Professional Competencies in Health Psychology

by

Joanne Brooke

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The exploration of self-regulation and transfer anxiety within stroke patients transferred from a hyper acute stroke unit to a ward

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Abstract

Stroke services provide patients with immediate assessment and treatment on a hyper acute stroke unit prior to being transferred for intense rehabilitation. Patients' experience of transfer from a hyper acute stroke unit has yet to be explored. A patient's beliefs regarding their illness are important factors that aid a patients' recovery yet these have not been fully explored in patients following a stroke.

The aims of this study are to explore the patients' perspectives of transfer from a hyper acute stroke unit to a stroke unit and their illness beliefs.

Data were collected from a purposive sample of patients (n=6) on a stroke unit following transfer from a hyper acute stroke unit. Semi-structured interviews were carried out to explore patients' experience of transfer and their illness beliefs. The interview schedule was based on literature and interviews with a Clinical Nurse Specialist and a stroke patient. Data were analysed using Interpretative Phenomenological Analysis (IPA).

The emergent super-ordinate themes included: disassociation from being in the world, search for understanding, strive for independence and acceptance of support, and hope and uncertainty. A chronic illness model of illness representation dimensions emerged; higher reporting of identity, consequences, and timeline was associated with lower personal and treatment control and an emotional response.

Self-regulatory coping strategies and health beliefs within patients following a stroke were identified as important constructs to include in healthcare assessments with the aim of improving psychological, physical and social outcomes.

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Chapter 1: Introduction to the Study

1. Background

Stroke is an acute medical emergency and a long term illness. Stroke services in London have been reconfigured to ensure each patient receives immediate assessment and treatment on a hyper acute stroke unit prior to being transferred for intense rehabilitation. Patients' experiences of the new stroke care pathway have yet to be understood including the impact of hyper acute assessment and treatment and the transfer from a hyper acute unit to a rehabilitation unit. A patient's beliefs regarding their illness are important factors that aid a patient's recovery yet these have not been fully explored in patients following a stroke. The aims of this study are to explore the impact of stroke as a medical emergency, patients' perspectives of transfer from a hyper acute stroke unit and their illness beliefs.

1.1 Stroke

Stroke is the third leading cause of death in the world (Strong, Mathers and Bonita 2007). The World Health Organization estimates 5.71 million people died from stroke in 2004 (Bonita and Beaglehole 2007). In the UK stroke is the leading cause of adult neurological disability (National Audit Office 2010) and over 150,000 people are affected by stroke (Stroke Association 2011). The incidence rate of stroke in the UK appears to have fallen in the last decade (Dey, Sutton, Marsden, Leathley, Burton and Atkins 2007), but with increasing numbers of older people in the population and the number of people surviving a stroke the overall burden of stroke is set to increase (Rothwell, Coull, Silver, Fairhead and Giles 2005). People surviving a stroke are likely to require specific health, social and psychological care (Langton-Hewer and Tennant 2003) as a stroke can have a profound effect on all domains of life (Jagger, Matthews, Spiers, Brayne, Comas-Herrera, Robinson, Lindesay and Coft 2007).

The World Health Organization in Hatano (1976) have defined stroke as the:

> *"Rapidly developing clinical signs of focal or global disturbance of cerebral function, lasting more than 24 hours or leading to death with no apparent course other than vascular origin."* (p. 541).

Stroke has a vascular origin as involves the disruption of blood flow to the brain, which can occur through occlusion (ischemic stroke) or rupture of a blood vessel (hemorrhagic stroke). The main risk factors for an ischemic stroke include; smoking and hypercholesterolemia, whereas the main risk factor for hemorrhagic stroke is hypertension (Bhatnagor, Scarborough, Smeeton and Allender 2010). The result of a stroke is a lack of adequate blood carrying oxygen and glucose to the brain cells, which die when their stores are quickly depleted (Alexandrov 2010). The impact and severity of the consequences of a stroke partially depend on the part of the brain affected and the size of the area involved (Kelly-Hayes, Roberston, Broderick, Duncan and Hersehy 1998). Physical symptoms following a stroke include; sudden numbness or weakness of the face, arm and leg (hemiparesis), trouble speaking (dysarthria and/or expressive dysphasia) or understanding speech (receptive dysphasia), visual impairments (hemianopia, cortical blindness), swallowing difficulties (dysphagia), unsteadiness (ataxia) and intention or sensory, motor or representational neglect (Plummer, Morris and Dunai 2003).

Psychological symptoms following a stroke include; depression, apathy, emotional lability and personality changes (Stroke Association 2006). Depression occurs in one third of stroke survivors (Hackett, Yapa, Parag and Anderson 2006) and is associated with poor functional outcomes regardless of age, gender and initial disability (West, Hill, Hewison, Knapp and House 2010). A strong association between apathy and depression has been demonstrated (Robinson, Jorge, Clarence-Smith and Starkstein 2009). However, apathy is characterized by the loss of emotion, while depression is characterized by intense sadness (Marin, Firinciogullari and Biedrzicky 1993). Depression and apathy can both be treated by pharmaceutical methods (Robinson et al. 2009). Emotional lability is characterized by sudden and easily provoked episodes of crying or laughing which appear out of context with the individual's emotional state (Sloan, Brown and Pentland 1992). Emotional lability affects between 11-52% of stroke survivors (Schiffer and Pope 2005; Tang, Chan and Chiu 2004) and can last from a week to several years (Kim 1997). Personality changes are commonly reported by family members of the stroke survivor (Stone, Townend, Kwan, Haga and Dennis 2004). Personality changes may involve previous traits becoming reversed, although more commonly existing traits are exaggerated (Stroke Association 2006).

1.11 Stroke care and management

Traditionally stroke care and treatment was purely supportive, the medical concept of stroke was the end result of a long term condition, cardiovascular disease (Demarin, Zikic and Zikic 2011). Stroke was presumed to occur with increasing age leading to death or severe disability (National Institute for Health and Clinical Excellence NICE 2008). However, in recent decades stroke has been recognized as an acute event and a medical emergency with new investigations and treatment strategies. Thrombolysis has been an acute treatment for an ischemic stroke in the UK since 2002 (Wahlgren, Ahmed, Davolos, Ford and Grond 2007). Ischemic strokes account for 80% of all strokes (Power 2004). Thrombolysis is the provision of a type of clot-busting drug and provides modest yet significant improvement in clinical outcome if given three to four and half hours after symptom onset (Hacke, Kaste, Bluhmki, Brozman and Davolos 2008). However, thrombolysis is nearly twice as efficacious when administered within the first hour and a half of symptom onset, as with each hour, the brain loses as many cells as it does in almost 3.6 years of normal ageing (Saver 2006).

The National Sentinel Audits (2011) in the UK have monitored the evolving improvement of stroke care and management for the past decade, including 9 key indicators of:

- Patients treated 90% of their stay on a stroke unit
- Screen for swallow disorders completed within the first 24 hours
- Brain scan within the first 24 hours
- Commenced on aspirin by 48 hours post stroke
- Physiotherapy assessment within 72 hours of admission
- Occupational therapist assessment within 4 working days of admission
- Weighed at least once during admission
- Mood assessed by discharge

- Rehabilitation agreed by the multidisciplinary team by discharge

The indicators demonstrate the change in approach of stroke care and treatment to include an acute event and the importance of immediate assessment and treatment (Bamford 2001). The first indicator relates to the importance of a patient being admitted to a stroke unit whilst in hospital. Stroke units improve patient outcomes such as reduced mortality, dependency and requiring institutionalised care, these outcomes are independent of the patients' age, gender or stroke severity (Stroke Trialists Collaboration 2007).

The National Sentinel Audit (2011) reported in 2008; 94% of patients were admitted to specialist stroke units at some point within their hospital stay, but only 53% of patients were admitted to a specialist stroke unit within the first four hours. The Lord Darzi's report 'Framework for Action' (2007) highlighted the inequality of access to specialist stroke units for patients within London. In response, the Royal College of Physicians, Healthcare for London and the Stroke and Cardiac Network developed the Stroke Strategy for London (2008), which defined a new stroke care pathway addressing the issues of; stroke as an acute event and medical emergency, access to specialist stroke units within the first four hours of stroke, and equal access for all patients within London. An assessment of London's population, incidence and prevalence rates of stroke was undertaken and highlighted the need for 130 hyper acute stroke beds and 550 stroke beds (Healthcare for London 2009). The new stroke care pathway reconfiguration equated these figures to 8 Hyper Acute Stroke Units (HASUs) and 24 Stroke Units (SUs).

The HASUs were geographically located throughout London ensuring any patient was only a 30 minute ambulance drive to one of these specialist units. London Ambulance Service were involved in the implementation of the new stroke care pathway and have define stroke as a 'Category A' priority, with a response time of eight minutes. A patient suspected of a stroke is transferred to the nearest HASU passing other hospitals and Accident and Emergency Units (Liu, Rudd and Davie 2011).

A patient suspected of having an acute stroke will remain on a HASU for 3-5 days during which time comprehensive assessments, investigations and acute treatments are completed by a specialized stroke team. HASU provides intense monitoring of the patient with high levels of nursing staff and the continuous presence of the medical team. On completion of this stage the patient is transferred to their local stroke unit for sub-acute treatment and the commencement of rehabilitation (Stroke Strategy for London 2008). The process of transfer occurs through repatriation of the patient to their local stroke unit, which may or may not be in the same NHS Trust this is defined by the London Look Up (London Stroke and Cardiac Network 2009). Clear protocols define safe and effective transfer, see figure 1 and 2. Figure 1 (page 11) demonstrates the basic criteria to establish the patient is medically stable, the use of PAR scoring (Patient At Risk) is a further criteria which provides a detailed assessment of each patient (Stroke Strategy for London 2008). Figure 2 (page 11) demonstrates the contact between a HASU and SU and the information shared on a daily basis to ensure a safe and effective transfer within and between NHS Trusts.

Figure 1: Protocol for HASU to SU transfer

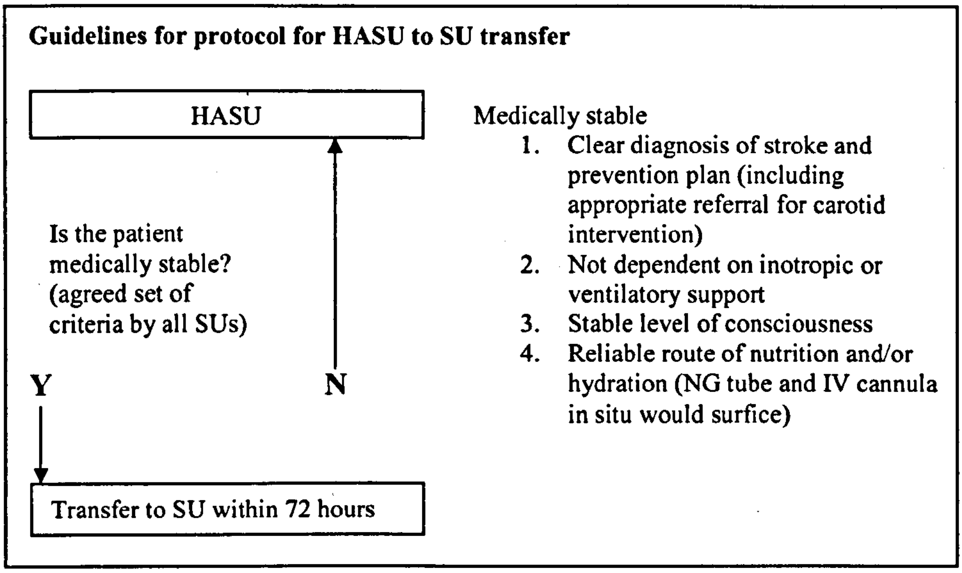
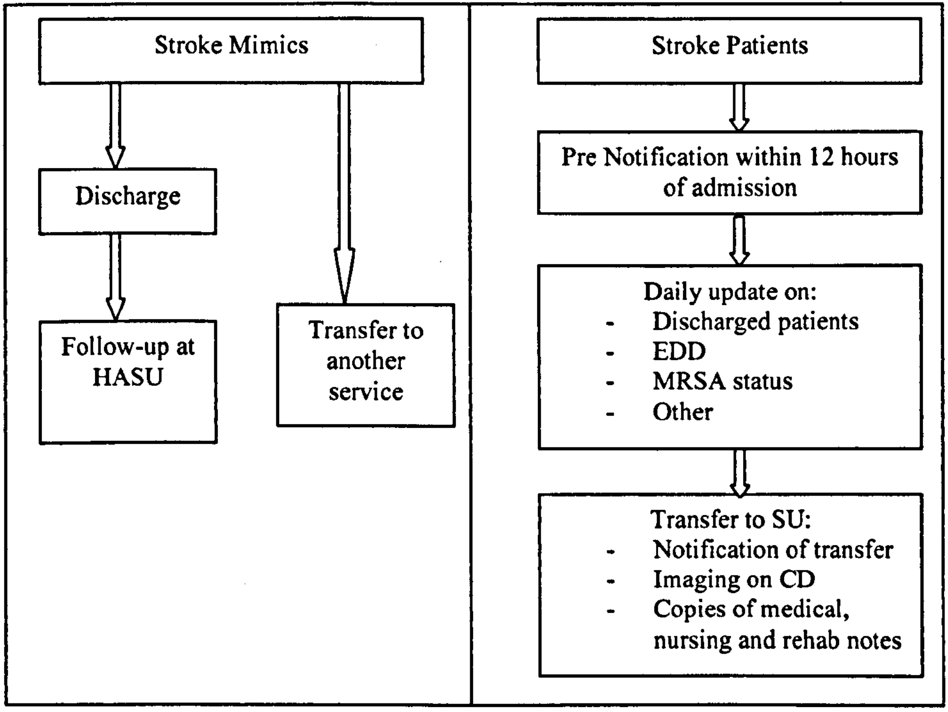


Figure 2: Pan London Transfer Policy



Source adapted from: London Stroke and Cardiac Network (2010)

The implementation of the new stroke care pathway was completed in 2010, all units are staffed by multidisciplinary teams specialized in stroke care (Fraser, Fenwick-Elliot and

Cohen 2012). Preliminary results have shown an increase in thrombolysis rates from 3.5% between February 2009 and July 2009 to 12% for the same period in 2010 (Liu et al. 2011). Further results demonstrate the new stroke pathway has reduced mortality rates, reduced the length of hospital stay and increased the likelihood of the patient being discharged home (Brooke, Kar and Ames 2010; Cohen, Bathula, Fenwich-Elliot and Hogan 2010).

1.12 Stroke and quality of life

The preliminary results from the implementation of the new stroke pathway in London demonstrate the positive outcome of reduced neurological deficits for patients. However, the impact and severity of the consequences of a stroke only partially depend on the neurological deficits, as a stroke impacts on all domains of life (Jagger et al 2007). There is an association between neurological deficits and quality of life, although this association is not synonymous (De Haan, Aronson, Limburg, Langton-Hewer and van Crevel 1993) or stable (Suenkeler, Nowak, Misselwitz, Kugler and Schreiber 2002). Quality of life has been defined by the World Health Organization (1997) as:

> *"An individual's perception of their position in life in the context of the culture and value systems where they live and in relation to their goals, expectations, standards and concerns."* (p. 1).

Hopman and Verner (2003) measured quality of life at two time points post stroke, during inpatient rehabilitation and 6 months post discharge. The patients perceptions of their neurological deficits and quality of life improved during inpatient rehabilitation, but had significantly declined 6 months post discharge. Similar results were found twelve months following discharge; neurological deficits and disability remained unchanged, although patients reporting of mental and social functioning had declined (Suenkeler et al. 2002). However, changes in quality of life were identified three years post stroke in the domain of mental health which was found to be satisfactory (Patel, Tilling, Lawrence, Rudd and Wolfe 2006).

The studies which explored the effect of stroke on quality of life (Hopman and Verner 2003; Suenkeler et al., 2002; Patel et al., 2006) occurred prior to the emergence of stroke as a medical emergency and the implementation of hyper acute stroke services. The impact of hyper acute stroke care and management on patients' perceptions of their neurological deficits and quality of life is unknown.

The changes in and perceptions of quality of life reported by patients following a stroke are partially mediated by coping strategies (Emstahl, Summer and Hagberg 1995). Coping strategies applied in stroke research have been defined as tenacious goal pursuit and flexible goal adjustment (Brandstadter and Renner 1990). Tenacious goal pursuit involves an individual actively adjusting their circumstances in order to obtain a life-style comparable to life before their stroke. Flexible goal adjustment involves an individual accepting the implications of their stroke on their life-style and adjusting personal preferences and goals (Smout, Koudstall, Ribbers, Janssen and Passchier 2001). Studies applying these definitions of coping strategies in stroke have found flexible goal adjustment is related to higher levels of quality of life (Smout et al., 2001; Darlington, Dippel, Ribbers, van Balen, Passchier 2007). Patients' who adjusted their personal preferences when a situation changed reported higher levels of quality of life than patients' trying to maintain their personal preferences and previous life-style (Smout et al., 2001).

Several phenomenological studies have gone beyond the measures of quality of life and coping strategies and have begun to provide an understanding of the comprehensive changes in individuals' lives following a stroke including physical, psychological and social impact (Kvigne and Kirkevold 2003).

Burton (2000) identified recovery from a stroke as an intensely personal experience, which involved rebuilding and restructuring of the individual's world. Burton (2000) placed rebuilding and restructuring in a social context, which went beyond physical functioning rehabilitation goals. However, in the acute stages following a stroke Nilsson, Jansson and Nordberg (1997) identified an individual's struggle to find meaning in life and that physical, psychological and social losses were overwhelming. In the struggle to find meaning in life individual's had to address the concept of 'being', which encompassed more than just physical, psychological and social losses, adding an existential element. Kirkevold (2002) reiterated the personal experience of recovery from a stroke and the multiple phases an individual passes through in the process of recreating an understanding of themselves and their new life.

However, further phenomenological studies are required to explore the impact of an individual having their stroke treated as a medical emergency and following the new stroke care pathway in London. The impact of new stroke treatment has reduced neurological deficits and maintains a focus on stroke as an acute treatable condition and the effects of this approach on individuals following a stroke are unknown.

1.2 Transfer anxiety

The admission of a patient to a critical care setting is usually sudden, unexpected and a very stressful event for both the patient and their family (Quinn, Redmond and Begley 1996). Critical care settings involve invasive and complex technology in an alien environment (Coyle 2001). The stress of a life threatening illness and adapting to the new environment leaves the patient and their family members feeling anxious and frightened (Coyle 2001). However, the new surroundings soon become familiar and stress levels begin to diminish as the environment is understood to be reassuring and safe (Jenkins and Rogers 1995).

Leaving a critical care setting should be viewed as a positive stage in the patient's recovery, but patients and their family members may view the transfer as unsafe due to; less monitoring equipment, new rules, different staff expectations and reduced presence of the healthcare team (Cutler and Garner 1995). Following transfer from a critical care setting patients and their family members have expressed feelings such as; abandonment, vulnerability, helplessness and unimportance (Chaboyer, Kendall, Kendall and Foster 2005).

The psychological and physical problems experienced by patients and family members on transferring from a critical care setting to a general ward has been defined as 'transfer anxiety' or 'relocation stress' (Schwarz and Brenner 1979; McKinney and Deeny 2002). Transfer anxiety has been defined in the American Nursing Diagnosis (2000) as:

"A state in which an individual experiences psychological and/or psychosocial disturbances as a results of transfer from one environment to another." (Carpenito 2000 p.123).

The defining characteristics of transfer anxiety include; depression, anger, apprehension, anxiety, dependence, insecurity, lack of trust and a need for excessive reassurance (Carpenito 2000).

Transfer anxiety from a critical care setting to a general ward can be explained as containing three elements; primary anxiety, fright anxiety and expectant anxiety (McKinney and Melby 2002). Primary anxiety is a result of the transfer process and relates to the timing and type of transfer. An abrupt transfer due to an emergency admission of another patient does not give the patient and their family the opportunity to prepare and understand the transfer process. An abrupt transfer exacerbates patients and family members' feelings of abandonment, loss and insecurity (Saarman 1993).

Fright anxiety can occur through two processes; from the patient's acknowledgement of their illness, which was life threatening and the impending transfer from leaving the security of the critical care setting (Saarman 1993). The secrure and highly technical environment of the critical care setting is considered reassuring and safe (Jenkins and Rogers 1995), as patients depend on; the high technical machinery, one-to-one nursing and the presence of the medical team, which is viewed as life-saving and life-supporting (Roberts 1986). Theoretical concepts to support fright anxiety, include: separation anxiety (Coyle 2001). Separation anxiety has been developed from attachment theory (Bowlby

1958), a child's relationship with their mother was defined through separation, deprivation and bereavement. Attachment theory continues into adult life and can be directed towards individuals outside the family (Crowell and Treboux 1995). In adults, attachment behavior commonly occurs during times of ill health and stress (Bowlby 1980). Attachment behavior within critical care may occur due to shared experiences of traumatic events (Sawden, Woods and Proctor 1995), attentiveness of staff (Simpson, Armstrong and Mitchel 1989) and the constant and consistent support of staff (Owen, Provine and Stephenson 1992).

Expectant anxiety can occur when patients and family members only partially understand the transfer and predict the situation to be dangerous (Rogers 1986). Transfer to a ward involves reduced attentiveness, presence of medical staff and technical machinery (McKinney and Melby 2002). Patients may not perceive their recovery to be sufficient enough to be discharged from a critical care setting to an environment where levels of monitoring and care will be reduced (Jenkins and Rogers 1995). Many patients continue to perceive themselves to be critically ill and require high levels of care following their transfer from a critical care setting (Coyle 2001).

Hospital anxiety has been associated with demographic, clinical and social factors (Shuldham, Cunningham, Hiscock and Luscombe 1995; Kim, Moser, Garvin, Riegel and Doering 2000; Garvin, Moser, Riegel, McKinley and Doering 2003). Hospital anxiety was higher in patients over 60 years of age and higher in women compared to men (Shuldham et al., 1995; Kim et al., 2000; Garvin et al., 2003). Clinical factors increasing hospital anxiety include; urgency of hospital admission and sudden transfer from a critical care setting

(Mitchell and Courtney 2004; Culter and Garner 1995). Social factors associated with lower hospital anxiety were social support and support through the transfer process for the patient and their family members (Leith 1999). However, many of these studies examined hospital anxiety rather than transfer anxiety. Recent exploration in transfer anxiety demonstrated higher transfer anxiety in women patients with less social support and longer length of critical care stay, but did not support the other variables involved in hospital anxiety (Brodsky-Israeli and DeKeyser-Ganz 2011).

Studies exploring transfer anxiety and hospital anxiety focus on transfer from a critical care setting such as an intensive care unit or a coronary care unit (Mitchell and Courtney 2004; Culter and Gardner 1995; Leith 1999; Brodsky-Israeli and DeKeyser-Ganz 2011). Further development of these studies to include different hyper acute settings is required to extend the understanding of transfer anxiety.

Transfer anxiety increases patients' demands on nursing staff, reporting of physical symptoms, length of hospital stay and readmissions to a critical care setting (Cutler and Garner, 1995; Griffiths and Jones 1999). A meta-synthesis of qualitative research exploring transfer from a critical care setting to a ward highlighted adult patients' ongoing physical and psychological problems (Bench and Day 2010). Physical symptoms included lethargy, weakness, impaired mobility, pain, loss of appetite and difficulties in swallowing and eating. Psychological symptoms included high levels of anxiety, sleep disturbances, nightmares, hallucinations, amnesia and symptoms of depression (Bench and Day 2010).

Family members are often involved in the psychological well-being of the patient in the critical care setting through their continued presence and social interactions (Burr 1998). Patients receiving psychological and social support report high levels of coping (Wesson 1997). Patients with no social contact were more critical of staff and the care they received (Hupcey 2001). However, family members can only provide the support if they understand the transfer process and have confidence in the safety of the general ward. Reducing family members transfer anxiety is an important aspect to aid the patients' adjustment to the ward and their overall recovery (Bailey, Sabbagh, Loiselle, Boileau and McVey 2010).

Patient and family members experiencing high level of transfer anxiety are susceptible to postintensive care syndrome: the new or worsening physical, cognitive or mental health problems arising from a critical illness experience, which persists beyond discharge from hospital (Needham, Cohen, Hopkins and Weiner 2012). Family members' mental health problems may persist over four years, impacting on their ability to provide support and care (Davidson, Jones and Bienvenu 2012). Reducing transfer anxiety will reduce patient and family member burden in this area.

Strategies to reduce transfer anxiety have developed using a patient-centered approach including: standard letters (Bouve, Rozmus and Giordano 1999), individualized education (Tel and Tel 2006), individualized transfer method (Mitchell and Courtney 2004), care conferences with patients and family members (Bokinskie 1992) and the use of liaison nurses (Chaboyer, Thalib, Alcorn and Foster 2007). In these randomized controlled trials transfer anxiety has been measured by the State Trait Anxiety Inventory (STAI), originally developed by Spielberger (1985). The STAI identifies: state anxiety (the appropriate anxiety which is temporary and a reaction to a perceived threat in the environment) and trait anxiety (the relatively stable level of anxiety and response style of an individual). Transfer anxiety is measured by controlling trait anxiety and measuring state anxiety before and after transfer from a critical care setting to a general ward.

The transfer letter intervention (Bouve et al., 1999) was a study completed in a Pediatric Intensive Care Unit (PICU) and involved a short letter explaining the transfer as a positive step in the child's progress and outlined the differences between the PICU and the ward, such as less monitoring by staff and equipment and general information about the ward.

The interventions based on individualized education (Tel and Tel 2006) and individualized transfer method (Mitchell and Courtney 2004) both involved a booklet tailored to the needs of the patient and their family members. The booklets included information regarding transfer to the ward and the nature of the illness, causative factors and treatment. In both interventions the patient and their family members were given the booklet to read and subsequently met with staff to discuss.

The care conference (Bokinskie 1992) involved a nurse from intensive care unit (ICU) organizing a meeting with a nurse from the receiving ward and one of the patients' family members. The meeting involved a discussion on the new ward layout, expectations of patients and their family members and information on recovery. The care conference addressed any concerns raised by the family member and concluded by identifying patient-centered goals.

The liaison nurse (Chaobyer et al., 2007) coordinated the process of transfer by providing information to both ICU and ward staff and giving practical and emotional support to the patient and their family members; however this intervention did not reduce transfer anxiety. This study measured transfer anxiety prior to the transfer of the patient, when patients and family members remained in the secure environment of a critical care setting. Measuring transfer anxiety post transfer might have demonstrated more clearly if the intervention had been effective in preparing the patient and their family members for the new environment and therefore reducing transfer anxiety compared to standard care.

All the remaining studies measured transfer anxiety pre-intervention and post transfer to the general ward. A meta-analysis of the above studies found family members transfer anxiety was significantly reduced in all interventions excluding the liaison nurse (Brooke, Hasan, Slark and Sharma 2012).

A common theme through all interventions was the organized planning of the transfer procedure from the critical care setting to a general ward and the provision of information specifically tailored to the individual patient and their family members. Written documentation to patients' family members in a critical care setting has been found to significantly improve relatives' satisfaction with care (Medland and Ferrans, 1998). The written information in the studies discussed allowed family members to take accurate information away to discuss among themselves and with the patient, which generated questions they could then formulate and have ready to ask the staff at their next meeting.

The process allowed the patient and their family members to understand the transfer and the impending ward environment.

A meta-synthesis of qualitative data (Bench and Day 2010) went beyond physical and psychological symptoms and highlighted four further themes patients' identified as important in the transfer process: making progress, the need to know, safety and security and the needs and importance of relatives. Making progress; was identified by the patients as transfer from the critical care setting signified improvement and recovery, but also feelings of fear and anxiety. Patients did not feel ready for transfer, which increased feelings of helplessness, vulnerability, unimportance, and dependence (Bench and Day 2010). The need to know: patients' identified the need for more information regarding goals for further treatment and rehabilitation and to be involved in this process to empower them, to improve their coping strategies and reduce fear of the unknown. Safety and security: patients identified the different levels of nursing staff and felt they did not receive appropriate levels of care on the ward. Patients reported going from complete helplessness to independence upon transfer, with no transition period, which was viewed as unsafe. Finally the needs and importance of relatives: relatives reported the lack of visible staff on the ward as concerning, ward staff were perceived not to be as skilled as critical care staff and relatives reported feeling obliged to provide some personal care themselves (Bench and Day 2010).

Transfer anxiety was originally a concept on transfer from an ICU to a general ward (Schwarz and Brenner 1979). The objective of an ICU has been defined by Valentin and Ferdinande (2011):

> *"The monitoring and support of threatened or failing vital functions in critically ill patients who have illnesses with the potential to endanger life, in order to perform adequate diagnostic measures and medical or surgical therapies to improve outcome."* (p. 1576).

ICU is an independent unit staffed by specialist staff trained in intensive care medicine and emergency medicine (Royal College of Nursing 2003). The ratio of nurses to patients depends on the level of care the patient requires (Tarnow-Mordi, Hau, Warden and Shearer 2000; Dang, Johantgen, Pronovost, Jenckes and Bass 2002), which is defined from I to III (Valentin and Fernande 2011). Level of care III (highest) represents patients with multiple organ failure which is acutely life-threatening, these patients require pharmacological, as well as mechanical support, such as respiratory assistance. The minimum nurse/patient ratio for level of care III is 1:1. Level of care II represents patients with one vital organ failing, which requires pharmacological and mechanical support. The minimum nurse/patient ratio for level of care II is 1:2. Level of care I (lowest) represents patients experiencing signs of organ dysfunction requiring continuous monitoring and minor pharmacological or mechanical support. The minimum nurse/patient ratio for level of care I is 1:3. However, the minimum ratio of nurse/patient does not allow for staff breaks or other duties apart from direct patient care and therefore needs to be higher than the minimum required (Royal College of Nursing 2003).

Transfer anxiety has also been highlighted and investigated in Coronary Care Units (Tel and Tel 2006). CCUs were introduced following medical advances in coronary care from thrombolysis to primary angioplasty in the 20th Century (British Cardiovascular Society 2011). A CCU provides specialist, multi-disciplinary cardiac care, including cardiac investigations and interventions at all times (British Cardiovascular Society 2011). CCU has similarities to ICU including: invasive monitoring and life supporting equipment (Mangan 1996), highly specialist staff, with a recommendation of 75% of nurses having completed formal training/courses (Depasse, Pauwels, Somers and Vincent 1998), nurse/patient ratios depending on the level of care required and transfer when a patient's condition becomes stable. The European Society of Cardiology Working Group on Acute Cardiac Care recommend the following nurse/patient ratios on CCU; 1:2 or 1:3 depending on level of care required by the patient (Hasin, Danchin, Filippatos, Hersa and Janssens 2005).

The implementation of the new stroke care pathway throughout London has created Hyper Acute Stroke Units (Stroke Strategy for London 2008), which have similarities with CCUs and ICUs. A patient is admitted to a HASU during the acute and life threatening episode of a stroke and when stable transferred to a SU. A HASU has similar nurse/patient ratio of 1:2 or 1:3 depending on the level of care required by the patient (Stroke Strategy for London 2008), intensive monitoring, invasive investigations and treatment. Although implementation of the new stroke care pathway is relatively new, education of the multi-disciplinary team has been addressed with the Stroke-Specific Education Framework (DH 2009) and specifically in London for nurses' with the Hyper Acute Stroke Unit Nursing Competency Workbook (London Cardiac and Stroke Network 2011).

Interhospital transfer of critically ill patients from both accident and emergency units and critical care settings has become routine and safe (Iwashyna, Christie, Khan and Asch 2009; Stevenson, Fiddler, Craig and Gray 2005). Iwashyna and Courey (2011) address the appropriateness of the destination of the transfer, which should be an informed choice. Transfer from a HASU is organized throughout London with clear guidelines and protocols for the safe and appropriate transfer of patients (Stroke Strategy for London 2008). However, throughout the documentation and planning of the new stroke pathway, transfer anxiety had not been addressed. No formal provision of information is provided to the patient to inform them and their family members of transfer from a HASU. The transfer may occur from a large teaching hospital to a district general hospital and a patient following this pathway may have concerns on being admitted to their local hospital following a life threatening event.

1.3 Common Sense Model

Coping strategies within stroke and transfer anxiety impact on the psychological, physical and social outcomes of the patient and their family members (Darlington et al., 2007; Smout et al., 2001; Wesson 1997). The Common Sense Model of Self-Regulation (Leventhal, Meyer and Nerenz 1980) is a theoretical approach which allows an exploration of individual's emotional and cognitive responses to a health threat. The Common Sense Model identifies the relationships between emotional and cognitive responses, coping strategies and outcomes for a patient above and beyond the progression of the biological illness (Leventhal, Brissette and Leventhal 2003). An exploration of these constructs provides an understanding of emotional and cognitive responses and coping strategies that impact negatively on an individual's outcome. Identification of factors leading to poorer health outcomes informs interventions to improve self-regulation of a health threat and the management of chronic diseases. An intervention based on emotional regulation, cognitive reappraisal and behaviour change can impact on self-regulation, self-management and quality of life (Petersen, van dan Berg, Jansessn and van den Bergh 2011).

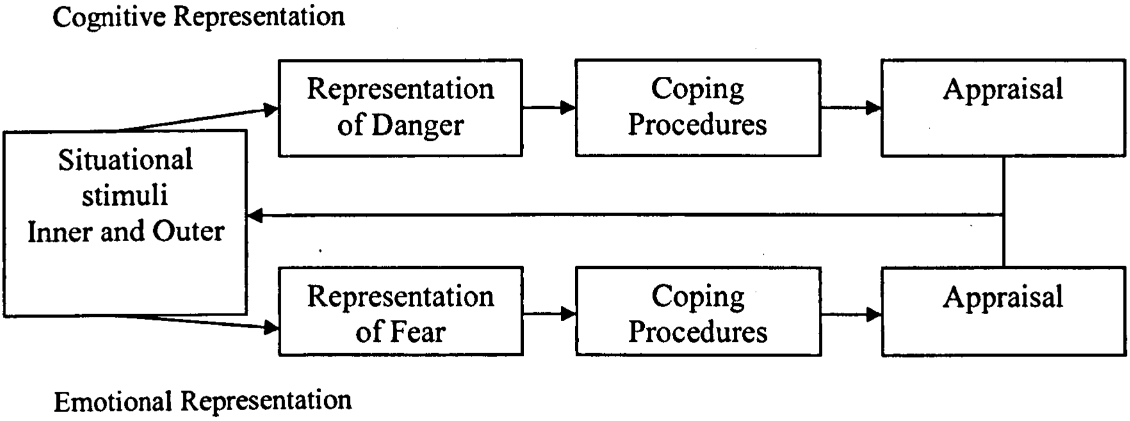
The Common Sense Model of Self-Regulation (Leventhal et al. 1980) incorporates the theoretical approach of self-regulation. Self-regulation models contain three elements; the explicit consideration of goals, a view of the individual as active in planning their own behaviour and an emphasis on volitional processes in goal striving (Ridder and de Wit 2006).

Individuals adjust and monitor their behaviour to attain identified goals (Scheier and Carver 2003). Goals within self-regulation theory are defined as principles that individuals' consciously and intentionally set to effectively plan their behaviour (Ridder and de Wit 2006). The construct of goals may vary such as; process goals and outcome goals (Zimmer and Kitsantas 1997). Process goals are implemented when a new goal is identified; an outcome goals occurs when process behaviour has been implemented and the focus changes to the outcome of the behaviour (Zimmer and Kitsantas 1997). Goals provide meaning and purpose to an individual's life (Scheier and Carver 2001). Understanding the individual means understanding the individual's goals (Scheier and Carver 1999). Self-regulation does not occur by an individual in isolation, but through social interaction which is necessary for successful self-regulation of both physical health (House, Landis and Umberson 1988) and mental health (Thoits 1983). An individual's self-regulation system is shaped and reshaped by the social environment (Leventhal et al., 2003).

The Common Sense Model describes self-regulation as the process of an individual monitoring conscious thoughts, behaviours and emotions to maintain equilibrium in psychological and physical functioning (Leventhal, Diefenbach and Leventhal 1992). A health threat such as a stroke disrupts an individual's equilibrium and motivates them to engage in psychological and behavioural activities to reinstate their equilibrium or status quo (Cameron and Leventhal 2003). The Common Sense Model is a motivational system involving interpretation, coping and appraisal, which are interrelated and on-going creating a dynamic model (Leventhal et al. 2003).

The interpretation of a health threat generates both emotional states of fear and distress (Leventhal et al. 2003). Interpretation occurs through symptom perception; symptoms are interpreted by the individual internally and externally through their social context (Leventhal et al. 2003). Interpretation occurs at two levels; cognitive and emotional creating a parallel processing model (Leventhal 1970). Coping strategies are implemented to reduce the negative emotions evoked by the health threat (fear control) and reducing the threats themselves (danger control). As demonstrated in figure 3 emotional responses provoke coping strategies to manage fear control and cognitive responses provoke coping strategies to manage danger control (Leventhal et al. 2003). Figure 3 demonstrates the important process of appraisal. Individuals appraise how their coping strategies have impacted on their health threat (Croyle 1992). The outcome of the appraisal influences the individual's perception of their health threat and the deployment of further coping strategies. Appraisal is dynamic and an important element of the common sense model, but the least explored and defined (Hagger and Orbell 2003).

Figure 3: The parallel process model



Source: Adapted from Cameron and Leventhal (2003)

Coping strategies within the Common Sense Model are influenced by the emotional and cognitive responses to the health threat and the appraisal of current coping strategies to resolve the health threat (Leventhal et al., 2003). Lazarus and Folkman (1984) in the theoretical model of transactional stress and coping define coping as the cognitive and behavioural responses to manage external and internal demands that are appraised as exceeding an individual's resources. Individual's faced with similar health threats may apply different coping strategies due to; different health beliefs and appraisals of previous coping strategies (Stowell 2001).

