - he loves joking with his grandchildren…as they were taking him downstairs, there was his youngest grandson and him one of his usual phrases!, so he wasn't completely off. He still wanted to joke with him and managed to say it to him.

I: Did you experience any feelings?
P: No, i was very calm...
B: Problematic situations are stressful for him...

I: Stress increases the risk of stroke...
B: There was a period where we were really stressed out this last month...because of political reasons...to be fair...we were stressed
P: and the house
[5:00]
B: the house...since we are going to move house...that's at the back of our minds...its traumatic...
P: at our age...I am 82, Marlene is 80...

I: So, you had no plan of action when this all started...
P: No, no

I: Since you didn't realise what was going on...
P: No, no
B: I can assure you - when it comes to healthcare - he just doesn't care, he doesn't know anything...in fact I tease him that he's not like a medical doctor's son! because his father was a general practitioner.

I: He was lucky you were around though
P: of course, very lucky, she's exactly opposite...

I: So what was your first action?
B: I immediately called an ambulance. I was talking to my daughter on the phone, and she asked me what had happened to dad. I told her something is wrong with him. I didn't tell her that he had suffered a stroke at that point, since I didn't want him to hear that..
[6:00]
B: I called the ambulance straight away. And in no time the ambulance was here. My daughter and her husband live in the apartment underneath, and they ran to our place to help me...I prepared everything…well I didn't bring much...just his pyjamas...and then the following day I brought the rest of his stuff...and we prepared to go to hospital...but otherwise I kept very calm...I didn't show him that I was terrified...I was acting really... Because I was utterly terrified about what had happened – I knew exactly what was going on...as I never expected he would be fine again after a couple hours...
[7:00]
P: I still have some amnesia of what happened that day...for example the ambulance...i do not recall that..

I: Were there any barriers for you calling for an ambulance? Or did you want to wait a bit before calling the ambulance?
B: No, no, absolutely not.. I acted as urgently as possible. No straight away...I told them...an ambulance...if it were for him he would think this was nothing and wouldn't act
P: Because I am a very positive person...
B: I asked my daughter to call for an ambulance herself as I couldn't remember the telephone number… the 112…I couldn't recall this number. That I left to my daughter. I knew what was going on from the very start as though I was a medical doctor myself. Because it was very obvious.

I: How long did it take you to arrive to hospital?
B: Well it started at twenty to ten...before half ten we arrived...before half ten.
[8:00]

I: how do you think you manged this stroke situation?

B: Myself? I tried to keep as calm as possible and to take the appropriate action as quickly as possible. So that the things that needed to be done were done!

I: How would you assess yourself for your actions?
B: No i think…I think
P: I would score her a 9 out of 10.
B: I think I did the right thing…not to be proud of myself...but I was aware of it...John used to tell me to go straight to hospital if something like this ever happened…without asking our GP or uncle Carol first. I called the GP after two days and told him 'just to let you know…Louis has suffered a stroke bla bla bla'…
[9:00]

I: Do you feel you had enough knowledge about stroke before this happened?
P: No, I had no experience what so ever…
B. And he never thought this could have happened to him.

I: Do you know any signs and symptoms of stroke?
P: The visual signs – yes, I knew…but otherwise I didn't know…are you understanding?

I: Are you aware of any stroke campaigns? For example the FAST campaign?
B: No

I: Or any form of stroke education?
B: No, in fact I grabbed some leaflets about stroke in hospital which I am currently reading…and I am telling everyone if you see any signs…this I will continue to preach…straight to Mater Dei…no GP.
[10:00]

I: Are you aware of which treatment you received in hospital?
P: The treatment…I think they gave me Simvastatin again which I had stopped…they kept my aspirin but also added a new drug.

I: Do you recall which acute treatments you received on your arrival to hospital?
P: No when we arrived there, they placed me on the bed…and…

I: Yes that's during the thrombectomy procedure…
B: But that's the last thing that happened…he's asking you what happened before that…when you came though the emergency department
P: No, they didn't do anything in the A&E.
B: What? They didn't do anything?
P: I don't recall what was happening during this time.
B: You were still confused. I thought he was administered that famous injection…the PTA?
[11:00]

I: Yes he was given t-PA
B: Ah, so he had it as well...so why did the nurse tell me otherwise?
P: Does that help further?
I: Yes, it does since it acts as 'bridging therapy'…it starts working until the interventional team arrives to hospital for the thrombectomy.
B: so why does it help you?

I: It prevents clot propagation and stops the evolution of stroke.

B: Of course, they told us about the risks associated with the proposed treatment…I was with my son Joe and he told me "mum what can you do? Leave him like this?" and there was a very nice doctor called Marija who told me hat if this had happened to her dad, she would agree to this treatment. So, I told her that we would follow her advice…

I: Do you think that the treatment you received was beneficial?
B: Oh yes!
P: Obviously! Isn't it obvious that it would have helped me?

I: No…
P: Whatever was done to him was done to perfection…

I: No, sometimes the treatment is less successful…and patients may not improve significantly after this treatment…
B: He didn't know what was happening, he didn't know.
P: But I asked the interventionalist, I even asked him how long I it was going to take…
B: Perhaps he was already improving after the TPA…
[13:00]

I: He was also suffering from neglect.
B: What's that?

I: It means that the affected brain completely ignores the contralateral side…so you would completely ignore people speaking to you from that side.
B: You completely ignore them!
P: I asked the interventionalist how long the procedure would take and he told me about 45 minutes..
B: And they told us around 2.5 hours so that we would's worry if it took longer...then the anaesthetist came out first…but they didn't give him a total anaesthetic?

I: No, his procedure was performed under local anaesthesia, but an anaesthetist is always present to provide backup in case something goes wrong.

B: And he told us "he's stable" …so I have 3 children…my elder daughter tends to panic a bit…my son is more practical and nervous and the younger daughter is much calmer…so when he told us "he's stable" my elder daughter told me "mum what does that mean?". John told her "It's the opposite of unstable!" …but she was so anxious that stable didn't mean anything to her!

I: Can you mention signs and symptoms of stroke?
P: As Marlene said previously, I would look for facial asymmetry and drooping, upper limb weakness…they asked me raise your hand…but I couldn't do it.
B: It was completely dead
P: I tried to but couldn't manage…those are the most important signs…patients can also fall down to the ground.
B: I think if more time had passed he would have dropped down to the ground! God must have kept a close eye on him.
[15:00]
B: He was close to an armchair so I helped him to sit down immediately.
P: We were a bit lucky, I suppose…
B: The interventional team was in hospital very quickly…because they are not in hospital but were 'on call'.

I: How would you react if your wife had to suffer a stroke?
P: I would jump from somewhere! (laughs)…I think I would do the same thing now that I know…I would immediately call for an ambulance.

I: What do you know about stoke?
P: If someone cannot speak to me all of a sudden, I would think he might have a stroke.

I: The main symptoms are summarised in FAST: F stand for face which you just described, A is for arms which you also mentioned, S is for speech and T is Time. Which means that you have described all the major symptoms of stroke.
P: I also had a headache…as I never suffer from headaches…

I: Has someone described to you how you can reduce the risk of stroke in the future?
P: Yes, they gave me a bunch of papers

I: Have you had time to read through?
P: Yes, I have read them all.

I: So what are you going to do to reduce future risk of stroke?
P: I shall drink more whiskey…(laughs)…no my wife will…
B: I though he was kidding me initially but when I saw his eyes staring like that…i knew straight away.
P: She realised because she's very attentive.
B: You asked him a question?

I: Yes about strategies to reduce future strokes.

B: We will try to go for regular walks, take care of our diet, reduce our alcohol intake…
P: Professor Frederick Fenech used to tell me…one shot a day is good for your health.

I: Did this episode change your life?
P: No till now it hasn't.
B: He needs to change his lifestyle…he's always very busy…going up and down the stairs…why do you do this? You are abusing of the situation…your body talks to you! You shouldn't over do it Lu! Try to relax a bit! There's a limit.

I: Were you provided with stroke information during your hospital stay?
B: Not really, but they gave us some leaflets…in my own time I will read them over and over again.

I: Which medium do you think is best to deliver stoke education? Leaflets? Internet?
P: Something visual is always better because it's more practical…especially to understand the symptoms and so on.

I: Do you want to add something else to this interview?
P: Yes – can I continue with my normal life?

I: It is really important not to stress yourself…its fine to keep yourself active but you shouldn't stress yourself out – try to avoid such situations.
P: What are the chances that I will suffer another stroke?

I: Up to 5-10% of patients may suffer another episode within the first 2 months – so this period is a crucial one…They have thoroughly assessed your heart and carotid arteries and also carried out a number of blood test to make sure no underlying cause is identified. You have also been prescribed treatment like aspirin and clopidogrel which are also known to reduce the chances of this happening again.
P: the thing that worries me most is the fact that you have no notice what so ever!