One classification of coping strategies is active versus avoidant coping (Billings and Moos 1981). Active coping involves both cognitive and behaviour components, such as a cognitive reappraisal of the health threat which results in a positive reappraisal of the situation and coping strategies implemented. A behavioural component may include the implementation of behaviours to reduce the stress of the health threat, such as seeking complementary and alternative medicine (Sollner, Maislinger, DeVries, Steixner, Rumpold and Lukas 2000). Avoidant coping is the denial of a stressful event and an individual choosing to ignore a health threat. Avoidant coping can be effective with short term threats (Suls and Kletcher 1985). However, individuals implementing avoidant coping may report less stress, but demonstrate larger physiological changes than individuals implementing active coping strategies (Nyklicek1998). Folkman and Lazarus (1980) suggest coping styles implemented are influenced by the situation and the degree of the threat encountered.

Problem-focused versus emotion-focused coping is a further classification of coping strategies (Carver and Connor-Smith 2010). Problem-focused coping is defined as active, planful problem solving, seeking specific kinds of assistance to help the problem solving process, such as; information, family/peer support and guidance from experts (Carver and Connor-Smith 2010).

Problem-focused coping such as seeking information improved the quality of life in women undergoing treatment for breast cancer (Ransom, Jacobsen and Schmidt 2005). Problem-focused coping also improved mental and physical well-being as indicators of quality of life in individuals with rheumatoid arthritis (Englbrecht, Gossec, DeLongs, Scholte-Vashaar and Sokkta 2012). Although individuals diagnosed with other long term conditions including; muscular dystrophy and postpolio syndrome where found to use problem-solving coping infrequently which impacted on their mobility and quality of life (Natterlund and Ahlstrom 1995). Problem-solving strategies are viewed as more adaptive in situations appraised as changeable (Lazarus and Folkman 1984). When problem-solving strategies are implemented in unchangeable situations the individual is left feeling frustrated, defeated or disillusioned (MacNair and Elliott 1992).

Emotion-focused coping is the application of cognitive and emotional strategies to regulate the emotional response to a health threat (Billings and Moos 1981). Emotion-focused strategies include; avoidance, distancing, selective attention, positive comparisons and finding positive values in negative events (Schuster and Hammitt 2002). Emotion-focused coping is also an interpretation strategy; an individual changes their conception of a stressful event rather than the event itself (Kaplan and Kaplan 1982).

Emotion-focused coping has been explored in depression; individuals diagnosed with depression relied excessively on emotion-focused coping strategies reducing their quality of life (Rauindran , Matheson, Griffiths, Merali and Anisman 2002). Emotion-focused strategies such as worrying can also maintain depression in women (Nolen-Hoeksema and Girgus1994). However emotion-focused strategies are more adaptive in unresolvable situations (Lazarus and Folkman 1984).

However, in some chronic stressful conditions, both problem-focused and emotion-focused coping have appeared to have positive benefits on health and quality of life (Ingledew, Hardy and Cooper 1997; McQueeney, Stanton and Sigmon 1997). The effects of coping may not depend on problem-focused or emotion-focused, but strategies which are active rather than avoidant (Stowell 2001).

When individuals were asked to describe their illness/disease in as much detail as possible, 90% of their responses could be assigned to one of five dimensions; identity, cause, consequences, timeline and cure/control (Lau, Bernard and Hartman 1989; Bauman and Leventhal 1985; Lacroix, Martin, Avendano and Goldstein 1991). The Common Sense Model refers to these interpretations of a health threat as illness representation dimensions (Leventhal, Nerenz and Steele 1984). The five dimensions have been expanded to include a further dimension for timeline and control, and new dimensions of illness coherence and emotional representation (Moss-Morris 2002). Illness representations are interpretations of health threat by the patient and are not necessarily medically correct (Diefenback and Leventhal 1996).

The dimension of identity includes the label or name given to an illness or a group of symptoms that comprise an illness, the label can be generated by the individual or assigned by a healthcare professional. 'Cause' is the main reason the individual attributes to the cause of their illness and can vary from stress, environmental pollution and other pathogens, and is not necessarily medically correct. Cause is also influenced by both personal and vicarious experience with a disease (Lykins, Grave, Brechting, Roach, Gochett and Andrykowski 2008). ‘Consequences’ involves the individual’s beliefs on how the illness is going to impact on their life, both the quality of their life and their functional capacity. ‘Timeline acute/chronic’ is the individual’s beliefs of how long the illness or symptoms they are experiencing will last. Chronic timeline beliefs are associated with a higher incidence of depression (Llewellyn, McGurk and Weinman 2007). ‘Timeline cyclical’ allows for the beliefs that the illness will go through cycles of exacerbation and remission. ‘Personal control’ is the individual’s beliefs on how much control they have over their illness/symptoms. Personal control may not remain stable over time, in chronic progressive conditions such as osteoarthritis personal control may decrease (Kaptein, Bijsterbosch, Scharloo, Hampson, Kroon and Kloppenburg 2010). ‘Treatment control’ is the individual’s beliefs on how much the treatment can control their illness/symptoms. ‘Illness coherence’ includes the individual’s understanding of their illness, as this is expected to change and develop over time and experience of the illness. An accurate understanding of an illness has been associated with improvement in self-management (Huston and Houk 2011). The ‘emotional representation’ dimension represents the parallel processing of the Common Sense Model and allows the measurement of emotional representation of the health threat. Emotional representations have been associated with mental health outcomes (Rozema, Vollink and Lechner 2009).

Illness representation dimensions are formed from a range of different social and cultural sources including; education, information from the media and health professionals regarding the illness, personal and past experiences of illness and illness experiences of family and friends (Garro 1994). Illness representations are constructed following a number of rules, including; the symmetry rule, the stress-illness rule, the age-illness rule, and prevalence and duration rules (Leventhal, Benyam, Browniee, Leventhal and Patrick-Miller 1997). The symmetry rule suggests that an individual is under stress to connect abstract experience with labels. An individual will seek labels for the symptoms they are experiencing and once a label has been defined the individual will seek symptoms to confirm the label (Easterling and Leventhal 1989). The stress-illness and age-illness rules suggests that an individual seeks to understand their experiences as symptoms of an illness or biological disease or as functional changes due to stress or age (Baumann and Leventhal 1985). The prevalence and duration rules suggest that an individual accesses the potential seriousness of a symptom, the failure of a stress symptom to respond to treatment will confirm the stress interpretation. Duration of symptoms is one of the most powerful predictors for seeking help (Mora, Robitaille, Leventhal, Swigar and Leventhal 2002) and is a rule for judging the seriousness of a symptom. However, if symptoms are prevalent among family members or peers this will reduce the interpretation of the symptom as serious (Croyle and Jemmott 1991).

Illness representation dimensions are not isolated dimensions but are related (Cameron and Morris 2004; Hagger and Orbell 2003). Significant and positive correlations were demonstrated between identity and consequences, identity and timeline and timeline and consequences (Hagger and Orbell 2003). Therefore the more an individual identifies with the illness and labels numerous symptoms as related to the illness the impact of the illness is going to be perceived as having more serious consequences and a longer timeframe. Significant and negative correlations were demonstrated between; cure/control and consequences, identity and cure/control, and timeline and cure/control (Hagger and Orbell 2003). Therefore the more an individual perceives the illness is curable and under their control then the fewer consequences the illness is perceived to have. The more an individual identifies with the illness and attributes numerous symptoms to the illness the less the individual perceives the illness is controllable or curable.

Hagger and Orbell (2003) in their meta-analysis conclude that a profile of illness representation dimensions for each chronic or long term illness occurs. However, a general chronic illness model has been identified including; a chronic timeline, numerous consequences and less perceived personal control (Fischer, Scharloo, Abbink, van Hul, van Ranst and Rudolphus 2010). Although individual patterns of illness representation dimensions occur due to the different symptoms and timeline of each illness. A more recent meta-analysis confirmed these results, with an illness specific pattern occurring between identity and cyclical timeline (Brooke and Lusher 2012). The diagnosis of Parkinson's disease and alopecia were negatively associated with cyclical timeline. The diagnosis of breast cancer was positively associated with cyclical timeline. There are distinct differences between these illnesses, the treatment of Parkinson's disease and alopecia is focused on the control of long term symptoms. However, breast cancer treatment can provide a cure of the current episode. Individuals remain susceptible to reoccurrences, but will be free from symptoms while in remission. These differences demonstrate the importance of considering the illness and the treatment of an illness when exploring illness representation dimensions.

The Common Sense Model proposes illness representation dimensions have an indirect impact on health outcomes as coping strategies mediate the effect of illness representation dimensions on health outcomes (Leventhal et al., 1980). For coping to be classified as a mediator four relationships have to be defined: illness representation dimensions significantly affect a health outcome, coping significantly affects a health outcome, illness representation dimensions significantly affect coping and lastly coping has a greater affect on health outcomes when illness representation dimensions are added to the equation (Baron and Kelly 1986).

Hagger and Orbell's (2003) and Brooke and Lusher's (2012) meta-analysis explored the correlations within constructs of the Common Sense Model including the mediating role of coping. Hagger and Orbell (2003) found coping did partially mediate illness representation dimensions on health outcomes, but illness representations also directly impacted on health outcomes. Brooke and Lusher (2012) found coping did not mediate illness representation dimensions on health outcomes and a stronger correlation between illness representations and health outcomes was identified. However, both meta-analyses supported the individual constructs of the Common Sense Model.

The Common Sense Model has not been explored in the condition of stroke since the recognition of stroke as a medical emergency and a long term chronic illness. Previous exploration of illness representation dimensions of individuals following a stroke is limited (Twiddy, House and Jones 2012). Qualitative research exploring individuals' beliefs regarding recovery after stroke highlight the importance of the dimension of control (Jones, Mandy and Partridge 2008; Bendz 2003). Jones et al., (2008) suggested that personal control of goals, which were set by the individual, may be an important factor in making sense of their life post stroke and actively managing their recovery following stroke. Bendz (2003) found individuals rehabilitation post stroke was negatively influenced by individuals who expressed a loss of control. An individual's response to stroke is highly individualised; stroke survivors may set themselves goals to return to pre-stroke living, in an attempt to regain control in their life (Hartigan, O'Connell, McCarthy and Mahony 2011). The goals set are unique and specific to each individual, however the goals need to match the rehabilitation goals of health professionals' for rehabilitation outcomes to be improved (Alaszewski, Alaszewski and Potter 2004).

Discrepancies in illness representation dimensions in individuals following a stroke and their carers demonstrated carers reported more symptoms, longer timeline and more consequences of a stroke (Twiddy et al., 2012). The discrepancies impacted on both carer distress and physical disability of the stroke survivor (Twiddy et al., 2012). However, a pattern of illness representation dimensions of individuals' following a stroke was not highlighted or discussed. Therefore the important element of understanding a stroke survivors illness representation dimensions is missing in current research. Illness representations are important in patients who have had a stroke as these impact on patient outcomes over and above the biological illness. Following a stroke, patients need to engage in physiotherapy and for this to occur the patient will need have the belief that their contribution to physiotherapy will improve their physical functioning.

1.4 Aims

Stroke has evolved as a medical emergency requiring immediate assessment and treatment. The development and implementation of the new stroke care pathway in London has reduced patients' neurological deficits and length of hospital stay and increased the likelihood of being discharged home rather than to institutionalized care. Previous studies have explored the impact of stroke identifying coping strategies, quality of life and an intensely personal recovery experience. However, phenomenological studies have not explored the impact of an individual having their stroke treated as a medical emergency. Stroke care and treatment now focuses on stroke as an acute and treatable condition and the impact of this on the patient is unknown.

The first aim of this study is to explore the impact of stroke on individuals following the new stroke care pathway in London, including their hyper acute assessment, treatment and management.

Transfer anxiety has been documented and identified since the implementation of critical care units providing mechanical assistance and one-to-one nursing care for patients with a life threatening illness. Critical care settings encompass intensive care units and coronary care units, which are both similar to the new hyper acute stroke units. Strategies to reduce the negative effects of transfer anxiety have been widely implemented in both ICU and CCU settings, but as yet have not been considered or deployed in the HASU setting.

The second aim of this study is to explore patients' experience and understanding of transfer from a hyper acute stroke unit to a rehabilitation stroke unit within the new stroke care pathway in London.

The Common Sense Model of Self-Regulation identifies illness representation dimensions as patients' beliefs regarding their illness. Illness representation dimensions influence both the strategies an individual deploys and the individual's quality of life above and beyond the outcome of their biological disease. Patterns of illness representation dimensions across different chronic diseases are beginning to be described. Interventions to improve positive illness representation dimensions demonstrate effective changes in health beliefs which impact on coping strategies and health outcomes. Although extensive research has occurred using the theoretical constructs of the Common Sense Model, few studies have included patients with a diagnosis of stroke.

The third aim of this study is to explore illness representation dimensions of individuals recently diagnosed with a stroke.

Chapter 2: Research Methods

2. Methodology

The theoretical drive for this study was phenomenology as the study endeavours to understand how participants make sense of their experience of having a stroke and the new stroke care pathway. Qualitative data was collected via semi-structured interviews and analysed using Interpretative Phenomenological Analysis (IPA). The data was then revisited to identify the emergence of transfer anxiety and illness representation dimensions.

2.1 Interpretative Phenomenological Analysis

The three components of IPA include; phenomenology (the study of experience), hermeneutics (the theory of interpretation) and idiographic (a particular person making sense of their experience) (Smith, Flowers and Larkin 2009).

2.11 Phenomenology

IPA is phenomenological as the analysis involves the exploration of experience when lived experience becomes significant or important for a person, such as dealing with a health threat. The experience can be explored when a person becomes aware of what is happening to them and begin to reflect on the significance and importance of the experience. The experience can then be described as 'an experience' rather than just experience (Smith et al., 2009).

Smith (2011) defines IPA as:

"Interpretative Phenomenological Analysis is concerned with the detailed examination of personal lived experience, the meaning of experience to participants and how participants make sense of that experience." (p. 9).

Phenomenologists are concerned with the experience of being human and a person's lived world (Finlay 2009). Phenomenological philosophy provides structure to begin the process of understanding the lived experience. There are many variations in phenomenological methods (Finlay 2009). However, the majority of psychological phenomenological approaches include the following steps: phenomenological reduction, description and search for essences (Girogi 1997). Phenomenologists relevant to the understanding of phenomenology in IPA include; Husserl, Heidegger, Merleau-Ponty and Sartre (Smith et al., 2009).

Husserl explained phenomenology as the rigorous examination of human experience and was interested in finding how an individual may come to understand or accurately know their own experience (Smith et al., 2009). Husserl argued that once the essential features of an experience are identified these would transcend the individual's particular circumstances and become relevant to others (Smith et al., 2009).

Husserl described the necessity of adopting a 'phenomenological attitude', which involved the transformation of an individual's approach to understanding with a suspension of their natural attitude and presuppositions to beyond the taken-for-granted understanding (Finlay 2008). This stance involves a reflective element to examine every day experiences by turning from the objects in the world to an inward exploration of those objects. Husserl (1927) stated:

> *"Through reflection, instead of grasping simply the matter straight-out –the values, goals and instrumentalities – we grasp the corresponding subjective experiences in which we become 'conscious' of them, in which they 'appear'. For this reason they are called 'phenomena'."* (p. 3).

Most phenomenologists would agree that this stance is one of the more significant dimensions of phenomenological research (Finlay 2008). Husserl defined this stance as a phenomenological method, which was used to identify the core structures and features of human experience. Within the phenomenological method Husserl describes 'bracketing', where an individual needs to account for and take into consideration their own perceptions or taken-for-granted views of living in the world to be able to concentrate on that world (Hamil 2010). Husserl explained bracketing as a method of reductions, a reduction when it occurs allows for a different way of thinking about the phenomena under investigation (Finlay 2008). Reduction is not an isolated event, but a series of events and with each reduction the researcher is moving away from their own perceptions or taken-for-granted view of the living world and towards the essence of the experience of the phenomena (Keller 2004).

An explanation of Husserl's phenomenological method can be applied to the experience of having a stroke. Everyone has different symptoms, perceptions and experiences of this acute and chronic disease and yet each of these perceptions has something in common.

Therefore Husserl would argue the task would be to identify the core of the subjective experience of a having a stroke, the 'essence' or 'idea' of a stroke.

Husserl described transcendental reduction and eidetic reduction, where the nature of consciousness was explored. Transcendental reduction involved an individual standing outside of their perceptions and taken-for-granted realizations and to focus on consciousness itself. Eidetic reduction or the free imagination variation is where aspects of the phenomena are changed to identify essential features from factual features and the essences of the phenomena then appear (Finlay 2008).

Husserl's work is relevant to IPA as the detailed process of reflection provides clear guidance on the examination of consciousness and the lived experience (Smith et al., 2009). Husserl's bracketing is important in qualitative research to begin the process of a valid and reliable method for data collection (Morse, Barrett, Mayan, Olson and Spiers 2002). IPA involves Husserl's attempt to understand a phenomena from an individual's experience, however IPA does not progress to find the essence of that experience (Smith et al., 2009).

Wertz (2005) argues although qualitative research methods apply the method of reflection and the researcher applies the phenomenological attitude or orientation, they do no focus on 'the things in their appearing' or the essence of the experience and therefore cannot be considered phenomenological. However, the phenomenological attitude as described by Churchill, Lowery, McNally and Rao (1998) as an 'empathic dwelling', is consistent with the approach of IPA as the researcher is becoming ever-more open to the participant's experience and the information, feeling and thoughts that are being communicated. In this definition IPA remains a phenomenological method and approach.

Heidegger's approach to phenomenology is the beginning of a move away from transcendental reduction and the introduction of a hermeneutic and existential emphasis in phenomenological philosophy (Shinebourne 2011). Husserl was primarily concerned with perception, awareness and consciousness, whereas Heidegger was more concerned with practical activities and relationships that individuals are caught up in and in which the world appears to them in a meaningful manner (Parsons 2010). Heidegger used the term 'Dasein' as 'there being' or 'being there', by which he implied that individuals by their very nature are always somewhere, always located and always among and involved with some kind of meaningful context (Larkin, Watts and Clifton 2006).

Heidegger extended his conceptual basis of existence to include a 'worldly' perspective. The individual is the intentional actor with a range of physically-grounded (what is possible) and intersubjectively-grounded (what is meaningful) options (Russell and Reynolds 2011). Intersubjectivity is an individual's shared, overlapping and relational nature of their engagement in the world. An individual's relatedness-to-the-world is a fundamental part of their constitution and intersubjectivity is the concept which aims to describe this relatedness and to account for individual's ability to communicate with and make sense of each other (Larkin et al., 2006).

Heidegger emphasized 'worldliness' as the situated interpretative quality of an individual's knowledge about the world and as an individual 'being-in-the-world'. Merleau-Ponty described the 'embodied' nature of an individual's relationships to the world and how this leads to the individual situated perspective of the world (Alerby 2009). Merleau-Ponty focused on individuals as engaged in looking at the world rather than being subsumed within it (Smith et al., 2009).

Merleau-Ponty described 'embodiment' as the process of observing and experiencing empathy for another individual. However, an individual can never entirely share the other's experience, because experience belongs to their own embodied position in the world. Merleau-Ponty places the 'body', such as sensations and physiological components rather than cognitive components as a central element in experience (Albery 2009).

Sartre adds a further dimension by stressing the developmental aspect of being an individual. Sartre suggested that individuals are not pre-existing entities to be understood, but are evolving and developing (Webber 2006). Kierkegaard (1974) captured this element:

> *"An existing individual is constantly in the process of becoming."* (p. 79).

Sartre explored 'nothingness' things that are absent are as important as those that are present in defining individuals and how they see the world (Sartre 1943). Sartre described relationships with others as an acknowledgement that the world is not an individual's alone and the individual recognizes that the world is shaped by the presence of others (Sartre 1943).

Husserl, Heidegger, Merleau-Ponty and Sartre are leading figures in phenomenological philosophy (Macann 1993). Husserl focuses his work on experience and perception.

Heidegger, Merleau-Ponty and Sartre develop Husserl's work in unique ways and contribute to the understanding of an individual as embedded in a world of objects and relationships. Heidegger, Merleau-Ponty and Sartre all move away from transcendental interests towards a more interpretative and worldly position, with a focus an individual's involvement in the lived world, including the individual's relationship to the world and others (Smith et al., 2009). Experience is viewed as a lived process, evolving and developing meanings which are unique to the individual's embodied and situated relationship to the world.

IPA therefore encompasses phenomenology as a broad definition, with a core concern regarding the exploration of human lived experiences. Phenomenological philosophers have all added different dimensions; Husserl's phenomenology has been described as 'intrapsychic' whereas Heidegger and Sartre have focused on existential inquiry and Merleau-Ponty with the importance of embodiment in phenomenology. The theoretical basis of IPA is an inclusion of these philosophers' work for a holistic phenomenological approach (Smith et al., 2009).

2.12 Hermeneutics

Phenomenology is only one aspect of IPA, hermeneutics and idiographic need to be considered. IPA is a phenomenological method involving an interpretive process (hermeneutic process). Schleiermacher classified interpretation as the grammatical and psychological interpretation of a text (Smith et al., 2009). Grammatical interpretation involves the exact and objective meaning of the text, while psychological interpretation involves understanding the writer of the text (Gjesdal 2009). Schleiermacher described a holistic analysis of interpretation, and IPA involves a holistic, systematic and detailed analysis of text (Smith et al., 2009).

Heidegger's approach is also consistent with IPA as he believed the meaning of phenomenological description as a method lies in interpretation (Heidegger 1962). Heidegger considered phenomenon to translate as 'show' or 'appear' suggesting something which 'appears' does so in a new state of awareness. The appearance is different to a previous state, when it was not present (Mackey 2005). The construct of appearance involves both visible meanings and concealed or hidden meanings. Heidegger's concept of phenomenology is the understanding of the thing which 'appears' and what has brought the thing to appear (Mackey 2005).

Heidegger elaborates on interpretation as all interpretation is based on fore-conception. For Heidegger fore-conception is what the reader or researcher brings into the process including; prior experiences, assumptions and preconceptions. An individual will look at new things from their own fore-conceptions and experiences (Carman 2003). Heidegger suggested that when an interpretation of a new experience is occurring; priority should be given to the new experience rather than fore-conceptions. Although fore-conceptions precede an understanding of a new experience, the relevant fore-conceptions may not be identified until the encounter with the new experience and therefore the understanding the new experience may highlight fore-conceptions. Hence interpretation is the encounter of a new experience and fore-conceptions (Laverty 2003).

Husserl and Heidegger's theoretical approach have implications for the process of bracketing; Husserl implied the concept of bracketing to involve the individual taking into account all their preconceptions prior to the understanding process. However, Heidegger implied individuals would not fully understand their preconceptions until the new experience had been encountered (Laverty 2003).

The practical element of understanding involves the interpretation of data and the hermeneutic circle, which is dominant in hermeneutic theory. The hermeneutic circle is the dynamic relationship between the part and the whole, which can be identified at a series of levels (Smith et al., 2009) refer to Table I (page 49) for examples. Table 1 provides examples of the part and the whole at different levels. The part and the whole both require understanding to interpret a text.

Table I: The Hermeneutic circle: the part and the whole

Level	**The part**	**The whole**
I	The single word	The sentence in which the word is embedded
II	The single extract	The complete text
III	The particular text	The complete oeuvre
IV	The interview	The research project
V	The single episode	The complete life

Source: Adapted from Smith, Flowers and Larkin (2009)

The hermeneutic circle is required to understand the part, when reference is made to the whole; to understand the whole reference is made to the part. The hermeneutic circle is non-linear and allows for interpretation to occur at a deeper and deeper level (Smith 2007). IPA involves the process of moving back and forth from the data to acquire a deeper understanding. A skilled researcher will require the understanding of when to stop the hermeneutic circle and the interpretation reached is 'good enough' (Smith 2007). Heideggerian research is concerned with how a phenomenon appears and the researcher is implicated in facilitating and making sense of that appearance (Smith et al., 2009).

Smith and Osborn (2003) applied the phrase 'double hermeneutic' to the interpretation process within IPA. Double hermeneutics in this context involves the researcher trying to understand the participant who is trying to understand an event, experience or health threat. Smith and Osborn (2003) identified the dual role of the researcher as being both similar and dis-similar to the participant. The researcher only has access to the participant's experience through the participant's explanation of that experience, and the researcher is interpreting the explanation from their own experience and knowledge.

The researcher within IPA is attempting to understand the participant's experience from both an 'insider's perspective' (Conrad 1987) and moving away from the exact explanation of the participant to an interpretation of the experience. Ricoeur (1970) defines two hermeneutic positions; hermeneutics of empathy and hermeneutics of suspicion. IPA is the involvement of both these positions as the approach of hermeneutics of empathy is the attempt to understand the original experience and the approach of hermeneutics of suspicion is the application of theoretical structures to the experience. The approach of both hermeneutics of empathy and suspicion allows for a holistic interpretative understanding of the participants experience. The dual approach of hermeneutics will be applied in this study.

IPA therefore includes a theoretical basis of both phenomenology and hermeneutics. The phenomenological approach of attempting to understand a complex human experience, but with the recognition of the interpretation that occurs both in the participant's explanation of the experience and the researchers understanding of the experience including pre-conceptions and further interpretation (Smith et al., 2009).

2.13 Idiographic

The German philosopher Winderband in 1904 termed 'idiographic' as the exploration that is particular to the individual case, whereas 'nomothetic' as the exploration of general laws (Runyan 1983). Exploration of the particular in IPA operates at two levels; the particular is explored in detail and therefore an in depth analysis, but also the exploration of the particular experiential phenomena (the event, relationship or illness) from the perspective of particular people in particular contexts (Smith et al., 2009). The consequence of the idiographic approach in IPA is the small purposively selected sample of participants for research. Case studies have been the recommended format for IPA research (Smith 2004), although the majority of IPA studies range from 3-15 (Reid, Flowers and Larkin 2005). The maintenance of the idiographic approach is an important aspect on defining the sample size in IPA studies; the requirement of detailed analyses of particular cases of lived experience (Smith et al., 2009).

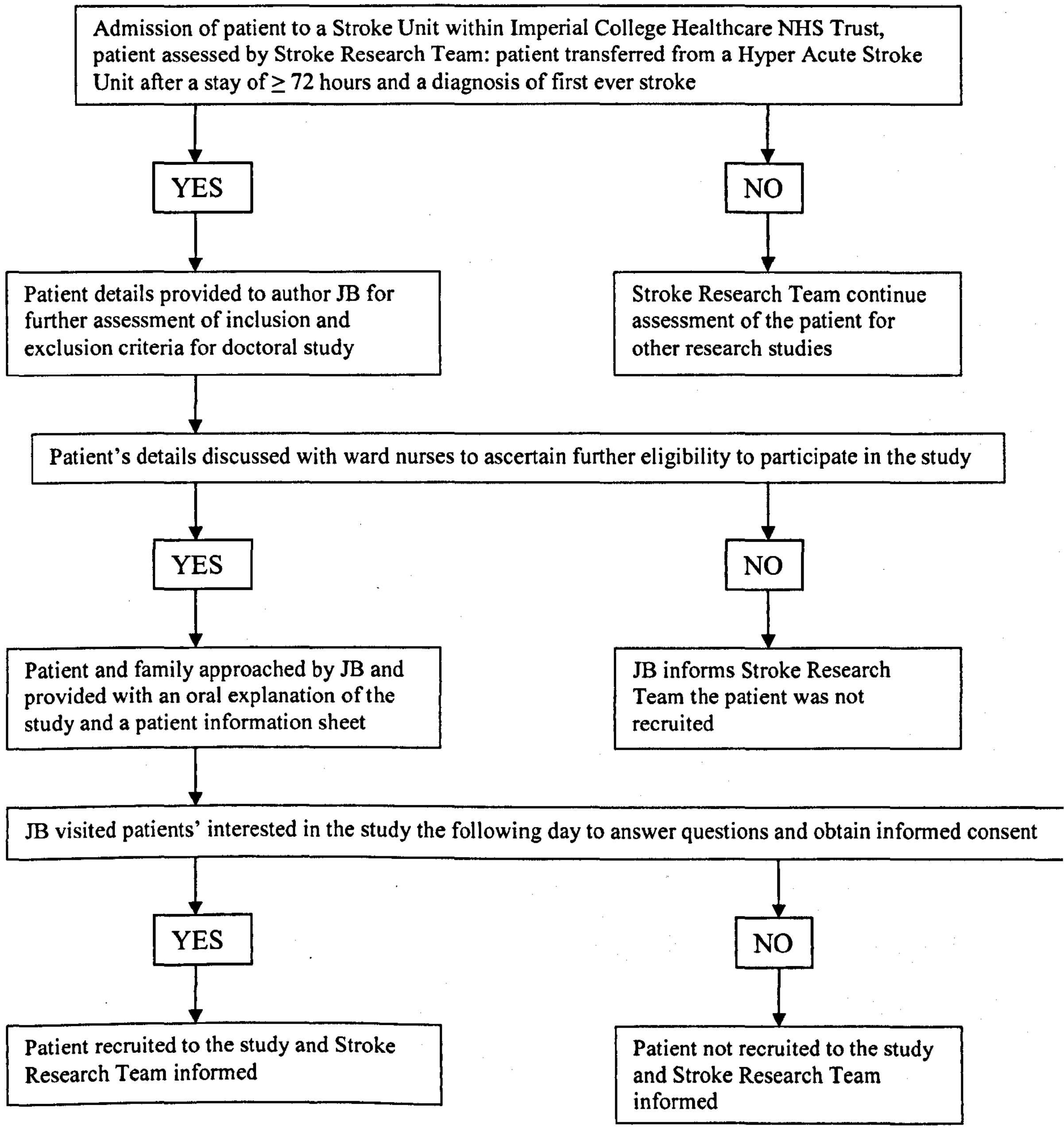
2.2 Participants

2.21 Recruitment

The recruitment of patients with a diagnosis of a stroke into research has been recognized as problematic: patients with a predominantly mild to moderate stroke are recruited (Jones, Mandy and Partridge 2010) and this remains a limitation within this study. A current study is exploring the decision making process of patients, carers and healthcare professionals regarding consent and assent for inclusion of patients into research studies in the hyper acute and acute period (Murtagh and Stobbart 2006). The study aims to develop a robust explanatory framework for the purpose of seeking informed consent/assent. However, to date the outcome and proposed framework from this research is not currently available.

Recruitment occurred for the current study from two stroke units within Imperial College Healthcare NHS Trust. The multi-disciplinary stroke team includes a research team to recruit and monitor all patients entered into research trials. The research team is responsible for ensuring individual patients are not over recruited into research and to identify patients who cannot be recruited for further research due to the criteria involved in a major on-going clinical trial. The stroke research team identifies patients eligible for all on-going research studies. Once potential participants are identified through the inclusion and exclusion criteria of each study the information is provided to the appropriate researcher (refer to Figure 4 for further clarification, page 51). Potential participants for the current study were then approached.

Figure 4: Recruitment process



Recruitment of participants into the study was problematic for a number of reasons; the admission rate of patients being diagnosed with a stroke had reduced significantly since the planning of this study and one of the stroke units had reduced their bed capacity from 14 to 7. The level of care required by the patients was high and therefore the inclusion and exclusion criteria for this study excluded many patients. Therefore recruitment of participants was extended for a further month. Due to the issues concerning recruitment of participant's to the study the second interview, which was planned to be conducted once the participant had been discharged from hospital had to be cancelled. A further study will be planned to understand the experience of patients who have completed the new stroke care pathway.

2.22 Inclusion and exclusion criteria

Participants were required to have a primary diagnosis of a first ever stroke (ischemic or haemorrhagic). A primary diagnosis of stroke was important to exclude patients with multiple comorbidities and the complex nature of understanding the impact of all their conditions on their experience rather than the impact of their stroke alone. Participants with a medical history of long term conditions such as; hypertension or diabetes were included as these conditions are major risk factors for stroke. However, participants with a medical history of a previous stroke were excluded as their illness coherence, understanding of assessment and treatment and coping strategies may have evolved since their first stroke.

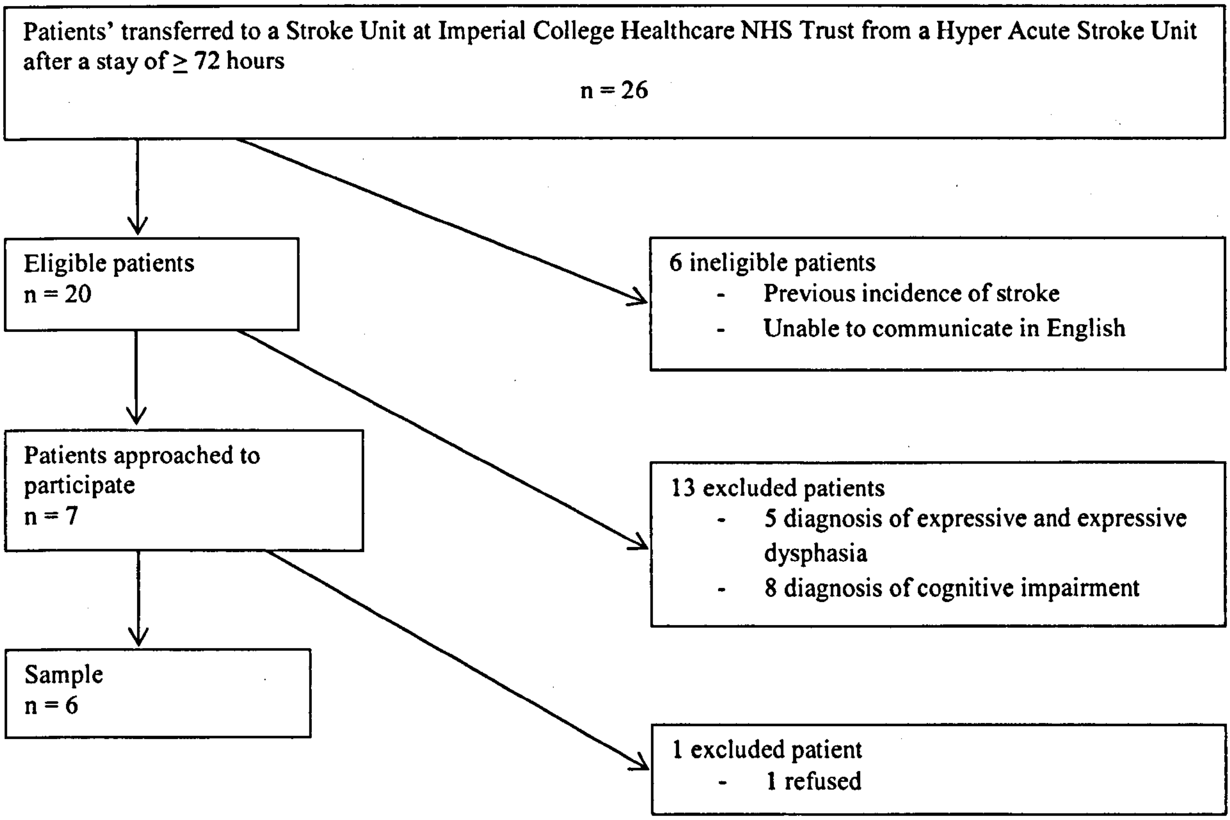
The ability of the participant to communicate in English was deemed necessary due to the qualitative approach of relying on language to obtain rich and meaningful data. Only one patient approached refused to participate in the study, explaining they were concerned their English would not be of an appropriate level.

Participants were only eligible if they had been admitted to a hyper acute stroke unit within London, and their stay was at least 72 hours long. The participants' minimum stay was important to allow the highly technical environment of the hyper acute stroke unit to become familiar and reassuring.

Patients with a diagnosis of cognitive impairment were excluded from the study. Cognitive impairment was identified through patients' previous medical history or through the assessment process on admission to the hyper acute stroke unit which includes the administration of the Mini Mental State Exam. The qualitative approach requires the participant to have an understanding of their experience and the ability to reflect and evaluate the experience both emotionally and cognitively. Patients with cognitive impairment may not be able to provide in-depth information and might have found this approach distressing as the interview could highlight the impact of their cognitive problems.

Due to the possible impact of a stroke on a patient's language, patients with expressive or receptive dysphasia were excluded from the current study. Patients with receptive dysphasia may not understand verbal communication or follow a conversation. Whereas, patients with expressive dysphasia may not be able to speak or speak at a normal rate but what they say is unrecognizable and has limited meaning. Therefore the diagnosis of either of these language problems would hinder the ability to acquire informed consent and the patients' ability to provide rich and meaningful data. Patients diagnosed with these language problems may find the process of being involved in this study unnecessarily stressful. For an overview of the inclusion and exclusion criteria refer to Figure 5 (page 54).

Figure 5: Inclusion and exclusion criteria



2.23 The Sample

The size of the sample was 6 participants recruited from a stroke unit at Imperial College Healthcare NHS Trust. Participants were recruited and interviewed during the months of October and November 2012. The inclusion and exclusion criteria was applied to all consecutive patients admitted to the stroke unit at Imperial College NHS Trust and all potential participants were approached. Only one potential participant the researcher approached refused to participate in the study. A total of six participants were recruited, three male and three female, three were transferred from a HASU outside of Imperial College NHS Trust and three were transferred from the HASU within the Trust, ages ranged from 68 – 94, with a mean age of 78, interviews occurred from 6 to 10 days following a diagnosis of stroke and lasted between 11 – 35 minutes, see Table 2 (below) for further details of each participant, pseudonyms have been applied to maintain confidentiality. The length of each interview depended on the participants' well-being as all participants were in the acute stage following a stroke, which is characterised by increased lethargy (Stroke Association 2012).

Table 2: Demographic details of participants

Participant	**Ethnicity**	**Age**	**Internal or External transfer to SU**	**Length of time on the hyper acute stroke unit (days)**	**Length of time on the stroke unit (days)**	**Length of interview (minutes)**
Mrs A	British White	94	Internal	3	3	24
Mr B	British White	68	External	6	4	35
Mrs C	British Black	76	External	4	4	28
Mr D	American White	83	Internal	3	3	34
Mrs E	British White	72	Internal	6	3	11
Mr F	British White	79	External	3	2	33

2.3 Ethical considerations

Ethical approval was obtained from the NRES Committee London – City Road and Hampstead, REC reference number 12/LO/0690 and Site Specific Assessment was completed and approved by the Research and Development department for Imperial College Healthcare NHS Trust.

London Metropolitan University was the sponsor for this study as the study constitutes part of the requirements for the fulfillment of the Professional Doctorate of Health Psychology.

The study was conducted in accordance with the recommendations for research on human subjects adopted by the 18th World Medical Assembly, Helsinki, 1964 and later revisions and adhered to Good Clinical Practice and the NHS Research Governance Framework to Health and Social Care (2nd Edition).

2.31 Informed consent

Potential participants for the current study were approached and provided with both an oral explanation of the study and a participation information sheet (Appendix A). All participants were provided with at least 24 hours to decide if they wished to become involved in the study and were encouraged to discuss the study with friends and family members. As all participants were inpatients it was specifically explained that the study was not connected to their medical care and treatment and their participation or non-participation would not impact on their medical care and treatment. All participants provided informed written consent prior to the commencement of data collection (Appendix B).

2.32 Confidentiality

Data collection occurred in a quiet room within the ward environment or by the participant's bedside if they were being cared for in a single room. When participants were not able to mobilize to the quiet room ward staff helped to transfer the patient to a wheelchair and transport them to the quiet room. Therefore the interview was confidential and not overheard by other patients or medical staff. Following informed consent all participants were reminded the interview would be audio-recorded prior to the commencement of the interview. All interviewing, transcribing and analysis was completed by the author.

2.4 Data collection

Qualitative data was collected via semi-structured interviews, which were audio taped and transcribed verbatim, to allow interpretative phenomenological analysis. A semi-structured in-depth interview allowed the participants the time and scope to talk about their experiences regarding their stroke and following the new stroke care pathway. The semi-structured in-depth interview was based on an interview schedule (Appendix C), which contained questions thought to be important to the topic, but was flexible and revisions occurred as the research progressed.

A Heideggerian phenomenological approach to data collection was implemented, as the researcher bracketed fore-conceptions when they were identified. For example, one participant began to discuss 'other people' and the researcher was unsure who the 'other people' were. However, the researcher identified the 'other people' as the other patients on the ward. The researcher was able to recognize the fore-conception of individuals on the ward being identified as patients not people. Once this fore-conception was identified the researcher was able to bracket this understanding and become more open to the participants experience.

2.41 Interview schedule

The aim of the interview schedule was to ensure the participant was able to provide a detailed account of their stroke and experience of the new stroke care pathway in London. The questions were structured to encourage the participant to talk in length with minimal input from the researcher (Biggerstaff and Thompson 2008). The importance of the interview schedule was to allow the participant to tell their own story in their own words (Smith et al., 2009). The first question on the schedule was 'Can you explain what happened to bring you into hospital?' This question allowed the participant to begin telling their story in a narrative from. Once a participant became comfortable telling their story, the research asked more analytical questions such as; 'How do you feel the stroke has affected you?' All interviews were led by the participant as the researcher asked the questions in the order appropriate to each participant. This process allowed the participant to guide the interview and the researcher to follow-up interesting possibilities emerging during the interview (Shinebourne and Smith 2010).

The interview schedule was based on previous phenomenological research with individuals following a stroke and with individuals following transfer from an intensive care setting (Banja, 2011; Odell 2000; Macduff 1998; Bright, Kayes, McCann and McPherson 2011; Popvich, Fox and Bandagi 2007). The interview schedule was discussed with a Clinical Nurse Specialist in stroke and a patient on a stroke unit. Both discussions generated only minor changes to the interview schedule. The importance of discussing the interview schedule with a patient on the stroke unit was emphasised when the patient suggested one of the questions might be unduly upsetting. The patient suggested the question 'What impact do you think your stroke will have on your future?' be changed to 'What impact do you think your stroke will have when you go home?' The patient suggested this change as thinking about the impact of a stroke on a person's future may be too overwhelming and as yet not contemplated. However, all patients are not on the stroke rehabilitation unit and planning their discharge home. The advice of the patient was taken and the question was changed.

2.42 Conducting the interviews

Individual interviews were conducted as recommended by Smith (1995) for the provision of rich in-depth data. During each interview all participants were provided with as much time as needed to answer each question before moving on to new questions or prompts. All questions were framed without the inclusion of medical terminology. Participants' diagnosis was only referred to as stroke by the researcher once the participant had identified this terminology. This process was to ensure the researcher was not applying a label to the participant's condition, which the participant would not have applied themselves.

The interviews involved participants' reflection on sensitive experiences and for some participants this caused them to become distressed. Smith (1995) acknowledges the researcher has ethical responsibilities towards the participant and is required to respond to their distress. Within the present study two participants became tearful during their interview and the researcher responded in an empathetic manner and confirmed with the participants they were willing to continue with the interview.

The interview with Mrs E, the fifth interview to occur was the shortest interview as Mrs E also had a diagnosis of Multiple Sclerosis. Although Mrs E had a diagnosis of a major comorbidity, during the recruitment process Mrs E's health prior to her stroke had been one of independent living. Mrs E explained her multiple sclerosis was currently responding well to medication and had not impacted on her life. Mrs E's hospital admission was due to her primary diagnosis of a stroke and was therefore eligible to be recruited into the present study. During the interview it became apparent that talking was putting too much strain on her voice and the researcher and participant agreed to end the interview early, although some insightful information was obtained. The strain on Mrs E's voice was a combination of lethargy post stroke and her diagnosis of multiple sclerosis, although this was the only impact of her multiple sclerosis that Mrs E acknowledged.

2.5 Data analysis

The data was analysed using the six stages as described for use within IPA research (Smith et al., 2009). Although a detailed approach to analysis is described it is acknowledged to be a set of common processes and principles which can be applied flexibly according to the requirements of individual studies (Reid et al., 2005). The six stages including; reading and re-reading, initial noting, developing emergent themes, searching for connections across emergent themes, moving to the next case and looking for patterns across cases (Smith et al., 2009).

All data was transcribed verbatim by the author and then the first stage of analysis commenced with the reading and re-reading of an individual transcript. The author bracketed all the information gained through the interview process such as observations, initial reactions and thoughts. Due to the researcher's experience of a nurse working with patients following a stroke, it was important to bracket information regarding the severity of the participant's stroke to allow an understanding of the participant's beliefs of the impact of their stroke. The re-reading facilitates the understanding of the structure of the interview and how different components of the interview build from broad and general, to specific and detailed, and finally to a summary. Each interview was read and re-read by the author to facilitate an understanding of the participants experience and the important elements of the experience of having a stroke to the participant. Understanding of important elements developed that had not necessarily been identified by the author during the original interview. The author had not identified the use of the word 'hope' by one participant and the phrase 'I don't know' by another participant throughout their interviews.

The following stage was initial noting and an exploratory analysis of the semantic content and language used by the participant. The stage allowed the author to have a comprehensive set of notes on the transcript and begin to identify the ways in which the participant talks, understands and thinks about the experience (Smith et al., 2009). The author annotated comments on each script and developed these comments on each reading of the scripts. The notes commence with comments that are phenomenological in nature as describe the participants experience and remain close to the explicit meaning the participant provided regarding the experience. The original notes made by the author included the use of participants' own language to remain close to their experience. The use of the word 'hope' and the phrase 'I don't know' were included in the notes of two participants. However, alongside these notes are the interpretative notes, which help in the understanding of patterns and meanings of the participant's lived-experience. The notes were developed by the author to have an overarching understanding of each participant's experience. This stage allowed the author to move from exploratory commenting on the content and language towards conceptual commenting. The conceptual noting included participants overarching understanding of the experience of stroke and generated further questions that will required the author to return to the transcript to address. For example, participants discussed the importance of independence and accepting decisions made by family and healthcare professionals, the author had to return to the transcripts to understand the participants applied understanding of independence.

Once the initial note taking was complete the author had comprehensive notes on the transcript which needed to be condensed but at the same time maintain the complexity of the information involved, this occurred during the next stage of the development of emergent themes. The process involved both the identification of themes from specific parts of the transcript, but at the same time ensuring the themes addressed what had been learnt from the whole of the transcript. The author analysed the initial notes with the transcript for emergent sub-ordinate themes, this was completed by acknowledging the importance of the part and the whole of the transcript. The author acknowledged the importance of individual episodes of care for participants in relation to the whole experience of being treated for a stroke. The themes included the participants' words and thoughts and the author's interpretation.

The following stage was the searching for connections across emergent themes, not all emergent themes were included at this stage, for instance the level of noise on both wards was especially relevant to one participant, but this aspect was not commented on by any of the other participants. Therefore the level of noise in the ward environment was not included as a sub-ordinate theme although this information was retained for an overview of this participant's experience. This stage involved the drawing together of relevant themes in a coherent structure which included all the most interesting and important aspects from the participant's transcript. An element of interest, which occurred across all participants' transcripts, was their disassociation from the acute event of the stroke and the impact of this on their bodies and self-image. The transcripts allowed the author to analysis how the participants spoke about their body and themselves following their stroke.

Patterns and connections between emergent themes can be identified by numerous processes including; abstraction, subsumption, polarization, contextualization, numeration and function (Smith et al., 2009). Abstraction; the putting of like quotes or notes with like and developing a name for the cluster of emergent themes. The author placed all quotes/notes with the use of the word hope in one theme and independence in another theme. Subsumption is the linking together of emergent themes. Polarization focuses on differences rather than similarities and examining each transcript for oppositional relationships. The author placed quotes/notes with independence and acceptance of help into a theme as although these concepts appear opposite, at this stage were considered polar ends of the same theme. Contextualization involves the narrative elements of the context are explored to identify connections between the emergent themes. Numeration involves the frequency of text supporting a particular theme, although this is not the only indicator to be used to validate a theme and the importance of the theme. Function describes when an emergent theme can be for a specific function. At the end of this stage final super-ordinate themes will have been identified and the analysis of this participant is complete.

The following two stages involved moving on to analyse the transcript of the next participant and finally when all transcripts had been analysed the process of looking for patterns across cases occurs. The process of exploring all themes to identify super-ordinate themes began with the author re-reading the themes for each participant and understanding each theme and returning to the transcripts to explore as necessary. The author then began to explore the connections between themes, how a theme from one participant aided in the understanding of a theme from another participant and which themes are most potent.

At this stage the author identified the super-ordinate themes from the sub-ordinate themes and the prevalence of the sub-ordinate themes within each participant's transcript to ensure all themes represented the essence of all participants' transcripts.

2.6 Reflexivity

Reflexivity has been defined as the process of the researcher reflecting on the research process (Spencer et al., 2003; Yardley 2000). Qualitative research methods have been acknowledged to be influenced by researchers' beliefs and assumptions. Based on the researcher's own beliefs and assumptions decisions are made to how they will collect and analyse data. An important element of qualitative research is the clarity of these beliefs and assumptions, the current author's beliefs and assumptions are summarised in the following section.

2.61 Self-reflexivity

I qualified as a registered nurse in 1988 and have over two decades of experience of caring for patients with different conditions/diseases in various locations both in hospital and in the community setting. I acknowledge my familiarity with hospital settings and how I find them to be reassuring and safe. I have an in depth knowledge of hospital hierarchy, process and routines, which I understand is not applicable to individual's outside of the healthcare profession. Whilst I have this experience I have never been a patient myself and cannot assume I understand the experience of being a patient.

I am aware of the influence of my experience of being a nurse and the possibility of being identified by participants as a nurse, although during the process of collecting data my role is of a trainee Health Psychologist. During the process of collecting research for this study I will be honest with participants if they ask if I am a nurse, but will introduce myself as a trainee health psychologist.

In terms of my phenomenological approach I aim to bracket my understanding of the stroke care pathway and patients' experience prior to conducting interviews, as described by Husserl, but I am also aware I may need to bracket pre-conceptions as they arise as described by Heidegger.

My previous clinical post as a senior nurse involved the implementation of the stroke care pathway in a London NHS Trust. From this post I became interested of the impact of transfer from a hyper acute stroke unit to a rehabilitation stroke unit, as I was aware there was no provision of written documentation to provide to the patients' and their families to explain this process/pathway. My interest in stroke and the stroke care pathway has remained and led to my decision to develop the current study.

Chapter 3: Results

3. Results

3.1 Sub-ordinate themes

The themes reported are one possible account of the experience of having a stroke and following the new stroke care pathway in London. The themes do not cover all aspects of the patients' experience and were selected due to their relevance to the aims of the research. The prevalence of each theme within this cohort of participants is demonstrated in Table 3 (below). Sub-ordinate themes were grouped together for the formation of super-ordinate themes as demonstrated in table 4 (page 68) identifies relevant sub-ordinate themes.

Table 3: Prevalence of each sub-ordinate theme within participants' accounts

Sub-ordinate theme	**Mrs A**	**Mr B**	**Mrs C**	**Mr D**	**Mrs E**	**Mr F**
Disassociation from dead/failing bodies	-	-	X	X	X	X
Disassociation from self	-	-	X	X	X	-
Disassociation through memory loss	X	X	-	-	-	-
Cause of the stroke	-	X	-	X	-	X
Severity of the stroke	X	X	-	X	X	-
Impact of stroke on future	X	-	X	-	-	X
Need for independence	X	X	X	X	-	X
Allowing others to make decisions	X	X	X	-	X	-
Acceptance of support	X	-	X	X	X	-
Physical recovery	X	X	X	-	-	X
Return to normal	X	X	X	X	-	X
Alternative treatments to aid recovery			-	X	-	-

Table 4: Super-ordinate and relevant sub-ordinate themes

Super-ordinate themes	Sub-ordinate themes
Disassociation from being in the world	Disassociation from dead/failing body Disassociation from self Disassociation through memory loss
Search for understanding	Cause of stroke Severity of stroke Impact of stroke on future
Strive for independence and acceptance of support	Need for independence Allowing other to make decisions Acceptance of support
Hope and uncertainty	Physical recovery Return to normal Alternative treatments to aid recovery

3.2 Super-ordinate themes

Emergent super-ordinate themes included; disassociation from being in the world, search for understanding, strive for independence and acceptance of support and hope and uncertainty. Refer to Appendix D and E for an overview of each super-ordinate theme with participants' quotes.

3.21 Disassociation from being in the world

The emergent super-ordinate theme of disassociation from being in the world was expressed through participants' descriptions of their bodies, self and abilities. Each participant disassociated themselves with their body, self or abilities when describing the impact of their stroke. The process of disassociation allowed the participants to separate themselves from their changing bodies, self and abilities and avoid their current being in the world. All participants used disassociation during their description of the impact of their stroke on their being in the world; disassociation was temporary and fluctuated during their descriptions. The fluctuations occurred as the participants described their recovery from the stroke. The temporary nature of disassociation allowed the participants to discuss the impact of their stroke and how they were recovering from their stroke. The super-ordinate theme of disassociation from being in the world was developed from the subthemes of; disassociation from dead/failing body, disassociation from self and dissociation through memory loss. Four participants disassociated themselves from their dead/failing body by describing their bodies as dead or lifeless, or by applying inanimate objects to describe parts of their body, such as bricks or potatoes. The participants discussed changes that occurred to their dead/failing body as occurring to 'the' foot, not 'their' foot. In this instance 'the' foot is conceptualised by the patient as separate from them. Two participants disassociated themselves from their social self, by describing the impact of their stroke in the third person or describing their past social self rather than their current self following their stroke. Two participants disassociated themselves from the impact of their stroke through describing their memory loss. One participant explained he could not remember his admission to a hyper acute stroke unit, where he spent 4 days or his transfer to the stroke unit and yet describes the impact of his stroke as minor. However, when the participant further describes his experience of nursing care he remembers the nurses attending to him during the night whilst admitted to the hyper acute stroke unit.

Disassociation from dead/failing body

Disassociation from dead/failing body is evident in Mrs C's explanation of her stroke. Mrs C discusses the fact her body went dead and then recovered, except her foot, which she refers to as 'the foot', demonstrating a disassociation from her limb which she is unable to move:

Mrs C: I had no life in my body, none at all...(describing her stroke) it went dead, all of my body went dead... but umm... the foot is the main thing now compared to the rest of my body. The rest of my body has come back, but the foot is the main thing...

However during the same interview Mrs C's disassociation with her foot changes through her recovery process:

Mrs C: It (her foot) is coming back gradually, my foot is better because a couple of days ago I couldn't walk without help from the nurses, and now I can walk.

Two participants apply disassociation when discussing the impact of their stroke on their bodies and use the labelling of inanimate objects:

Mr F: I got as far as the door then just went backwards like a dead brick, that's when I banged the back of my head, elbow, all down my back... that's when I think the stroke started.

Mr D: My centre of gravity is now on the left side because this arm (left arm) is like a sack of potatoes and if I lean this way (to the left) it will pull me over so I must stand straight.

Disassociation from new self

Disassociation involved not only the separation of self from the body, but also a separation of self from social identity. One participant applied disassociation to the evaluation of his current ill health and discussed his situation in the third person. Mr D begins by describing the impact of his stroke as imagining it had occurred to another person, although in the same sentence includes his own reaction to his stroke:

> *Mr D: Can you imagine that an active person who has had a stroke becomes so depressed he can't move his leg he can't move his arm he is confined to the chair... it is a terrific shock... confined even to the bed.*

One participant, Mrs E, when discussing her independence prior to her stroke commences using the past tense, but during the same sentence reverts to the presence tense to suggest that she will remain independent. However it is clear from the severity of Mrs E's stroke and her later acknowledgement of accepting nursing home care this will not happen:

> *Mrs E: Before this (stroke) I was independent. I lived on my own, I have MS but that hasn't stopped me living at home on my own. I like to be independent... I have a district nurse who visits me and monitors my MS, my medication and my blood levels. But I remain independent. I like to do things for myself, I like to be independent.*

Disassociation through memory loss

One participant applied disassociation with the severity of his stroke through memory loss, Mr B reported he could not remember his hyper acute admission or admission to the stroke unit. Mr B explains he remembers 'waking up' on the stroke unit following a minor stroke. However, when discussing an aspect of nursing care he had received during his hyper acute phase following his stroke he remembered the nurses being very attentive during the night as he was extremely ill:

Mr B: I was found on the floor, I was 13 hours on the floor, I don't remember ever going to the other hospital. I didn't know that at all. I don't remember coming here, but I woke up and they said I was at this hospital... apparently I had a light stroke, which was one good thing.

Later in the same interview Mr B discusses some memories of his admission to the hyper acute stroke unit:

Mr B:But I remember seeing the nurses regularly during the daytime and night time over there (other hospital) cause I was so sick... they became like best friends sort of thing.

One participant described her stroke as a 'nice little nap', but later in the interview, Mrs A explains she does not remember being admitted to hospital through A+E, dissociating herself from the impact of her stroke:

Mrs A: It (the stroke) was just like I was having a nice little nap. Beyond that of having a cup of tea I don't remember anything until I was there (pointing towards the hyper acute stroke unit).

3.22 Search for understanding

The emergent super-ordinate theme of search for understanding was expressed through participants' exploration of why their stroke had occurred and the impact of their stroke on their future lives. Participants expressed both the importance and the need to understand why their stroke had occurred. Participants were currently working through assessments of their health prior to the stroke to identify factors that may have suggested they were at risk of a stroke. This was a current process for some of the participants as they were still receiving medical investigations to clarify their risk factors. Search for understanding also involved the need to understand the severity and impact of the stroke for the future, participants completed social comparisons to aid this understanding. Downward comparisons of people with more severe focal neurology and cognitive impairment were completed. Positive downward comparisons included lucky and/or fortunate when participants compared themselves with other patients on the ward or friends who had had a stroke. The super-ordinate theme of search for understanding was developed from the subthemes of; cause of stroke, severity of stroke and impact of stroke on future. One participant discussed being puzzled as to why his stroke occurred, when another participant applied hindsight to his explanation of early warning signs that he had been at risk of a stroke. Five participants explored the severity of their stroke and the impact on their future by applying social comparisons of both patients on the stroke unit and friends they knew who had recovered from a stroke. Downward comparisons allowed the majority of participants to minimize the severity and impact of their stroke, as they evaluated themselves in a positive light to others. One participant with more severe focal neurology completed an upward comparison to understand how it was possible to have multiple comorbidities, severe focal neurology and still recover well from a stroke.

Cause of the stroke

One participant described his shock at becoming unwell and diagnosed with a stroke. Mr D reported being fit and healthy prior to his stroke and therefore could not understand how this could happen to him; at the time of the interview Mr D was going for further investigations to clarify the cause of his stroke:

> *Mr D: It was a great shock to me that I felt very unwell and with great anxiety, after being so well and active and played lots of sports and never had any high pressure (blood) or anything like that... the fact that I could have a stroke is a big blow to me... I wonder how comes I got this... how comes I got this stroke.*

Another participant had begun a search for understanding and had identified two previous episodes of ill health that might have been a warning that he was at risk of having a stroke. Mr F describes incidences of possible Transient Ischemic Attacks which are predictive of a stroke if preventive measures are not commenced:

> *Mr F: Three weeks prior to that (stroke) at home I had two nights on two occasions when I couldn't sit upright a 3am... I called an ambulance and they checked me over and the report said everything was perfectly alright... but had I followed up the complaint and had a head scan it might have saved me from having this stroke...*

Another participant, Mr B was still in the process of having a number of investigations and expressed his lack of understand of the cause of his stroke and of the reason for further investigations:

> *Mr B: I don't know why I had this stroke. I had an MRI scan and I don't know when I'm going to see the results. I asked when I would get the results and they (doctors) said today. But then... just before you came, they (doctors) said you are going down for another scan today, as they want to see about something – I don't know what. So I am going for another scan. I don't know what type of scan, I don't know... I should know.*

Severity of the stroke

Participants compared their own characteristics, circumstances and the results of their stroke to those of others. Mr B completed a downward comparison, comparing his own and another patient's cognitive abilities and concluding his own stroke was a light stroke and he had not been adversely affected:

> *Mr B: Apparently I had a light stroke, which was one good thing because the people around me are really out of it... he (describing a fellow patient) shouts and screams, then he cries. He wanders all over the place; honestly he can't help it.*

Another participant completed a more general downward comparison of other patients on the stroke unit. Mrs A demonstrates the importance for her of remaining cognitively astute:

Mrs A: So I am very lucky really there are people much worse off than me in here and I don't want to boast but I do still have a little bit left up here (points to her brain). I think if that goes... well I won't know anyway but there you are, fingers crossed that it won't.

One participant with severe weakness of his arm and leg completed an upward comparison to understand the severity of his stroke and the impact on his future. Mr D discussed an acquaintance that was in poor health prior to his stroke, but recovered fully from his stroke. The acquaintance Mr D discussed was the same age as Mr D, which might have made the comparison more relevant:

Mr D: I have seen people with a stroke... a person with two new knees a heart bypass and he had a stroke, he was an 83 year old chap but two weeks later was back walking.

Impact of the stroke on the future

During the search for understanding of the impact of the stroke one participant reappraised his life as a family man and the importance of family and family support:

Mr F: This stroke has brought them (children) all together and I'm happy about that... even my son and daughter. It has brought closeness together which I am really happy, about, it has made me feel it's good to be a family and you need a family.

During the search for the understanding of the impact of the stroke Mrs C reappraised her life and her relationship with her daughter:

Mrs C: I can manage at home; I can walk to the toilet with my stick... I can manage to wash and dress... I don't need help like that... I don't need help like that... I like my home, I like my daughter coming. I'm not going anywhere but home.

One participant exploring the impact of the stroke on her future explores the importance of social companionship and how lucky she is still to have social support from her friends and neighbours:

Mrs A: I do like company you know not raudy rowdy company but I do have a young lady who comes and it has developed into more than just that, we have become bosom friends. She has come down every day to see me. So I am very lucky in that way. I have one or two neighbours that are very helpful so I'm very lucky.

3.23 Strive for independence and acceptance of support

The emergent super-ordinate theme of strive for independence and acceptance of help was expressed through participants declarations of being independent and the need to remain independent but simultaneously expressing the acceptance of support from others including; healthcare professionals, family and friends. Participants strived for independence with reliance on their own capabilities, judgments and recourses. The majority of participants discussed the importance of returning home and living independently. Although participants strived for independence once discharged from hospital they acknowledged the support from medical staff, nurses, physiotherapists, family and friends to ensure decisions were made, care was organised and plans were being implemented for their return home. Participants with more severe focal neurology accepted the need for on-going support in hospital and once discharged. The super-ordinate theme of strive for independence and acceptance of support was developed from the subthemes of; need for independence, allowing others to make decisions and acceptance of support. Participants expressed the importance of remaining independent and how they strived to achieve this. The majority of participants discussed the need for hard work and physiotherapy to recover from the stroke and remain independent. However, participants also acknowledged they allowed others to organise their discharge and accepted some form of help.

Need for independence

One participant expressed the need to remain independent and to live at home as her greatest fear was being admitted to a nursing home:

Mrs A: I shall stagger on a bit, I shall be 95 next month. I'm trying, I need to, my one fear and it is a fear I have always been frightened of going into a home. I would fight that to the nail if I could you know...

One participant expressed her independence as being capable of looking after her own needs at home:

Mrs C: I'm not going to bother with more support (when goes home)... I did have more support once for a month, but I didn't like it at all...who would want help at home you know help at home to do that...

Another participant, Mr B expressed his need of being able to complete his own activities of daily living when discussing meeting his hygiene requirements:

Mr B: When I first had a shower, a girl (nurse) was drying me you know, but now you dry yourself, it isn't that easy drying yourself, but I will dry myself, I don't want a girl drying me.

Strive for independence was expressed by the majority of participants as requiring hard work and completing physiotherapy:

Mrs C: I'm getting better all the time doing the physiotherapy. I have been there today, it is good for me to do you know... hard work.

Mr D: When I stand up I get wobbly because my knee is weak and can give way. I need to practice standing still, to stand strong. I need to keep practicing to stand strong and strengthen my knee.

Mr F: I have physio every day, the day before yesterday they (physiotherapists) put me on that cycle machine, today they got me to stand and try and transfer my weight to my left leg, this afternoon is the bike again, so I need to keep working at it.

Allowing others to make decisions

Mrs A, who expressed her need to remain independent allowed others to make decisions for her, for example her cousin who visited from Australia arranged social services and the nurses on the ward contacted social services further and her GP:

Mrs A: She (nurse) said she is going to get on to social services and another one has got on to my surgery so I am sure something will be organised.

Mrs A: My cousin has made arrangements for social services to come in morning and afternoon for about 6 weeks umm... until I get home to see the papers, she had made a folder of what she had done, but until I get home I don't know quite what she had done.

One participant who lives alone in a one bedroom flat, allowed his brother and the nursing staff to make the decisions regarding this discharge home:

Mr B: My brother is taking me home, he has had a word with one of the... oh I don't know nurses, I don't know who it is... someone in charge. They (brother and nurse) reckon I should stop her until Monday, if they think that I will. I will listen to them.

One participant expressed being informed of the decision making process regarding her discharge home, but ultimately allowed the doctors and her daughter to plan her discharge:

Mrs C: The nurses I think have spoken to my daughter, so she speaks to the nurses and tells me what is happening, the doctors they tell me what is happening, my daughter will speak to the nurses...

Acceptance of support

Mrs A who expressed her need to remain independent, although allowed others to make decisions for her regarding support to remain independent accepted this support as necessary at the present:

Mrs A: I must admit to be perfectly honest I would rather they didn't (social services visit), but that is just one of those things and when you are in the situation that I'm going to be in for a while at least one has to do is knuckle under a bit.

Mrs C who clearly expressed her need to be independent and not requiring support from social services discusses in the same interview the need for someone to come in and cook for her:

Mrs C: Sometimes I can't manage in the kitchen you know sometimes I can't just manage in the kitchen at all. Cause when I just got to stand up I would feel dizzy as I have got a low iron count, so when I stand up I feed dizzy and my head starts spinning round and that is not safe at all not safe in the kitchen.

Mr D whose current focus neurology is more severe discusses the need and acceptance of support whilst in hospital and details the practical support he requires from the nurses, care support workers and physiotherapists:

Mr D: Some staff don't realise if you are incapacitated... for instance I need all this (point at objects) on the table; I need it to be left within my reach. Some people do not realise that I need this and need this close, but also the water jug I need the handle facing me and not too much water in the jug to be able to pour water into my glass.

Mr D: We (physiotherapists and himself) work the muscles. We have been working on my fingers, because clearly I cannot move my fingers at the moment, so we try and activate the muscles of my fingers by the physios moving them.

One participant acknowledged the impact of her stroke and had accepted the need for on-going support:

Mrs E: My left side is useless… but they (physiotherapists) are doing physiotherapy with me, but it is extremely painful. It is extremely painful and hard work. There is talk of me going to a nursing home, because of the amount of care I need. I don't mind going… if I get the care and attention I need I don't mind going.

In the current study Mrs E was the only participant to have a significant comorbidity and the impact of this long term degenerative disease may have altered her coping mechanisms. Mrs E expressed acceptance of her condition and the possibility of requiring nursing home care and felt nursing home care would be appropriate as she would receive the care and attention she now requires. However, prior to the stroke Mrs E was living independently at home on her own. Mrs E's diagnosis of multiple sclerosis may have provided her with extra time to evaluate the possible outcomes of being diagnosed with a long term degenerative disease, which aided her acceptance of her current situation.

3.24 Hope and Uncertainty

The emergent super-ordinate theme of hope and uncertainty was the participants' expression of outcome-orientated hope for their future and their uncertainty regarding the extent of their recovery from the stroke. Participants associated hope with positive outcomes, which could be achieved by applying both internal and external resources. Internal resources included humour and the ability to work hard and external resources included the provision of physiotherapy. Doctors remain unable to accurately predict an individual's recovery from a stroke and therefore an element of uncertainty remains. Participants' linked uncertainty with the extent to which their recovery from the stroke would enable them to achieve their outcome-orientated hopes. The super-ordinate theme of hope and uncertainty was developed from the sub-ordinate themes of; physical recovery, return to normal and alternative treatments to aid recovery. Four participants' expressed the hope they would fully recover from their stroke, return to their normal selves and lives, although uncertainties of how and when this would happen were simultaneously discussed. Participants discussed returning to social activities outside of their home and being able to live independently within their home. Outcome-orientated hope did not emerge from the two participants with more severe focal neurology following their stroke. General hope for return to normal was expressed by one participant with severe focal neurology and the need to complete drug trials and alternative therapies to improve his recovery process. This participant was uncertain of the possible extent of his recovery from the stroke and expressed he was desperate to try all possible options to aid his recovery.

Physical recovery

One participant, Mrs A explained her hope of only minor effects of her stroke on the recovery process:

Mrs A: They (the doctors) tell me fortunately it (her stroke) is only a minor one and I hope to goodness it is, I can't say there is anything wrong with my arms or legs.

However, Mrs A acknowledged her uncertainty regarding her stroke and expressed the hope that her condition would not worsen. Mrs A expressed the concern that although she had recovered from the stroke further consequences of the stroke may still occur:

Mrs A: I can't say I actually notice any difference in me (since the stroke) unless there is more to come out that I don't know about yet. I hope not.

One participant expressed hope that he was recovering from his stroke and his uncertainty regarding the length of the recovery process:

Mr F: I seem to be doing alright, I hope so. I think it is just me I'm impatient, very impatient; probably not a good thing, but that has been my life. I mean I have never stopped working; I have always been an active person. I want to get back on the caravan.

Return to normal

One participant linked hope and the return to her normal self with internal resources of hard work and external resources of daily physiotherapy:

Mrs C: I'm getting better all the time doing the physiotherapy, I have been there today, it is good for me to do you know... hard work. I will recover and hope to come back to my normal self.

Mrs C also expresses uncertainty regarding the length of her recovery process:

Mrs C: I will come back to do things for myself... like you know... make a cup of tea and things like that. It is going to take a while, like a month this is going to take a long time.

One participant simply expressed the hope to return to normal life:

Mr D: I just want to get back to normal life; I really hope I can get back to normal life...

Mr B expressed hope to return to normal by returning to his hobbies which he completed prior to his stroke, which included attending the local football club and socialising at a café with his friends:

Mr B: I hope to go back to watch the home games (Premier League football club) again when I leave here and go to the café. I have a café what I use... this café I've been going there for about oh blimey 20 years, and it's like a working men's club they care, you see all the regulars, it doesn't really matter what time it is... I hope to go back and chat with all my mates.

However, Mr B acknowledged uncertainty about the impact of his stroke for returning to normal:

Mr B: I'm going back to live on my own... I don't really know how I will cope, because at the moment I'm stuck in bed or by the bed, one of the two. I will have to wait until I get home and then see what it is like.

One participant acknowledged the external resources of physiotherapy, but also the internal resources of being able to complete her own activities of daily living:

Mrs A: I have had some physiotherapy and apparently passed that with flying colours and am fortunate I can just keep myself in my home.

However, Mrs A remains uncertain about the length of time she will require some help from social services:

Mrs A: I do hope it will only be for a week or a few weeks (social service support at home) but unfortunately life is such and uncertain that you can't tell a thing can you?

Alternative treatments

One participant searched for drug trials and alternative therapies which would impact positively on his recovery, although expressed his uncertainty of the impact of these on his recovery. Mr D describes a drug trial he is currently participating in:

Mr D: I am in another trial looking at different types of plaster, there are three plasters, one is the real plaster, one is the standard treatment and one is nothing. I don't know which plaster I have, neither does the doctor, but they will tell me at the end (pointing to a patch possibly releasing a trial drug). I am desperate I will try everything.

Mr D also describes an alternative therapy he has been considering, which may aid his recovery process but the uncertainty these will be accepted by the medical profession:

Mr D: I was thinking about hypnosis, apparently hypnosis could be a good thing, to start using your brain power and to help you work your limbs to mobilise... I will ask the doctor what he thinks but he will probably think that I am mad. I would be interested if anybody had tried hypnosis as therapy for stroke.

3.3 Transfer Anxiety

The data was re-visited to explore participants' experience of the transfer from HASU to SU and to explore any reported issues demonstrating transfer anxiety. The topic guide had included open ended questions regarding transfer and the participants' experience of care on both units. Participants discussed their transfer from HASU to SU and through their explanation began to understand the importance of the transfer. Participants' descriptions of the information healthcare professionals had provided regarding the transfer from HASU to SU varied greatly. Some participants were provided with information from doctors or nurses, whilst other participants could not being provided with any information. This led to some participants only understanding the reason for their transfer once on the stroke unit and they had commenced the rehabilitation process. No differences of provision of information or the experience of transfer was expressed by participants completing an inter-hospital transfer compared to participants completing an intra-hospital transfer. From the participants interviewed only one participant discussed aspects that reflected elements of transfer anxiety, this participant has completed an intra-hospital transfer. The emergent themes identified from the data included; understanding the stroke care pathway including; information gained from healthcare professionals and information gained from experience, lack of control over the transfer process and transfer anxiety, refer to table 5 for the prevalence of each theme within these participants.

Table 5: Prevalence of each theme within participants' accounts of transfer

Themes	**Mrs A**	**Mr B**	**Mrs C**	**Mr D**	**Mrs E**	**Mr F**
Understanding the stroke care pathway including:						
- Information gained from healthcare professionals	X			X		X
- Information gained from experience					X	
Lack of understanding and control			X			
Transfer Anxiety						X

3.31 Understanding the stroke care pathway

Four participants had a clear understanding of the new stroke care pathway, three participants had been provided with this information by healthcare professionals and the remaining participant understood the reason for the transfer from her experiences on both HASU and SU.

Information gained from healthcare professionals of stroke care pathway

Mr D discussed the nurses' explanation of the transfer process as important to begin the rehabilitation process, and physiotherapy was necessary to 'cure' his stroke:

> *Mr D: They (nurses) told me I had to move here to this ward (SU) they said it was important as the only way to get cured was hard work and rehabilitation with the physios that is why they moved me here for physiotherapy.*

Mrs A discussed the nurses' explanation of the transfer to the SU as progression of her recovery, and although she could not recall the exact details understood the necessity of the transfer:

> *Mrs A: They (nurses) told me I was coming to this ward yesterday afternoon, or the day before... the nurses told me... I gather this is a sort of umm... halfway house as it were, you know if I pass all the tests here I can go nearer home.*

One participant, Mr F explained the doctors had discussed the transfer from HASU to SU, as the HASU was the acute ward and the SU as the treatment ward:

> *Mr F: After a couple of days (on HASU) they shot me round here (SU). I think it was because this was the treatment ward and the ward I was on before was the acute ward, the doctor came and explained that to me and my family.*

Gaining understanding of the stroke care pathway through experience

However, Mrs E was provided with little or no information on her transfer, instead Mrs E felt she was 'shipped out' as she was the only patient left in the bay:

Mrs E: They (nurses) didn't really tell me why I was coming over here (SU)... they had begun to empty the bay I was in... and everyone else (patients) had moved and I was the only one left so they decided to transfer me and ship me somewhere else...

However, Mrs E understood the new stroke care pathway due to her involvement in the pathway:

Mrs E: If you are asking me the difference between this ward and that one. I don't know, I would say that one (HASU) is where you come in when you have your stroke and then as the gym for physiotherapy is over here on this ward, then you come over here if you need to keep having physio. But I don't know.