I: Yes, in fact stoke is sometimes referred to as a "brain attack".
P: In fact, you don't notice that it's happening unfortunately…it's like what had happened with my heart…they had performed a by-pass on me but I didn't experience any chest pain. In fact, the cardiologist had told me you had no red lights to alert you!
B: So, he discovered this during a pre-operative visit for an elective hernia repair...and they realised something was not quite right with his heart…he also had a murmur which required a valve replacement.

I: Most often warning signs in stroke are minor strokes that occur months or days before …sometimes TIAs may also occur...this stands for transient ischaemic attacks which resembles a stroke but the symptoms are self-limiting and usually resolve within a couple of minutes.
B: My father used to have that.

Appendix 16 – Qualitative codes

1. Barriers for bystander/ patient action

a) Self-confidence (decision to call for an ambulance)
b) Could not call ambulance as preferred to stay with patient
c) Not wishing to make a big deal of it so as not to scare relatives

2. Bystander's plan for stroke prevention

a) Exercise
b) Diet
c) Reduce alcohol intake
d) Reduce stress
e) Quit smoking

3. Bystander's reflections on action taken

a) Happy that they called an ambulance
b) Wished to call for an ambulance

4. Bystander action

a) Called ambulance first
b) Called relative first, then ambulance
c) Called GP
d) Went to hospital by private transport
e) Decided to wait and see if symptoms improve

5. Bystander insight

a) Knew that s/he has stroke
b) Had no idea what was wrong

6. Bystander observation of symptoms

a) Confusion
b) Loss of muscle power (legs/arms)
c) As if chocking
d) Slowing of movement
e) Limb stiffness
f) Speech
g) No symptoms
h) Vomiting

7. Bystander post stroke knowledge

a) Take patient straight to hospital by calling an ambulance
b) Still call GP first
c) Identification of symptoms
d) Causes of stroke
e) Treatment of stroke

8. Bystander pre-stoke knowledge

a) Know that have to call an ambulance

b) Stroke campaigns
c) Signs and symptoms
d) Treatment
e) TV
f) Leaflets
g) Reading medical literature
h) None
i) From relatives

9. Information provided by health carers after stroke

a) Documents with information or leaflets
b) No information
c) Smoking cessation advice
d) Diet advice
e) Information regarding causes and nature of stroke
f) Information on what to do in case of other eventuality

10. Interactions with health carers

a) Confusion regarding understanding medics / communication problems
b) Advice regarding treatment/action
c) Lack of information given
d) Misdiagnosis by GP
e) Explanations

11. Knowledge seeking after stroke

a) No knowledge seeking
b) Radio

12. Patient feelings during onset

a) Calm
b) Sad
c) Confused
d) Helpless
e) Scared
f) Panicked

13. Patient plan for stroke prevention

a) Quit smoking
b) Reduce alcohol intake
c) Reduce stress
d) Diet
e) Compliance to medication
f) Exercise

14. Patient post stroke insight/knowledge/awareness

a) Stroke symptoms
b) Treatment options

c) Action to take
d) Prevention

15. Patient's recollection of events

a) Decreased muscle power
b) Speech problem
c) Facial numbness
d) Dizziness
e) General weakness
f) Mouth deviated
g) Mobility problems
h) Headache

16. Patient's reflections on actions taken

a) Nothing much to do
b) No idea what should be done
c) Acting quick is necessary

17. Patient actions during onset

a) Told relative
b) GP
c) Wait to get better
d) Hospital by ambulance

18. Patient behaviour after previous stroke

a) No change

19. Patient insight/knowledge

a) No insight
b) Was aware something was wrong
c) Realised it's a stroke

20. Patient pre-stroke knowledge

a) No relevant knowledge
b) Some knowledge eg. Symptoms

21. Perceived stroke precipitators

a) Stress

22. Perception of effectiveness of treatment

a) Effective

23. Preferred mode of receiving information

a) Visual eg. TV
b) Auditory eg. Radio
c) Reading

24. Previous symptoms

a) Confusion
b) Limb and facial numbness

25. Sources of stroke related information

a) Significant others who are knowledgeable
b) TV
c) Radio

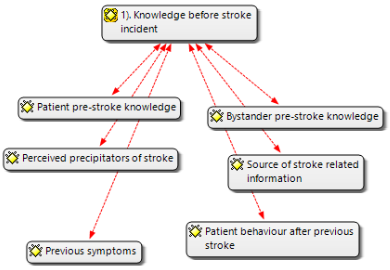
26. Time from onset to help

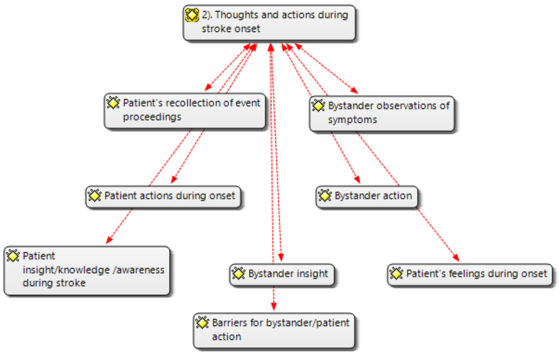
a) Less than 1 hour
b) More than 5 hours
c) 2-3 hours

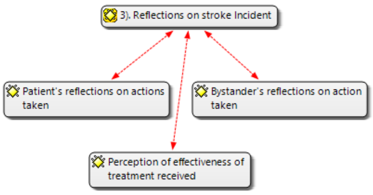
27. Willingness to receive more information

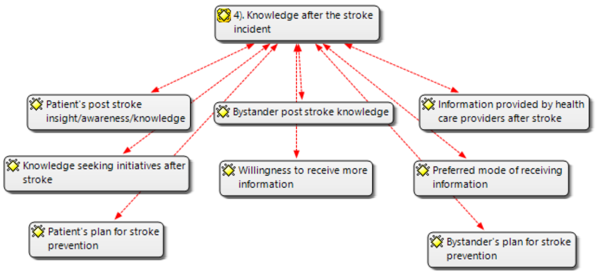
a) No willingness
b) Yes

Appendix 17 - Network view (Atlas.ti)

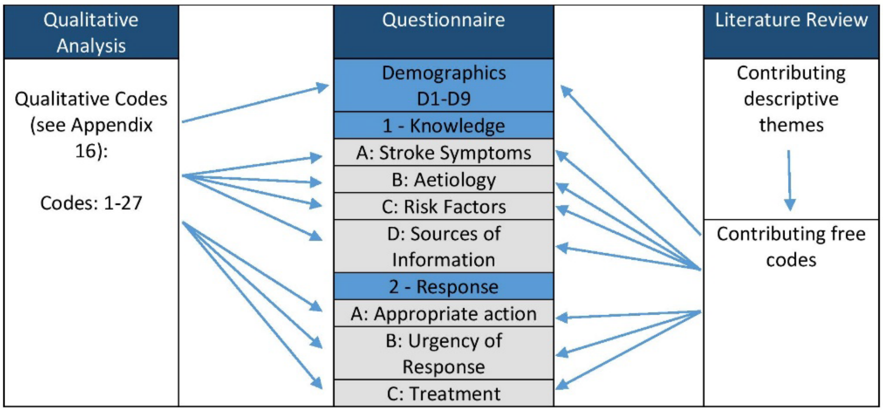








Appendix 18 - *Framework for construction of Matrix (adapted from Figure 3.2)*



Appendix 19 – Matrix

QUALITATIVE ANALYSIS		QUESTIONNAIRE		LITERATURE REVIEW	
			Code		Section
		DEMOGRAPHICS			**Contributing Analytical Themes** Sections 2.3, 2.11
		Age	**D1**	**Contributing descriptive themes:** 2.3.2.1 **Contributing free codes:** Yoon et al. (2001); Greenlund et al. (2003); Johnston et al. (2003); Silver et al. (2003); Jurkowski et al. (2008); Reeves et al. (2008); Hickey et al. (2009); Jones et al. (2010); Marx et al. (2010)	
		Gender	**D2**	**Contributing descriptive themes:** 2.3.2.3 **Contributing free codes:** Menon et al. (1998); Cheung (2000); Yoon et al. (2001); Barr et al. (2006); Muller-Nordhorn et al. (2006); Marx et al. (2010)	
		Nationality	**D3**	**Contributing descriptive themes:**	

				2.3.2.2 **Contributing free codes:** Kothari et al. (1997); Yoon et al. (2001); Pandian et al. (2005); Das et al. (2007); Marx et al. (2008); Hickey et al. (2009)	
		Ethnicity	**D4**	**Contributing descriptive themes:** 2.3.2.2 **Contributing free codes:** Horner et al. (1991); Stern et al. (1999); Jones et al. (2000); Reeves et al. (2002); Greenlund et al. (2003); Schneider et al. (2003); Shen et al. (2004); Ferris et al., (2005); DuBard et al. (2006); Lutfiyya et al. (2008); Jones et al. (2010); Lutfiyya et al. (2010); Malek et al. (2014)	
		Education	**D6**	**Contributing descriptive themes:** 2.3.2.4 **Contributing free codes:** Baker et al. (1996); Parikh et al. (1996); Pancioli et al. (1998); Williams et al. (1998); Lee (1999); Lasater et al., (2001); Yoon et al. (2001);	
		Income	**D7**		

				Reeves et al. (2002); Travis et al. (2003); Nicol and Thrift (2005); Wilson et al., (2005); Alkadry et al. (2006); Ellis et al. (2009); Hickey et al. (2009); Kleindorfer et al. (2009); Marx et al. (2010); Jones et al. (2010); Lutfiyya et al. (2010)	
		Risk Factors	**D8**	**Contributing descriptive themes:** 2.3.2.5 **Contributing free codes:** Kothari et al. (1997); Williams et al. (1997); Rodgers et al. (1999); Yoon et al. (2001); Travis et al. (2003); Bellolio et al. (2007); Jones et al. (2010); Goldstein et al. (2011); Weltermann et al. (2013)	
		Region of Malta	**D5**	**Contributing descriptive themes:** 2.3.2.2; 2.11.2; 2.11.3 **Contributing free codes:** Agius et al. (1990); Kothari et al. (1997); Yoon et al. (2001); Das et al. (2007); Marx et al. (2008); Hickey et al (2009); World Health Organisation (2014); Mallia et al. (2015) Agius et al. (1990); Kothari et	

				al. (1997); Yoon et al. (2001); Das et al. (2007); Marx et al. (2008); Hickey et al (2009); World Health Organisation (2014); Mallia et al. (2015)	
		Healthcare Worker	**D9**	**Contributing descriptive themes:** 2.3.5 **Contributing free codes:** Dewey et al. (1999); Rancatore et al. (1999); Nor et al. (2004); Wojner-Alexandrov et al. (2005); Harper (2007); Kirchoff-Torres et al. (2011); Devon and Zrelak (2012); Sangeeta et al. (2013); Kawano et al. (2014); Chenna et al. (2014); Park et al. (2015)	
Contributing themes: ▪ Knowledge before stroke incident ▪ Thoughts and Actions during stroke onset ▪ Reflections on Stroke Incident		**1: KNOWLEDGE**			**Contributing Analytical Themes** Sections 2.3, 2.5, 2.6, 2.7, 2.9, 2.11

- Knowledge after the stroke incident					
	Contributing codes: 1,6,7,14,15,20	**A: Stroke Symptoms**		**Contributing descriptive themes:** 2.3.3.1; 2.3.5; 2.5.2; 2.11.4	
	Contributing quotes:			**Contributing free codes:**	
	14a	*Hemiplegia/hemiparesis*	**(K14)**	Kothari et al. (1997); Williams et al. (1997); Pancioli et al. (1998); Yoon et al. (2001); Schneider et al. (2003); Nor et al., 2004; Nicol and Thrift (2005); Agyeman et al. (2006); Harper et al. (2007); Das et al. (2007); Hickey et al. (2009); Jones et al. (2010); Addo et al. (2012); Caruana et al. (2013); Park et al. (2015)	
	6b, 15f,7c, 14a, 20b	*Loss of muscle power*	**(K14)**		
	6c	*Feeling as if choking*			
	6e	*Limb stiffness*			
	6h	*Vomiting*			
	6g, 14a	*No symptoms*	**(K13)**		
	15e	*General weakness*	**(K14)**		
		Sudden numbness	**(K12)**		
	6a	*Confusion*			
	15c, 15f, 7c, 14a	*Visual problems*	**K4**		
	6d, 15d, 15g, 7c 1a	*Difficulty walking /dizziness*			
	6f, 15b, 7c, 14a	*Difficulty with speech*	**K7**		
	15h	*Headache*	**K11**		
		Negative option	**(K3)**		
		B: Aetiology		**Contributing descriptive themes:** 2.3.2; 2.3.3	
				Contributing free codes:	
		Prevalence	**K2, (K8)**		

		Gender distribution	**(K9)**	Kothari et al. (1997); Inzitari et al. (2000); Nicol and Thrift (2005); Jones et al. (2010)	
		Organ affected	**(K6)**		
		Pathology			
	Contributing codes: 2,13,21,14	**C: Risk Factors**		**Contributing descriptive themes:** 2.3.2; 2.3.3	
	Contributing quotes:			**Contributing free codes:**	
	2d, 13c, 21a	*Stress*		Kothari et al. (1997); Williams et al. (1997); Rodgers et al. (1999); Yoon et al. (2001); Travis et al. (2003); Bellolio et al. (2007); Jones et al. (2010); Goldstein et al. (2011); Weltermann et al. (2013)	
	2e, 13a, 14d	*Smoking*	**K1**		
	2c, 13b	*Alcohol*			
	2a, 13f, 14d	*Sedentary lifestyle*	**(K16)**		
	2b, 13d, 14d	*Diet*			
		Diabetes	**K10**		
		Cardiovascular disease			
		Previous stroke/TIA	**K5**		
	Contributing codes: 8,25,10,9,8,20,23,11,27	**D: Sources of Information**		**Contributing descriptive themes:** 2.3.3.2; 2.6; 2.7	
	Contributing quotes:			**Contributing free codes:**	
		Formal education		**Contributing descriptive themes:** 2.6.10 **Contributing free codes:** Wein et al. (2000); Morgenstern et al. (2007); Werner et al. (2012); Navarro et al. (2013)	

		Previous experience/family history			
	8b	*Educational campaigns*	**K15**	**Contributing descriptive themes:** 2.6.2-2.6.10; 2.3.5.3; 2.7.2 **Contributing free codes:** Farquhar et al. (1977); Kothari et al. (1997); Becker et al. (2001); Yoon et al. (2001); Morgenstern et al. (2002); Silver et al. (2003); Travis et al. (2003); Emr et al. (2006); Das et al. (2007); Hodgson et al. (2007); Prochaska et al. (2008); Marx et al. (2008); Tadros et al. (2009); Boden-Albala et al. (2010); Jones et al. (2010)	
	8i, 25a	*Relatives*			
		Health Carers			
	10b, 9a, 9c,9d,9e,9f	*Advice given*	**(K16)**		
	10c,10d, 9b	*No/wrong advice given*	**(K16)**		
		Health literacy & Stroke Education e.g.		**Contributing descriptive themes:** 2.9.2.1; 2.9.2.2	

	10a	*Communication problems with health carers*		**Contributing free codes:** Fang et al. (2009); Mohan et al. (2011); Bushnell et al. (2013); Sanders et al. (2014); Hahn et al. (2015)	
	8f	*Leaflets*	**K17**		
	8e, 25b, 25c, 20b	*Media*	**K17**		
	8g	*Medical literature*			
	20a	*Others*			
	Preferred sources of information:				
	23a	*TV*	**K17**		
	23b, 11b	*Radio*	**K17**		
	23c	*Reading material*	**K17**		
	11a, 27a	*No information wanted*			
Contributing themes: ▪ Thoughts and actions during stroke onset ▪ Knowledge before stroke incident ▪ Reflections on stroke incident ▪ Knowledge after the stroke incident		**2 - RESPONSE**			**Contributing Analytical Themes** Sections 2.3, 2.4, 2.5, 2.8, 2.9, 2.10, 2.11
	Contributing codes:	**A: Appropriate action**		**Contributing descriptive themes:**	

	17,4,8,14,16,7,5,19			2.4.2	
	Contributing quotes:			**Contributing free codes:**	
	17d, 4a, 8a	Calling 911/ Emergency services	**(R2), R5, R12**	Williams et al. (1997); Schroeder et al. (2000); Yoon et al. (2001); Harraf et al. (2002); Billings-Gagliardi and Mazor (2005); Ritter et al. (2007); Fogle et al. (2008); Jurkowski et al. (2008); Fussman et al. (2010); Jones et al. (2010); Jurkowski et al. (2010)	
	17b,4c, 7b, 14c	Calling GP first			
	4d	Going to hospital by own transport	**(R14)**		
		Eliminating the GP call e.g.	**(R1)**		
	4e, 17c	Waiting to get better			
	4b, 14c, 17a	Call relatives	**(R4)**		
	16a, 16b, 7a, 14c	No idea of appropriate action			
		Insight during stroke e.g.	**R13**		
	5a, 19c	Aware that these symptoms characterise a stroke			
	5b, 19a, 19b	No idea what is wrong			
		Inability to make the call	**(R17)**		
		Role of by-stander			