3.32 Lack of understanding and control

One participant clearly expressed that she had no understanding of why she had been transferred to the stroke unit. Mrs C expressed the view that her transfer to the SU was further away from her house, although Mrs C acknowledged the benefit of the physiotherapy on the SU, she could still not understand why she had been transferred to this SU:

Mrs C: They (nurses) said I would come to a stroke ward if I came here... but I don't know why I came to this hospital I don't live near this hospital... they do have a place on the ward and I go there for physiotherapy. I have done physiotherapy for two days on the run now, since I have been here...so I am getting better all the time doing the physiotherapy.

One participant explicitly expressed a lack of control over the transfer process. Mrs C describes the transfer as a decision made beyond her control and without any explanation:

Mrs C: I came here by ambulance, I didn't have a choice they (nurses) explained I had to come here (SU) and that was that, here I am... So I don't understand why I came to this hospital, I don't understand really...

3.33 Transfer Anxiety

One participant reported amnesia during admission to HASU and only remembers the care he received on arriving at the SU. Only one participant expressed concerns regarding his transfer from HASU to SU and reported having vivid distressing dreams.

Transfer anxiety was not directly expressed by any participants in the current study; however, Mr F expressed how he felt ostracized following the transfer and having distressing and vivid dreams:

Mr F: The first time I came here (SU) it was like I had been sent to Coventry, it was quite and cold and dark and I had dreams I thought I would never have... The French war with big bayonets, the First World War in the muds and the trenches, then the Second World War with the American on the beaches. So it was all dreams really, but I thought in the morning after these dreams I thought I don't like this room... there is too much evil in here. But that was just me.

Mr F was transferred from a ward on HASU to a side room on SU, which may account for the feeling of 'being sent to Coventry', implying the staff were not talking to him. Although another patient was also transferred from a ward on the HASU to a side room and expressed an opposing view. Mrs E felt as though her transfer had been provided as part of preferential treatment:

> *Mrs E: I came over to this ward (SU) and into this side room. I felt I was given preferential treatment... I like having this room as I can rest when I want, I can watch television when I want, I can have privacy when I want...*

3.4 Common Sense Model

The data was revisited following the original analysis to identify themes consistent with the common sense model. The five cognitive dimensions of identity, consequences, control/cure, timeline and cause, and the emotional response to the stroke were explored. All participants spoke about their experience of having a stroke using the dimensions of identity, consequence and control/cure, only two participants referred to a timeframe of the impact of their stroke. Only one participant actively searched for the cause of his stroke, although participants were not explicitly asked if they understood or could provide the reason/cause for their stroke.

3.41 Identity

All participants identified their diagnosis as a stroke and were able to describe and label the symptoms of their stroke. Mr F assigned the lack of coordination of his left arm and the weakness of his left leg as symptoms of his stroke.

Mr F: I can't move this arm very well... if I tried to put my finger on my nose now... I can't get it there. That is the stroke with this arm on this side and this leg is weak, it is 5% weaker than on the left, so that is the effect of the stroke.

Mr B described one of his symptoms of the stroke as affecting his already deteriorating memory:

Mr B: I think memory wise is not that brilliant to be quite honest with you, I didn't have a great memory previously anyway, but it has got worse since the stroke.

Mr B also identified himself as a stroke survivor as he had accepted the opportunity to join a stroke support club:

Mr B: That's a stroke club (pointing at a leaflet), would you like to go they said and I couldn't say no, because you know... because I am one of them.

3.42 Consequences

All participants expressed the consequences of their stroke, which included; functional disabilities, tiredness and lethargy, restricted socialization and the possibility of requiring nursing home care. Mr D explained the consequences of his functional disabilities and the need for specific support and the general consequences of his stroke:

Mr D: The water jug... I need the handle facing me and not too much water in the jug to be able to poor the water into my glass.

Mr D: I am unable to do what I want to do, me who could play a lot of games, fit...

Mr F described the consequences of the stroke as extreme tiredness and lethargy which impacted on his function capabilities:

Mr F: My speech is very good until... when I get drowsy I get lazy and when I get lazy it is one word at a time. It's not my actual speech it is because I get so tired. My speech is OK and fluent, it is just tiredness and lethargy.

Mrs E described the level of care she now required as a consequence of her stroke and not her multiple sclerosis:

Mrs E: There is talk of me going to a nursing home, because of the amount of care I now need. I don't mind going. If I get the care and attention I need I don't mind going, because I need a lot of care since the stroke and a nursing home is where I will get this care and attention.

3.43 Cure/control

Participants highlighted the need for physiotherapy to improve their functional skills following stroke and described physiotherapy as the treatment for their stroke. Physiotherapy was expressed as both personal and treatment control. Mr D views physiotherapy as a ‘cure’ for his stroke, but also the collaborative work between himself and the physiotherapists:

Mr D: We (Mr D and physiotherapists) have been working on my fingers, because clearly I cannot move my fingers at the moment, so we try and activate the muscles of my fingers by the physios moving them.

Mrs C expresses the importance of her active involvement and therefore personal control over physiotherapy to improve her functional skills:

Mrs C: I have done physiotherapy for two days on the run now I have been doing it so... I'm getting better all time doing the physiotherapy... I have been there today... it is good for me to do you know.

However, Mrs E expresses a lack of both personal and treatment control over her recovery process:

Mrs E: I do physio most days and it is extremely painful to my arm and my leg each time I have to do this. I have pains in places I didn't know I had. I can't see any improvement.

3.44 Timeline

The timeframe for recovery from stroke was discussed by two participants within the current study. Both participants discussed a timeframe for recovery from their stroke; no participants discussed the permanent impact or long term impact of the consequences of their stroke. The participants referring to a timeframe for their recovery from their stroke had less functional disabilities than participants not referring to a timeframe for recovery. Mrs A referred to the use of social services as temporary, although was unsure of the exact timeframe:

Mrs A: I hope it (social services) will only be for a week or a few weeks, but unfortunately life is such and uncertain that you can't tell a thing can you?

Mrs C discussed returning to normal and being able to do things for herself, but recognized this would take time:

Mrs C: I will come back and do things for myself... like you know... make a cup of tea and things like that. I will do that for myself. It is going to take a while, like a month this is going to take a long time.

3.45 Emotional Response

An emotional response to the stroke was discussed by two participants. The participants spoke about being 'down' since their stroke and being frustrated by not being able to complete any tasks for themselves.

Mr D considered the possibility of being depressed and considered the need to take anti-depressants:

Mr D: I think I am down, I think I have to take anti-depressants... I don't know they would do me any good, I don't know whether I should...

Mrs E discussed her mood in general terms and was aware the doctors were monitoring her mood:

Mrs E: The doctors say that I'm brighter, but I don't really feel brighter… not being able to do anything for yourself is very frustrating, before this I was independent.

Both participants who discussed an emotional response to their stroke were participants with severe leg and arm weakness.

3.46 Patterns of Illness Representation Dimensions

Mrs A reported few symptoms attributed to her stroke (identity), minimal impact as on her home life (consequences) and the impact would hopefully only last a short period of time (timeline).

Mr B discussed no remaining symptoms attributed to his stroke (identity) and only deterioration in his already poor memory (consequences).

Mrs C discussed her recovery leaving only one symptom attributed to her stroke (identity), minimal impact on her independence (consequences), defined a relatively short timeframe for recovery (timeline) and the improvement through participating in physiotherapy (personal and treatment control).

Mr D discussed multiple severe symptoms following his stroke (identity), the impact of these on his functional and social capabilities (consequences), the importance of physiotherapy and alternative treatments (personal and treatment control) and the possibility of being depressed (emotional response).

Mrs E discussed severe symptoms following her stroke (identity), the impact on her functional and social capabilities (consequences), lack of improvement through physiotherapy (personal and treatment control) and a low mood (emotional response).

Mr F reported symptoms of his stroke (identity), some impact of his symptoms on his social functioning (consequences) and the importance of physiotherapy (personal and treatment control).

The emergent themes from the original analysis; disassociation from being in the world, search for understanding, strive for independence and acceptance of support, and hope and uncertainty reflect the participants experience of suffering from a stroke and progressing through the stroke care pathway. Illness representation dimensions from the common sense model were applicable to these participants following there stroke. However, transfer anxiety was only identified in one participant.

Chapter 4: Discussion, Conclusions, and Recommendations

4. Discussion

The aim of the study was to gain an in-depth understanding of the impact of having a stroke and following the new stroke care pathway in London. This was carried out through analysing semi-structured interviews using Interpretative Phenomenological Analysis. To date no studies have examined the impact of the new stroke care pathway in London on patient experience and understanding. Therefore, it was hoped the current study would begin to form knowledge in this area.

A further aim of the study was to gain an in-depth understanding of illness representation dimensions from the Common Sense Model of Self-Regulation within individuals recently diagnosed with a stroke. The CSM has been applied widely to other long term conditions but limited research has occurred in the area of stroke. Therefore, it was hoped that the current study would add to existing knowledge in this area.

4.1 Emergent super-ordinate themes

The findings suggest following an acute stroke participants in the current study disassociated themselves from their new being in the world, searched for understanding of their stroke, strived for independence although acknowledged acceptance of help, and whilst uncertain regarding their recovery from the stroke, expressed hope to return to normal. Participants disassociated themselves from their body and their self during the acute phase of stroke, although disassociation from their body fluctuated and embodiment occurred during the recovery process. Participants searched for an understanding of their stroke, why this had occurred and the impact of the stroke on their future by completing both downward and/or upward social comparisons. Participants strived for independence and to return to their lives prior to the stroke and to achieve this understood the requirement of hard work and physiotherapy. Participants simultaneously acknowledge the need to accept some form of support to achieve their independence. Participants reported an element of uncertainty regarding their recovery from the stroke although expressed the hope that recovery would enable a return to their normal lives. Overall participants did not express elements of transfer anxiety and demonstrated an understanding of the stroke care pathway. The dimension of identity, consequences, timeline and control/cure as described by the Common Sense Model of Self-Regulation were identified and a pattern consistent with the theory emerged.

4.11 Disassociation from being in the world

The theme disassociation from being in the world draws on Heidegger's phenomenology of 'Dasein', which is interpreted as 'there being' or 'being there'. Individuals are always somewhere, always located and always among and involved with some kind of meaningful context (Larkin et al., 2006). Heidegger expanded his view of a person as a fundamental part of a meaningful world and therefore a person can only be understood as a function of their various involvements with that world. The meaningful world is also a fundamental part of the person and can only be understood by their involvement with it (Larkin et al., 2006).

The participants in the current study were completing self-evaluations to understand their current being in the world due to the impact of their stroke. Each participant's being in the world had changed from independent living and an active person in the community, to a patient in hospital requiring assistance to complete activities of daily living. The contrast in the change of being in the world was difficult for participants to understand and cope with. Whilst participants tried to understand and recover from the impact of their stroke they disassociated themselves from their current being in the world. Participants used disassociation to distance themselves from the impact of their stroke on their body and their social self, some participant's reported memory loss to aid this process.

An element of disassociation from being in the world was disassociation from dead/failing body. Disassociation in relevant literature has been referred to as disembodiment (Wilde 1999; Morse and Mitcham 1998; Taylor, Richardson and Cowley 2000). Disembodiment is an individual's attempt to physically distance themselves from their own body and is a coping mechanism applied following; trauma, injury or severe pain (Wilde 1999). Embodiment is central to Merleau-Ponty's phenomenological philosophy and is the general concept for bodily aspects of human subjectivity. Merleau-Ponty's human subjectivity involved the 'body' as a central component, including; sensations and physical elements. The understanding of embodiment occurs through speech and language (Wilde 2003). Therefore an aspect of disembodiment is the individual's description of their own body using depersonalized language such as 'it', 'the' and 'this'. Individual's applying disembodiment as a coping strategy refer to their body parts using the definite article (the hand) rather than the possessive (my hand) (Morse and Mitcham 1998; Taylor et al., 2010).

Disembodiment is not a consistent state but fluctuates through injury/illness to recovery and is a process to cope with extreme; anxiety, stress and pain. Morse and Mitcham (1998) found patients with a severe burns injury tended to use depersonalized language during the most intense episodes of pain, but not when describing their body immediately prior to the injury and during less painful rehabilitation. Taylor et al., (2010) found patients' use of disembodiment occurred in the first few days following surgery for colorectal cancer, patients tried to distance themselves from bodily events that were too unpleasant to contemplate. Similar findings emerged from the current study as participants described aspects of their own body using the definitive article (the foot) rather than the possessive article (my foot). Participants' description of their affected limbs fluctuated between the use of the definitive article and the possessive article as the recovery process improved the movement and sensation of their limbs. Disassociation from dead/failing body occurred during participants' descriptions of their acute phase of stroke when the effect of their stroke was most profound. The use of disassociation in the current study allowed participants to provide an accurate description of the impact of their stroke by distancing themselves from an event which was extremely distressing and difficult to understand.

A model of restoring embodied control has been proposed (Taylor et al., 2010). The first three stages of the model of restoring embodied control progress in a linear fashion, commencing with disembodiment, then restoring embodiment and reclaiming control (Taylor et al., 2010). The final stage of managing embodied control was associated with resolution, guarding and return to reclaiming control.

Taylor et al., (2010) identify the first stage of disembodiment as both positive and negative. Positively, disembodiment allowed the patient to deal with unthinkable bodily insults and embracement. In the instance of stroke, the immediate investigations and treatment, as well as the inability to perform activities of daily living and the care provided by the nursing staff, can be identified as unthinkable bodily insults and the causes of embarrassment. Disembodiment has a negative impact as the patient has to realign their relationship with their body, which has become fragmented, deconstructed and disowned (Taylor et al., 2010). Although the model emerged from participants' explanation of their recovery from surgery for colorectal cancer, similarities with patients recovering from a stroke can be identified. Disembodiment for patients' recovery from colorectal surgery and stroke allowed the patients to emotionally and cognitively detach themselves from their physical body to cope with the stress of the event. Both events involved the impending threat of disability and loss of life.

The next stage of the model 'restoring embodiment' focused on the struggle of the patient to increase functional capacity and regain familiarity with their own bodies (Taylor et al., 2010). Patients recovering from colorectal surgery resolved all their functional difficulties. Following a stroke participants in the current study had to re-familiarise themselves with a body that was failing them and acknowledge the hard work required to increase functional capacity. This stage remains relevant following a stroke as patients need to re-learn how their body works and how to increase and adapt to their new level of functioning.

Taylor et al., (2010) explored the participants experience of their inability to self-manage part of their body; such as stoma care, whereas, participants in the current study were unable to self-manage aspects of their own activities of daily living, such as walking to the toilet. Participants in the current study used disassociation when explaining the occurrence of their stroke, but as soon as the rehabilitation process commenced and improved sensation and movement was identified the participants moved to the stage of restoring embodiment. The final elements of the model 'reclaiming control' and 'managing embodied control' were important for participants in the current study as they described the need for embodied control and expressed this need as independence.

A tentative application of the model of restoring embodied control for patients following a stroke can be applied. Further research in this area is required to understand the application of this model for patients following a stroke and the impact of not obtaining full functional capacity, but also the relevance of disembodiment for patients following a stroke and the impact of this coping strategy on their rehabilitation.

A further element of disassociation from being in the world was disassociation from self. Disassociation in relevant literature is referred to as dissociation (Putman 1994; Dell and O'Neil 2009). The term dissociation is a psychological process that occurs on a continuum from a mild detachment from being in the world to severe detachment from physical and emotional responses (Dell and O'Neil 2009). Dissociation involves the detachment from reality rather than a loss of reality (Dell 2006). Detachment in dissociation occurs due to an individual's altered accessibility of memory and knowledge which then impacts on the individual's sense of self (Putman 1994). The role of traumatic experiences in the development of dissociation is acknowledged (Putman 1994) and dissociation is described as a coping mechanism to deal with the stress of a traumatic event (Weifen and Lloyd 2008). Participant's traumatic event in the current study was their stroke. Dissociation is relevant to the current study as participants were able to describe accurately their traumatic experience of their stroke and the realistic impact of the stroke on their bodies and abilities. However, during participants' descriptions of their stroke they were able to detach these descriptions from the concept of their self.

Participants' disassociation from self or their new self of being in the world appeared to be constant in participants with more severe focal neurology. However, participants' use of disassociation from dead/failing body fluctuated during their descriptions and their recovery from the stroke. The fluctuations may have occurred as participants identified improvements in their functional capacity which impacted on their use of disassociation from their bodies. Improvements in functional capacity for participants with more severe focal neurology were less significant and not aligned to enable them to return to life prior to stroke. Therefore, these participants use of dissociation from self could be an active coping strategy, whilst in the acute stage of their stroke when the uncertainty remains to the extent of their recovery.

Eilertsen, Kirkevold and Bjork (2009) identified four distinct phases of post stroke recovery, focusing on the understanding of self did not occur until phase 3, which was generally 6-12 months following the stroke. Eilertsen et al., (2009) found participants emotionally began to process the impact of their stroke on their self. Participants expressed impacts of their stroke that had not been expected, such as forgetfulness, loss of energy and the increased need for rest (Eilertsen et al., 2009). The participants in the current study had not begun the evaluation of self and how the stroke would impact on them emotionally. Therefore, participants' active use of dissociation from self may be challenged later during their on-going recovery process. Further research is required to explore disassociation of self in more depth, addressing implications of dissociation on recovery and the nature of disassociation from self over time.

4.12 Search for understanding

Participants in the current study were searching for understanding of the cause, severity and the impact of their stroke on the future. Understanding the cause and severity of the stroke is captured by search for meaning and self-enhancement within the Theory of Cognitive Adaptation (Taylor, Lichtman and Wood 1984). Three processes of dealing with a threatening event such as an acute illness are described in the Theory of Cognitive Adaptation (Taylor et al., 1984), including search for meaning, a search for mastery and a process of self-enhancement. A search for mastery did not emerge in the current study, as participants remained in the acute phase of their health threat and were actively involved in the process of understanding the cause and severity of the stroke. Participants were still completing their rehabilitation programme and remained uncertain about the extent of the recovery, which did not allow for the cognitive evaluation of search for mastery. Search for meaning was relevant to participants in the current study as they needed to understand the cause of their stroke. Self-enhancement emerged as participants continued to search for understanding by applying social comparisons to understand the severity of their stroke and the likely impact on their future lives.

Individual's searching for an understanding of a health threat will apply causal attributions (Taylor 1983). Following a threatening event attribution theory implies that individuals will make attributions to understand predict and control their environment (Heider 1958). Three dimensions have been identified that may influence how an individual makes causal attributions; stability, controllability and locus of causality (Weiner 1974). Stability involves the identification of whether the cause is stable or unstable and can affect what individual's expect to happen in the future. Participants in the current study explored the impact of their stroke and the stability of their recovery. Controllability involves the identification of causes that are controllable or out of the individual's control. Participants in the current study expressed an aspect of control over their recovery process through hard work and physiotherapy. Perceived locus of causality is relevant to emotional reactions; internal attributions for an undesirable event are frequently associated with self-focused negative emotions, such as guilt or blame. External attributions for an undesirable event are generally associated with externally focused emotions such as anger and resentment (Gundlack, Douglas and Martin 2002; Weiner 1985). Participants in the current study reported negative emotions, such as feeling down and depressed but had not formulated this in connection with an internal locus of causality at this stage.

Taylor (1983) found 95% participants diagnosed with cancer had an explanation of why their cancer had occurred, while only 63% of their spouses had an explanation. Taylor (1983) suggests the importance of causal attributions is greater to the patient than their family members. An exploration of how patients identified causal attributions following an acute myocardial infarction found causal attributions included physiological, psychological and social influences (Fukuoka, Dracup, Koboyashi, Ohno, Froelicher and Hiraama 2004). An exploration of causal attributions of patients with Chronic Obstructive Pulmonary Disease (COPD) found patients with causal attributions of psychological factors such as stress were more likely to have poorer emotional adjustment and quality of life (Hoth, Wamboldt, Bowler, Make and Holm 2011). Causal attributions impact on patients' future decision making regarding health decisions (Roesch and Weiner 2001) and the likelihood of illness recurrence (Michela and Wood 1986). Participants in the current study tried to understand why their stroke had occurred and preventative measures they could have implemented. The participants in the current study were still forming their causal attributions and this identifies the possibility of the healthcare team influencing this process. The healthcare team could aid the patient to form physiological causal attributions rather than psychological, which could have a positive impact on the patient's outcome. However, this is a tentative suggestion and would require further investigation.

The meaning of causal attributions was explored by Taylor (1983), the meanings ranged from stress, diet or an injury but no attribution was correlated with psychological adjustment. Runions, Arnaert and Sourial (2006) explored causal attributions in individuals following a diagnosis of stroke or a transient ischemic attack (TIA), identifying internal and external attributions. Internal attributions included; anxiety, hypertension and life style. External attributions included stress and fate. Both internal and external attributions were described as controllable and uncontrollable, however Runions et al., (2006) found external attributions were associated with poorer health outcomes than internal attributions. The current study identified participants attempting to construct causal attributions and these included internal and external attributions. The causal attributions in the current study remained partially formed as participants were still searching for understanding. The methodological differences between the two studies may account for the differences in findings as Runions et al., (2006) participants were interviewed 2 months to 15 years post their stroke or TIA and had minimal residual neurological deficits, whereas the current study participants were interviewed 5-10 days post stroke and residual neurological deficits ranged from minimal to severe. The participants in the current study were in the process of constructing causal attributions and this allowed the emergence of how these attributions were being constructed. One participant explained he had seen 3 different healthcare professionals prior to his stroke and all had failed to identify his risk for a stroke. However, this participant formed an internal attribution of how he should have followed up his complaint further, rather than an external attribution of blame towards the healthcare professionals.

The participants in the current study continued to search for meaning and forming causal attributions. The participants continued searching for meaning can be interpreted in two ways; firstly, the participants are still experiencing the acute phase of their stroke. Secondly, participants could continue to search for meaning with no conclusion to their search. Kernan and Lepore (2009) identified four search for meaning patterns in women following breast cancer, including; continuous, exiguous, delayed and resolved. Exiguous referred to low searching for meaning. Continuous searching for meaning was associated with greater negative affect; however a significant proportion of participants used exiguous searching for meaning (Kernan and Lepore 2009). Therefore identifying patients who continuously search for meaning is important as these patients may be involved in a lengthy, unsuccessful search for meaning which impacts negatively on their well-being. Interventions and information provided by healthcare professionals can support the patient to complete this process or to focus the patient on a different aspect of their illness/recovery. In the current study participants were in the acute stages of their stroke and the pattern of their search for meaning was indiscernible. Although some participants remained actively searching for meaning, one participant has accepted her stroke and the care she now required. The current qualitative study supports the four patterns in the acute stage of stroke, but cannot identify how this will develop or change over time. Further longitudinal research is required to identify if patients following a stroke apply the four search for meaning patterns identified by Kernan and Lepore (2009).

Searching for meaning involves a cognitive reappraisal of self, identity and important aspects of an individual's life. Taylor (1983) found 61% of the participants diagnosed with cancer had reappraised their lives. Taylor (1983) found participants reordered their priorities, giving low priority to everyday activities such as housework and high priority to relationships with family and friends. Participants finding positive meanings when reordering their priorities were found to have better psychological adjustment to their illness (Taylor 1983). The current study supports this finding, as participants reappraised their lives following their stroke. One participant discussed the importance of being a family man and how his family had grown apart, both physically and geographically, but the stroke has reaffirmed the importance of his family and felt his family had been reunited due to the stroke. This participant's reappraisal of his life had a positive impact, however not all participants reappraisals were positive. One participant's reappraisal was negative due to his current severe neurological deficits.

Patients' causal attributions have been associated with emotional adjustment and behavioural outcomes in several medical conditions (Taylor 1983; Fukuokma et al., 2004; Kernan and Lepore 2009; Hoth et al., 2011), however few studies have examined illness attributions among patients following a stroke and no studies have occurred following the change of treatment for a stroke from purely rehabilitative to acute and rehabilitative. Therefore this is an important area for further research.

Participants in the current study discussed their stroke in comparison with other patients on the ward and friends who had recovered from a stroke, completing both downward and upward comparisons. Self-enhancement within the Theory of Cognitive Adaptation (Taylor et al., 1984) is defined as a motivation process which allows individuals to make sense of their world compared to others (Corcoran et al., 2011). Downward comparisons can be created when an individual is experiencing a negative event and need to enhance their own well-being, this occurs through comparison with individuals less fortunate than themselves (Wills 1981). Through the process of self-enhancement the participants in the current study were engaging in social comparisons, Festinger's (1954) social comparison theory suggests that individuals have a basic need to maintain a stable and accurate view of themselves. This process is achieved through self-evaluation, which is the need and motivation to complete self-enhancement through social comparison (Festinger 1954).

Wood, Taylor and Lichtman (1985) explored social comparisons in women following breast cancer. Women who felt their sense of self had been threatened by the diagnosis compared themselves primarily with other women whose condition was more critical, in the process of self-enhancement (Wood et al., 1985). Individuals' diagnosed with rheumatoid arthritis completed downward comparisons to help them adjust to their illness (Affleck, Tennen, Pfeiffer, Fifield and Rowe 1987). Downward comparisons have also been explored and evident in a variety of other illnesses such as; chronic pain, eating disorders, depression, AIDS and heart disease and found to contribute to subjective well-being (Buunk and Gibbons 1997).

Festinger (1954) defined social comparison, as a cognitive task which allows an individual to gain accurate self-knowledge, for this to occur the individual will need to select someone who is similar to themselves on the critical dimension which is being compared. One participant in the current study uses an upward comparison of someone who has had a stroke and is the same age. The selection of someone similar is important to allow diagnostic information and for self-evaluation (Festinger 1954). Upward comparisons can motivate people and provide information on how to make progress, which was demonstrated in the current study.

However, Festinger's (1954) original social comparison theory concluded patients would avoid upward comparisons as comparing oneself to an individual who is better off would damage the individual's self-esteem. However, Mollemann, Pruyn and Knippenberg (1986) found cancer patients preferred to compare themselves to cancer patients that were similar or slightly better than them. Upward comparisons fulfil the need to self-improve and can motivate people and can provide information on how to make progress (Corcoran et al., 2011). The upward comparison of the participant in the current study was to provide a role model to demonstrate the possibility of improved physical functioning and to provide hope (Taylor and Lobe 1989).

Research involving Meniere's disease, a disease of the inner ear characterized by episodes of dizziness, tinnitus and progressive hearing loss identified five categories of social comparison which were related to quality of life (Dubb and Yardley 2006a). The social comparison categories included; upward positive and downward positive comparison, upward negative and downward negative comparison and comparing for information (Dubb and Yardley 2006). The implication is the complexities of social comparison in chronic illness, however greater levels of social comparison by patients with Meniere's disease was associated with a deteriorating quality of life over a 10 month period (Dibb and Yardley 2006b).

A recent evaluative study reviewed social comparison in patients with chronic illnesses and assessed the evidence for the inclusion of social comparison as a component in interventions to improve biopsychosocial recovery/adaptation (Arigo, Suls and Smyth

2012). The review found social comparisons among medical patients where common, although not all social comparisons produced positive consequences. Positive upward comparisons were described as the identification of a person with better coping skills or a positive downward comparison with someone more ill (Arigo et al., 2012). The review included various chronic illnesses such as; rheumatoid arthritis, cardiovascular disease, cancer, Meniere's disease, multiple sclerosis, sickle cell disease, HIV and diabetes, however articles exploring stroke and social comparisons were not included.

Panculturality of self-enhancement has been intensively debated; however consistencies between self-enhancement and psychological well-being have been demonstrated in participants from the west (United States) and from the east (China) (O'Mara, Gaertner, Sedikes, Zhou and Liu 2012). Panculturality of self-enhancement is an important contribution to the self-enhancement construct but also the applicability to patients following a stroke in London, as London is a multi-ethnic and multi-cultural city.

The current study is the first study to identify both upward and downward social comparisons in participants following a stroke; the participants performed both upward positive and downward positive social comparison; however the impact of these cognitive tasks on quality of life and well-being is unknown. Further research in this area is required to expand current understanding.

4.13 Strive for independence and acceptance of support

The participants in the current study strived for independence and simultaneously accepted physical and social support. Participants expressed the need to return to independent living, whilst allowing others to make decisions and plan their transfer home and organise social services. Participants accepted the decisions of healthcare professionals and family members. None of the participants were actively involved in the planning of their discharge or expressed their need to be involved in this process, as long as they were being discharged to their home. Only one participant actively searched for alternative therapies to aid his recovery from the stroke and suggest these to his healthcare team.

Participants lack of involvement in the decision making process is an important finding as an emphasis and belief in patient involvement is longstanding (WHO 1978). National policies in the UK have reflected involvement of patients, lay carers and the public, such as the Patient and Public Involvement in the new NHS (Department of Health 1999). Patient knowledge regarding health and healthcare has also increased over the last two decades due to voluntary group book/leaflets, help-lines, advertisements on national television and the wide availability of the internet (Eysenback 2000). Patient involvement allows patients' perceptions, values and preferences to be considered when planning treatment and care (Sullivan 2003). Thompson (2007) explored patient involvement in healthcare consultations and identified three domains in a dynamic model, which influence the demand of the patient to be involved. Firstly, the need for healthcare; if the illness was acute and serious there was less demand for patient involvement than if the illness was chronic with less serious implications. Secondly, personal characteristics the level of involvement required by the patient was dependent on their knowledge and personality traits. Thirdly, professional relationship a high level of trust reduced the demand for patient involvement when low levels of trust increased the demand for patient involvement (Thompson 2007). The current study supports this model to an extent; participants were recovering from an acute serious illness and expressed confidence in the staff caring for them. However, the participants in the current study with less residual disability were less likely to be involved in the decision making process regarding the provision of their healthcare than participants with more severe focal neurology. Therefore participants within the acute stage of stroke with serious consequences may be more involved, which is inconsistent with the model (Thompson 2007). The inconsistency may be stroke specific as stroke is classified as an acute emergency and a long term condition. Knowledge of stroke was not explored within this study, although two participants demonstrated a good understanding of the risk factors for a stroke. The importance of patient involvement for patients following a stroke needs to be explored further as the current study demonstrated the participants with less residual disability were content with not being involved, but allowing their family to liaise with healthcare professionals.

One participant strived for independence through seeking out alternative therapies to improve his recovery from his stroke. Throne, Paterson, Russell and Schultz (2002) explored the use of complementary and alternative therapies in patients with a diagnosis of; HIV/AIDS, multiple sclerosis (MS) or diabetes. Thorne et al., (2002) found the patients' use of complementary and alternative therapies depended on the chronic illness; patients with diabetes reported the use of reflexology to address pain associated with neuropathy, patients with MS reported the use of chiropractic, acupuncture or massage to address muscle spasms, while patient diagnosed with HIV/AIDs turned to complementary and alternative therapies to support a positive attitude and improve energy levels. Complementary and alternative therapies have been explored in patients following a stroke in Korea, Indian and the US (Shin, Yang, Joo, Lee, Kim and Lee 2008; Pandian, Toor, Arora, Kaur, Dheera, Bhullar and Sylaja 2012; Shah, Engelhardt and Oubiagele 2008). All three studies found the use of complementary and alternative therapies was reported by 33 per cent to 68 per cent of patients following a stroke. However, Shah et al., (2008) in their study in the US found participants reported the use of complementary and alternative therapies was to avoid medical costs. Therefore, Shah et al., (2008) data needs to be considered in relation to patients in the UK where complementary and alternative therapies are likely to involve cost and not medical care received by the NHS.

Only one participant in the current study reported interest in complementary and alternative therapies; however the current study interviewed participants whilst in hospital and receiving active physiotherapy for their stroke. Complementary and alternative therapies may be considered by patients following discharge from hospital and the completion of their rehabilitation provided by the NHS. Therefore further research is required to explore patient decision making, timing and the amount of use of complementary and alternate therapies by patients following a stroke.

Independence has been explored in female participants following a stroke when discharged home (Kvigne, Kirkevold and Gjengedal 2004). Kvigne et al., (2004) adopted a feminist approach and explored the impact of living independently on women. Participants described practical difficulties they struggled with on a daily basis and the enormous amount of energy required to remain living independently (Kvigne et al., 2004). Similar findings were reported by Eilertsen et al., (2009) in phase 2 of recovery from stroke; focusing on activities of daily living, which occurred on discharge from hospital. Women participants reported less energy, which made practical everyday activities burdensome and twice or thrice as much time to complete (Eilertsen et al., 2009). Kvigne et al., (2004) reported participants also discussed the importance of having a strong will and determination to remain living at home. Whilst Eilersten et al., (2009) reported participants' need to combat fatigue to allow a return to normal everyday life. Although the studies completed by Kvigne et al., (2004) and Eilersten et al., (2009) took place in participants' homes when discharged the need and importance of living independently is similar to the participants in the current study who were currently striving to live independently. The issue of striving for independence appears to transcend gender.

Independence has also been explored in patients with osteoarthritis and osteoporosis; both diseases can have an impact on physical functioning. Gignac, Cott and Badley (2000) found independence/dependence ranged over 5 domains including personal care, in-home mobility, community-mobility, household activities and valued activities. The current study supports these domains as participants discussed the importance of independence in personal care, walking to the toilet, making a cup of tea and returning to valued activities such as attending football matches. However, the current study also found the emergence of acceptance of support on medical staff, nurses and relatives for the organisation of their transfer from hospital to home.

4.14 Hope and Uncertainty

Participants in the current study expressed hope and uncertainty simultaneously when discussing their physical recovery, return to normal and alternative treatments to aid recovery. Hope is a broad concept and will have different meanings in different contexts (Wiles, Cott and Gibson 2008). The psychological construct of hope within health has been defined as an important part of the process of recovery from illness and trauma (Tutton, Seers and Langstaff 2012). Theoretically hope has been defined as a necessary condition to motivate a person to action to achieve a goal, the likelihood and the importance of the goal impacts on the strength of the hope (Stotland 1969).

Hope with specific relevance to stroke and recovery from stroke has been explored, although many studies have alluded to the importance of hope as an integral part of the recovery process, few studies have explicitly studied its influence (Hafsteinsdottir and Grypolonck 1997). However, due to the positive influence of hope in the recovery process, hope has become an emerging philosophy of stroke rehabilitation (Arnet, Filteau and Sourial 2006). Studies exploring the impact of hope on the recovery process focus on the influence of hope over long term recovery rather than the immediate stage post stroke (Cross and Schneider 2010), therefore the findings of the current study and the emergence of hope within the first 10 days following a stroke are of importance.

Popvich, Fox and Bandagi (2007) explored how individuals cope with a stroke and specifically asked the questions ‘what hopes do you have since your stroke?’ and ‘what keeps you going or gives you hope?’ Therefore participants in this study were prompted to examine the construct of hope. Popvich et al., (2007) categorized the participants’ responses into two broad themes of general and specific hopes. General hope included; general hope for recovery, hope that one’s condition would not worsen and hope to accomplish future goals. Although the current study did not aim to explore hope, four participants naturally described their general hope for recovery, that their condition would not worsen and the hope to return to normal life.

Specific hope (Popvich et al., 2012) included hopes for independence that stroke specific deficits would resolve, to return to pre-stroke activities and hopes related to family and friends. Hope expressed by participants in the current study included; hopes for independence and not requiring social services on returning home, one participant expressed the need for social services but expressed the hope this would be for a few weeks only, returning to pre-stroke activities, one participant expressed his wish to watch Chelsea football team play home games as had recently required a season ticket. One participant expressed hope relating to his family and how the stroke had brought his family close together and the need for a supportive family at this time.

Arnaert et al., (2006) described 5 themes related to hope in their qualitative study including; importance of storytelling, vision of hope, worries and concerns for the future, passive and active hope and self-healing. Similar emergent themes occurred in the current study including hope and uncertainty. In the current study the formation of uncertainty is comparable with the worries and concerns theme. Arnaert et al., (2006) defined passive and active hope in the acute stage of stroke. Passive hope was identified in participants who retained negative feelings regarding their stroke which prevented them from progressing in their recovery. Active hope was identified in participants who expressed progression from a suffering stage to a healing phase. Passive hope as defined by Arnert et al., (2006) can be identified in the current study as one participant who had accepted the suffering stage and was unlikely to move to the healing stage as acknowledged the need for nursing home care. Active hope can be identified in the current study as participants reported improvements in their physical functioning and this provided hope to continue with rehabilitation and working towards regaining independence.

A recent systematic review and concept analysis explored hope following a stroke (Bright, Kayes, McCann and McPherson 2011). The review included all definitions of hope, such as 'hope as essential', 'hope as a way of being' and 'hope as a goal orientated process' (p. 493). Bright et al., (2011) proposed a working model of hope for individual's after stroke. The model defines hope as a multidimensional and complex construct, which can be separated into three elements. Firstly, hope was developed through individual's internal, stroke-related and external sources. Secondly was defined through attributes including internal state of being, outcome orientated and an active process. Lastly hope which aided positive outcomes and impacted on the person's internal state and recovery promoted further hope (Bright et al., 2011).

The first attribute of hope as an internal state of being was defined as an inner strength, being positive in nature and as being essential for recovery and living well after stroke (Bright et al., 2011). The participants in the current study internal state of being was expressed in various forms, one participant expressed his work ethic as an inner strength to ensure he would recover from his stroke, another participant expressed his determination as an inner strength.

The second attribute of hope was outcome orientated and was generally defined as broad and/or specific hopes. Bright et al., (2011) acknowledged the number of studies reflecting participants hope to return to normal including a normal way of life, normal roles, and normal activities and to being the same person they were before. This attribute is consistent with the study competed by Popvich et al., (2007) and the participants within the current study as participants expressed the hope to return to normal, live independently and complete activities that had prior to the stroke, such as watching their favourite football team.