		Health literacy		**Contributing descriptive themes:** 2.9.2	
A	**Contributing codes:** 4,17,26,1	**B: Urgency of Response**		**Contributing descriptive themes:** 2.4.3; 2.5.2; 2.8.1; 2.10.3; 2.10.4	
	Contributing quotes:			**Contributing descriptive themes:** 2.4.3; 2.5.2	
	4e, 17c	'wait and see' approach / delay in presentation	**R3, (R8)**		
	Time taken from onset to arrive to hospital:		**R15, R16**		
	26a	Less than 1 hour			
	26c	2-3 hours			
	26b	More than 5 hours			
	1a,1b	Psychological processes	**(R7)**	**Contributing descriptive themes:** 2.4.3.2; 2.4.3.3; 2.8.1	
	1a,1b,1c	Barriers for action	**(R4)**	**Contributing descriptive themes:** 2.4.3.2	
		In-hospital delay		**Contributing descriptive themes:** 2.5.3	
	Contributing codes: 7,14,22	**C: Treatment**		**Contributing descriptive themes:** 2.3.3.3; 2.11.5	
	Contributing quotes:			**Contributing free codes:**	

		‘Time-window’ of AIS treatment	**R15**	Pancioli et al. (1998); Travis et al., (2003); Kleindorfer et al. (2009); Berkhemer et al. (2015); Campbell et al. (2015); Goyal et al. (2015); Jovin et al. (2015); Mallia et al. (2015); Micallef et al. (2015); Saver et al. (2015)	
		‘Time is Brain’ concept	**R16**		
	22a	Effectiveness of treatment	**R6, (R7), (R11)**		
		Negative option	**(R9)**		
	7e, 14b	Types of treatment available	**R15**		

Appendix 20 – Questionnaire

Demographics Section

D1	Age	__ yrs
D2	Gender	M F
D3	Nationality	Maltese Other
D4	Ethnicity	
D5	Region of Malta	Gozo North Central South
D6	Education[2]	Primary Secondary Tertiary
D7	Income	< between >
D8	Risk Factors	Previous stroke Cardiovascular disease Diabetes Hypertension Smoking History
D9	Healthcare Worker	Y N

Likert Scale:

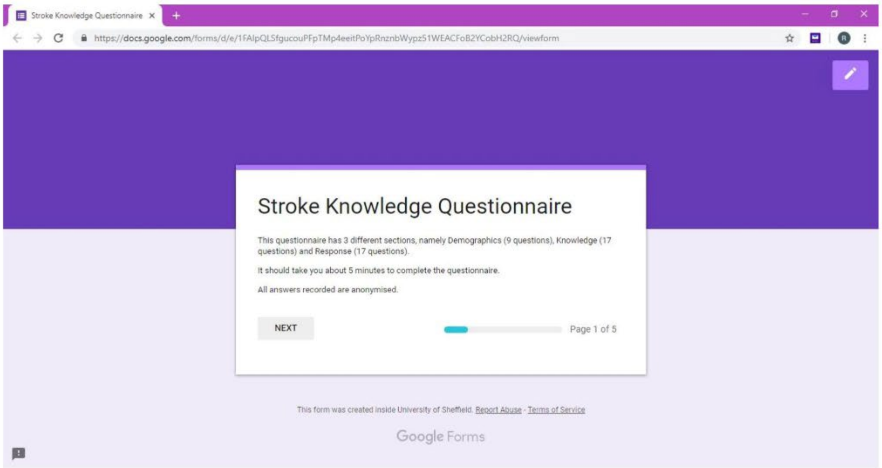
1 **Strongly Agree**	**2** **Agree**	**3** **Undecided**	**4** **Disagree**	**5** **Strongly Disagree**
☐	☐	☐	☐	☐

		-ve	Answer
Knowledge			
K1	Smoking is a risk factor for stroke		T
K2	Stroke is commoner than breast cancer		T
K3	Chest pain is a common symptom of stroke	N	F
K4	Loss of vision and vertigo can be secondary to stroke		T
K5	Previous transient ischaemic attacks (TIAs) increase future stroke risk		T
K6	Stroke affects the heart	N	F
K7	Difficulty to talk or understand speech should raise suspicion of stroke		T

K8	Stroke is a rare cause of long-term disability	N	F
K9	Stroke is more common in females		T
K10	Diabetes increases the risk of stroke		T
K11	Headache may occasionally be secondary to stroke		T
K12	Sudden loss of sensation is not related to stroke	N	F
K13	Stroke is always characterised by symptoms	N	F
K14	Muscle or limb power is not affected in stroke	N	F
K15	The acronym ‘FAST’ in the ‘Act FAST’ campaign stands for Face, Arms, Speech and Time		T
K16	Patients who have suffered a stroke should be advised to adopt a sedentary lifestyle	N	F
K17	Mass media adverts and educational leaflets on stroke are effective in increasing stroke awareness and education		T
Response			
R1	One should only call his GP if his symptoms fail to improve	N	F
R2	One should attend a polyclinic or a nearby hospital immediately	N	F
R3	One should act fast and avoid unnecessary delays		T
R4	One should discuss with his/the patient’s relatives before taking any action	N	F
R5	The emergency phone number is 112		T
R6	Stroke symptoms and long term outcome may improve if the appropriate treatment is given		T
R7	Prognosis of stroke patients is invariably poor	N	F
R8	One should ‘wait and see’ before taking any action	N	F
R9	The patient should have his lower limbs elevated	N	F
R10	Paracetamol is not an effective treatment against stroke		T
R11	Stroke will progress no matter one’s reactions	N	F
R12	One should call for an ambulance immediately		T
R13	The affected person may not realise that he is suffering a stroke		T
R14	If the patient is able to drive to the emergency department, he should do so immediately	N	F
R15	‘Clot buster’ treatment (t-PA) cannot be administered after 6 hours		T
R16	Brain cells are damaged irreversibly in stroke, and the extent of damage is time-dependent		T
R17	A stroke sufferer should always call for help himself so as not to be a burden on others	N	F
TOTAL		16	

Appendix 21 - Questionnaire (Google Forms)

https://docs.google.com/forms/d/e/1FAIpQLSfgucouPFpTMp4eeitPoYpRnznbWypz51WEACFoB2YCobH2RQ/formResponse



Stroke Knowledge Questionnaire

This questionnaire has 3 different sections, namely Demographics (9 questions), Knowledge (17 questions) and Response (17 questions).

It should take you about 5 minutes to complete the questionnaire.

All answers recorded are anonymised.

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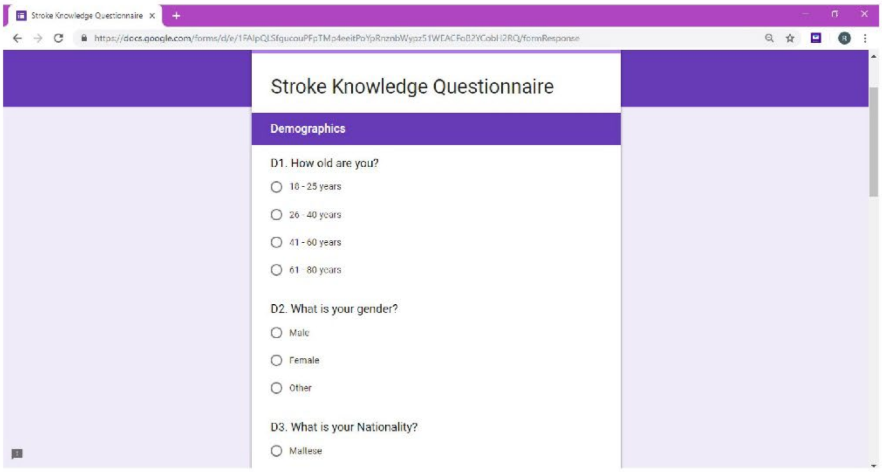


Stroke Knowledge Questionnaire

Demographics

D1. How old are you?

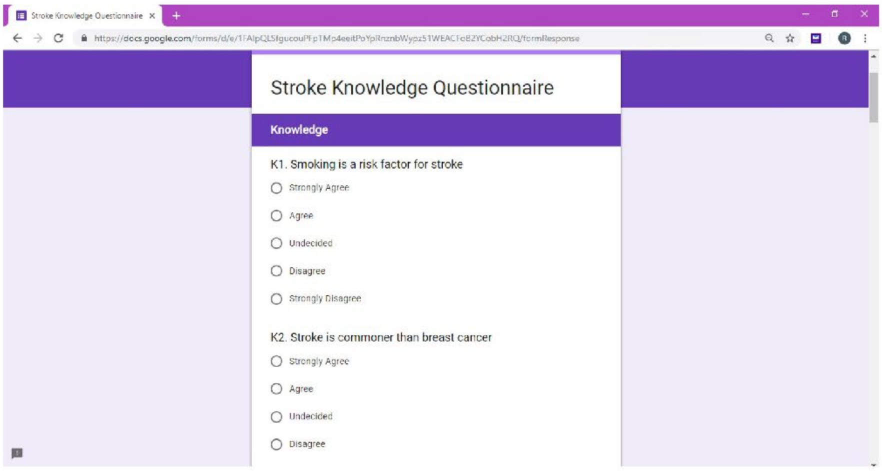
○ 18 - 25 years
○ 26 - 40 years
○ 41 - 60 years
○ 61 - 80 years

D2. What is your gender?

○ Male
○ Female
○ Other

D3. What is your Nationality?