The third attribute of hope was an active process which incorporated both a cognitive and physical application of hope. The cognitive application of hope included; an appraisal about the individual's current situation and future, comparisons with others and hope orientated thoughts (Bright et al., 2011). Participants in the current study completed cognitive appraisals including hopes and positive anticipation for the future, such as living independently at home and not requiring social services input.

Hope impacted positively on internal states such as perseverance, motivation, coping and mood and improved outcomes such as increased participation, on-going recovery and improved quality of life. The model of hope after stroke (Bright et al., 2011) is an important model of a working definition of hope, which will allow patients with less hope to be identified and the identification of decreased participation in the recovery process identified.

4.2 Transfer Anxiety

Transfer from HASU to SU signifies the end of acute monitoring and treatment and the beginning of the rehabilitation process, which is similar to transfer from a critical care setting to a general ward. The study explored the theoretical construct of transfer anxiety within the new stroke care pathway to begin the understanding of patients' perspectives of being transferred from a Hyper Acute Stroke Unit to a Stroke Unit.

McKinney and Melby (2002) define transfer anxiety as containing three elements of anxiety: primary, fright and expectant. Not all of these elements emerged in the current study, primary anxiety did not emerge as all of the participants had been informed of their impending transfer. None of the participants were transferred during the night or without any notice to allow the admittance of a new patient. Therefore participants' anxieties were not exacerbated by sudden feelings of loss and insecurity (Sarman 1993). Only one participant expressed fright anxiety in the form of separation anxiety (Coyle 2001) as he felt the staff in the SU were not as attentive and the constant and continuous support of the clinical staff in the HASU had been removed. The same participant expressed expectant anxiety as initially misunderstood the lack of presence of the healthcare team as being ignored or in his words 'sent to Coventry'. The perspective of transfer anxiety from this participant within the current study is similar to the expression of other patients on transfer from intensive care settings (Simpson, Armstrong and Michel 1989; Owen, Provine and Stephenson 1992).

Transfer anxiety experienced by patients on transfer from intensive care settings to a ward occurs due to the lack of presence of the healthcare team, but also from the impression of less specialist healthcare team members (Simpson et al., 1989). Therefore patients' anxiety includes the concerns that staff are not as knowledgeable regarding their condition on the ward as they were in ITU (Owen et al., 1992). Participants in the current study discussed the knowledge and understanding of the nurses on both units and believed them to be comparable; this may have impacted on the participants transfer anxiety as they had confidence in the nurses caring for them.

Only one participant in the current study expressed fears and concerns similar to the theoretical construct of transfer anxiety. An explanation from this finding could involve the structure of both the HASU and the SU. The HASU provides rapid assessment and care and treatment during the life threatening episode of stroke, with a similar nurse patient ratio to an ICU of 1:2. However, mechanical support, such as respiratory assistance does not occur in the HASU. The HASU involves monitoring equipment that is regularly used in A+E and therefore the lack of invasive mechanical support to assist living is absent, which may have a direct impact on transfer anxiety.

The structure of the SU may also impact on transfer anxiety as the SUs main focus is rehabilitation. Transfer anxiety has been reported when patients are transferred to a general ward where rehabilitation is less evident (McKinney and Melby 2002). Once patients have been transferred to the general ward they have expressed feelings of helpless and unimportant and not receiving the attention required from the healthcare team (Chaboyer et al, 2005; Coyle 2001). Participants in the current study commenced their rehabilitation programmes on the SU and all participants acknowledged the SU included the provision of physiotherapists and a gym to provide daily physiotherapy. Participants reported attending the gym, meeting with and being assessed by doctors and occupational therapists on a daily basis. The activities and attention of the rehabilitation focus on the SU might have increased participants awareness of the presence of the healthcare team and addressed their anxieties of less acute monitoring. Participants reported the benefits of working with the physiotherapists and attending the gym, describing this as a necessary process to recover from their stroke. The participants' understanding of the process of recovery may have removed their anxieties regarding their transfer to this new environment.

Transfer anxiety has been associated with women, with less social support and longer critical care stay (Brodsky-Israeli and DeKeyser-Ganz 2011). Although this was not evident in the current study, social support may have impacted on the participant's experience of transfer anxiety. One participant reported vivid dreams on transfer to the SU, however these only lasted for a short period of time and the participant internalized the reasoning for the dreams as within himself and not the new ward environment. Patients have reported vivid dreams whilst inpatients in intensive care settings (Jones, Griffiths, MacMillan and Palmer

1994). Vivid dreams including vivid stories, severe persecutory beliefs and involving members of staff were reported by 48% of patients at a follow-up appointment (Allenby-Smith and Pierce 2001). The participant in the current study reported vivid dreams of being a soldier in various wars through the last two decades. Dreams reported by patients whilst in intensive care have been defined as common and unlike true dreams as the patients were able to recall their dreams in minute detail (Allenby-Smith and Pierce 2001). This is congruent with the participant's reports of his dreams in the current study as he was able to explain each part of his dreams in extreme detail. This participant had already expressed the importance of family and the need for family support, and his family had grown closer through this experience. The social support the participant received may have reduced his experience of transfer anxiety and the discontinuation of the dreams; however this is only a tentative suggestion.

Transfer anxiety has been reported to impact negatively on patients' physical and psychological symptoms including lethargy, weakness, nightmares and depression (Bench and Day 2010). Participants in the current study discussed all of these symptoms, which could imply transfer anxiety not directly expressed during the interview. Participants may have withheld sensitive information due to the methodology applied in data collection. However, these symptoms could be attributed to their stroke. Therefore a recommendation from this study would be the application of an anxiety measure to evaluate patients' levels of anxiety or symptoms of their stroke so appropriate treatment strategies can be implemented.

Transfer anxiety has not been explored in patients being transferred to a different hospital following their stay on a critical care unit. In the current study three participants experienced an internal transfer and three participants experienced an external transfer. The participants understanding of their transfer to a different hospital following their discharge from HASU varied, but did not affect reported levels of transfer anxiety. The one participant experiencing fears and concerns similar to the theoretical construct of transfer anxiety experienced an internal transfer. Transfer anxiety may be relative to individual differences as one participant experiencing an external transfer was angry and confused about her transfer to a hospital further from her home. The participant experiencing transfer anxiety discussed his emotional reaction and coping strategies since the stroke, including his use of humour and re-evaluating the importance of his family. Therefore the element of individual differences and person-centred care remains essential in healthcare.

An aspect of transfer anxiety which emerged from the current study was the provision of information to inform both patients and their family of the process. The reduction of transfer anxiety from a critical care setting is routinely addressed by the provision of formal and informal information (Bench and Day 2010). Information is provided in the form of written documentation and care conferences with patients and family members (Bouve et al., 1999; Tel and Tel 2006; Bokinskie 1992). However, the current study revealed no written explanation of the transfer was provided and only three participants were given verbal explanations. The transfer process left one participant puzzled and confused. This is the first study to explore the transfer process within the new stroke care pathway in London. Further explorative studies are required to identify transfer anxiety and information provision through the stroke care pathway. The development of information for patients and their family members explaining the stroke care pathway and the reasoning for transfer is a recommendation from this study.

4.3 Common Sense Model

Illness representation dimensions of; identity, consequences, control/cure, timeline and emotional response were identified in the current study. All participants identified their condition as a stroke and labelled the symptoms of their stroke. Early interventions to address symptoms assigned to coronary heart disease prior to discharge have been associated with an increase in rehabilitation programmes effectiveness (Lau-Walker 2007). Rehabilitation programmes are extremely important in the recovery from stroke and therefore the accurate labelling of symptoms due to the stroke is required. All participants in the current study described physical and cognitive symptoms attributed to their stroke. The emphasis is placed on the healthcare team to ensure these attributions are accurate.

All participants within the current study described the consequences of their stroke, which were relative to their level of functional disability. Consequences in patients with diabetes have been described as categories including; life impact, physical outcomes, self-care, emotions and health-system activities (Huston and Houk 2011). Diabetes and stroke are both long term conditions, but consequences may not be comparable. Consequences emerging from the current study included; physical outcomes, self-care and emotions. All participants discussed physical outcomes and the relation of these to self-care. Emotional consequences such as feeling low in mood or depression were described by three participants. The current study demonstrates some relevance of the categories of physical outcomes, self-care and emotions across stroke and diabetes.

The illness representation dimension of control/cure within the current study was expressed through the participants need for physiotherapy. All but one participant described their active involvement in physiotherapy and described personal control and treatment control as jointly important in the process of improving physical functioning. One participant, with severe right sided weakness expressed no personal or treatment control as physiotherapy was not improving her condition. In progressive conditions such as osteoarthritis personal control has been found to decrease over time (Kaptein et al., 2010). Personal and treatment control in patients following a stroke may also decrease over time when their rehabilitation plateau is reached and no further gains in physical functioning are achievable. Longitudinal studies exploring personal and treatment control with patients following a stroke are required.

Only two participants in the current study discussed the timeline of their stroke. However, the possibility of a lack of support for the illness representation of timeline could have been influenced by the timing of the interviews. All participants were interviewed whilst in the acute stage of their stroke. The two participants discussing an acute timeline were expecting to be discharged home within the week and had mild functional disabilities. Further exploration of this illness representation within patients following a stroke at a later timeframe is required. Timeline beliefs are important as chronic timeline beliefs are associated with depression (Llewellyn et al., 2007). Therefore there is a need to identify chronic timeline beliefs in patients following a stroke who are already at risk of developing depression (Llebetrau, Seen and Skoog 2008; Robinson 2003) is important.

An emotional response was discussed by two participants in the current study. Emotional representations have been associated with poorer mental health outcomes (Rozema et al., 2009). The current study supports this connection as both participants discussed a negative emotional response and the possibility of a diagnosis of depression and the requirement of anti-depressant medication. An emotional response has also been linked with emotion-focused coping (Billings and Moos 1981). Emotion-focused strategies such as avoidance and distancing would impact negatively on patients recovering from a stroke.

Patterns of illness representation dimensions have been debated, including a general chronic illness model (Fischer et al., 2010) and specific models for each chronic disease (Hagger and Orbell 2003). Further debate for a combination of the two models has occurred to include specific symptoms of each chronic illness (Brooke and Lusher 2012). The general chronic illness model identified the relevance of the following illness representation dimensions; chronic timeline, numerous consequences and less perceived control (Fischer et al., 2010). The current study is one of the first studies to explore the pattern of illness representation dimensions within patients following the new stroke care pathway. The emergence of a model of illness representations for patients with a diagnosis of stroke supported the general chronic illness model (Fischer et al, 2010). The current tentative suggest is that lower reporting of identity, consequences, and timeline was associated with more personal and treatment control. A higher reporting of identity, consequences, and timeline was associated with less personal and treatment control and an emotional reaction. The emergence of this model supports the previous work of Bendz (2003) and the importance of personal and treatment control in the active participation of physiotherapy. However personal control of goals in the rehabilitation process did not emerge in the current study as demonstrated by Jones et al., (2008).

The importance of a chronic illness model is to identify illness representation dimensions within patients following a stroke as the higher reporting of identity, consequences, timeline and emotional representation has been associated with higher reporting of anxiety, depression, stress or a mood disorder (Brooke and Lusher 2012; Hagger and Orbell 2003). However, higher reporting of personal and treatment control has been associated with lower reporting of anxiety, depression, stress or a mood disorder (Brooke and Lusher 2012; Hagger and Orbell 2003). This study provides further evidence of the need for healthcare professionals to monitor illness representation dimensions as these constructs are associated with health outcomes above and beyond the progression of the biological illness (Brooke and Lusher 2012; Hagger and Orbell 2003) and a pattern of illness representation dimensions has now been identified in patients following a stroke.

Interventions to alter illness representation dimensions have demonstrated some success (Knoop, van Kessel and Moss-Morris 2012; Moss-Morris, Humphrey, Johnson, and Petrie, 2007; Broadbent, Ellis, Thomas, Gamble and Petrie 2009). The interventions in each of these studies have explored the illness representation dimensions of the individual and explained their illness and treatment within these dimensions. The aim of the interventions was to increase personal and treatment control and reduce consequences. The illness outcomes within these studies was diverse and included; the reporting of fatigue in multiple sclerosis, chronic pain and management and recovery from a myocardial infarction. The current study has confirmed a general chronic illness model within stroke and the identification of illness representation dimensions. Therefore a recommendation from this study would be further exploration of illness representation dimensions in patients following a stroke and how information and treatment plans can be tailored to increase positive beliefs such as personal and treatment control and to reduce negative beliefs such as consequences.

4.4 Limitations

The study applied a phenomenological method to explore the lived experience of a stroke, issues of transfer anxiety and illness representations of individuals following the new stroke care pathway in London, the following discussion addresses how the characteristics of qualitative interviews and the inclusion of appropriate participants was addressed.

Characteristics important in qualitative interviews were outlined by Smith et al., (2009) and included the extent of spontaneous, rich and relevant descriptions from the participants, the researcher encouraging the participant to clarify meanings and the interpreting throughout the interview and verifying interpretations with the participant. All but one participant were able to provide rich and relevant descriptions of the concepts explored. One participant had no recollection of his stroke or transfer from the HASU to the SU; however the patient was able to provide a rich and relevant description of how his stroke had affected him and how this would impact on his life. During each interview the researcher was able to clarify information and provide summaries to ensure any interpretations were consistent with the information provided by the participant.

The recruitment of participants for this study addressed the characteristics acknowledged to be important in completing phenomenological research. Kvigne and Kirkevold (2003) identified three important characteristics including; the participant must be 'open' to their experience and able to consciously perceive and reflect on their experience. The participant needs to be able to focus on the phenomena for the duration of the interview, excluding participants with memory loss or inability to concentrate. The participant requires a degree of narrative competence, the ability to logically describe an experience in detail and reflect on the experience as well as answering the researcher's questions, which will require the participant to move back and forth from the present to the past. The inclusion and exclusion criteria of the present study addressed some of these characteristics; no diagnosis of cognitive impairment prior or post the stroke. All participants in the current study demonstrated narrative competence and the ability to move back and forth from the past to the present.

A limitation of this study which might be considered is the cross-sectional nature of data collection, data were only collected at one time point post stroke whilst participants remained in the acute phase. This method of data collection does not allow for an exploration of how the emergent themes developed and changed over time as the participants condition became stable and further recovery from the stroke unlikely. Another consideration of qualitative cross-sectional data collection is the reliance of a good rapport to develop between the researcher and the participant, to allow the participant to feel comfortable and explore sensitive information. However, participants discussed their stroke and recovery process openly and explored their emotions allowing an in-depth understanding of the experience of their acute stroke and commencing their rehabilitation stage.

The sample size of the study was not considered a limitation, although important to discuss. IPA challenges the traditional linear relationship between the number of participants and the value of the research (Reid et al. 2005). IPA is the detailed account of individual experience and the complexity of most human experience requires a detailed analysis of a small number of cases. Smith et al. (2009) suggests for IPA to maintain an idiographic focus, ten participants is the highest number recommended for a sample size and requires experienced interpretive phenomenological analysts. The larger the sample size the larger the amount of data generated, which becomes problematic when trying to remain 'true' to IPA's commitments.

One limitation of the study was the participants' perception of the research as part of their medical team, which may influence their openness of their discussion. However, only one participant raised the question following the interview and then correctly identified the researcher as a qualified nurse. The identification of the researcher as a nurse may have occurred during one interview, as the participant had severe weakness of his left arm and demonstrated this by lifting his arm and allowing it to fall next to his chair. However, after this demonstration the participant was unable to pull his arm back onto the chair and the pillow it had been resting on. Therefore, the researcher helped the participant to correctly place his limb on the pillow and it was at this moment the participant questioned the researcher on her qualifications. The act of the researcher was a natural instinct as a qualified nurse, not a researcher and with hindsight the researcher understands how her role changed from researcher to nurse in this moment of care provision. The researcher's act could have impacted on further information the participant provided. However, the participant continued to discuss the impact of his stroke and further use of alternative and complementary treatments to aid his recovery.

4.5 Recommendations for Practice

The current phenomenological study explored the experiences of participants following their stroke and their transfer from a Hyper Acute Stroke Unit to a Stroke Unit. Interpretative Phenomenological Analysis was performed on the text and the emergent super-ordinate themes included disassociation from being in the world, search for understanding, strive for independence and acceptance of help, and hope and uncertainty.

Disassociation from being in the world may be a positive coping strategy to deal with the immediate disability following a stroke, however the commencement of rehabilitation and physiotherapy should enable embodiment and embodied control. The healthcare team needs to identify patients not progressing through these stages as this will be detrimental to the patient's rehabilitation outcomes. Patient's evaluations of self are important in the recovery process and could be included as an element of a rehabilitation programme. Further longitudinal research is required to understand a patient's dissociation with self following a stroke.

Search for understanding of the course, severity and impact of the stroke was important for these participants; however the identification of patients completing a lengthy and negative search for meaning is important as the healthcare team can provide support through this process which could otherwise impact negatively on the patients' well-being. The need of participants to complete positive upward and positive downward comparisons in the current study was enabled by being inpatients on a dedicated stroke ward, which is an important element to consider prior to any re-arrangement of services.

The emergence of hope and uncertainty demonstrated the participants need to cope with the impact of the stroke on their future. A model of hope for stroke has been outlined but only briefly incorporates the acute stage. Further exploration of hope and the formation of a model involving the hyper acute and acute stage of stroke is required to understand hope and uncertainty and both of these constructs impact on a patient's rehabilitation.

Strive for independence and acceptance of hope were both expressed by participants. However, the participants were not involved in the decision-making progress of their treatment or care. The participants allowed their family and the healthcare professionals to plan their treatment and future care. The impact of this finding needs further exploration as patient involvement and informed choice has been a priority within the NHS for many years.

Transfer anxiety did not emerge from the current data; however patients expressed the need for more information regarding the transfer from HASU to SU. The reason for transfer only became apparent to several of the participants following the transfer. The provision of literature explaining the new stroke care pathway for patients and their family is a recommendation from this study; an emphasis should be placed on patients being transferred to a SU in a different NHS Trust.

A chronic illness model of illness representation dimensions emerged for patients diagnosed with a stroke. This study if the first to identify a chronic illness model within stroke. The chronic illness model supported previous models of patients diagnosed with different chronic conditions. The model included the reporting of higher identity, consequences, timeline and lower personal and treatment control and emotional response. The importance of the identification of illness representations of patients following a stroke is to provide interventions to reduce the risk of poorer psychological health and well-being. This study recommends illness representation dimensions are identified by the healthcare team in the acute phase of stroke and negative illness representation dimensions addressed.

4.6 Conclusion

The study explored participants' experience of an acute stroke following the new stroke care pathway in London. Emergent themes included 'disassociation from being in the world', 'search for understanding', 'strive for independence and acceptance of help' and 'hope and uncertainty'. Transfer anxiety was only expressed by one participant and a model consistent with a chronic illness model based on the Common Sense Model of Self-Regulation emerged. Recommendations include the monitoring of patient's use of disassociation and search for understanding as prolonged use may impact negatively on their rehabilitation progress. A further recommendation is the introduction of a measure of anxiety on transfer to a SU to ensure symptoms are appropriately treated. The last recommendation is for healthcare professionals to understand patients' illness representation dimensions to inform the process of information provision to enable patients' optimum recovery following their stroke.

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Appendix A: Participant Information Sheet

PARTICIPANT INFORMATION SHEET

A study exploring illness beliefs and transfer from a hyper acute stroke unit to a ward

You are being invited to take part in a research study.

Before you decide it is important for you to understand why the study is being done and what it will involve.

Please take the time to read the following information carefully, and discuss it with others if you wish.

What is the purpose of the study?

Across London Hyper Acute Stroke Units (HASU) and Stroke Units (SU) have been introduced and the purpose of this study is to understand your perspective of the transfer between these units and to understand your beliefs regarding your stroke.

We hope by asking patients about their perceptions of transfer between these units the healthcare professionals involved may better understand the needs of the patient at this time. Also by asking patients about their beliefs regarding their stroke the healthcare professionals may better understand different beliefs and incorporate this understanding to work collaboratively with patients.

Why have I been chosen?

We ask are asking all patients receiving care on the hyper acute stroke unit at Imperial College Healthcare NHS Trust and then transferred to a stroke unit within this Trust.

Do I have to take part?

It is up to you to decide whether or not to take part. If you decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not have any consequences for you or the care you are receiving.

What happens once I agree to take part?

We will ask you to sign a consent form to show that you have agreed to take part in this study.

Joanne Brooke will arrange a time with you that is convenient for you to complete the first interview. The first interview will occur while you are still in hospital on the stroke unit, a second interview will be arranged when you have been discharged from the stroke unit.

The first interview will last approximately 40 – 45 minutes and will be held in a private room on the ward of 9W Charing Cross Hospital or Grafton Ward St Marys' Hospital.

The interview will involve Joanne Brooke asking general questions about your experiences and perceptions of your transfer between units and about your beliefs regarding your stroke.

The second interview will also last approximately 40 -45 minutes and will be held at your discharge destination or within a private room following a clinic appointment.

The information you give is anonymous, no-one (apart from Joanne Brooke) will be able to identify which comments and ideas belong to which participant.

For the information collected to remain accurate and to reflect your experiences and comments truthfully the interview will be audio taped. The tape will be transcribed by Joanne Brooke; no one else will have access to this information.
Your GP will be informed you have taken part in this study, but will not be informed of your comments or experiences.

What are the possible disadvantages and risks of taking part?
If you agree to take part in this study, the interview will involve questions regarding your care and your thoughts and beliefs regarding your stroke, which may be upsetting to you.
During the interview if you become distressed enough time will be allowed for you to talk through your concerns. Information will also be provided on support groups within and outside the hospital. Lastly, Joanne Brooke will also ask you if you would be happy for her to mention your concerns to your care team, and only if you agree will she do this.

What are the possible benefits of taking part?
The benefit of taking part in this study is discussing your thoughts and beliefs regarding the care you have received and regarding your stroke with the purpose to inform healthcare professionals of the patients' perspective.

We cannot promise the study will help you individually, but by taking part in this study we hope to understand your perceptions of the transfer between units and beliefs regarding your stroke and this may highlight aspects healthcare professionals have not previously considered.

What if something goes wrong?

This study is covered by London Metropolitan University Indemnity for research. Regardless of this, if you wish to complain, or have any concerns about any aspects of the way you have been treated during the course of the study then you should immediately inform the supervisor of this study:

Dr Pankaj Sharma Phone: 020 8846 1184
Email: pankaj.sharma@imperial.ac.uk

The normal National Health Service complaints mechanisms are also available to you. If you are still not satisfied with the response, you may contact the Imperial AHSC Joint Research Office.

Will my taking part in this study be kept confidential?

All information which is collect about you during the course of the research will be kept strictly confidential. Any information reported or published will not have your name on it and you will not be recognised from it.

What will happen to the results of the study?

The information from this study will be used to write reports and publications to inform the multidisciplinary team of the views of stroke patients regarding there transfer between units their beliefs regarding their stroke.

Who is organising and funding this study?

The research is being organised in conjunction with Imperial College Cerebrovascular Research Unit and Imperial College Healthcare NHS Trust.

There is no specific funding for this research Joanne Brooke's contribution is part of her academic responsibilities as a Senior Lecturer to the University of Greenwich and completion of a Professional Doctorate in Health Psychology with London Metropolitan University.

Who has reviewed the study?

The study has been reviewed by the AHSC Joint Research Office, Imperial College London and Imperial College Healthcare NHS Trust. The study has also been reviewed by the City Road and Hampstead Research Ethics Committee and given a favourable ethical opinion.

Contact for further information:

Joanne Brooke Phone: 020 8331 8737
Email: j.m.brooke@greenwich.ac.uk

Thank you for taking the time to read this information sheet!

Appendix B: Consent Form

Study Protocol Number:

Consent Form

A study exploring illness beliefs and transfer from a hyper acute stroke unit to a ward

Name of Principal Investigator: Joanne Brooke

Please
box

1. I confirm that I have read and understood the participant information sheet dated 16/06/2012 Version 0.2 for the above study and have had the opportunity to ask questions which have been answered fully. ☐

2. I understand the study involves two interviews which will be conducted by Joanne Brooke, which will be audio recorded and transcribed. ☐

3. I understand that my personal details, which I provided, are being stored on a secure file. ☐

4. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason and without any consequences. ☐

5. I understand that sections of my research notes may be looked at by responsible individuals from Imperial College Healthcare NHS Trust or from regulatory authorities where it is relevant to my taking part in this research. I give permission for these individuals to access my records that are relevant to this research. ☐

6. I understand who to contact if I have a complaint or concern about the study. ☐

7. I agree to my GP being informed of my participation in this study. ☐

8. I agree to take part in the above study. ☐

Name participant________________________Signature__________________Date_________

Name Investigator_______________________Signature___________________Date________

Appendix C: Interview Schedule

Main question:
- Can you explain what happened to bring you into hospital?

Prompts:
- Can you explain what happened when you arrived at the hospital?
- Can you explain what treatment you had?

Main question:
- How did the stroke affect you?

Prompts:
- Do you have any arm or leg weakness?
- How does that make you feel?

Main question:
- Can you explain your transfer to this unit?

Prompts:
- What information were you given about your transfer?
- What did you understand about your transfer?

Main question:
- How are you coping with the effects of your stroke?

Prompts:
- How is your rehabilitation process going?
- How is your physiotherapy?

Main question:
- What impact do you think your stroke will have when you go home?

Prompts:
- How have you started planning your discharge home?
- What are the plans for your discharge home?

Appendix D: Example of super-ordinate themes of disassociation from being in the world and search for understanding

	Disassociation from being in the world	Search for understanding
Mrs A	**Disassociation through memory loss:** "It (the stroke) was just like I was having a nice little nap. Beyond that of having a cup of tea I don't remember anything until I was here (pointing towards the HASU)."	**Severity of stroke:** "So I am very lucky really there are people much worse off than me in here and I don't want to boast but I do still have a little bit left up here (points to her brain). I think if that goes... well I won't know anyway but there you are, fingers crossed that it won't." **Impact of stroke on future:** "I do like company you know not raudy rowdy company but I do have a young lady who comes and it has developed into more than that, we have become bosom friends. She has come down every day to see me. So I am very lucky in that way. I have one or two neighbours that are very helpful so I'm very lucky."
Mr B	**Disassociation through memory loss:** "I was found on the floor, I was 13 hours on the floor, I don't remember ever going to that other hospital. I didn't know that at all. I don't remember coming here, but I woke up and they said I was at this hospital..." "But I remember seeing the nurses (at the first hospital) regularly during the daytime and night time cause I was so sick... they became like best of friends sort of thing."	**Cause of stroke:** "I don't know why I had this stroke. I had an MRI scan and I don't know when I'm going to see the results. I asked when I would get the results and they (doctors) said today. But then... just before you came, they (doctors) said you are going down for another scan today, as they want to see about something... I don't know what. So I am going for another scan. I don't know what type of scan, I don't know... I should know." **Severity of stroke:** "Apparently I had a light stroke, which was one good thing because the people around me are really out of it... he (describing a fellow patient) shouts and screams, then he cries. He wanders all over the place, honestly he can't help it."
Mrs C	**Disassociation from dead/failing body:** "I had no life in my body, none at all... (describing her stroke) it went dead, all of my body went dead... but umm... the foot is the main thing now compared to the rest of my body. The rest of my body has come back, but the foot is the foot is the main thing..." "It (her foot) is coming back gradually, my foot is better because a couple of days ago I couldn't walk without help from the nurses, and now I can walk." **Disassociation from self:** "When it (the stroke) happened I called the ambulance to bring me to hospital, it was just the leg that had been affected... I have never had a stroke before, so it was just the leg that had been affected."	**Impact of stroke on future:** "I can manage at home; I can walk to the toilet with my stick... I can manage to wash and dress... I don't need help like that... I don't need help like that... I like my home, I like my daughter coming. I'm not going anywhere but home."

Mr D	**Disassociation from dead/failing body:** "My centre of gravity is now on the left side because this arm (left arm) is like a sack of potatoes and if I lean this way (to the left) it will pull me over so I must stand straight." **Disassociation from self:** "Can you imagine that an active person who has had a stroke becomes so depressed he can't move his leg he can't move his arm he is confined to the chair… it is a terrific shock… confined even to bed."	**Cause of stroke:** "It was a great shock to me that I felt very unwell and with great anxiety, after being so well and active and played lots of sports and never had any high pressure (blood) or anything like that… the fact that I could have a stroke is a big blow to me… I wonder how comes I got this… how comes I got this stroke." **Severity of stroke:** "I have seen people with a stroke… a person with two new knees a heart bypass and he had a stroke, he was an 83 year old chap but two weeks later was back walking."
Mrs E	**Disassociation from self:** "Before this (stroke) I was independent. I lived on my own. I have MS but that hasn't stopped me living at home on my own. I like to be independent… I have a district nurse who visits me and monitors my MS, my medication and my blood levels. But I remain independent. I like to do things for myself, I like to be independent."	**Severity of stroke:** "Nutrition is a bit of a problem. The problem is getting enough nourishment into my body, the nurses and the nutrition lady tell me to drink more… drink this… drink this… but I find it difficult, so they are talking about surgery, putting in a feeding tube of some sort. This makes me nervous."
Mr F	**Disassociation from dead/failing body:** "I got as far as the door then just wen backwards like a dead brick, that's when I banged my head, elbow, all down my back… that's when I think the stroke started."	**Cause of stroke:** "Three weeks prior to that (stroke) at home I had two nights on two occasions when I couldn't sit upright at 3am… I called an ambulance and they checked me over and the report said everything was perfectly alright… but had I followed up the complaint and had a head scan it might have saved me from having this stroke…" **Impact of stroke on future:** "This stroke has brought them (children) all together and I'm happy about that… even my son and daughter. It has brought closeness together which I am really happy, about, it has made me feel it's good to be a family and you need a family."

Appendix E: Example of super-ordinate themes of strive for independence and acceptance of help and hope and uncertainty

	Strive for independence and acceptance of help	**Hope and uncertainty**
Mrs A	**Need for independence:** "I shall stagger on a bit, I shall be 95 next month, I'm trying, I need to, my one fear and it is a fear I have always been frightened of going into a home. I would fight that to the nail if I could you know..." **Allowing others to make decisions:** "She (nurse) said she is going to get on to social services and another one had got on to my surgery so I am sure something will be organised." "My cousin has made arrangements for social services to come in the morning and the afternoon for about 6 weeks umm... until I get home to see the papers, she had made a folder of what she had done, but until I get home I don't know quite what she had done." **Acceptance of support:** "I must admit to be perfectly honest I would rather they didn't (social services visit), but that is just one of those things and when you are in the situation that I'm going to be in for a while at least one had to do is knuckle under a bit."	**Physical recovery:** "They (the doctors) tell me fortunately it (her stroke) is only a minor one and I hope to goodness it is, I can't say there is anything wrong with my arms or legs." "I can't say I actually notice any difference in me (since the stroke) unless there is more to come out that I don't know about yet. I hope not." **Return to normal:** "I have had some physiotherapy and apparently passed that with flying colours and cam fortunate I can just keep myself in my home." "I do hope it will only be for a week or a few weeks (social service visits) but unfortunately life is such and uncertain that you can't tell a thing can you?"
Mr B	**Need for independence:** "When I first had a shower, a girl (nurse) was drying me you know but now you dry yourself, it isn't that easy drying yourself, but I will dry myself, I don't want a girl drying me." **Allowing others to make decisions:** "My brother is taking me home, he has had a word with one of the... oh I don't know nurses, I don't know who it is... someone in charge. They (brother and nurse) reckon I should stop her until Monday, if they think that I will. I will listen to them."	**Return to normal:** "I hope to go back and watch the home games (football team) again when I leave here and to the café. I have a café, what I use... this café I've been going there for about oh blimey 20 years, and it's like a working men's club they care, you see all the regulars, it doesn't matter what time it is... I hope to go back and chat with all my mates." "I'm going back to live on my own... I don't really know how I will cope, because at the moment I'm stuck in bed or by my bed, one of the two. I will have to wait until I get home and then see what it is like."
Mrs C	**Need for independence:** "I'm not going to bother with support (when goes home)... I did have more support once for a month, but I didn't like it at all... who would want help at home you know help at home to do that..." **Allowing others to make decisions:** "The nurses have spoken to my daughter, so she speaks to the nurses and tells me what is happening, the doctors they tell me what is happening, my daughter will speak to the nurses..." **Acceptance of support:**	**Physical recovery:** "A couple of days ago I couldn't walk without the help of the nurses, and now I can walk, I can just walk with a stick to the bathroom and back... without the help of the nurses... so I am getting back to normal." **Return to normal:** "I'm getting better all the time doing physiotherapy, I have been there today, and it is good for me to do you know... hard work. I will recover and hope to come back to my normal self." "I will come back to do things for myself... like you know... make a cup of tea and

	"Sometimes I can't manage in the kitchen you know sometimes I can't just manage in the kitchen at all. Cause when I just got to stand up I would feel dizzy as I have got a low iron count, so when I stand up I feel dizzy and my head starts spinning round and that is not safe at all not safe in the kitchen."	things like that. It is going to take a while, like a month this is going to take a long time."
Mr D	**Need for independence:** "When I stand up I get wobbly because my knee is weak and can give way. I need to practice standing still, to stand strong. I need to keep practicing to stand strong and strengthen my knee." **Acceptance of support:** "Some staff don't realise if you are incapacitated… for instance I need all this (points to objects) on the table; I need it to be left within my reach. Some people do not realise that I need this and need this close, but also the water jug I need the handle facing me and not too much water in the jug to be able to pour water into my glass." "We (physiotherapists and himself) work the muscles. We have been working on my fingers, because clearly I cannot move my fingers at the moment, so we try and activate the muscles of my fingers by the physios moving them."	**Return to normal:** "I just want to get back to normal life; I really hope I can get back to normal life…" **Alternative treatments to aid recovery:** "I am in another trial looking at different types of plaster, there are three plasters, one is the real plaster, one is the standard treatment and one is nothing. I don't know which plaster I have, neither does the doctor, but they will tell me at the end (pointing to a patch possibly releasing a drug). I am desperate I will try everything." "I was thinking about hypnosis, apparently hypnosis could be a good thing, to start using your brain power and to help you work your limbs to mobilise… I will ask the doctor what he thinks but he will probably think that I am mad. I would be interested if anybody had tried hypnosis as therapy for stroke."
Mrs E	**Allowing others to make decisions:** "I'm not aware of any future plans at the moment. I have spoken to the doctors and they are very good at listening… I have great confidence in them. The nurses have also been excellent, they couldn't be more caring, if they suggest I need nursing home care then I will." **Acceptance of support:** "There is talk of me going into a nursing home, because of the amount of care I need. I don't mind going… if I get the care and attention I need I don't mind going."	
Mr F	**Need for independence:** "I have physio every day, the day before yesterday they (physiotherapists) put me on that cycle machine, today they got me to stand and try to transfer my weight to my left leg, this afternoon is the bike again, so I need to keep working at it."	**Physical recovery:** "I seem to be doing alright. I hope so. I think it is just me I'm impatient, very impatient; probably not a good thing, but that has been my life. I mean I have never stopped working. I have always been an active person. **Return to normal:** "I just want to get back on the caravan. I have a group of friends and we go caravanning it is great fun. I can't wait to re-join them."

Appendix F: Transfer Anxiety

	Transfer Anxiety
Mrs A	**Understanding the stroke care pathway from healthcare professionals:** "They (nurses) told me I was coming to this ward yesterday afternoon, of the day before... the nurses told me... I gather this is some sort of umm... halfway house as it were, you know if I pass all the tests here I can go nearer home."
Mr B	
Mrs C	**Lack of understanding and control of the stroke care pathway** "They (nurses) said I would come to a stroke ward if I came here... but I don't know why I came to this hospital I don't live near this hospital... they do have a place on the ward and I go there for physiotherapy. I have done physiotherapy for two days on the run now, since I have been here... so I am getting better all the time." "I came here by ambulance, I didn't have a choice they (the nurses) explained I had to come here (SU) and that was that, here I am... So I don't understand why I came to this hospital, I don't understand really..."
Mr D	**Understanding the stroke care pathway from healthcare professionals:** "They (nurses) told me I had to mover here to this ward (SU) they said it was important as the only way to get cured was hard work and rehabilitation with the physios that is why they moved me here for physiotherapy." "It was the same care there (HASU) as it is here (SU)... the physios are so busy here they cannot attend there, so I need to come here."
Mrs E	**Understanding the stroke care pathway from experience:** "They (nurses) didn't really tell me why I was coming over here (SU)... they had begun to empty the bay I was in... and everyone else (patients) had moved and I was the only one left so they decided to transfer me and ship me somewhere else..." "If you are asking me the difference between this ward (SU) and that one (HASU). I don't know, I would say that one (HASU) is where you come in when you have your stroke and then as the gym for physiotherapy is over here on this ward, then you come over here if you need to keep having physio. But I don't know."
Mr F	**Understanding the stroke care pathway from healthcare professionals:** "After a couple of days (on HASU) they shot me round here (SU). I think it was because this was the treatment ward and the ward I was on before was the acute ward, the doctor came and explained that to me and my family." **Transfer anxiety:** "The first time I came here (SU) it was like I had been sent to Coventry, it was quite and cold and dark and I had dreams I thought I would never have... The French war with big bayonets, the first world war in the muds and the trenches, then the second world war with the Americans on the beaches. So it was all dreams really, but I thought in the morning after the dreams I thought I don't like this room... there is too much evil in her. But that was just me."