○ Maltese



Stroke Knowledge Questionnaire

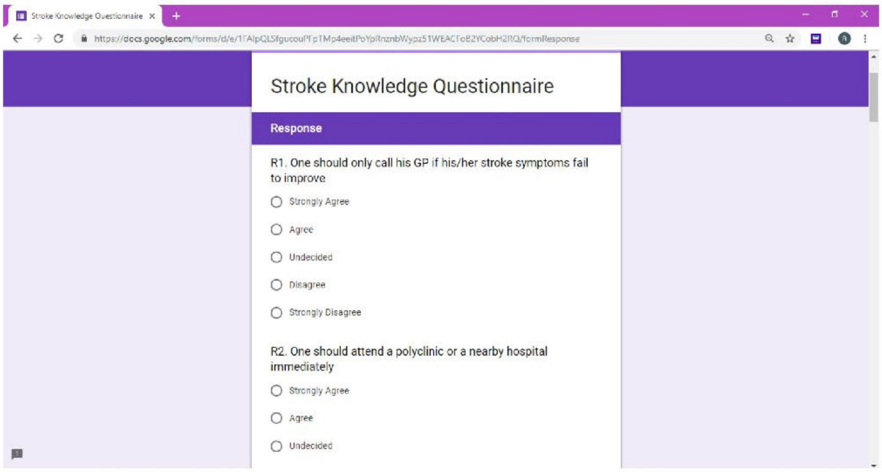
Knowledge

K1. Smoking is a risk factor for stroke

○ Strongly Agree
○ Agree
○ Undecided
○ Disagree
○ Strongly Disagree

K2. Stroke is commoner than breast cancer

○ Strongly Agree
○ Agree
○ Undecided
○ Disagree



Stroke Knowledge Questionnaire

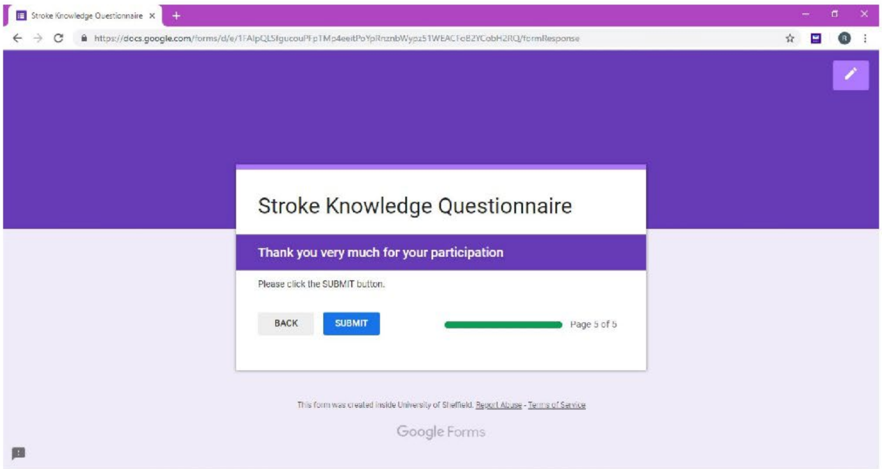
Response

R1. One should only call his GP if his/her stroke symptoms fail to improve

○ Strongly Agree
○ Agree
○ Undecided
○ Disagree
○ Strongly Disagree

R2. One should attend a polyclinic or a nearby hospital immediately

○ Strongly Agree
○ Agree
○ Undecided



Stroke Knowledge Questionnaire

Thank you very much for your participation

Please click the SUBMIT button.

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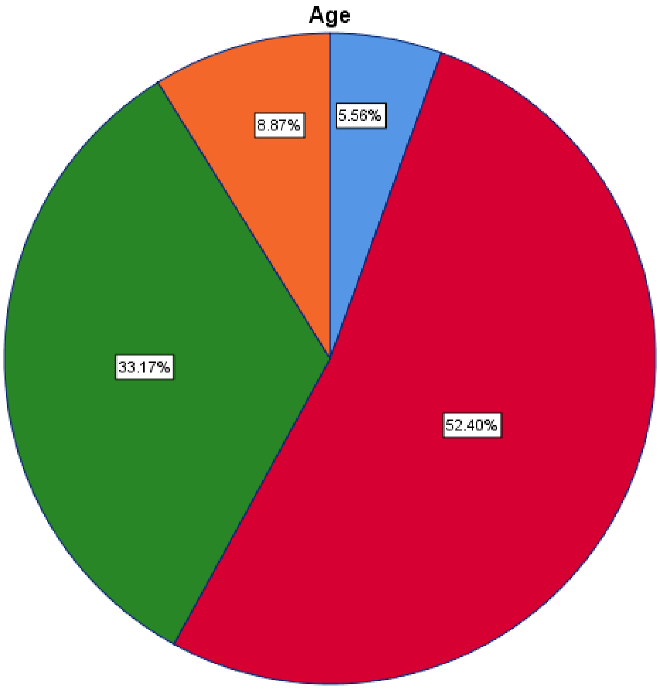
Appendix 22 – Demographic data of participants

D1 – Age

		Frequency	Percent
Valid	18–25 years	104	5.6
	26–40 years	981	52.4
	41–60 years	621	33.2
	61–80 years	166	8.9
	Total	1872	100.0

Age of Participants

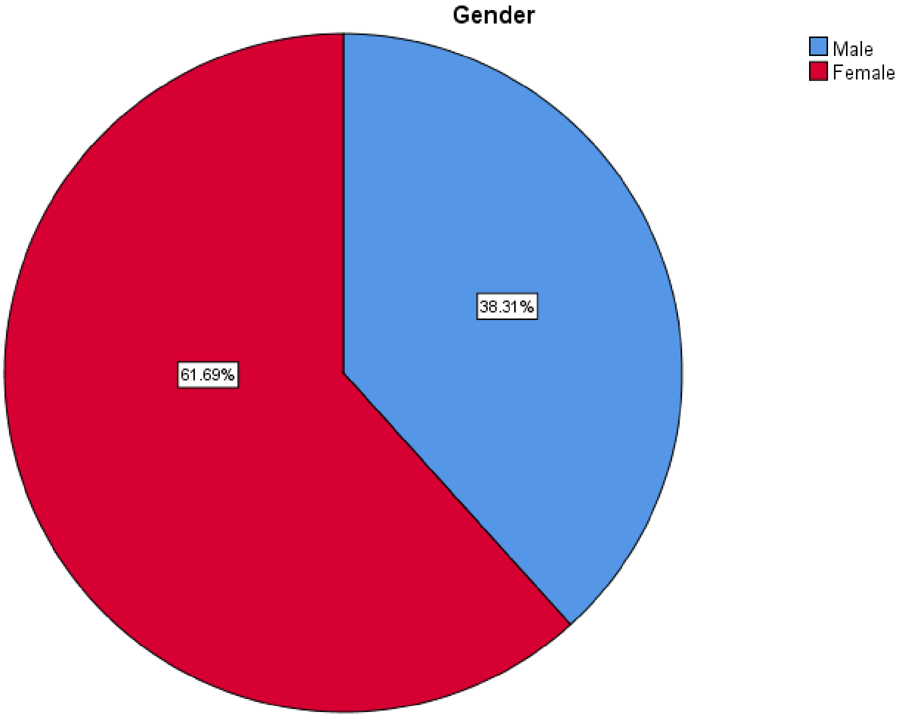


Pie Chart of Age Distribution of Participants

D2 – Gender

		Frequency	Percent
Valid	Male	716	38.2
	Female	1153	61.6
	Total	1869	99.8
Missing	System	3	0.2
Total		1872	100.0

Gender of Participants

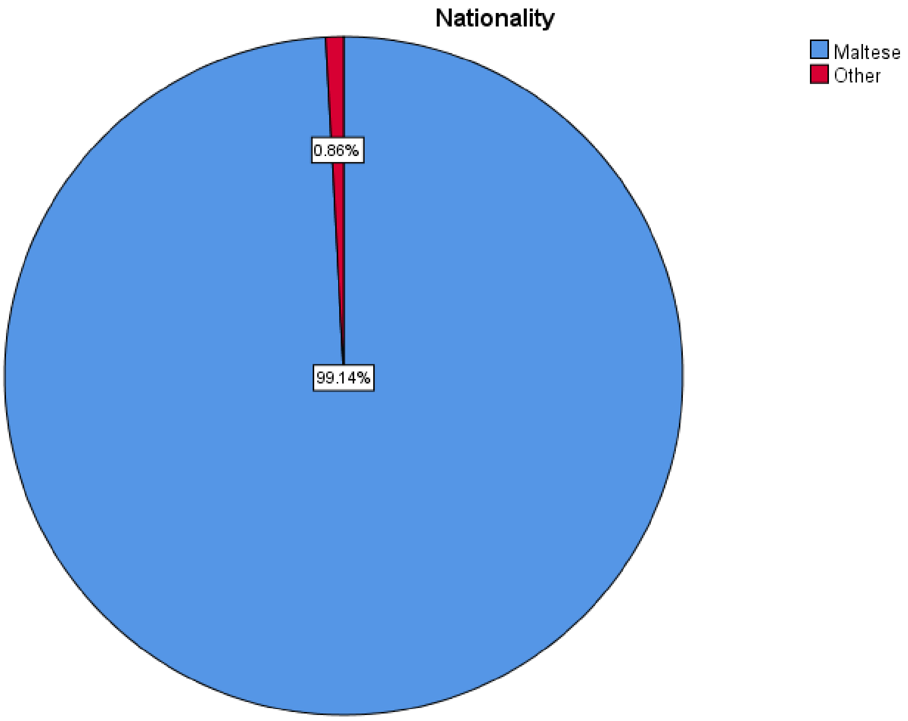


Pie Chart of Gender of Participants

D3 – Nationality

		Frequency	Percent
Valid	Maltese	1848	98.7
	Other	16	0.9
	Total	1864	99.6
Missing	System	8	0.4
Total		1872	100.0

Nationality of Participants

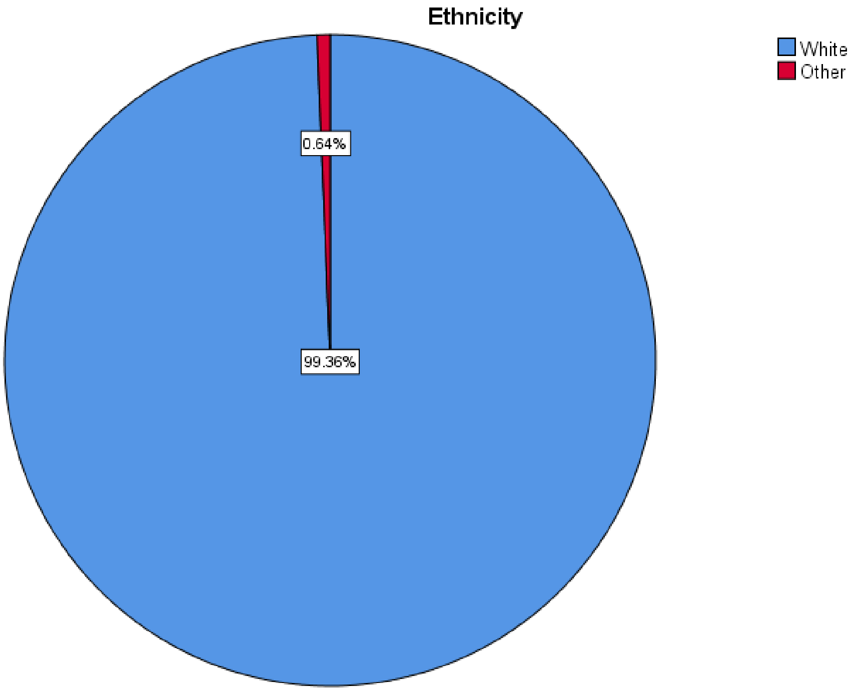


Pie Chart of Nationality of Participants

D4 – Ethnicity

		Frequency	Percent
Valid	White	1854	99.0
	Other	12	0.6
	Total	1866	99.7
Missing	System	6	0.3
Total		1872	100.0

Ethnicity of Participants

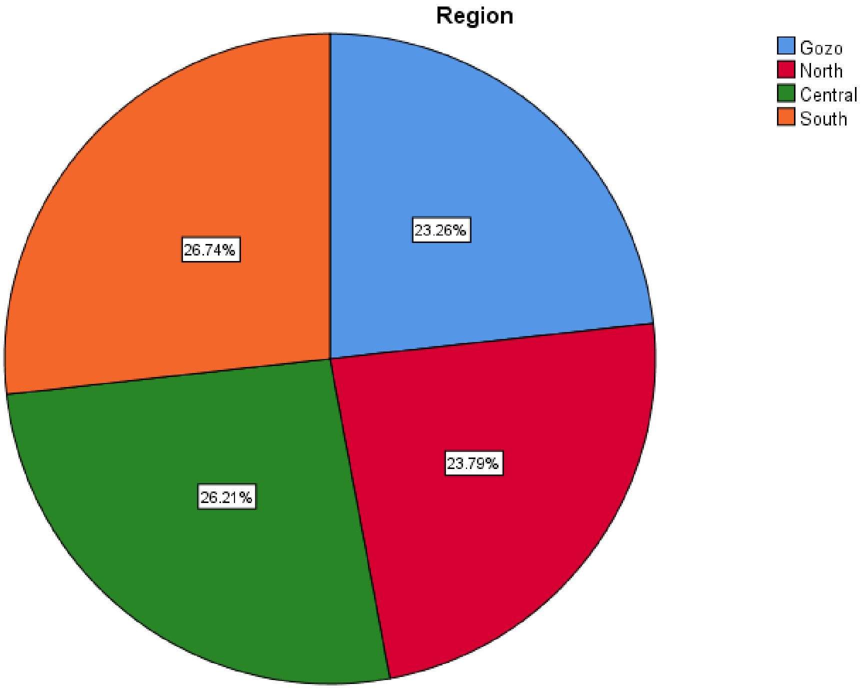


Pie Chart of Ethnicity of Participants

D5 – Region of Malta

		Frequency	Percent
Valid	Gozo	434	23.2
	North	444	23.7
	Central	489	26.1
	South	499	26.7
	Total	1866	99.7
Missing	System	6	0.3
Total		1872	100.0

Regional Distribution of Participants

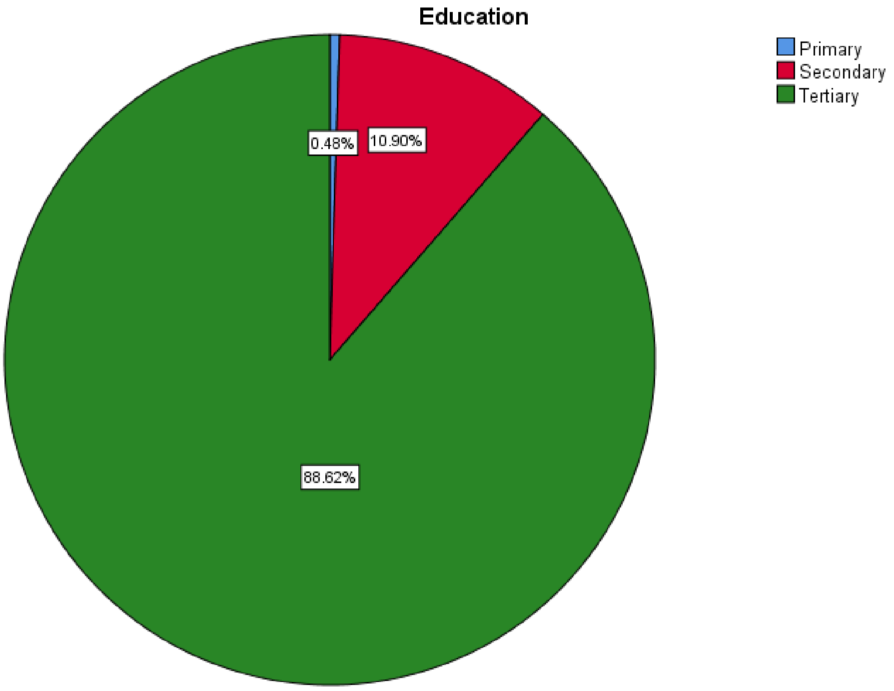


Pie Chart of Regional Distribution of Participants

D6 – Education

		Frequency	Percent
Valid	Primary	9	0.5
	Secondary	203	10.8
	Tertiary	1651	88.2
	Total	1863	99.5
Missing	System	9	0.5
Total		1872	100.0