Appendix G: Common Sense Model Illness Representation Dimensions

Participant	Identity	Consequence	Timeline	Control/cure
Mrs A	I had a little stroke. They (doctors) tell me fortunately it was only a minor one (stroke).	I don't know whether the stroke has... (affected me) but I can't say I have actually noticed any difference in me.	I do hope it (social services) will only be for a week or a few weeks, but unfortunately life is such and uncertain that you can't tell a thing can you?	I have had physiotherapy, yes but apparently I have passed that with flying colours so that is one thing after all I am 95. Almost 95 I shall stagger on a bit I shall be 95 next month.
Mr B	That's a stroke club (pointing at a leaflet), would you like to go and I couldn't say no, because you know... because I am one of them.	I think memory wise is not that brilliant to be quite honest with you, I didn't have a great memory previously anyway, but it has got worse since (the stroke)...		I haven't had physio, so there is nothing I have had... oh bleeding hell... pills... I reckon I can fill a chemist up. The amount of pills I've had, I must have had oh, I would say... I must have had about 60.
Mrs C	I had cramp in my right leg, I was not able to lift it at all and um... I thought it was a stroke and today I found out it was a stroke.	I will recover, and hope to come back to normal, well maybe not 100% but back to normal.	A couple of days ago I couldn't walk without help from the nurses and now I can walk with a stick to the bathroom and back... I walked with the stick before I had my stroke.	I have done physiotherapy for two days on the run now I have been doing it so... I'm getting better all the time doing the physiotherapy... I have been there today... it is good for me to do you know.
Mr D	I tried to get up (after a fall) and look for a chair and I crawled to the chair practically and then I realized this was something more serious.	I am unable to do what I want to do, me who could play a lot of games, fit... The water jug... I need the handle facing me and not too much water in the jug to be able to pour the water into my glass.		The nurses told me I had to move to this ward (SU) they said it was important as the only way to get cured was hard work and rehabilitation with physios.
Mrs E	I also suffer from MS (multiple sclerosis) so that complicates things rather... I was admitted to the stroke unit for further tests to decide if it was a stroke or my MS...	There is talk of me going to a nursing home, because of the amount of care I need. I don't mind going... if I get the care and attention I need I don't mind going, because I do need a lot of care and attention...		I do physio most days and it is extremely painful to my arm and my leg each time I have to do this. I have pains in places I didn't know I had. I can't see any improvement.
Mr F	I can't move this arm very well... if I tried to put my finger on my nose now... I can't get it there. That is the stroke with this arm on this side and this leg is weak, it is 5% weaker than on the left, so that is the effect of the stroke.	My speech is very good until... when I get drowsy I get lazy and when I get lazy it is one word at a time. It's not my actual speech it is because I get so tired. My speech is OK and fluent, it is just tiredness and lethargy.		I have physio every day, the day before yesterday they put me on that cycle machine, and they were here this morning getting me to stand up and to try and transfer my weight to my left leg.

Professional competencies in health psychology reflective commentary

by

Joanne Brooke

Reflective commentary Submitted in Partial Fulfillment
of the Requirements for the Professional Doctorate of Health Psychology

London Metropolitan University

January 2013

The aim of this reflective commentary is to demonstrate my progression through identified professional health psychology competences to an appropriate standard to enable me to practice independently in the discipline of health psychology. I acknowledge through developing competence I am accountable to the Health and Care Professionals Council, The British Psychological Society as the representative body for psychology and psychologists in the UK and the Nursing and Midwifery Council as my current post as a senior lecturer is within the faculty of Health and School Care. However, for this reflective commentary I will remain with my development towards becoming an independent health psychologist. The reflective commentary will be structured using the professional competencies outlined by the British Psychological Society (BPS) in the Qualification in Health Psychology (Stage 2) Candidate Handbook (BPS 2009) including; practice within legal and ethical boundaries, practice as an autonomous professional, demonstrate the need to engage in continuing professional development, communicate effectively, provide appropriate advice and guidance on concepts and evidence derived from health psychology, build alliances and engage in collaborative working effectively, and lead groups or teams effectively.

Practice within legal and ethical boundaries

For a health psychologist to practice within legal and ethical boundaries an understanding of the current governing bodies and their standards is required. The discipline of health psychology is governed by the Health and Care Professional Council (HCPC). The HCPC regulates 16 health care professions and one of these is the 'practitioner psychologists', within this category there are 9 protected titles including Health Psychologist. Each of the 16 health care professions regulated by the HCPC are also regulated by at least one other professional body. For practitioner psychologists this is the British Psychological Society (BPS), which is involved in promoting the profession, representing members, curriculum frameworks, post registration training and continuing professional development. Both the HCPC and the BPS provide guidelines and standards for psychologists to work within; Standards of conduct, performance and ethics (HCPC 2008) and Generic Professional Practice Guidelines (BPS 2008). The HCPC provides specific advice for health psychologists in the; Standards for proficiency; Practitioner psychologists (HCPC 2010) and the BPS extend their generic guidelines to include specific guidelines regarding ethics and conduct in the; Code of Ethics and Conduct (BPS 2009). Due to my current post I am also governed by the Nursing Midwifery Council (NMC) and the; The Code; Standards of conduct performance and ethics for nurses and midwives (NMC 2008).

During the past two years I have practiced within legal and ethical boundaries across many different circumstances and with different groups such as; students, patients, my colleagues within my institution and external colleagues, my line manager, my supervisor, and with research participants. I have found myself in certain situations where legal and ethical issues have been raised.

The Generic Professional Practice Guidelines (BPS 2008) explain the responsibilities of psychologists completing research and the importance of obtaining ethical approval and working within the approved proposal. During the last two years I have been involved in a number of research projects requiring ethical approval and I have completed the required documentation depending on the stage of the project, either a new application or a substantial amendment. During all of the processes to acquire ethical approval I have adhered to the ethical principles documented in the Code of Ethics and Conduct (BPS 2009); respect, competence, responsibility and integrity. I have respected the knowledge and experience of my participants when collecting qualitative data on their experiences of having a stroke and progressing through the new stroke care pathway. The projects I have proposed are within my current competency and have included clinical or academic supervisors to support me should I need advice. I have maintained responsibility for each project ensuring clear documentation throughout the process and the dissemination of results. With regard to integrity an incident occurred when I was working with a colleague on a study interviewing nurses regarding their perspectives on the new stroke care pathway when recruitment became very difficult. My colleague suggested I interviewed the senior nurse managers, although I discussed this proposal with my colleague I highlighted that the research protocol identified band 5 and 6 nurses, which are more junior nurses and interviewing senior nurse managers at bands 7 and 8 would be outside the current ethically approved protocol. I suggested that if it was important to consider the perspectives of the senior nurse managers I would return to ethics for an amendment. However, at this stage my colleague acknowledged it was more of a convenient sample rather than a necessary sample and we progressed to discuss strategies to improve our current recruitment problems. I feel this example demonstrates my integrity to work within the approved project proposal.

Practice as an autonomous professional

During my training to become a health psychologist I have continuously worked as an autonomous professional, I have identified my strengths and weakness and worked with my line manager and supervisor when I have required advice. A strength and weakness of mine is my independent working style and my infrequent contact with both my line manager and my supervisor. During the past two years I feel I have developed a more open working relationship with both my line manager and supervisor. The Code of Ethics and Conduct (BPS 2009) has highlighted this process to me as it is a requirement under the ethical principle of competence to 'seek consultation and supervision' when the need arises. I have found through this process I am in contact more regularly with both my line manager and my supervisor and discuss my current progress on various commitments. A recurrent theme and discussion again with both my line manager and supervisor is my willingness to take on further commitments and at times I have found I have struggled with competing commitments. Although I am aware of this weakness and now discuss commitments with my line manager my enthusiasm for research and further projects continues.

An example of working as an autonomous professional occurred during my role as a senior lecturer. I am responsible for the support of students attending a number of clinical placements and to ensure students and their mentors are supported within each clinical placement an annual educational audit is completed annually, which is a requirement by the NMC (2010). I have never been involved in an educational audit of a clinical environment prior to commencing this post, so it was essential I recognised my limitations and worked with a senior colleague to gain the required experience. I was then able to work as an autonomous professional and complete further educational audits. I have found the process of completing the audit is beneficial for maintaining working relationships with the staff on the clinical units. The audit allows a two way communication process and discussion involving; the students and the support they require in clinical practice, but also the needs of the mentors and the support they require in mentoring the students. The audit and feedback process of the students and the mentors maintains a good learning environment in very different clinical areas (Tremayne 2007).

Demonstrate the need to engage in continuing professional development

I commenced my training to become a health psychologist in January 2011 and had only been in my current post of senior lecturer for less than 8 months. The training highlighted many areas in which I needed to engage in continuing professional development. One major area was within my role as a senior lecturer and many of these needs were addressed during my completion of the Post Graduate Certificate in Higher Education and becoming a fellow of the Higher Education Academy in 2012. I feel over the last two years I have developed within my role and now understand the many and complex responsibilities of a senior lecturer.

An example of working within legal and ethical boundaries, which demonstrated my need to engage in continuing professional development within my role as a lecturer occurred during my interaction with an undergraduate student. I am aware of the possible power imbalance between a lecturer and a student, and the multiple interactions of power within the classroom environment. However, as a lecturer I have responsibilities to guide the student in the learning process and it is impossible to relinquish all of the power in these interactions (Cornelius and Herrenkohl 2004). The student approached me regarding her turnitin report which demonstrated an 88% match to a previous students work. During the following discussion the student adamantly denied any act of plagiarism or any acknowledgement of how this could have occurred. I informed the student if she submitted this work then a plagiarism incident would occur. I acknowledge my own limited knowledge of the universities rules regarding plagiarism and although the student was using a revision tool, the student had demonstrated to me her work contained an 88% match, and I was unaware of how to act on this information. Due to my limited experience and knowledge regarding plagiarism incidents I referred the student to the department's Professional Lead to discuss further. I acknowledged my limitations and referred the student to another professional as outlined in the Standards of conduct, performance and ethics (HCPC 2008). Since this incident I have worked with the Professional Lead on plagiarism incidents and interviews to aid my understanding of this process.

Another example of my need to engage in continuing professional development involved my role as Principal Investigator on a study exploring nurses' perspectives of the new stroke pathway in London. The first stage of this study had been completed with the collection of qualitative data, now the second stage of analysis and construction of a questionnaire was required. I was aware of the complexities of constructing questionnaires, such as longitudinal, concurrent, construct, content, criterion, discriminant and face validity as well as reliability (Sushil and Verma 2010). However, I have never practically completed this process. Therefore I identified my need and the requirement of further training before I began this process and thought it was appropriate to attend a workshop in questionnaire construction organised by the University of Greenwich. I found this workshop was practical in the construction of the questionnaire but also informative on the processes of validity and reliability. The workshop also enabled me to commence collaborative working with new colleagues to assist in the process of the construction of my questionnaire.

Other areas of recognizing the need for continued professional development to be able to work independently as a health psychologist included; working with the statistician on a systematic review and meta-analysis which highlighted the need for me to understand the statistical package further to enable me to complete the analysis on my own in the future, attending a course coordinators course to understand the roles and responsibilities of being a course coordinator for a second year undergraduate course and a post graduate course, attending training to understand the implementation of 'Moodle' instead of the current 'Web CT', meeting with representatives to understand ERASMUS and becoming involved in ERASMUS teaching, attending a marking and feedback workshop organized within my faculty as the grading criteria has changed, working with the Professor of Nursing and the Business Development Manager to apply for funding for a research project and the need to understand the costing of a research project, these are just a few examples.

Communicate effectively

I feel my communication skills over the last two years have developed incredibly. I have developed different communication skills for lecturing large and small groups, facilitating seminar sessions for undergraduate and postgraduate students both in health and psychology, engaging students on an individual basis, presenting research for colleagues and at various conferences, becoming involved in departmental meetings and discussions, responding to ethic committee's questions regarding my proposals, speaking to patients with a diagnosis of a stroke and their relatives regarding participation in research, facilitating qualitative interviews with qualified nurses and when discussing my work with my supervisor and line manager.

Provide appropriate advice and guidance on concepts and evidence derived from health psychology

On commencement of this program I was unsure how relevant health psychology was to my role of senior lecturer within the faculty of Health and Social Care. However I have begun to understand the need for healthcare professionals to have a good understanding of health psychology and the implications of health psychology for their practice. I have proposed a health psychology component for our pre-registration Adult Nurses and the commencement of post registration courses for senior nurses who are involved in advising patients regarding secondary prevention. Although currently the financial restraints of the NHS might limited the CPD course, which would almost be defeating the object as secondary prevention provided appropriately for each individual patient would in the long term reduce costs of recurrent admissions. An example is the cost effectiveness of the adherence to comprehensive cardiac rehabilitation following a myocardial infarction (NICE 2007).

My role has allowed the provision of information and guidance on concepts derived from health psychology to qualified nurses providing patients with secondary prevention advice following a stroke (Lawrence 2011). The nurses provide this advice without a clear understanding of health psychology and how to help their patients to change their health behaviours. I was astonished to find the nurses I had contact with thought patients would change their health behaviours because they were told to! However, on exploring this further with the nurses they began to consider this in more depth and realised the complexities of behaviour change. The only formal support the patients are offered is in the form of smoking cessation and they can be referred to a NHS support service, when I asked the staff about other support services none were mentioned. I found this very interesting and demonstrated the importance for the role of health psychology within clinical teams.

Secondary prevention advice regarding health behaviour change is a theme through the majority of acute and chronic illnesses and therefore an important element to be addressed within the NHS, which currently within the service of stroke this, is not apparent.

I have been able to discuss concepts derived from health psychology when presenting my research for my Professional Doctorate in Health Psychology at research meetings within an acute trust in London. The meetings are attended by all healthcare professions, but dominated by the medical profession and this allowed for an interesting discussion of the Common Sense Model of Illness Representations (Leventhal, Nerenz and Steele 1984) and the impact of the dimensions from within this model on health outcomes above and beyond the biological progression of the biological disease.

I have also been able to discuss concepts derived from health psychology through the completion of my systematic review; 'The components of the common sense model of self-regulation revisited: a systematic review and meta-analysis' (Brooke and Lusher 2012), which I have published and presented at the 5th International Scientific Conference, Slovenia (2012) and am due to present at the RCN International Nursing Conference (2013).

On reflection health psychology is very relevant to my role as a senior lecturer within the faculty of Health and Social Care and without my progress through this program the importance of addressing the training of nurses to include health psychology concepts may not have occurred at the University of Greenwich. I also feel my research has been influenced by my increasing knowledge of health psychology and how this can impact on services and patient outcomes.

Build alliances and engage in collaborative working effectively

During the process of commencing and completing my research for this programme I have had to build alliances and engage in collaborative working as I am no longer clinically attached to a stroke unit and my specialist area of interest is currently within stroke. I have worked with the Clinical Nurse Specialist (CNS) and a senior Neurologist on different projects to maintain collaborative working. One project was the completion of a systematic review and meta-analysis (Brooke et al. 2012). This was my first experience of collaboration with colleagues from a different institution, I found this process at times challenging as the publication was my priority, but not that of the CNS, Neurologist or Statistician involved. I maintained contact with the team by attending their Monday morning meetings and reporting on the progress of the work. The completion of the project to publication took much longer than I had originally planned. The work commenced in June 2010, submitted the paper in September 2011, accepted for publication in January 2012 and finally published in August 2012. I have learnt through this collaborative work how difficult it is for all members to remain focused especially as the collaboration was across institutions and not a priority for the majority of the team members.

I have also learnt that all collaborations or attempts to collaborate with colleagues within my institution or across institutions are not always appropriate. I was involved with meeting colleagues from three different institutions to form a proposal for a research project focused on dementia awareness; the aim of the collaboration was also to approach local NHS Trusts to become involved with the research from the outset. However, the main institution driving the project forward were vague about the practical elements of the project, even though discussed in some depth and it became clear that their approach was one that would not work with myself and colleagues from the University of Greenwich, so no further work was completed.

I feel during the process of building alliances and engaging in collaborative working I have discovered that it is possible the work might not come to fruition or it is possible for the interests and direction of collaborators to be different that the proposed work would not be possible. I have learnt to be more enquiring during such collaboration meetings to ensure I am aware of colleagues orientation, needs and interests and then to make an informed choice about working with them.

Lead groups or teams effectively

One of my responsibilities as a senior lecture is as a Personal Tutor Group Leader; I currently have two personal tutor groups (PTGs) and through my experience have changed my leadership style. Leadership styles were first defined broadly into three categories authoritarian, democratic and laizzez-fair (Lewin et al. 1939). These categories have been further expanded in more recent work, but for my analysis I am going to remain with these three categories. I was allocated my first PTG in September 2010 as they commenced their nursing degree and it is my responsibility to meet with the students and support them through their studies. All the students' feedback sheets from assignments and exams are sent to me and I discuss these with the students, the students also submit their Practice Assessment Document and I document the amount of clinical hours they have completed. During the process of supporting these students I had a relaxed and informal manner and offered help with all aspects of their studies. I feel my leadership style with this PTG was similar to a laissez-fair approach as I would facilitate group discussions and as a group we would decide on relevant deadlines for the completion of work and even the amount of genetic competencies the students had to complete in any given semester, although they had to complete all 7 before completing their program. However, I feel my relaxed leadership style with the students didn't lead to commitment from the students to comply with deadlines and completing the appropriate amount of work.

I have since been allocated another PTG who commenced their programme in May 2012 and as this is a larger group I have changed my leadership style to authoritarian. On meeting these students for the first time I provided clear expectations for what they need to do, when it should be done and how they should complete it. I hadn't consciously decided to change my leadership style, but on reflection as these students are just commencing their programme and it is appropriate to have a clear division between myself and the students as I can provide the guidance and support they need. I have found with my new PTG they have responded well my authoritarian approach and have engaged more with me.

I feel I have learnt on leading groups effectively through this process and sometimes my relaxed informal approach, perhaps laissez-fair leadership style may provide the wrong impression for the students and a more formal approach, perhaps authoritarian with clear deadlines is helpful. After a PTG meeting with the May 2012 cohort when I had provided strict guidelines on submission dates and documentation in their Practice Assessment Documents and highlighted practices that were not acceptable I received a number of emails from the students thanking me for my clear provision of information and support.

I feel during my two years as a trainee health psychologist I have been pro-active in my learning and understanding my new discipline, and have developed my competencies to work as an independent practitioner in this field. My examples in this reflective summary are just a small amount of the work I have completed.

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Behaviour change intervention case study and reflective report

by

Joanne Brooke

Case Study and Reflective Report Submitted in Partial Fulfillment
of the Requirements for the Professional Doctorate of Health Psychology

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Introduction

The aim of this report is to demonstrate my progression through designing, developing, delivering and evaluating a behaviour change intervention to an appropriate standard which goes towards enabling me to practice independently in the discipline of health psychology. The report includes a case study of a behaviour change intervention I have conducted and a reflective report comparing and contrasting two theoretical models in relation to the behaviour change intervention. The case study includes an understanding of current behaviour on a health outcome, the formulation of a hypothesis to target the health behaviour, the design of an intervention based on the assessment, hypothesis and relevant health psychology theory and finally an evaluation of the outcomes of the intervention and how these results will be disseminated. The behaviour change intervention aimed to increase student healthcare professionals' fruit and vegetable consumption via a brief online intervention derived from the Theory of Planned Behaviour (Ajzen 1991) and Implementation Intentions (Gollwitzer 1999).

Assessment/Formulation

The consumption of fruit and vegetables is associated with a reduced rate of coronary heart disease, cardiovascular disease, colorectal cancer, diabetes and high blood pressure (Dauchet, Hercberg and Dallangeville 2005; Liu, Manson, Lee, Cole, Hennenkens, Willett and Buring 2000; Michels, Giovannucc, Josphipura, Rosner, Stamplter, Fuchseta et al., 2000; Harding, Wareham, Bingham, Khaw, Luben, Welch et al., 2008; John, Ziebland, Yudkin, Roe and Neil 2002). The World Health Organisation (WHO) and the Food and Agriculture Organisation (FAO) in 2002 recommended that daily consumption of an 'adequate quantity' is needed to reduce these health risks. WHO and FAO defined 'adequate quantity' as at least 400 grams per day, which is equivalent to 5 portions of 80 grams of fruit and/or vegetables (WHO and FAO 2003). For individuals eating less than the recommended amount an increase of just one-quarter of a portion of fruit or vegetable consumption could result in a 4% reduction in cancer risk (World Cancer Research Fund 1997). A large European study found individuals who consume 5 portions of fruit and vegetables a day had a 26% lower risk of stroke compared to those who ate less than 3 portions a day (Boffetta, Couto, Wichman, Ferrari, Trichopoulos and Bueno-de-Misquita 2010). However, in 2008 the average daily consumption of fruit and vegetables in the UK was only 3.7 portions, which was a decrease from 3.9 portions in 2007 (Office of National Statistics and the Department for Environment, Food and Rural Affairs 2010). On average only 13% of men and 15% of women in the UK consume the recommended quantity of 5 portions of fruit and vegetables a day (Henderson, Gregory and Swan 2002).

Fruit and vegetable consumption is lowest among young adults (Doyle and Hosfield 2003). Young adults are in the transitional period from a child in a family environment to self-sufficiency and health behaviours of young adults may be more amenable to change as they have yet to become habits (Armitage 2007). A proportion of young adults attend university, which includes student healthcare professionals, although consumption of fruit and vegetables may be higher in student healthcare professionals than the general student population due to their gaining an understanding of nutritional requirements and the impact on their health.

Healthcare professionals, including nurses, advocate patient education for primary and secondary prevention of chronic diseases. Primary and secondary prevention includes health behaviours related to; diet, physical activity, alcohol and smoking. However, Miller, Alpert and Cross (2008) in the US found 54% of nurses, advanced practice nurses and nurse educators were overweight or obese. Luszczynska and Hayes (2009) in the UK found similar rates of obesity among student nurses and midwives. The findings of these two studies suggest healthcare professionals do not conform to their own advice.

Health campaigns have so far only achieved limited success on increasing fruit and vegetable consumption suggesting the need for interventions based on psychological models of health behaviour (Michie and Abraham 2004) and no studies have specifically recorded fruit and vegetable consumption and the impact of a brief intervention with student healthcare professionals.

The current behaviour change intervention was formulated to examine student healthcare professionals' consumption of fruit and vegetables and to explore the efficiency of a brief online intervention to increase their consumption of fruit and vegetables.

Intervention and integration of theory and practice

The rationale of the intervention was to increase fruit and vegetable consumption in student healthcare practitioners. The intervention was based on the Theory of Planned Behaviour (Ajzen 1991) and Implementation Intentions (Gollwitzer 1999).

The Theory of Planned Behaviour (TPB) evolved from the Theory of Reasoned Action with the inclusion of behavioural intention (Ajzen 1988). The TPB explains the relationship between the dimensions of attitude, subjective norm and behavioural intention to predict behaviour. Ajzen (1988) included the dimension of perceived behavioural control as an individual's appraisal of their ability to perform certain behaviour. Therefore perceived behavioural control should predict behavioural intention when an individual's perceptions of control accurately reflect their control over the behaviour. Behavioural intention should then predict behaviour. A student healthcare professional's attitudes, subjective norm and intention to consume five portions of fruit and vegetables daily, and their appraisal of being able to complete this behaviour should then predict their consumption of fruit and vegetables.

The TPB has received extensive support (Ajzen and Fishbein 2000). Godin and Kok's (1996) review of TPB and health behaviours, found the dimensions of the TPB explained an average of 41% of the variance in behavioural intention. However the prediction of behaviour from TPB variables is considerably less and ranges between 27% - 31% (Godin and Kok 1996; Armitage and Connor 2001).

Implementation intentions (Gollwitzer 1990) include two distinct phases to achieve goal attainment; the deliberative phase and the implemental phase. The formation of goal intentions to perform a goal-directed behaviour occurs in the deliberative phase, this is the motivational stage of goal setting. An individual will then plan when, where and how to carry out a goal-directed behaviour in the implemental phase, such as 'I intend to perform X whenever Y conditions are encountered'. The planning of the goal-direct behaviour has been termed implementation intentions (Gollwitzer 1990). Gollwitzer and Brandstatter (1997) found students whose goal intention was to write an assignment over the winter break were twice as likely to submit their work on time if they created an implementation intention to support their goal intention. Implementation intentions can increase the performance of a health behaviour when a goal intention is present, such as breast self-examination and healthy eating (Orbell, Hodgkins and Sheeran 1997; Verplanken and Faes 1999). However, it remains unclear how implementation intentions affect behaviour. One explanation is the impact of implementation intentions on memory, the memory for a behaviour is increased by included environmental and contextual cues, which may act as an unconscious reminder when encountered (Gollwitzer 1999).

The construction of the behaviour change intervention commenced with the formation of questionnaires to understand the student healthcare professionals' current fruit and vegetable consumption, attitudes, norms, perceived behavioural control and behavioural intention to consume the recommended daily intake of fruit and vegetables over the next week.

The format to gain information on how many portions of fruit and vegetables consumed over the past week was structured on a previous study by Kellar and Abraham (2005). A series of questions asked: on how many days did the participant eat one piece of fruit or vegetable, on how many days did the participant eat two pieces of fruit or vegetables and this form of questioning continued up to the recommended 5 pieces of fruit or vegetables a day. On initial reading of this format I had found the questions confusing, as if the participant had consumed 5 portions for 7 days did they indicate 7 days for each question? However, on further examination of the questions I understood the importance of gaining the information on the exact amount of fruit and vegetable consumption of each participant and this method had previously been demonstrated to be reliable.

The Theory of Planned Behaviour (Ajzen 1988) variables have been measured in previous interventions to increase fruit and vegetable consumption (Jackson, Lawton, Knapp, Raynor, Conner, Lowe et al., 2005; Kellar and Abraham 2005; Luszczynska, Tryburcy and Schwarzer 2007; de Nooijer, Brug and deVries 2006). The questions on attitudes, norms, perceived behavioural control and intentions were constructed from these studies to ensure accurate measurement of each variable and to obtain comparable data. All questions relating to the Theory of Planned Behaviour were statements, with a 7 point likert response set of either; very easy to very hard or strongly agree to strongly disagree (refer to Appendix II for all questions).

Participants in the intervention were then provided with motivational statements regarding fruit and vegetable consumption and prompted to make plans to consume the recommended amount. Motivational statements to increase fruit and vegetable consumption have been defined and redefined by previous studies (Jackson et al., 2005; Kellar and Abraham 2005; Luszczynska et al., 2007; de Nooijer et al., 2006) and within the current behaviour change intervention included:

"Eating recommended daily intake of fruit and vegetables is not a difficult task. You can do this easily. Successfully managing your diet so that you eat 5 portions of fruit and vegetables a day is within your control." (p. 2386)

"You can do it, so do it this week. Make a firm decision now that you will eat the recommended daily intake of fruit and vegetables each day this week." (p.2386)

Following the motivational statements, implementation intentions were described and participants were prompted to plan three occasions over the next week when they would buy fruit and vegetables. Participants were then prompted to plan their fruit and vegetable consumption for the following week, including each meal time and a snack.

Participants in the control arm were provided with questions regarding how hard/easy the questionnaire was to complete, any recommendations to amend the questionnaire and how they would describe the questionnaire to a friend. Participants in the control condition were asked further questions to ensure the time spent completing the questionnaire was comparable to the intervention participants. All participants were requested to return in one week to document their fruit and vegetable consumption over the last week.

Intervention implementation

Brief interventions have had varying success in increasing fruit and vegetable consumption (Armitage 2007; de Nooijer et al., 2006). University students completing a pencil and paper intervention to form implementation intentions to eat an extra piece of fruit a day for the next two weeks were significantly more likely to do so than the control group (Armitage 2007). Adults completing an online intervention to form implementation intentions to eat an extra piece of fruit per day for the next 1.5 weeks were significantly more likely to do so than the control group (de Nooijer et al. 2006).

The behaviour change intervention questionnaires were constructed through software provided by the University of Greenwich. Qualtrics allows the construction of online surveys, the analysis of results and the formation of reports. Once a survey has been created in Qualtrics a link to the survey is created and the survey can be accessed through the link on any internet server. I constructed the survey with a password which I provided within the participant information sheet to ensure only student healthcare professionals within the University of Greenwich were able to access the link.

Randomisation to the intervention or control questionnaires of the study was achieved by separate links being created for the intervention and control, and then only one link was provided per participant information sheet and within the emails sent to the students.

The current behaviour change intervention was constructed as an online intervention rather than a paper-and-pencil intervention. Previous studies have examined the responses of online questionnaires and paper-and-pencil questionnaires across various settings including; adolescents and mental health and behaviour, and patients diagnosed with heart failure, aggression, impulsivity and health functioning (van de Looij-Jansen and Wilde 2008; Wu, Thorpe, Ross, Miceuski, Marquez and Strauss 2009; Suris, Borman, Lind and Kasher 2007). These studies found comparable results across online and paper-and-pencil questionnaires. The response rate and completeness of online questionnaires compared to paper-and-pencil questionnaires had also been explored, Kongsved, Basnov, Holm-Christensen and Hijollund (2007) found online questionnaires yielded higher completeness of data, but a lower response rate. Kays, Gathercual and Buhrow (2012) found online questionnaires yielded higher completeness of data on sensitive issues than pencil-and-paper questionnaires. Noyes and Garland (2008) highlight some difficulties of online questionnaires including the participant's IT skills and access to the internet, but these issues were not relevant to student healthcare professionals completing a degree within a university facility. The implementation of an online questionnaire would provide the students with further confidence in the confidentiality of their participation and responses.

All students completing a healthcare professional qualification within the University of Greenwich were approached to participate in the behaviour change intervention, including the following programmes; Adult Nurse (480 students), Mental Health Nurse (240 students), Child Nurse (18), Midwifery (44 students), Paramedic Science (42 students) and Learning Disabilities Nurse (18 students). I introduced the study in person at the end of main hall lectures and each student received an email to their university email account inviting them to participate in the study.

Professional and Ethical issues

Professional and ethical issues were considered throughout the behaviour change intervention. As a trainee health psychologist and a registered nurse I worked within the legal and ethical boundaries stipulated by the Health and Care Professional Council (HCPC), British Psychological Society (BPS) and the Nursing Midwifery Council (NMC). The codes of practice include: Standards of conduct, performance and ethics (HCPC 2008), Code of Ethics and Conduct (BPS 2009) and The Code; Standards of conduct performance and ethics for nurses and midwives (NMC 2008).

The proposal for the behaviour change intervention was reviewed by the University Research and Ethic Committee at the University of Greenwich and London Metropolitan University. The importance for ethical clearance from the University of Greenwich was to address my conflicts of interest. As a senior lecturer at the university I would be asking the students I have possibly taught to participate in a voluntary behaviour change intervention. My role in conducting the behaviour change intervention was one of a trainee health psychologist and not as a senior lecturer. I provided the students with a participant information sheet explaining the behaviour change intervention, which clearly outlined the study as part of my Professional Doctorate in Health Psychology and my role as a trainee health psychologist. I introduced the behaviour change intervention to the student healthcare professionals at the of a main hall lecture on a course I was neither teaching nor coordinating to ensure the students understood my separate role as a trainee health psychologist. The introduction of the behaviour change intervention allowed me to discuss with the student healthcare professionals the role of health psychologists and the importance of health psychology in their future roles as healthcare professionals.

The participant information sheet provided the students with links to the online questionnaire; the students were informed the questionnaire was confidential and no identifying information would be collected. The links were also sent to each student via an all student email to their university email account, students were informed accessing the questionnaire via this route remained confidential and there were no connections between the questionnaire and university email accounts. Finally the students were informed participating in the behaviour change intervention was voluntary and did not impact on their current status at the University of Greenwich.

The students provided informed consent online prior to completing the questionnaire. The participant information sheet was presented online, followed by statements which the students had to demonstrate agreement by ticking a box next to each statement. The statements included the information routinely presented on written consent forms. The student could only progress to the questionnaire if informed consent was provided.

Evaluation/outcome

The evaluation of the behaviour change intervention demonstrated a number of limitations with this approach with this cohort of student healthcare professionals. Firstly, the response rate for the behaviour intervention was low; of the 842 potential participants contacted only 46 completed the intervention or control questionnaire an overall response rate of 5.6%. However, different programmes had different response rates; the Adult Nurse response rate was 5.6%, Child Nurse 1.1%, Mental Health Nurse 0.8%, Midwife 6.8%, Paramedic 28.5%. See Table 1 for participant details (following page).

Recruitment for the behaviour intervention did not reach the requirement of the power calculation and for this report only descriptive statistics and outcomes will be presented.

Table 1: Participant information

	Intervention 33 n (%)	Control 13 n (%)
Female	24 (73)	10 (77)
Age		
18-24	7 (21)	6 (46)
25-34	12 (36)	4 (31)
35-44	8 (24)	2 (15)
45-54	6 (18)	1 (8)
Healthcare Programme		
Adult Nurse	20 (61)	7 (54)
Child Nurse	1 (3)	1 (8)
Mental Health Nurse	1 (3)	1 (8)
Midwife	3 (9)	0
Learning Disabilities Nurse	0	0
Paramedic	8 (24)	4 (31)
5 portions of fruit and vegetables reported to be consumed every day for the last 7 days prior to completion of the questionnaire	6 (18)	1 (8)

Participants who were given the opportunity to provide feedback on questionnaire found the questionnaire straight forward and easy to answer, understanding the relevance of each question. Although an aspect I had not considered in the construction of the questionnaire was to include the choice of 'no days' when collecting data regarding fruit and vegetable and consumption. The questions regarding fruit and vegetable consumption were answered by all participants, however when I totalled the days, on more than one occasion more days than the last 7 had been included. I feel this is a reflection on the way the information was collected. A recommendation for future studies is a clarification of these questions or an equation added so the total number of days for the five questions cannot outnumber 7.

Therefore data reported was confined to participants whose consumption of fruit and vegetables met the recommended 5 portions a day compared to those who reported less than this.

A limitation of the intervention was the students' adherence to the intervention protocol, not all students assigned to the intervention arm formed implementation intentions, only 54.4% of students completed all plans as directed, 30.3% completed partial plans and 15.1% completed no plans. However, this finding demonstrates a higher adherence to protocol than in previous studies applying simpler protocols, as adherence to the intervention protocol of creating implementation intentions ranged from 21% to 37% (Skar, Sniethotta, Molloy, Prestiwich and Araujo-Soares 2011: Rutter, Steadman and Quine, 2006; Michie, Dormandy and Marteau 2004). In the present behaviour intervention 54.4% completed full plans for the following week to consume the recommended amount of fruit and vegetables.

The different healthcare professionals included within this behavioural intervention were included as one sample, however the different response rates of each profession highlights important differences of the students within these different healthcare professionals. An understanding of why different student healthcare professionals had different response rates is required.

The return questionnaire response rate was 21% with only one response from the control condition, therefore further analysis of this data is not valid. However, the responses demonstrated an increase in the amount of fruit and vegetables consumed.

Reflective report comparing and contrasting two theoretical models

The current behaviour intervention was constructed on The Theory of Planned Behaviour (Ajzen 1988) and implementation intentions (Gollwitzer 1999); however other social cognitive models containing similar variables with a different emphasis could also have been considered. The Information-Motivation-Behavioural Skills Model (Fisher and Fisher 1992) focuses on informational, motivational and behavioural skills. The Information-

Motivation-Behavioural skills model (IMB) is a theoretical model originally developed to predict HIV preventative behaviour (Fisher and Fisher 1992). However, in the last decade the model has been broadly applied to predict positive health behaviour in a range of contexts including; diabetes, diet and exercise, condom use among women and medication adherence (Osborn and Egede 2010; Osborn, Amico, Fisher, Egede and Fisher 2010; Anderson, Wagstaff, Heckman, Winett, Roffman, Soloman et al., 2006; Rongkavilit, Naar-King, Kaljee, Panthong, Koken, Bunpuradah et al., 2010). The IBM model contains three variables which influence the performance of a health behaviour including; how well informed the person is regarding the behaviour, how motivated the person is to perform the behaviour and does the person have the correct skills to perform the behaviour and the confidence to do so across a variety of settings (Fisher and Fisher 2002).

The application of the IMB model involves three stages in implementing behaviour change interventions including; the identification or clarification of current information, motivation and behavioural skills of the target behaviour within the target population. The information can be gathered through questionnaires, surveys or focus groups; however this process needs to occur prior to the formation of an intervention. Once the information has been obtained and the data analysed behaviour-specific and group-specific interventions are designed to achieve the behavioural goals. The third stage is the evaluation-outcome research to assess whether the intervention produced the desired effects on information, motivation and behaviour skills compared to the original information gathered (Fisher, Fisher and Harman 2003).

Applying the IMB to the current behaviour change intervention would have changed the approach of the intervention, as the current intervention provided information on fruit and vegetable consumption including; pictorial views of 80 grams of different types of fruit and vegetables. The theoretical approach of the theory of planned behaviour is the exploration of attitudes, norms and perceived behaviour on predicting a behaviour intention. Therefore the information provided to the participant was to create a uniformed approach to measuring their fruit and vegetable consumption rather than providing participants with further information of how and why fruit and vegetable consumption is important. The application of the IMB model to the current behaviour change intervention would include the provision of further information of the importance of fruit and vegetable consumption on health outcomes. The provision of in-depth information regarding health outcomes could have been provided and understood by this cohort of student healthcare professionals. The implications of fruit and vegetable consumption in the current behaviour change intervention were discussed in one sentence which was included within the participant information sheet. The application of the IMB model would have highlighted the need to provide information to inform the participants the importance of fruit and vegetable consumption and the positive health outcomes. The provision of this information in the intervention rather than the control condition would have provided a clarification of the necessity of providing this information to student healthcare professionals.