Education Level of Participants

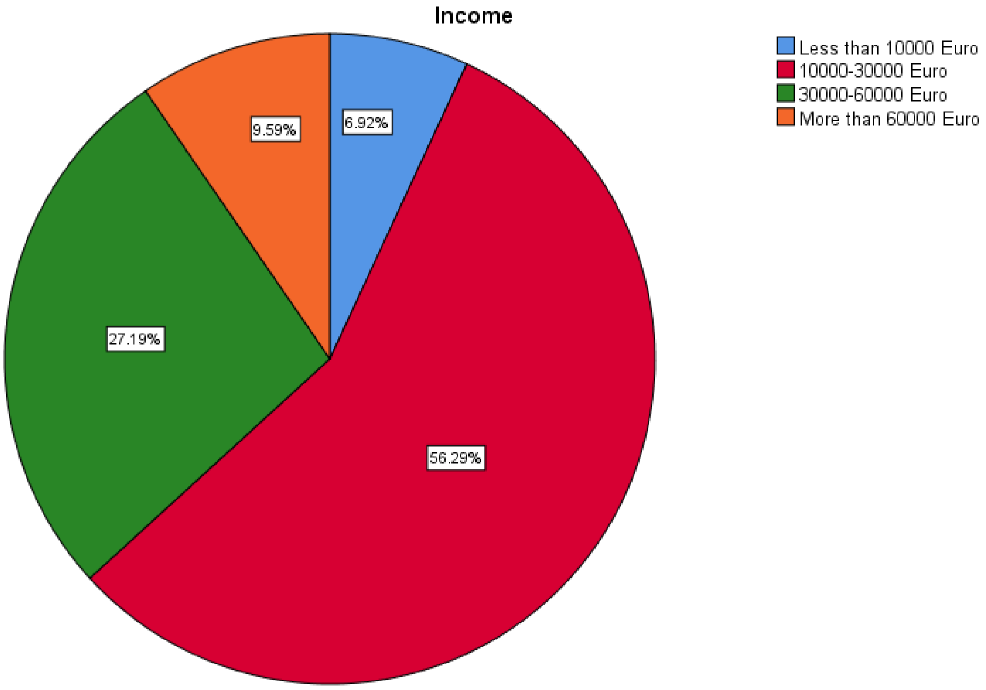


Pie Chart of Education Level of Participants

D7 – Income

		Frequency	Percent
Valid	< 10000 Euro	127	6.8
	10000–30000 Euro	1033	55.2
	30000–60000 Euro	499	26.7
	> 60000 Euro	176	9.4
	Total	1835	98.0
Missing	System	37	2.0
Total		1872	100.0

Income of Participants

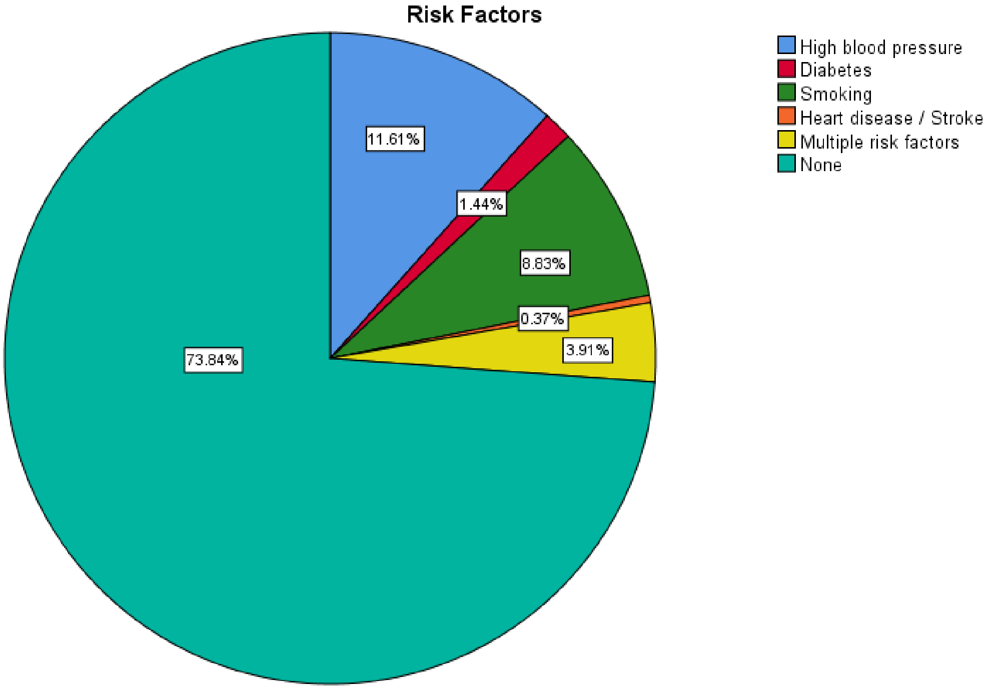


Pie Chart of Income of Participants

D8 - Risk Factors

		Frequency	Percent
Valid	High blood pressure	217	11.6
	Diabetes	27	1.4
	Smoking	165	8.8
	Heart disease/stroke	7	0.4
	Multiple risk factors	73	3.9
	None	1380	73.7
	Total	1869	99.8
Missing	System	3	0.2
Total		1872	100.0

Risk Factors of Participants

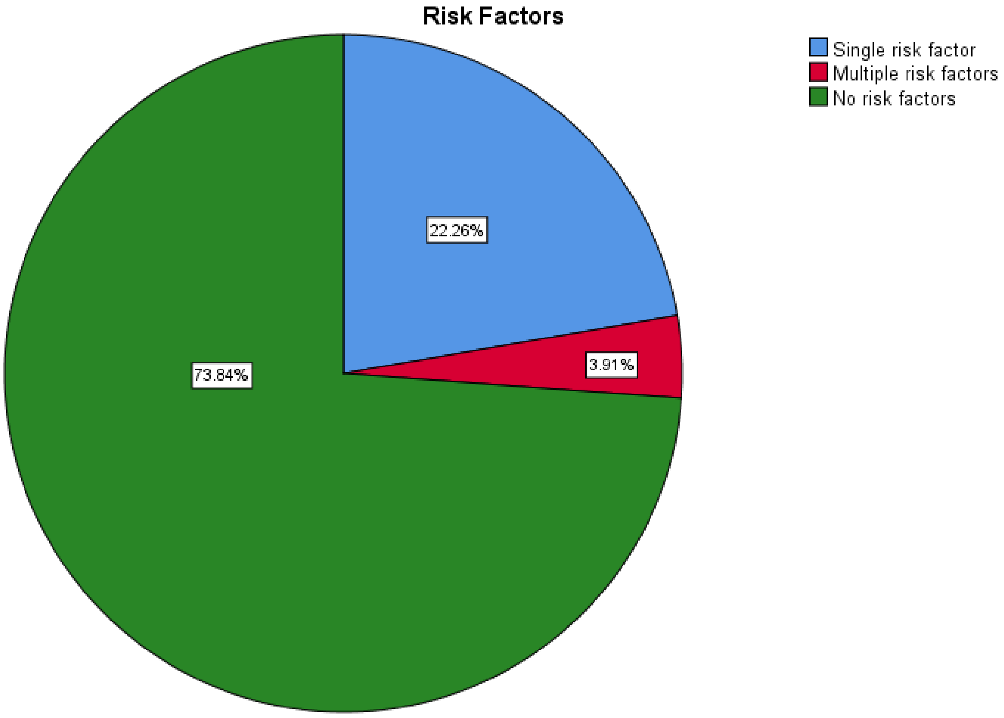


Pie Chart of Risk Factors of Participants

D8 - Risk Factors (Coded)

		Frequency	Percent
Valid	Single risk factor	416	22.2
	Multiple risk factors	73	3.9
	No risk factors	1380	73.7
	Total	1869	99.8
Missing	System	3	0.2
Total		1872	100.0

Risk Factors of Participants (Coded)

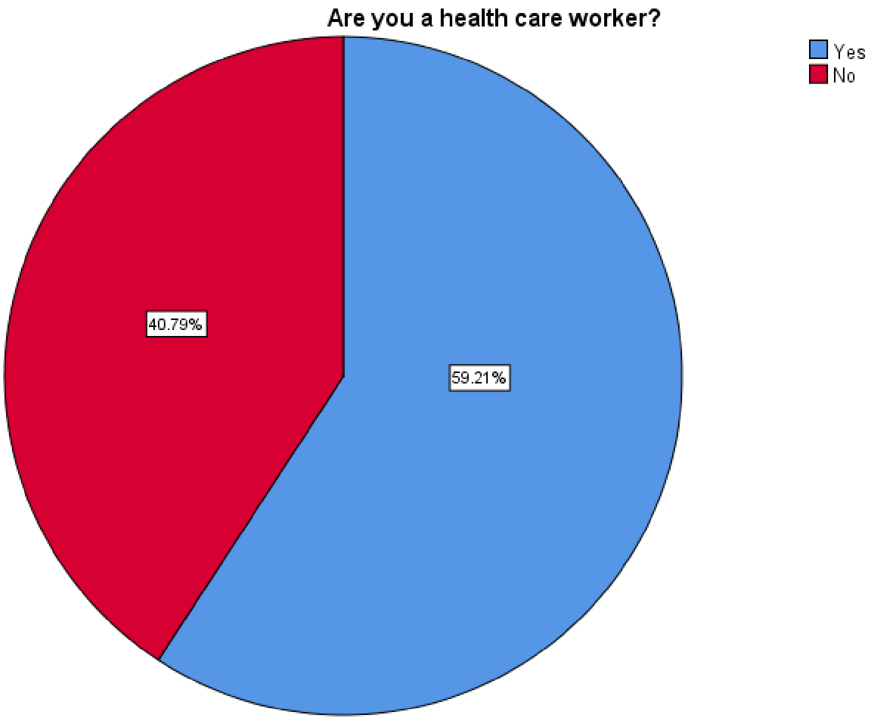


Pie Chart of Risk Factors of Participants (Coded)