A further variable within the IMB model is the motivation of the individual to perform the health behaviour; motivation was included in the current behaviour change intervention as an important element of forming implementation intentions (Gollwitzer 1999). Motivational statements were included in the intervention for participants to read prior to forming their implementation intentions. However, in the current behaviour change intervention the motivation statements were designed to address personal motivation. The IMB model emphasizes both personal motivation and social motivation (Fisher and Fisher 2002). Social motivation includes the person's perception of their social support; the current behaviour change intervention did not include social motivation or social support. The relevant variables measured from the theory of planned behaviour were social norms, and although not measuring social motivation or social support 91% of participants agreed with the following statement: 'most people who are important to me think I should eat the recommended amount of fruit and vegetables over the next week'. Tentative conclusions from this data could be to suggest these participants felt they had the support of the people who were important to them.

The final variable of the IMB model involves the skills of the person to perform the behaviour and have the confidence to do so across a range of settings (Fisher and Fisher 2002). The performance of skills was not included in the current behaviour change intervention, from the theoretical approach of the IMB model this would have been difficult to implement within an online questionnaire. If theoretical approach of the IMB model was applied the introduction of various fruit and vegetables and different menus could have been included with the information regarding the importance of consuming fruit and vegetables. Although the provision of information is not increasing participants' skills in preparing meals, it is highlighting ways of preparing new meals. Skills are relevant, the current behaviour change intervention assumed participants had the knowledge and skills of how to include a variety of fruit and vegetables into their daily eating habits and this would include various menus and different cooking techniques. Participants consuming minimal amounts of fruit and vegetables may not have skills or knowledge required to incorporate more fruit and vegetables into new and existing meals.

Conclusion

The report has provided an explanation of a behaviour change intervention from the theoretical approach of the theory of planned behaviour and implementation intentions. The behaviour change intervention was a brief online questionnaire open to all student healthcare professionals completing their programme within the University of Greenwich. Recruitment for the behaviour change intervention was extremely low and the reporting of the outcome of the intervention needs to be interpreted with caution. Then the report compared the theoretical approach of the theory of planned behaviour and implementation intentions with the approach of the information-motivation-behavioural skills model and how the behaviour change intervention would need to be amended to incorporate the new approach. However, the current brief online behavioural change intervention suggests the theory of planned behaviour and implementation intentions are appropriate for this form of intervention and within this cohort of student healthcare professionals, when the students participate.

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Appendix I

PARTICIPANT INFORMATION SHEET

A study exploring fruit and vegetable consumption in student healthcare professionals

You are being invited to take part in a research study, please take the time to read the following information carefully.

What is the purpose of the study?
Daily consumption of fruit and vegetables reduces the risk of cancer and cardiovascular diseases, however only 15% of the UK population consume the recommended amount. Do student healthcare professionals consume the recommended amount of fruit and vegetables and would a brief online questionnaire improve the level consumed.

Why have I been chosen?
All students completing a healthcare programme within the University of Greenwich will be approached.

Do I have to take part?
It is up to you to decide whether or not to take part. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not have any consequences for you or your progression on your programme.

What happens once I agree to take part?
You will be asked to access the online link to complete two questionnaires.

Online link: https://greenwichuniversity.eu.qualtrics.com/SE/?SID=SV_cHheEXhNbuMZIjz

The first time you access the link you will be asked for a password which is HEALTH. You will also be asked to create a password specific to you; this questionnaire will take no more than 10 minutes to complete. A week later you will need to access the link with your password to answer 5 short questions, this questionnaire will take no more than 5 minutes.

Online link: https://greenwichuniversity.eu.qualtrics.com/SE/?SID=SV_3NJi59xq0Tb28BL

Will my taking part in this study be kept confidential?
No identifiable information will be collected and no individual data will be presented.

What will happen to the results of the study?
The results of the study will be available from February 2013 and will be presented in lectures and available on the portal.

Who has reviewed the study?
The study has been reviewed by the University Research Ethics Committee.

Contact for further information:
Joanne Brooke Phone: 020 8331 8737
Email: j.m.brooke@greenwich.ac.uk

Thank you for taking the time to read this information sheet!

Appendix II

Please consent prior to completing the questionnaire, each statement needs to be read and acknowledged

(In qualtrics, the below will be in tick box format)

- I have read the information sheet about this study
- I have had an opportunity to ask questions and discuss this study
- I have received satisfactory answers to all my questions
- I have received enough information about this study
- I understand that I am free to withdraw from this study:
    - At any time
    - Without giving a reason for withdrawing
    - Without affecting my future with the University
- I agree to take part in this study

Please read the information on recommended daily intake of fruit and vegetables

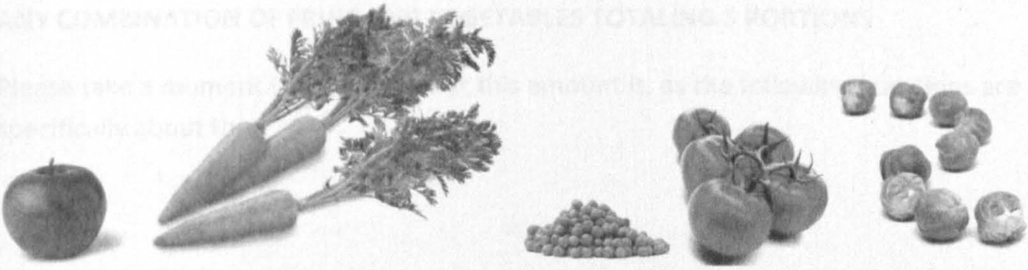
Then complete the following questions regarding your consumption of fruit and vegetables

This will take you less than 10 minutes

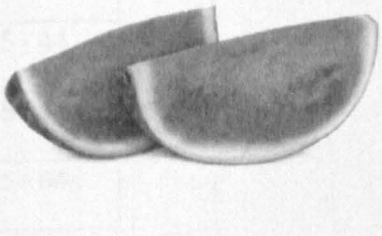
Thank you for your time

Recommend daily intake

The recommended daily intake of fruit and vegetables for adults is 5 servings per day. Below is a pictorial example of the recommended daily intake:



OR



OR

ANY COMBINATION OF FRUIT AND VEGETABLES TOTALING 5 PORTIONS

Please take a moment to visualize what this amount is, as the following questions are specifically about this.

Please answer the following questions

(In qualtrics, the below will be in tick box format)

Gender

Male	Female

Age

18 - 24
25 - 34
35 - 44
45 - 54
55 - 64

How many days did you eat one piece of fruit and vegetables over the last week?

Write the number of days	

How many days did you eat two pieces of fruit and vegetables over the last week?

Write the number of days	

How many days did you eat three pieces of fruit and vegetables over the last week?

Write the number of days	

How many days did you eat four pieces of fruit and vegetables over the last week?

Write the number of days	

How many days did you eat five pieces of fruit and vegetables over the last week?

Write the number of days	

Please chose one answer for each question

(In qualtrics, the possible answers will appear as lists for the student to select one answer)

For me to eat the recommended daily intake of fruit and vegetables over the next week would be:

Very easy	Easy	Slightly easy	Unsure	Slightly hard	Hard	Very hard

It would be beneficial for me to eat the recommended daily intake of fruit and vegetables over the next week:

Strongly agree	Agree	Slightly agree	Unsure	Slightly disagree	Disagree	Strongly disagree

Most people who are important to me think I should eat the recommended amount of fruit and vegetable intake over the next week:

Strongly agree	Agree	Slightly agree	Unsure	Slightly disagree	Disagree	Strongly disagree

People I know believe they ought to eat the recommended amount of fruit and vegetables over the next week:

Strongly agree	Agree	Slightly agree	Unsure	Slightly disagree	Disagree	Strongly disagree

I feel in complete control of whether or not I eat the recommended amount of fruit and vegetables over the next week:

Strongly agree	Agree	Slightly agree	Unsure	Slightly disagree	Disagree	Strongly disagree

How much control do you have over eating the recommended amount of fruit and vegetables over the next week?

Absolutely no control	No control	Unsure	Control	Total control

For me to eat the recommended amount of fruit and vegetables over the next week would be:

Very difficult	Difficult	Slightly difficult	Unsure	Slightly easy	Easy	Very easy

If I wanted to, I could easily eat the recommended amount of fruit and vegetables for the next week:

Very likely	Likely	Slightly likely	Unsure	Slightly unlikely	Unlikely	Very unlikely

I intend to eat the recommended amount of fruit and vegetables over the next week:

Definitely no	No	Possibly no	Unsure	Possibly yes	Yes	Definitely yes

I am going to eat the recommended amount of fruit and vegetables over the next week:

Definitely no	No	Possibly no	Unsure	Possibly yes	Yes	Definitely yes

Survey information for intervention participants

Please read the statements below and complete the following steps

(In qualtrics, the planning boxes will appear for students to type into)

Eating the recommended daily intake of fruit and vegetables is not a difficult task. You can do this very easily. Successfully managing your diet so that you eat 5 portions of fruit and vegetables a day is within your control.

You can do it, so do it this week. Make a firm decision now that you will eat the recommended daily intake of fruit and vegetables each day this week.

You are more likely to eat the recommended amount of fruit and vegetable intake if you plan in advance where, when and how you are going to do this.

Please form up to three plans for the next week. The more precise and personal you formulate these plans, the more they will be useful for you.

When and where I will buy fruit and vegetables...

Plan 1:

Plan 2: Plan 3:

What fruit and vegetables I will eat at lunch time...

Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday

What fruit and vegetables I will eat at dinner time...

Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday

What fruit and vegetables I will eat for a snack...

Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday

Please take the time to remember your plans to enable you to put them into action.

Thank you for your time and remember to come back in a week to complete 5 questions on you current fruit and vegetable consumption.

Thank you

Survey information for non-intervention participants

Please read the statements below and complete the following steps

Thank you for completing this questionnaire.

Please comment on how hard/easy this questionnaire was to complete:

Please comment if you have any recommendations to improve this questionnaire:

Please describe how you would explain this questionnaire to a friend:

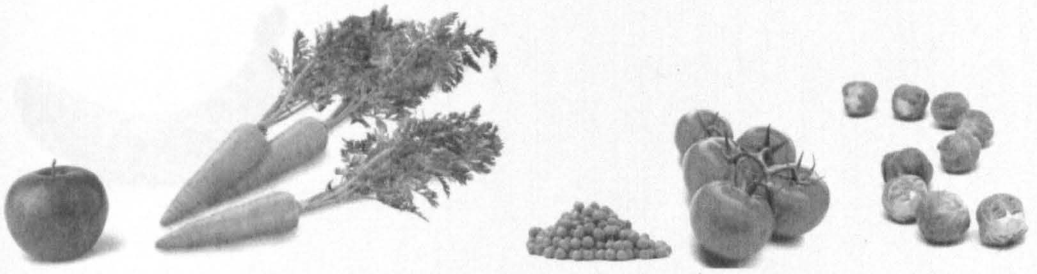
Thank you for your time and remember to come back in a week to complete 5 questions on you current fruit and vegetable consumption.

Thank you

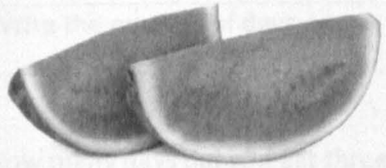
Thank you for returning to complete the questionnaire

A quick reminder:

The recommended daily intake of fruit and vegetables for adults is 5 servings per day. Below is a pictorial example of the recommended daily intake:



OR



OR

ANY COMBINATION OF FRUIT AND VEGETABLES TOTALING 5 PORTIONS

Please answer the following five questions

How many days did you eat one piece of fruit and vegetables over the last week?

Write the number of days	

How many days did you eat two pieces of fruit and vegetables over the last week?

Write the number of days	

How many days did you eat three pieces of fruit and vegetables over the last week?

Write the number of days	

How many days did you eat four pieces of fruit and vegetables over the last week?

Write the number of days	

How many days did you eat five pieces of fruit and vegetables over the last week?

Write the number of days	

Thank you for your time

The results of this survey will be available in February 2013 and will be made available through your programme portal.

Systematic review: The components of the Common Sense Model of Self-Regulation revisited: A systematic review and meta-analysis

by

Joanne Brooke

Systematic Review Submitted in Partial Fulfillment

of the Requirements for the Professional Doctorate of Health Psychology

London Metropolitan University

January 2013

The components of the Common Sense Model of Self-Regulation revisited: A systematic review and meta-analysis

Abstract

Purpose:

The aim of this review was to undertake a comprehensive systematic review to explore the relationships between the constructs of the Common Sense Model of Self-Regulation and how these constructs impact on health outcomes.

Materials and Methods:

MEDLINE, EMBASE, CINAHL, PsychINFO, Cochrane Database of Systematic Reviews and Google Scholar databases from January 1st 2003 - January 1st 2012 were searched. Bibliographies of identified articles were reviewed. Only studies exploring the constructs of the Common Sense Model of Self-Regulation, where illness representation dimensions were measured by the Illness Perception Questionnaire (IPQ) or the Revised Illness Perception Questionnaire (IPQ-R) were included. Coping measures and health outcomes were not predetermined. Correlation data was extracted to complete the meta-analysis.

Results:

Of 268 studies identified in the primary search, 13 studies enrolling 1309 participants met the inclusion criteria, patterns of illness representation dimensions occurred across illnesses. Illness representation dimensions were significantly associated with health outcomes (Correlation 0.247, 95% CI, 0.176-0.314, p=0.001). Illness representation dimensions and coping were not significantly associated, coping and health outcomes were not significantly related, therefore coping did not meet the criteria as a mediating variable.

Conclusions:

Negative illness representation dimensions can be identified and measured using the IPQ and IPQ-R and are associated with higher reporting of anxiety, depression, stress or a mood disorder.

Introduction

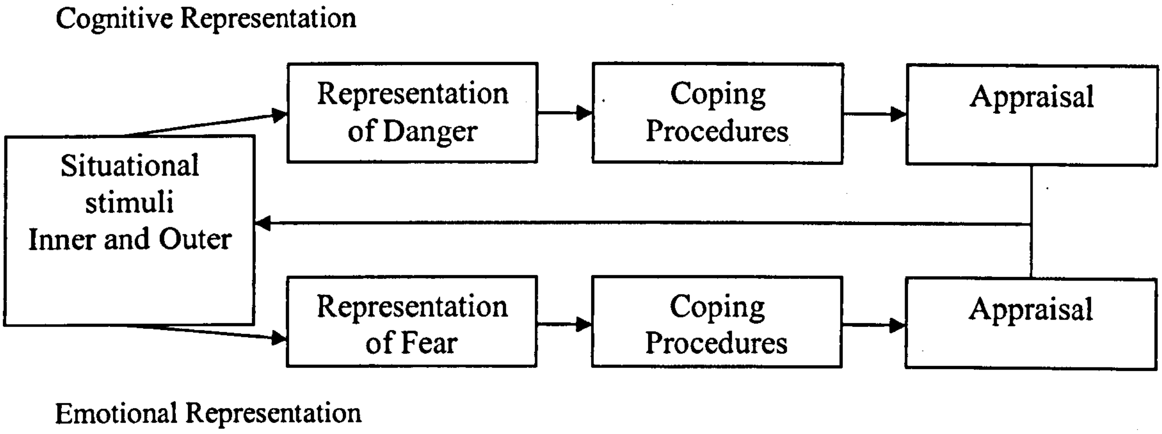
An important aspect of health psychology research is to explore and understand individuals' beliefs and representations of a health threat as these constructs impact on coping strategies and influence the outcome of the individual over and above the progression of the biological illness. A social cognitive approach the Common Sense Model of Self-Regulation (Leventhal, Meyer and Nerenz 1980) forms a theoretical basis to explore individuals' emotional and cognitive responses to a health threat. The Common Sense Model (CSM) allows the identification of beliefs, representations and coping strategies which lead to poorer outcomes. From this perspective health psychologists can develop interventions to improve self-management of a health threat. An intervention will include aspects of emotional regulation, cognitive reappraisal and behaviour change, thereby promoting health and quality of life (Petersen, van den Berg, Jansessns and van den Bergh 2011).

Health psychology and the CSM have never been more relevant than in the 21st Century due to the sharp increase in the UK of long term illnesses (Meerabeau 2011). Long term illnesses require an individual to adapt and adhere to complex medical regimes and /or health behaviours through problem-focused active coping strategies. In England alone 15.4 million individuals live with a long-term illness (Department of Health 2009) including; asthma, cancer, diabetes, HIV/AIDS, irritable bowel syndrome and arthritis. Anxiety and depression in long term illnesses are highly prevalent and contribute to worsening health, increased symptom perception and to higher rates of morbidity and mortality (Prince et al. 2007).

The Department of Health (DH 2009) has recognized the impact of long term illnesses on both the NHS and the lives of individuals diagnosed with an illness. The DH recommends empowerment of individuals by providing interventions to improve self-management, which includes the development of problem-solving coping. The CSM is a health-specific model of self-regulation and allows the opportunity to explore self-regulation in conjunction with self-management and the use of different coping strategies on health outcomes.

Self-regulation involves the process by an individual of monitoring conscious thoughts, behaviours and emotions to maintain equilibrium in psychological and physical functioning. A health threat disrupts an individual's equilibrium and they are motivated to engage in psychological and behavioural activities to reinstate their equilibrium or status quo (Cameron and Leventhal 2003). The CSM describes self-regulation as a dynamic motivational system involving interpretation, coping and appraisal, which are interrelated and on-going creating a dynamic model (Leventhal, Brissette and Leventhal 2003). Interpretation occurs through symptom perception; symptoms are interpreted by the individual internally and externally through their social context, such as friends' beliefs and/or a doctor's diagnosis. Interpretation occurs on a cognitive and emotional level, creating a parallel processing model. As demonstrated in figure 1 (page 211) emotional responses provoke coping strategies to manage fear control and cognitive representations provoke coping strategies to manage danger control (Leventhal, Brissette and Leventhal 2003). Coping strategies include approach coping and avoidance coping. Approach coping includes: active seeking of advice, help or medicine. Avoidance coping includes; the denial of symptoms and/or diagnosis and refusal to seek help. Following the implementation of coping strategies appraisal occurs when the individual determines if equilibrium has been restored and their coping strategies were successful or identification of failures and the need to develop and change their coping strategies.

Figure 1: The parallel process model



Source: Adapted from Cameron and Leventhal (2003)

The interpretations of a health threat within the CSM model are classified as illness representation dimensions and originally described as containing five dimensions; identity, cause, consequences, timeline and cure/control (Leventhal, Nerenz and Steele 1984). Each illness representation dimension is formed from three sources of information; lay information including information the individual has previously acquired and processed information from the individual's social environment, including peers and healthcare professionals and from the current experience of the biological illness such as somatic experiences and symptoms (Leventhal, Meyer and Nerenz 1980). The dimension of identity includes the label or name given to an illness or a group of symptoms that comprise an illness, the label can be generated by the individual or assigned by a healthcare professional. Cause is the main reason the individual attributes to the cause of their illness, the cause can vary from stress, environmental pollution and other pathogens, and is not necessarily medically correct. Consequences involve the individual's beliefs on how the illness is going to impact on their life, both the quality of their life and their functional capacity. Timeline is the individual's beliefs of how long the illness or symptoms they are experiencing will last. Cure/control dimension is the individual's belief regarding the curability of their illness and the amount of control the individual has over the progression of the illness.

Illness representation dimensions have been expanded to include a further dimension for timeline and control (Moss-Morris et al., 2002). Timeline cyclical allows for beliefs that the illness will go through cycles of exacerbation and remission, such as asthma or irritable bowel syndrome. Control was divided to include personal control, the individual's belief on how much control they had over their symptoms/illness and treatment control, the individual's belief on how much the treatment would control their symptoms/illness.

From the theoretical underpinning of the dynamic structure of the CSM two new dimensions were added; illness coherence and emotional representation (Moss-Morris et al., 2002). The dimension of illness coherence includes the individual's understanding of their illness, as this is expected to change and develop over time and experience of the illness. Emotional representation dimension represents the parallel processing aspect of the CSM and allows the measurement of emotional representation of the health threat.

Illness representation dimensions have traditionally been measure using the Illness Perception Questionnaire (Weinman, Petrie, Moss-Morris and Horne 1996), a theoretically driven questionnaire measuring the five illness representation dimensions. More recently the Revised Illness Perception Questionnaire (Moss-Morris et al., 2002) has been used to measure the expanded illness representation dimensions. The reliability and validity of the Illness Perception Questionnaire (IPQ) was originally explored in seven illness groups; diabetes, rheumatoid arthritis, renal dialysis, asthma, chronic fatigue syndrome and chronic pain (Weinman, Petrie, Moss-Morris and Horne 1996) and demonstrated internal consistency and test-retest reliability. The Revised Illness Perceptions Questionnaire (IPQ-R) further explored the IPQ and the added dimensions reliability and validity among eight illness groups; asthma, diabetes, rheumatoid arthritis, chronic pain, acute pain, multiple sclerosis and HIV. The analysis demonstrated the additional dimensions strengthened the psychometric properties of the IPQ and internal reliability of the dimensions. Moss-Morris et al., (2002) concluded the IPQ-R may need to be adapted to different illness groups, but provides a psychometrically acceptable measurement of all the components of the CSM.

More recently validation of the IPQ-R within patients recovering from myocardial infarction has occurred (Brink, Alsen and Cliffordson 2011).

The CSM identifies illness representation dimensions and the IPQ and IPQ-R measure these constructs in isolation, however these constructs are intrinsically associated. In an exploration of illness representation dimensions in chronic fatigue syndrome, Moss-Morris, Petrie and Weinman (1996) concluded a strong illness identity was positively correlated with; consequences (the more serious the consequence of the illness) and chronic timeline (the longer the duration of the illness). Hagger and Orbell (2003) argued 'a characteristic illness representation profile for each illness according to its symptomatic features and chronicity occurs'. However, Hagger and Orbell (2003) then discuss a pattern of illness representation dimensions which does occur across illnesses. The cure/control dimension was negatively associated with all other illness representation dimensions and the remaining illness representation dimensions were all positively associated. As yet, no comprehensive account of the relationships between illness representation dimensions across illnesses has been published.

The CSM proposes illness representation dimensions have an indirect impact on health outcomes as coping strategies are proposed to mediate the effect of illness representation dimensions on health outcomes (Leventhal, Meyer and Nerenz 1980). For coping to be classified as a mediator four relationships have to be defined; illness representation dimensions significantly effect a health outcome, coping significantly effects a health outcome, illness representation dimensions significantly effect coping and lastly coping has a greater effect on health outcomes when illness representation dimensions are added to the equation (Baron and Kelly 1986).

Hagger and Orbell's (2003) meta-analysis explored the correlations within constructs of the CSM as described by Leventhal, Meyer and Nerenz (1980), including the mediating role of coping. Hagger and Orbell (2003) found coping did partially mediate illness representation dimensions on health outcomes, but illness representations also directly impacted on health outcomes.

Hagger and Orbell's (2003) meta-analysis reported support for the constructs of the CSM, but only partial support of the role of mediation of coping strategies on illness representation dimensions and health outcomes. Since publication in 2003 several important developments and changes have occurred to warrant revisiting the CSM.

Firstly, Hagger and Orbell's (2003) meta-analysis only partially supports the relationships of constructs within the CSM and yet the CSM remains very popular within health psychology and is widely applied in research and discussed in health psychology literature. The CSM is being applied more widely to genetic testing decisions (Cameron et al. 2011) and disorders, such as eating disorders (Quiles and Terol 2011). The CSM is also being applied as the theoretical underpinning of interventions to change health beliefs and behaviour, such as cognitive behavioural therapy (Knoop, van Kessel and Moss-Morris 2012; Moss-Morris et al., 2007; Broadbent et al., 2009).

Secondly Hagger and Orbell's (2003) meta-analysis included published studies from 1989 to 2002, during this period and the following decade changes and advances have been made. The creation and publication of the IPQ occurred in 1996 and the IPQ-R in 2002. Hagger and Orbell's (2003) meta-analysis included 45 studies, of which 20 applied the IPQ and only 6 applied the IPQ-R. The IPQ-R strengthens the psychometric properties of the IPQ and the added dimensions involve a holistic assessment of illness representation dimensions.

Thirdly, a dramatic change in the UK is the increase of individuals with a long term illness that requires complex medical treatments and changes to health behaviours. The impact of long term illnesses on the NHS is decreasing lengths of hospital stays and empowerment of individual's to self-manage their illness at home (DH 2004). The introduction of the community matron was specifically to educate and empower individual's to self-regulate and manage their long term illnesses at home and this process may impact on an individual's illness representation dimensions and coping strategies.

These three factors demonstrate the need to revisit the CSM to; identify the relationships between constructs of the CSM to provide a sound theoretical base for research, investigate the impact of the IPQ-R and to understand the relationship between illness representation dimensions and coping as a mediator in this current climate. Therefore, the aims of this systematic review are to identify the:

- relationships between illness representation dimensions and identification of emerging patterns within or between illnesses.
- relationships between illness representation dimensions, coping strategies and health outcomes to explore coping as a mediator between illness representation dimensions and health outcomes.

Method

Literature Search

MEDLINE, EMBASE, CINAHL, PsychINFO, Cochrane Database of Systematic Reviews and Google Scholar databases from January 1st 2003 and up to and including January 1st 2012 were searched. The selection of these appropriate and multiple databases was to minimize the risk of introducing a database bias and maximize the yield of relevant studies (Schlosser 2007). Search words included: *common sense model, illness perceptions, illness representations, Leventhal's Model, self-regulatory model* in conjunction with *health outcomes, illness representations, coping* or *chronic illness* with *and/or* as Boolean operators. Table 1 demonstrates search words and combinations included (see page 216). All searches were limited to English Language. In addition all bibliographies of identified articles were manually searched for relevant studies. At all stages the 'related studies' radio button in MEDLINE was used. A manual search of the following journals was completed;

Journal of Psychosomatic Research, British Journal of Health Psychology and Psychology and Health. Searches for relevant dissertations, conference abstracts and book chapters were completed. The search method did not look for unpublished studies.

Table 1: Search terms and combinations

Search Term		Combination
common sense model	and	health outcomes
common sense model	and	illness representations
common sense model		
illness perceptions	and	chronic illness
illness perceptions	and	coping
illness perceptions	and	outcomes
illness perceptions		
Illness representation dimensions	and	coping
Illness representations	and	chronic illness
illness representations	and	coping
illness representations	and	outcomes
illness representations		
Leventhal's model	and	coping
self regulation model	and	coping
self regulation model	and	health outcomes
self regulation model	and	illness representations
self regulation model		

Inclusion Criteria

Comparable measures of illness representation dimensions; measures included the original Illness Perception Questionnaire (IPQ, Weinman, Petrie, Moss-Morris and Horne 1996) and the revised Illness Perception Questionnaire (IPQ-R, Moss-Morris et al., 2002). The IPQ-R contains three dimensions from the original IPQ – cause, identity and consequences. The timeline acute/chronic on the IPQ-R mirrors the timeline on the IPQ. Personal control on the IPQ-R mirrors the control/cure on the IPQ. The major amendments to the IPQ-R are the inclusion of illness coherence and emotional representations, which are not measured by the

IPQ, with these two dimensions outstanding previous meta-analysis has classified these two measures as equivalent (Hagger and Orbell 2003).

Comparable measures of coping; coping measures were not predetermined, although only recognized coping scales that identified coping approaches were included in the analysis. Comparable measures of self-reported health outcomes; health outcomes were not predetermined and included mental health and quality of life, the exclusion criteria were biological outcomes such as progression of the illness or physical disability or self-reporting of health behaviours.

Quality Assessment

The quality of each study was assessed using an appropriate tool for cross-sectional data collection via questionnaires. The tool was based on work completed by Crombie (1996) on critical appraisal, adapted by Petticrew and Roberts (2006) and implemented by Barnard et al., (2010). The tool assesses seven aspects of the quality of a cross-sectional study, producing a score of 7 (see appendix I for the seven aspects and the outcome for each study). No study reported power calculations or justification of numbers of participants recruited. However, three studies scored positively on the remaining 6 items (Carlisle, John, Fife-Schaw and Lloyd 2005; Evans and Norman 2009; Dorrian, Dempster and Adair 2009). The lowest score of 4 was due to low response rates, unknown response rates and participants recruited from internet support groups. It is unclear if participants from internet support groups are representative of clinic populations. Overall, all studies clearly described recruitment strategies, applied objective and reliable measures and analysed the data with appropriate statistical analysis.

Data Extraction and Analysis

A standard data abstraction table was adapted from Egan et al. (2003) data extraction form see Table 2: Study characteristics of studies included in the review (page 219-221).

The relationships between illness representation dimensions, illness representation dimensions and health outcomes, illness representations dimensions and coping, coping and health outcomes were expressed as Pearson's correlation coefficient. This allowed the extraction of correlations between constructs of the CSM. Stem and leaf analysis were completed with the production of box plots to demonstrate patterns across the studies. Only significant results at the level of $p<.01$ were included to avoid Type 1 error due to the large amount of variables (Yang 2010). To determine the strength of associations between the CSM constructs across studies, a meta-analysis was performed on studies reporting significant and non-significant Pearson correlation coefficients (Rozema, Vollink and Lechner 2009; Carlisle, John, Fife-Schaw and Lloyd 2005; Evans and Norman 2009; Kaptein et al., 2006; Gould, Brown and Bramwell 2009; Dorrian, Dempster and Adair 2009; Cartwright, Endean and Porter 2009). Heterogeneity was tested using chi-square test (Deeks, Altman and Bradburn 2001). This describes the variability in the effect estimate that is likely due to clinical and methodological diversity rather than chance alone. An I^2 of >50%, along with a significant p-value, could be suggestive of substantial study heterogeneity (Higgins and Green 2011).

Table 2: Study characteristics of studies included in the review

Study	Study Population	Sample size	Age Mean (SD)	Gender Male N(%)	Illness Representation constructions	Study Design	Coping Measures	Outcome measures	Coping as a mediator	Coping as a mediator
Knibb and Horton (2008)	Allergy sufferers	156	44.37 (19.43)	18 (12.0)	IPQ-R 1.Consequences (6) 2.Cause (4) 3.Personal control (6) 4.Treatment control (5) 5.Timeline – acute chronic (6) 6.Timeline cyclic (4) 7.Illness coherence (4) 8.Emotional representations (6) 9.Identity (10)	Cross-sectional	COPE	Perceived Stress Scale (PSS-14), General Health Questionnaire (GHQ-28)	Coping as a mediator accounted for between 5 and 12% additional variance in psychological distress	YES
Rozema, Vollink and Lechner (2009)	breast cancer	119	46.80 (8.21)	0	IPQ-R 1.Consequences (6) 2.Timeline - acute chronic (6) 3.Timeline cyclic (4) 4.Personal control (6) 5.Treatment control (5) 6. Emotional representations (6) 7.Identity (17) 8.Cause (8)	Cross-sectional	Utrecht Coping Questionnaire (UCL)	RAND-36	None of the coping strategies were found to be strongly related to perceived health – coping as a mediator was rejected	NO
Carlisle, John, Fife-Schaw and Lloyd (2005)	Rheumatoid arthritis	125	58.40 (12.60)	0	IPQ 1.Identity (12) 2.Timeline (3) 3.Cause 4.Consequences (7) 5.Cure and control (6)	Cross-sectional	London Coping with Rheumatoid Arthritis Questionnaire	General Health Questionnaire-12 (GHQ-12), modified Stanford Health Assessment Questionnaire (HAQ)	Avoidant and resigned coping partially mediated: identity and disability; Identity and psychiatric morbidity	YES - partially
Evans and Norman (2009)	Parkinson's disease	58	58.64 (5.01)	28 (48.3)	IPQ-R 1.Consequences (6) 2.Timeline - acute chronic (6) 3.Timeline cyclic (4) 4.Personal control (6) 5.Treatment control (5) 6. Emotional representations (6) 7.Identity (16) 8.Illness coherence (4) 9.Causes (4)	cross-sectional and longitudinal	Medical Coping Modes Questionnaire (MCMQ)	Hospital Anxiety and Depression Scale (HADS)	Avoidance mediated emotional representations and anxiety Acceptance resignation mediated emotional representations and depression	YES

Kaptein et al. (2006)	Huntington's disease	77	51.40 (11.40)	38 (49.4)	IPQ 1.Consequences (7) 2.Timeline (3) 3.Control (3) 4.Cure (3) 5.Identity (24) 6.Cause	cross-sectional	COPE	The Sickness Impact Profile (SIP), Unified Huntington Disease Rating Scale (UHDRS)	Mental disengagement was partially mediated identity and psychosocial functioning – not significant on test of significance of intervening variable effects	SMALL - NO
Gould, Brown and Bramwell (2010)	Gynaecological cancer	61	56.34 (18.41)	0	IPQ-R 1.Timeline (6) 2. Timeline cyclic (4) 3. Consequences (6) 4.Perosnal control (6) 5.Treatment control (7) 6. Illness coherence (5)	cross-sectional	COPE	Profile of Mood States-Short Form (POMS-SF)	Denial and disengagement mediated: Timeline cyclical and mood disturbance Partially mediated: Coherence and mood disturbance	YES
Walker, Lindner and Noonan (2009)	Chronic Fatigue Syndrome	156	43.50 (**)	34 (21.9)	IPQ-R 1.Illness severity (28)	cross-sectional	Ways of Coping Questionnaire (WOCQ)	Cardiac Depression Scale (CDS)	Depression explained 9% variance, coping explained 18% variance, depression and coping explained 27% of variance in perceived severity of illness	NO
Dorrian, Dempster and Adair (2009)	Inflammatory Bowel Disease	80	40.00 (**)	37 (46.0)	IPQ-R 1.Identity (12) 2.Cause (4) 3.Timeline acute chronic (6) 4.Timeline cyclical (4) 5.Consequences (6) 6.Personal control (6) 7.Treatment control (5) 8.Illness coherence (5)	cross-sectional	COPE	Hospital Anxiety and Depression Scale (HADS), Functional Limiations Profile (FLP)	Illness perceptions explained 32% for psychological distress, 21% for quality of life and 23% for functional independence. Coping contributed a further 3%, 2% and 6% respectively. Coping did not substantially change the associations between adjustment and illness perceptions.	NO
Rutter and Rutter (2007)	Irritable bowel syndrome	42	47.70 (**)	35 (17.0)	IPQ 1.Timeline (3) 2.Consequences (7) 3.Cure and control (6) 4.Cause (10) 5.Identity	longitudinal	COPE	WHOQOL-Brief, Hospital Anxiety and Depression Scale (HADS)	Illness perceptions explained 29% and 38% of the variance for anxiety at T1 and T2. Illness perceptions explained 24% of the variance for depression at T1 only. Coping did not mediate	NO

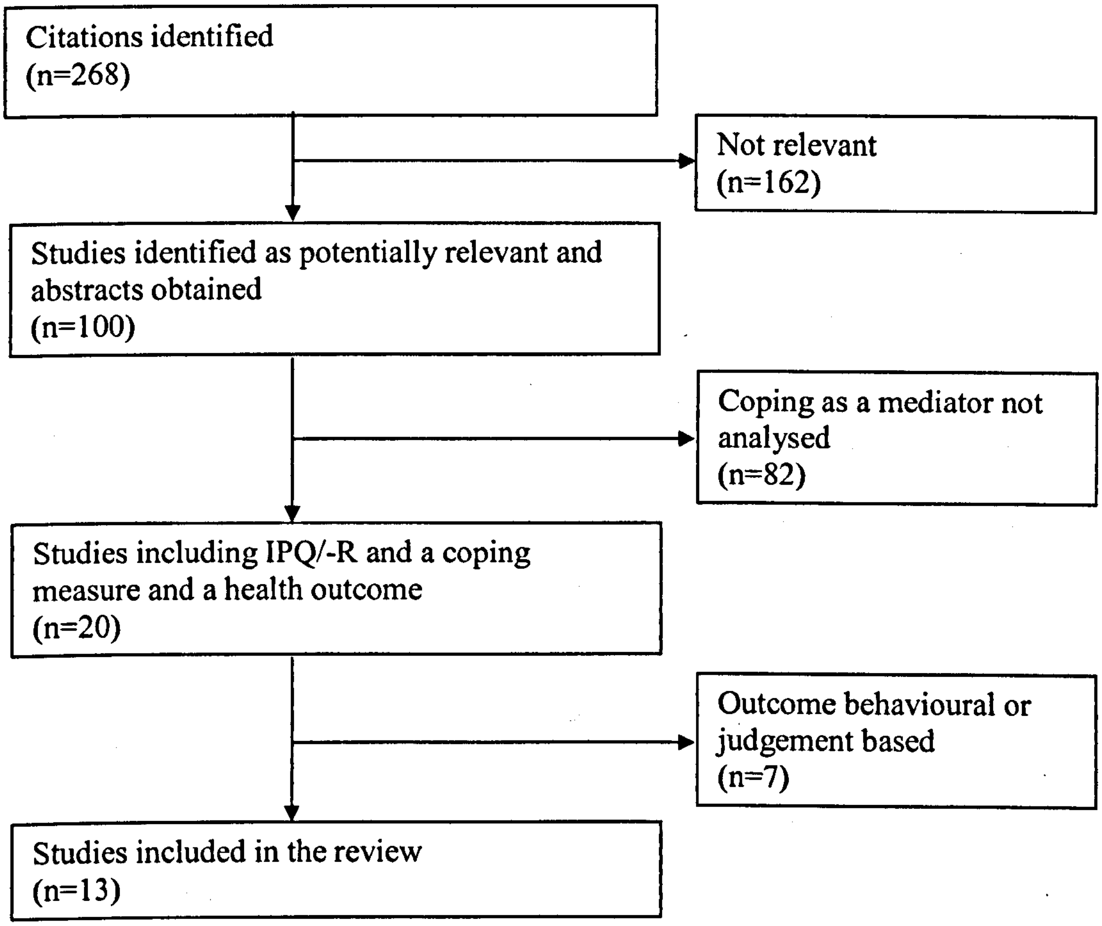
Cartwright, Endean and Porter (2008)	Alopecia	214	35.00 (10.70)	43 (20.1)	IPQ-R 1.Timeline acute chronic (6) 2.Consequences (6) 3.Personal control (6) 4.Treatment control (5) 5.Illness coherence (5) 6.Timeline cyclical (4) 7.Emotional representations (6) 8. Identity (17) 9.Causal (17)	cross-sectional	Brief COPE	The Dermatology Life Quality Index (DLQI)	Illness representations explained 35% of variance for QoL. Coping explained an additional 7% of variance of QoL	NO
Goldstein, Holland, Soteriou and Mellers (2005)	Epilepsy	43	36.07 (10.57)	15 (34.9)	IPQ 1.Identity (19) 2.Seriousness of illness (1) 3.Timeline (3) 4.Consequences (7) 5.Control/Cure (6) 6.Cause (13)	cross-sectional	Ways of Coping Questionnaire (WOCQ)	Hospital Anxiety and Depression Scale (HADS)	Coping explained 30.1% of variance for anxiety, illness representations explained a further 10.1% - no mediation by coping. Coping explained 25% of variance for depression, illness representations added no further variance, mediation of coping occured	Coping mediated illness representations and depression, but did not mediate the relationship between illness representations and anxiety
Llewellyn, McGurk and Weinman (2007)	Head and neck cancer	82	59.90 (12.50)	54 (65.9)	IPQ-R 1.Identity 2.Timeline acute chronic (6) 3.Time cyclical (4) 4.Consequences (6) 5.Personal control (6) 6.Illness coherence (5) 7.Emotional representations (6)	longitudinal	COPE	The European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire (QLQ-C30), The MOS Short-Form Health Survey (SF-12v2), Patient Generated Index (PGI), Hospital Anxiety and Depression Scale (HADS)	Coping explained 21% of the variance for depression, illness representations explained 28% of the variance for depression and satisfaction with information explained 18% of the variance for depression. Coping was not found to mediate illness representations and outcomes	NO
Knowles, Wilson, Connell and Kamm (2011)	Crohns Disease	96	37.80 (13.70)	34 (54.8)	IPQ Individual items not defined	Cross-sectional	COPE	Hospital Anxiety and Depression Scale (HADS)	Emotion-focused coping significantly mediated illness representations and depression and anxiety. Problem-focused coping significantly mediated illness representations and depression	Yes, partial mediation as problem-focused coping did not mediate anxiety

Results

Study Selection

The initial search generated 268 studies, of which 100 studies were retrieved for full review. Of these, 82 did not analyse the coping variable as a mediator, a further 7 included a behavioural outcome or a judgement based outcome, leaving 13 studies which met the inclusion criteria (see Figure 2: Process of inclusion flow diagram).