D9 - Healthcare Worker Status

		Frequency	Percent
Valid	Yes	1103	58.9
	No	760	40.6
	Total	1863	99.5
Missing	System	9	0.5
Total		1872	100.0

Participants who were Healthcare Workers



Pie Chart of Percentage of Participants who were Healthcare Workers

Appendix 23 - Frequency tables - Knowledge

k1

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	−1	18	1.0	1.0	1.0
	0	62	3.3	3.3	4.3
	1	430	23.0	23.0	27.2
	2	1362	72.8	72.8	100.0
	Total	1872	100.0	100.0	

Frequency Table for Knowledge Question 1

k2

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	−2	14	.7	.7	.7
	−1	117	6.3	6.3	7.0
	0	506	27.0	27.0	34.0
	1	820	43.8	43.8	77.8
	2	415	22.2	22.2	100.0
	Total	1872	100.0	100.0	

Frequency Table for Knowledge Question 2

k3

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	−2	140	7.5	7.5	7.5
	−1	382	20.4	20.4	27.9
	0	276	14.7	14.7	42.6
	1	782	41.8	41.8	84.4
	2	292	15.6	15.6	100.0
	Total	1872	100.0	100.0	

Frequency Table for Knowledge Question 3

k4

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	−1	79	4.2	4.2	4.2
	0	317	16.9	16.9	21.2
	1	810	43.3	43.3	64.4
	2	666	35.6	35.6	100.0
	Total	1872	100.0	100.0	

Frequency Table for Knowledge Question 4

k5

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	−1	6	.3	.3	.3
	0	396	21.2	21.2	21.5
	1	567	30.3	30.3	51.8
	2	903	48.2	48.2	100.0
	Total	1872	100.0	100.0	

Frequency Table for Knowledge Question 5

k6

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	−2	296	15.8	15.8	15.8
	−1	599	32.0	32.0	47.8
	0	244	13.0	13.0	60.8
	1	487	26.0	26.0	86.9
	2	246	13.1	13.1	100.0
	Total	1872	100.0	100.0	

Frequency Table for Knowledge Question 6

k7

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	−1	6	.3	.3	.3
	0	56	3.0	3.0	3.3
	1	497	26.5	26.5	29.9
	2	1313	70.1	70.1	100.0
	Total	1872	100.0	100.0	

Frequency Table for Knowledge Question 7

k8

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	-−2	153	8.2	8.2	8.2
	−1	328	17.5	17.5	25.7
	0	150	8.0	8.0	33.7
	1	667	35.6	35.6	69.3
	2	574	30.7	30.7	100.0
	Total	1872	100.0	100.0	

Frequency Table for Knowledge Question 8

k10

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	−2	5	.3	.3	.3
	−1	108	5.8	5.8	6.0
	0	421	22.5	22.5	28.5
	1	664	35.5	35.5	64.0
	2	674	36.0	36.0	100.0
	Total	1872	100.0	100.0	

Frequency Table for Knowledge Question 10

k11

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	−2	19	1.0	1.0	1.0
	−1	151	8.1	8.1	9.1
	0	294	15.7	15.7	24.8
	1	1016	54.3	54.3	79.1
	2	392	20.9	20.9	100.0
	Total	1872	100.0	100.0	

Frequency Table for Knowledge Question 11

k12

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	−2	41	2.2	2.2	2.2
	−1	178	9.5	9.5	11.7
	0	430	23.0	23.0	34.7
	1	808	43.2	43.2	77.8
	2	415	22.2	22.2	100.0
	Total	1872	100.0	100.0	

Frequency Table for Knowledge Question 12

k13

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	−2	154	8.2	8.2	8.2
	−1	582	31.1	31.1	39.3
	0	255	13.6	13.6	52.9
	1	677	36.2	36.2	89.1
	2	204	10.9	10.9	100.0
	Total	1872	100.0	100.0	

Frequency Table for Knowledge Question 13

k14

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	−2	23	1.2	1.2	1.2
	−1	53	2.8	2.8	4.1
	0	156	8.3	8.3	12.4
	1	736	39.3	39.3	51.7
	2	904	48.3	48.3	100.0
	Total	1872	100.0	100.0	

Frequency Table for Knowledge Question 14

k15

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	−2	16	.9	.9	.9
	−1	28	1.5	1.5	2.4
	0	491	26.2	26.2	28.6
	1	542	29.0	29.0	57.5
	2	795	42.5	42.5	100.0
	Total	1872	100.0	100.0	

Frequency Table for Knowledge Question 15

k16

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	−2	50	2.7	2.7	2.7
	−1	169	9.0	9.0	11.7
	0	145	7.7	7.7	19.4
	1	706	37.7	37.7	57.2
	2	802	42.8	42.8	100.0
	Total	1872	100.0	100.0	

Frequency Table for Knowledge Question 16

Appendix 24 - Frequency tables - Response

r1

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	−2	167	8.9	8.9	8.9
	−1	143	7.6	7.6	16.6
	0	61	3.3	3.3	19.8
	1	552	29.5	29.5	49.3
	2	949	50.7	50.7	100.0
	Total	1872	100.0	100.0	

Frequency Table for Response Question 1

r3

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	−2	3	.2	.2	.2
	0	8	.4	.4	.6
	1	214	11.4	11.4	12.0
	2	1647	88.0	88.0	100.0
	Total	1872	100.0	100.0	

Frequency Table for Response Question 3

r4

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	−2	135	7.2	7.2	7.2
	−1	279	14.9	14.9	22.1
	0	170	9.1	9.1	31.2
	1	613	32.7	32.7	63.9
	2	675	36.1	36.1	100.0
	Total	1872	100.0	100.0	

Frequency Table for Response Question 4

r5

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	−2	12	.6	.6	.6
	−1	6	.3	.3	1.0
	0	35	1.9	1.9	2.8
	1	227	12.1	12.1	15.0
	2	1592	85.0	85.0	100.0
	Total	1872	100.0	100.0	

Frequency Table for Response Question 5

r6

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	−2	3	.2	.2	.2
	−1	9	.5	.5	.6
	0	63	3.4	3.4	4.0
	1	427	22.8	22.8	26.8
	2	1370	73.2	73.2	100.0
	Total	1872	100.0	100.0	

Frequency Table for Response Question 6

r7

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	−2	24	1.3	1.3	1.3
	−1	82	4.4	4.4	5.7
	0	397	21.2	21.2	26.9
	1	805	43.0	43.0	69.9
	2	564	30.1	30.1	100.0
	Total	1872	100.0	100.0	

Frequency Table for Response Question 7

r8

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	−2	45	2.4	2.4	2.4
	−1	32	1.7	1.7	4.1
	0	82	4.4	4.4	8.5
	1	546	29.2	29.2	37.7
	2	1167	62.3	62.3	100.0
	Total	1872	100.0	100.0	

Frequency Table for Response Question 8

r9

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	−2	61	3.3	3.3	3.3
	−1	209	11.2	11.2	14.4
	0	959	51.2	51.2	65.7
	1	441	23.6	23.6	89.2
	2	202	10.8	10.8	100.0
	Total	1872	100.0	100.0	

Frequency Table for Response Question 9

r10

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	−2	55	2.9	2.9	2.9
	−1	121	6.5	6.5	9.4
	0	516	27.6	27.6	37.0
	1	550	29.4	29.4	66.3
	2	630	33.7	33.7	100.0
	Total	1872	100.0	100.0	

Frequency Table for Response Question 10

r11

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	−2	8	.4	.4	.4
	−1	70	3.7	3.7	4.2
	0	164	8.8	8.8	12.9
	1	917	49.0	49.0	61.9
	2	713	38.1	38.1	100.0
	Total	1872	100.0	100.0	

Frequency Table for Response Question 11

r12

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	−2	9	.5	.5	.5
	−1	11	.6	.6	1.1
	0	28	1.5	1.5	2.6
	1	347	18.5	18.5	21.1
	2	1477	78.9	78.9	100.0
	Total	1872	100.0	100.0	

Frequency Table for Response Question 12

r13

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	−2	4	.2	.2	.2
	−1	45	2.4	2.4	2.6
	0	63	3.4	3.4	6.0
	1	812	43.4	43.4	49.4
	2	948	50.6	50.6	100.0
	Total	1872	100.0	100.0	

Frequency Table for Response Question 13

r16

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	−2	12	.6	.6	.6
	−1	147	7.9	7.9	8.5
	0	353	18.9	18.9	27.4
	1	762	40.7	40.7	68.1
	2	598	31.9	31.9	100.0
	Total	1872	100.0	100.0	

Frequency Table for Response Question 16

r17

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	−2	52	2.8	2.8	2.8
	−1	96	5.1	5.1	7.9
	0	62	3.3	3.3	11.2
	1	648	34.6	34.6	45.8
	2	1014	54.2	54.2	100.0
	Total	1872	100.0	100.0	

Frequency Table for Response Question 17

Appendix 25 – Conceptual Framework

Conceptual Framework

Stroke Knowledge and Educational Needs in Malta: a Mixed Methods Study