Figure 2: Process of inclusion flow diagram.



The studies included a total of 1309 participants (range: 42-214). Illnesses included; allergies (Knibb and Horton 2008), rheumatoid arthritis (Carlisle, John, Fife-Schaw and Lloyd 2005), Parkinson's disease (Evans and Norman 2009), Huntington's disease (Kaptein et al., 2006), chronic fatigue syndrome (Walker, Linder and Noonan 2009), bowel disease

(Dorrian, Dempster and Adair 2009; Rutter and Rutter 2007; Knowles, Wilson, Connell and Kamm 2011), alopecia (Cartwright, Endean and Porter 2008), epilepsy (Goldstein, Holland, Soteriou and Mellers 2005) and cancer (Rozema, Vollink and Lechner 2009).

The majority (85%) of studies were cross-sectional in design (Knibb and Horton 2008; Rozema, Vollink and Lechner 2009; Carlisle, John, Fife-Schaw and Llyod 2005; Kaptein et al., 2006; Gould, Brown and Bramwell 2010; Walker, Linder, Noonan 2009; Dorrian, Dempster and Adair 2009; Cartwright, Endean and Porter 2008; Goldstein, Holland, Soteriou and Mellers 2005; Knowles, Wilson, Connell and Kamm 2011), the remainder were longitudinal in design (Rutter and Rutter 2007; Llewellyn, McGurk and Weinman 2007) and one study was of a mixed design of cross-sectional and longitudinal (Evans and Norman 2009).

Illness representation dimensions were measured by the IPQ (Carlisle, John, Fife-Schaw and Lloyd 2005; Kaptein et al., 2006; Rutter and Rutter 2007; Goldstein, Holland, Soteriou and Mellers 2005), the Brief IPQ (Knowles, Wilson, Connell and Kamm 2011), with the remaining applying the IPQ-R (Knibb and Horton 2008; Rozema, Vollink and Lechner 2009; Evans and Norman 2009; Gould, Brown and Bramwell 2010; Walker, Lindner and Noonan 2009; Dorrian, Dempster and Adair 2009; Cartwright, Endean and Porter 2008; Llewellyn, McGurk and Weinman 2007).

Coping was measured; Coping Operations Preference Enquiry (COPE) (Knibb and Horton 2008; Kaptein et al., 2006; Gould, Brown and Bramwell 2010; Dorrian, Dempster and Adair 2009; Rutter and Rutter 2007; Knowles, Wilson, Connell and Kamm 2011; Cartwright, Endean and Porter 2008; Llewellyn, McGurk and Weinman 2007), Utrecht Coping Questionnaire (Rozema, Vollink and Lechner 2009), Ways of Coping Questionnaire (Walker, Linder, Noonan 2009; Goldstein, Holland, Soteriou and Mellers 2005), the remaining two studies applied a coping questionnaire detailed to the specific long term condition under investigation; London Coping with Rheumatoid Arthritis Questionnaire (Carlisle, John, Fife-Schaw and Llyod 2005) and Medical Coping Modes Questionnaire (Evans and Norman 2009).

Outcome measures included measures of anxiety and depression; Hospital Anxiety and Depression Scale (Evan and Norman 2009; Dorrian, Dempster and Adair 2009; Rutter and Rutter, 2007; Knowles, Wilson, Connell and Kamm 2011; Goldstein, Holland, Soteriou and Mellers 2005; Llewellyn, McGurk and Weinman 2007) and the Cardiac Depression Scale (Walker, Linder, Noonan 2009). Measures of psychiatric morbidity included the General Health Questionnaire (Knibb and Horton 2008; Carlisle, John, Fife-Schaw and Lloyd 2005). Quality of life was measured by; WHO Quality of Life-Brief (Rutter and Rutter 2007), Dermatology Life Quality Index (Cartwright, Endean and Porter 2008), and the European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire (Llewellyn, McGurk and Weinman 2007). Other outcome measures included a generic measure of mental health; RAND-36 (Rozema, Vollink and Lechner 2009), a measure of stress; Perceived Stress Scale (Knibb and Horton 2008), a measure of psychological well-being; Sickness Impact Profile (Kaptein et al., 2006) and a measure of mood status; Profile of Mood States Short Form (Gould, Brown and Bramwell 2010).

Description of Included Studies

Recruitment of participants varied across studies, including the use of outpatient departments (Carlisle, John, Fife-Schaw and Lloyd 2005; Evans and Norman 2009; Kaptein et al., 2006; Gould, Brown and Bramwell 2010; Dorrian, Dempster and Adair 2009: Goldstein, Holland, Soteriou and Mellers 2005; Llewellyn, McGurk and Weinman 2007; Knowles, Wilson, Connell and Kamm 2011), online support groups and media outlets (Knibb and Horton 2008; Rozema, Vollink and Lechner 2009; Walker, Linder and Noonan 2009; Cartwright, Endean and Porter 2009) and one study general practitioners were providing questionnaires to eligible participants (Rutter and Rutter 2007).

Response rates reported varied widely between studies, low response rates ranged from 30.8% to 48.4% (Knibb and Hortaon 2008; Kaptein et al., 2006; Gould, Brown and Bramwell 2010); a number of studies were unable to report response rates due to the design of the study – invitations posted on online support groups, media outlets and recruitment from general practices; higher response rates ranged from 62% to 74.4% (Carlisle, John, Fife-Schaw and Lloyd 2005; Dorrian, Dempster and Adair 2009; Evans and Norman 2009).

Participants of all studies were provided with questionnaires to complete and return at a later date, except participants involved in the Kaptein et al., (2006) study, as this information was collected as part of a two hour face-to-face interview.

Relationships between Illness Representation Dimensions

Data reporting relationships between illness representation dimensions expressed as Pearsons correlation coefficients were published in 6 studies (Rozema, Vollink and Lechner 2009; Carlisle, John, Fife-Schaw and Lloyd 2005; Evans and Norman 2009; Kaptein et al., 2006; Gould, Brown and Bramwell 2010; Cartwright, Endean and Porter 2009).

Identity was; positively correlated with a chronic timeline (Rozema, Vollink, Lechner 2009; Carlisle, John, Fife-Schaw and Lloyd 2005); negatively correlated with a cyclical timeline (Evans and Norman 2009); positively correlated with a cyclical timeline (Cartwright, Brown and Bramwell 2010; Rozema, Vollink and Lechner 2009); positively correlated with consequences (Rozema, Vollink and Lechner 2009; Carlisle, John, Fife-Schaw and Lloyd 2005; Kaptein et al., 2006; Cartwright, Endean and Porter 2009); positively correlated to emotional representation (Rozema, Vollink and Lechner 2009; Cartwright, Endean and Porter 2009); negatively correlated to personal and treatment control (Rozema, Vollink and Lechner 2009).

Chronic timeline was; negatively correlated with personal and treatment control (Rozema, Vollink and Lechner 2009; Gould, Brown and Bramwell 2010; Cartwright, Endean and Porter 2009): positively correlated with emotional representation (Rozema, Vollink and

Lechner 2009); positively correlated with consequences (Rozema, Vollink and Lechner 2009; Carlisle, John, Fife-Schaw and Lloyd 2005; Gould, Brown and Bramwell 2010).

Consequences was; negatively correlated with treatment control (Rozema, Vollink and Lechner 2009; Cartwright, Endean and Porter 2009); positively correlated with cyclical timeline (Rozema, Vollink and Lechner 2009; Gould, Brown and Bramwell 2010); positively correlated with emotional representation (Rozema, Vollink and Lechner 2009; Carlisle, John, Fife-Schaw and Lloyd 2005; Cartwright, Endean and Porter 2009); negatively correlated with illness coherence (Cartwright, Endean and Porter 2009).

Emotional Representation was; negatively correlated with personal and treatment control (Rozema, Vollink and Lechner 2009); positively correlated with a cyclical timeline (Rozema, Vollink and Lechner 2009; Cartwright, Endean and Porter 2009).

Illness Representation Dimensions and Health Outcomes

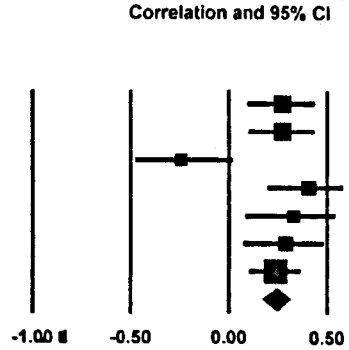
Of the 13 studies reviewed 92% reported at least one significant relationship between illness representation dimensions and health outcomes.

Data reporting associations between illness representation dimensions and health outcomes expressed as Pearsons correlation coefficients were published in 9 studies (Knibb and Horton 2008; Carlisle, John-Schaw and Lloyd 2005; Evans and Norman 2009; Kaptein et al., 2006; Gould, Brown and Bramwell 2010; Dorrian, Dempster and Adair 2009; Rutter and Rutter 2007; Cartwright, Endean and Porter 2008; Goldstein, Holland, Soteriou and Mellers 2005). Knowles, Wilson, Connell and Kamm (2011) reported significant associations between illness representation dimensions and anxiety and depression. However, the association was reported as one correlation for all illness representation dimensions, therefore not included in the analysis. All studies reported psychological outcomes including; anxiety, depression, stress, psychiatric morbidity and mood disturbance, which for this analysis were combined and titled mental health outcomes. The results of the stem and leaf analysis demonstrated clear patterns across the studies. A high reporting of identity, consequences, timeline and emotional representations were associated with higher reporting of mental health issues (see Appendix II for box plot). A higher reporting of control and illness coherence were significantly associated with lower reporting of mental health issues (see Appendix III for box plot).

Meta-analysis was conducted for the correlations between illness representation dimensions and health outcomes. Illness representation dimensions and health outcomes were significantly associated across studies (Correlation 0.247, 95% CI, 0.176-0.314, P=0.001). Figure 3 demonstrates the correlations and confidence intervals for each study included (page 227).

Figure 3: Illness representation dimensions and health outcomes

Study name	Statistics for each study				
	Correlation	Lower limit	Upper limit	Z-Value	p-Value
Rozema, Vollink and Lechner (2009)	0.272	0.097	0.431	3.005	0.003
Carlisle, John, Fife-Schaw and Lloyd (2005)	0.272	0.101	0.427	3.082	0.002
Evans and Norman (2009)	-0.243	-0.472	0.016	-1.839	0.066
Kaptein et al. (2006)	0.407	0.201	0.578	3.716	0.000
Gould, Brown and Bramwell (2009)	0.332	0.087	0.539	2.628	0.009
Dorrian, Dempster and Adair (2009)	0.291	0.076	0.480	2.629	0.009
Cartwright, Endean and Porter (2009)	0.240	0.109	0.362	3.556	0.000
	0.247	0.176	0.314	6.721	0.000



Meta-analysis results
Heterogeneity I^2 64.72, p=0.009

All studies remained significant at <p0.01, with the exception of Evans and Norman (2009). Studies reported a combination of positive and negative associations between illness representation dimensions and health outcomes, only Evans and Norman (2009) remained negative, possibly due to the inclusion of the variable of control.

Illness Representation Dimensions and Coping

Of the 13 studies reviewed 69% reported at least one significant relationship between illness representation dimensions and coping strategies.

Data reporting associations between illness representation dimensions and coping expressed as Pearsons correlation coefficients were published in 9 studies (Knibb and Horton 2008;

Carlisle, John, Fife-Schaw and Lloyd 2005; Rozema, Vollink and Lechner 2009; Evans and Norman 2009; Kaptein et al. 2006; Gould, Brown and Bramwell 2010; Dorrian, Dempster and Adiar 2009; Cartwright, Endean and Porter 2008; Goldstein, Holland, Soteriou and Mellers 2005). The studies used a variety of coping measures and reported the different scales of each coping measure. Knowles, Wilson, Connell and Kamm (2011) reported significant associations between illness representation dimensions and emotion-focused coping and problem-focused coping. However, the associations were reported for one correlation of all illness representation dimensions and therefore not included in the analysis. The analysis included Active/Problem-focused Coping defined as active coping, planning, seeking instrumental support, positive reinterpretation and growth, acceptance, emotional social support, problem-focused and acceptance and growth. Avoidant Coping defined as behavioural avoidant, cognitive avoidant, avoidant and resignation, avoidance, denial, venting emotions, mental disengagement and behavioural disengagement. The two categories of coping were defined to allow a clear and unambiguous analysis of the relationships between illness representation dimensions and coping, coping and health outcomes and coping as a mediator, this was in line with a previous meta-analysis of the variables within the CSM (Hagger and Orbell 2003). Clear patterns between illness representation dimensions and coping across the studies were identified. Higher reporting of active coping was significantly associated with higher reporting of control and illness coherence; higher reporting of avoidance coping was significantly associated with higher reporting of identity and emotional representation (see Appendix IV for the box plot). Higher reporting of active coping was significantly associated with lower reporting of emotional representation, higher reporting of avoidance coping was a significantly associated with lower reporting of illness coherence (see Appendix V for the box plot).

One study (Llewellyn, McGurk and Weinman 2007) reported Spearman's correlation coefficients between illness representation dimensions and coping strategies at 6-8 months post treatment and similarly reported the same emerging pattern. Higher reporting of identity and emotional representation was associated with avoidance coping, and higher reporting of personal control was associated with active coping (Llewellyn, McGurk and Weinman 2007).

Meta-analysis was conducted for the correlations between illness representation dimensions and coping. Illness representation dimensions and coping were not associated across studies (Correlation -0.055, 95% CI, - 0.128-0.018, P=1.39).

Coping and Health Outcomes

Of the 13 studies reviewed 84% reported at least one significant relationship between coping and health outcomes.

Data reporting associations between coping and health outcomes expressed as Pearsons correlation coefficients were published in 8 studies (Knibb and Horton 2008; Rozema, Vollink and Lechner 2009; Carlisle, John, Fife-Schaw and Lloyd 2005; Evans and Norman 2009; Kaptein et al. 2006; Gould, Brown and Bramwell 2010; Dorrian, Dempster and Adair 2009; Knowles, Wilson , Connell and Kamm 2011). One study reported coping strategies were not found to be correlated with any health outcomes (Knibb and Horton 2008). Clear patterns between coping and health outcomes across the studies were identified. Higher reporting of avoidance coping strategies was significantly associated with higher reporting of mental health issues, higher reporting of active coping strategies was significantly associated with lower reporting of mental health issues (see Appendix VI for box plot).

Meta-analysis was conducted for correlations between coping and health outcomes. Coping and health outcomes were not associated across studies (Correlation- 0.025, 95% CI, -0.098-0.048, P=0.506).

Mediation Role of Coping within the CSM

Of the 13 studies reviewed 46% reported no mediation of coping on illness representation dimensions and health outcomes, 54% reported partial mediation of coping on illness representation dimensions and health outcomes.

Coping as a partial mediator was reported in 7 cross-sectional studies (Knibb and Horton 2008; Carlisle, John, Fife-Schaw and Lloyd 2005; Evans and Normal 2009; Kaptein et al. 2006; Gould, Brown and Bramwell 2010; Goldstein, Holland, Soteriou and Mellers 2005; Knowles, Wilson, Connell and Kamm 2011) and coping as a mediator was rejected in 4 cross-sectional studies (Rozema, Vollink and Lechner 2009; Walker, Linder and Noonan 2008; Dorrian, Dempster and Adair 2009; Cartwright, Endean and Porter 2008). One longitudinal study found mediation effects in cross-sectional analysis only; coping did not mediate illness representation dimensions and health outcomes over a 6 month period (Evans and Norman 2009). The 2 remaining longitudinal studies both rejected coping as a mediator (Llewellyn, McGurk and Weinman 2007). Meta-analysis of coping as a mediator was not completed as the rules for mediation (Baron and Kenny, 1986) were not met.

Discussion

The present review aimed to identify the constructs and relationships within the Common Sense Model of Self-Regulation. This review supports the constructs within the CSM and the relationships between illness representation dimensions. However, the CSM proposes illness representation dimensions influence health outcomes through the mediation of coping and this was not demonstrated. Illness representation dimensions were significantly associated directly with health outcomes.

Relationships between Illness Representation Dimensions

Patterns between illness representation dimensions were found across studies. Identity was positively associated with a chronic timeline and consequences, emotional representation was negatively associated with personal and treatment control, a chronic timeline was negatively associated with personal and treatment control. These patterns demonstrate an individual's belief that personal health behaviours and/or treatment plans will not impact on the progress or consequences of their illness. Individuals how believe the consequences of their illness will continue even if they adhere to medical treatment and change health behaviours are unlikely to sustain these recommendations especially if they produce adverse side effects. Identifying an individual's illness representation dimensions will alert healthcare professionals to possible issues of non-adherence. Once an individual has been identified healthcare professionals can address the individuals' beliefs and provide further information and education with the aim to changing their illness representation dimensions, adherence and health outcomes.

An illness specific pattern occurred between identity and cyclical timeline. The diagnosis of breast cancer was positively associated with cyclical timeline. The diagnosis of Parkinson's disease and alopecia was negatively associated with cyclical timeline. There are distinct differences between these illnesses, the treatment for Parkinson's disease and alopecia is focused on the control of long term symptoms. However, breast cancer treatment can provide a cure of the current episode. Individuals remain susceptible to reoccurrences, but will be free from symptoms while in remission. These differences demonstrate the importance of considering the illness and the treatment of an illness when exploring illness representation dimensions. These results concur with the conclusion of Hagger and Orbell's (2003) meta-analysis that a profile of illness representation dimensions for each illness occurs due to the symptoms and the timeline of each illness.

The associations between illness representation dimensions found in this study are only applicable to the illnesses stated and should not be generalized beyond these. Studies including cardiovascular and cerebrovascular disease were not identified. These conditions include acute life threatening events and long term symptoms. Therefore, individuals may develop different patterns of illness representation dimensions to cognitively and emotionally understand the complexities of their condition. Further research would be required to identify the different patterns of illness representation dimensions in these conditions.

Illness Representation Dimensions and Health Outcomes

Patterns of illness representation dimensions and health outcomes across studies included a higher reporting of identity, consequences, timeline and emotional representation were associated with higher reporting of anxiety, depression, stress or a mood disorder. Personal and treatment control and illness coherence were associated with lower reporting of anxiety, depression, stress or a mood disorder. The significant association of illness representation dimensions and health outcomes remained in the meta-analysis. These associations are consistent with previous research (Hagger and Orbell 2003). The results of the two reviews demonstrate the importance of healthcare professionals to monitor illness representation dimensions as these constructs are associated with health outcomes above and beyond the biological progression of the illness. Further research supports this as Spence and Moss-Morris (2007) found individuals who sought healthcare for food poisoning and reported a strong identity, serious consequences and the condition was uncontrollable were more likely to develop irritable bowel syndrome six months later. Due to the ease and short time frame it would take for an individual to complete the IPQ-R in a clinical environment, the introduction of assessment of illness representation dimensions could be incorporated into an individual's medical assessment. The assessment of illness representation dimensions would highlight possible areas of concern for the medical team.

Interventions based on illness representation dimensions are beginning to be published. Three studies have reported the successful implementation of a cognitive behavioural therapy intervention to change negative illness representation dimensions (Knoop, van Kessel and Moss-Morris 2012; Moss- Morris et al. 2007; Broadbent et al. 2009). The intervention in each study explored the illness representation dimensions of the individual and explained their illness and treatment within these dimensions. The aim of the interventions was to encourage more personal and treatment control representations and reduce consequence representations, whilst developing an action plan. The illnesses and outcomes within these studies were diverse and included; the reporting of fatigue in multiple sclerosis, chronic pain management and recovery from a myocardial infarction. These studies have begun to demonstrate the wide applicability of illness representation dimensions as a base for an intervention to improve health outcomes.

Illness Representation Dimensions and Coping

Patterns of illness representation dimensions and coping occurred across studies, such as problem-focused coping was positively associated with personal and treatment control and negatively associated with emotional representations. Avoidant coping was positively associated with identity and emotional representation and negatively associated with coherence. Consequence was not associated to either coping approaches and this was consistent across all studies. Although, consequences may be more generally associated to all coping strategies as non-significant positive associations were reported to both active problem-focused coping and avoidant coping strategies. The impact of consequences on coping strategies is unclear, but a significant negative relationship between consequences and health outcomes is evident and consequences remain an important illness representation dimension to identify.

In previous research a strong identity was positively associated with expressing emotions and avoidance/denial and negatively associated with problem-focused coping (Hagger and Orbell 2003), which is consistent with the current pattern. However, the associations between illness representation dimensions and coping strategies did not remain significant in the meta-analysis. An aspect identified by the authors was the possibility that the coping measures applied were to generic to distinguish coping strategies individuals' with specific diseases may implement. However, one longitudinal study (Llewellyn, McGurk and

Weinman 2007) found more relationships between illness representation dimensions expressed prior to treatment and coping strategies at 6-8 months post treatment than at 1 month post treatment. This demonstrates the long term impact of illness representation dimensions and the need to implement an intervention at this stage if changes to health outcomes are a priority.

Coping and Health Outcomes

Patterns of coping and health outcomes occurred across studies, such as higher reporting of avoidance coping was positively associated with higher reporting of anxiety, depression, stress or a mood disorder. Higher reporting of active coping was negatively associated with lower reporting of these health outcomes. However, the associations between coping strategies and health outcomes did not remain significant in the meta-analysis. Various coping measures were applied across studies and measured the general coping approach of individuals. The meta-analysis result may be due to different coping strategies applied by individuals depending on their illness and the symptoms they are experiencing. These coping strategies may not have been identified by measuring the overall coping approach. For example, resting in an individual with multiple sclerosis may have a positive health outcome, resting for an individual with rheumatoid arthritis may have a negative health outcome, such as an increase in joint pain and stiffness.

Mediation Role of Coping within the CSM

Mediation analysis was not conducted due to the lack of significant correlations between illness representation dimensions and coping, and coping and health outcome in the meta-analysis.

Further analysis of coping as a mediator was considered not appropriate due to the limitation of completing this analysis on cross-sectional data. The use of cross-section design was acknowledged by authors as a limitation in the original publications. Cross-sectional design of a study and data collection does not allow conclusions to be drawn regarding the causal relationships between variables only an association or correlation between variables. Hagger and Orbell (2003) recommend the use of longitudinal data and the 3 longitudinal studies (Evans and Norman 2009; Rutter and Rutter 2007; Llewellyn, McGurk and Weinman 2007) in this review rejected the role of coping as a mediator. Relationships were identified between illness representation dimensions and coping, but not coping and health outcomes. Coping remains an important construct within the CSM, but not as a mediating variable.

Evaluation

A limitation of the included studies is the applicability of the results to a wider population as low response rates or undeterminable response rates were reported. A number of studies recruited from online support groups whose members may differ from individuals with the same illness who do not join support groups. Only one study reported the ethnicity of participants which demonstrated lack of ethnic diversity as 94% self-reported ethnicity as white (Knibb and Horton 2008). The ethnicity of participants also highlights the fact these studies have been conducted with individuals from Western societies, such as Europe, North America, New Zealand and Australia and therefore are only applicable to these societies, beliefs regarding illness in different cultures will vary considerably (Cameron and Moss-Morris 2010).

Future analysis should include studies from the systematic review completed by Hagger and Orbell (2003) that included the measures of IPQ or IPQ-R to have an overall synthesis of the data to date. Although a dynamic model is difficult to evaluate, the aspect of the CSM lacking from the current literature reviewed is the process of appraisal and how the individual appraises the effects of their coping strategies to return them to a state of equilibrium. Appraisal acts as a feedback loop to an individual's illness representation dimensions and further coping strategies implemented. This is an aspect of the CSM that requires further consideration in future research.

Implications

The implications of the current review are important for all healthcare professionals working with individuals dealing with a health threat. Illness representation dimensions as a construct within the CSM directly influence an individual's health outcome over and above the progression of the biological illness. Negative illness representations can be identified and measured using the IPQ and IPQ-R and are associated with higher reporting of anxiety, depression, stress or a mood disorder. Recent randomized controlled trials have demonstrated interventions can alter negative illness representation dimensions to the benefit of the individual. Future research concerning tailoring interventions to different illnesses and how these can be implemented in the healthcare setting to improve an individual's self-regulation and self-management are warranted.

Summary

The current review supports the constructs within the Common Sense Model. Patterns of illness representation dimensions across and between illnesses have been highlighted and this review has begun the process of identifying illnesses where patterns may differ. However, the relationships between constructs were challenged. Hagger and Orbell's (2003) meta-analysis found partial mediation by coping, this review found no support for coping as a mediating variable. Illness representation dimensions were significantly associated both positively and negatively with health outcomes. The importance of measuring illness representation dimensions to identify their negative impact on health outcomes has emerged from this review.

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Appendix

Appendix I:

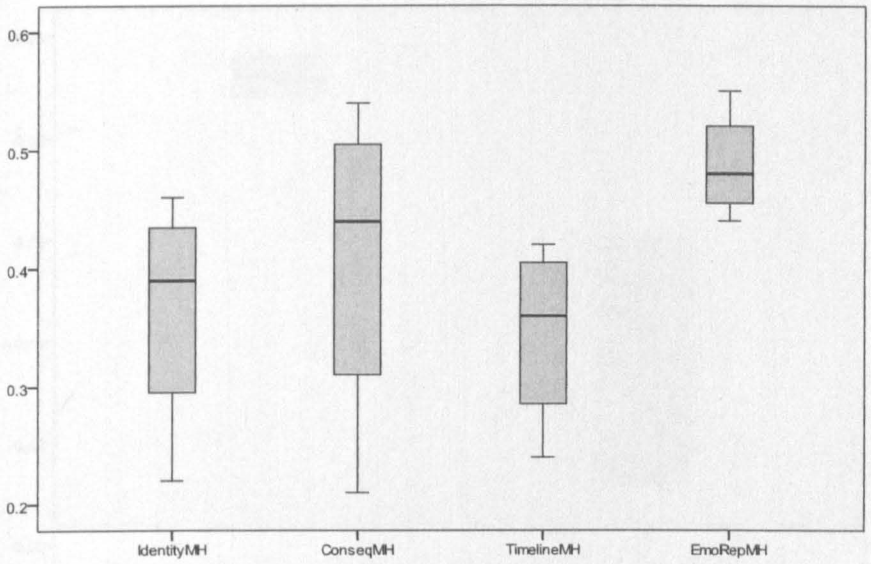
Quality assessment of cross-sectional studies

Author and year	Appropriate Research Design?	Appropriate Recruitment Strategy?	Response Rate?	Is Sample Representative? (All clinic populations)	Objective and Reliable Measures?	Power Calculation/ Justification of Numbers?	Appropriate Statistical Analysis?	Evidence of Bias?	Quality Indicators Met
Knibb and Horton (2008)	Yes	Yes	30.8%	Unclear sample from a national database	Yes	No	Yes	Acknowledged high level of white middle class women than expected in this patient group	4/7
Rozema, Vollink and Lechner (2009)	Yes	Yes	Unknown	Unclear sample from internet support group	Yes	No	Yes	Unclear of differences between individuals who join internet support groups and those who do not	4/7
Carlisle, John, Fife-Schaw and Lloyd (2005)	Yes	Yes	62.0%	Yes (of clinic population)	Yes	No	Yes	Convenience sample	6/7
Evans and Norman (2009)	Yes	Yes	74.4%	Yes (of clinic population)	Yes	No	Yes	Convenience sample	6/7
Kaptein et al. (2006)	Yes	Yes	48.0%	Yes (of clinic population)	Yes	No	Yes	Convenience sample	5/7
Gould, Brown and Bramwell (2010)	Yes	Yes	48.4%	Yes (of clinic population)	Yes	No	Yes	Convenience sample	5/7
Walker, Lindner and Noonan (2009)	Yes	Yes	Unknown	Unclear sample from internet support groups and other media outlets	Yes	No	Yes	Unclear differences between individuals who join internet support groups and those who do not	4/7
Dorrian, Dempster and Adair (2009)	Yes	Yes	64.0%	Yes (of clinic population)	Yes	No	Yes	Convenience sample	6/7
Rutter and Rutter (2007)	Yes	Yes	Unknown	Unclear sample from GP surgeries	Yes	No	Yes	Unclear if sample from GP surgeries represent clinic population	4/7

Cartwright, Endean and Porter (2008)	Yes	Yes	Unknown	Unclear sample from internet support group	Yes	No	Yes	Unclear differences between individuals who join internet support groups and those who do not	4/7
Goldstein, Holland, Soteriou and Mellers (2005)	Yes	Yes	Unknown	Yes (of clinic population)	Yes	No	Yes	Convenience sample	5/7
Llewellyn, McGurk and Weinman (2007)	Yes	Yes	Unknown	Yes (of clinic population)	Yes	No	Yes	Convenience sample	5/7
Knowles, Wilson, Connell and Kamm (2011)	Yes	Yes	Unknown	Yes (of clinic population)	Yes	No	Yes	Convenience sample	5/7

Appendix II:

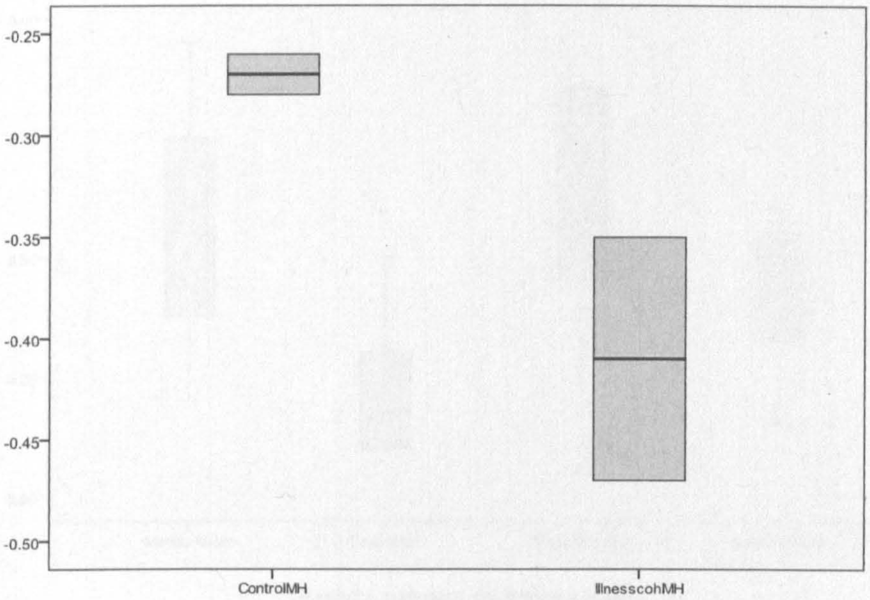
Positive correlations of illness representation dimensions and mental health outcomes



Pearsons correlation coefficients $p<0.01$
IdentityMH - higher reporting of identity higher reporting of mental health variables
ConseqMH - higher reporting of identity higher reporting of mental health variables
TimelineMH - higher reporting of chronic timeline higher reporting of mental health variables
EmoRepMH - higher reporting of emotional representations higher reporting of mental health variables

Appendix III:

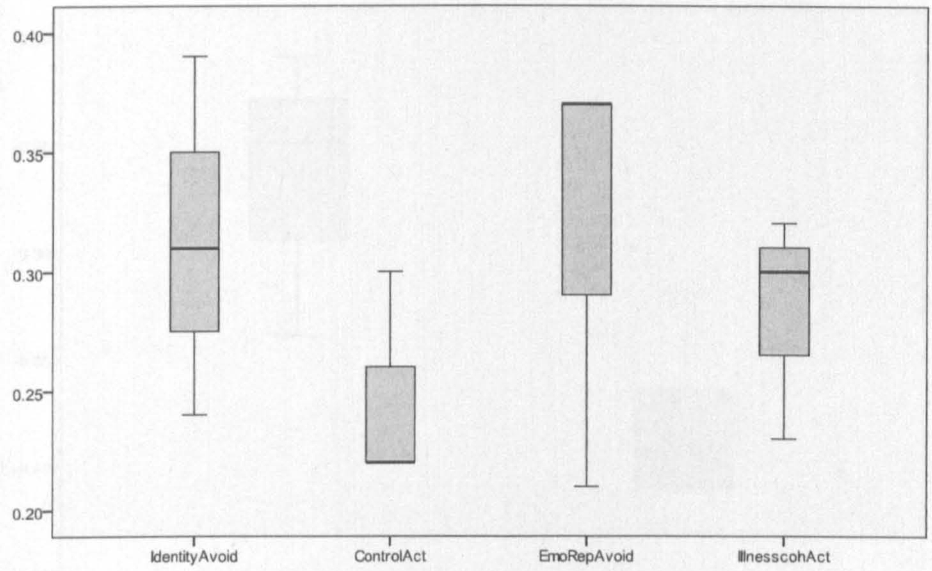
Negative correlations of illness representation dimensions and mental health outcomes



Pearsons correlation coefficients p<0.01
ControlMH - higher reporting of control lower reporting of mental health variables
IllnesscohMH - higher reporting of illness coherence lower reporting of mental health variables

Appendix IV:

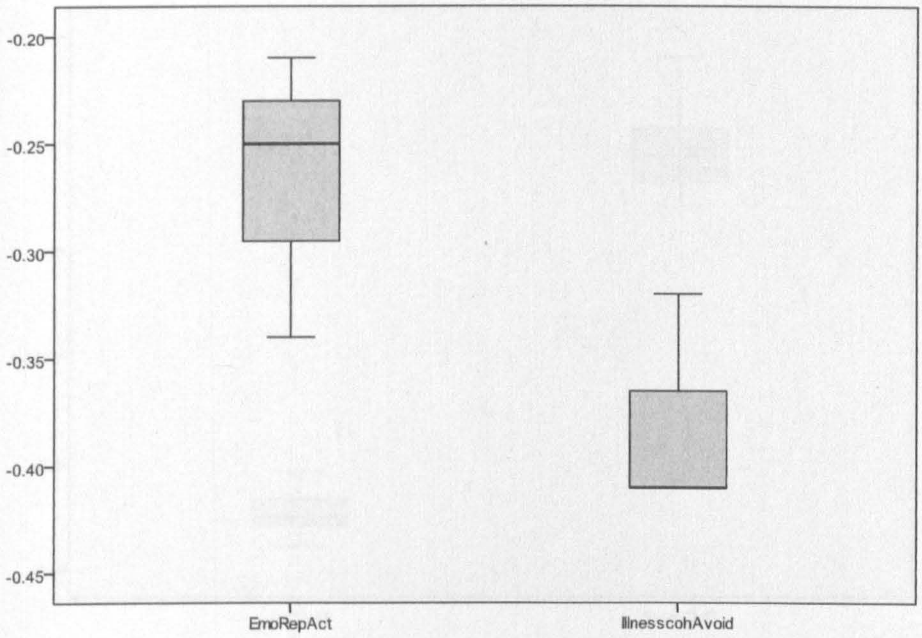
Positive correlations of illness representation dimensions and coping strategies



Pearsons correlation coefficients $p<0.01$
IdentityAvoid - higher reporting of identity higher reporting of avoidance coping variables
ControlAct - higher reporting of control higher reporting of active coping variables
EmoRepAvoid - higher reporting of emotional representation higher reporting of avoidance coping variables
IllnesscohAct - higher reporting of illness coherence higher reporting of active coping variables

Appendix V:

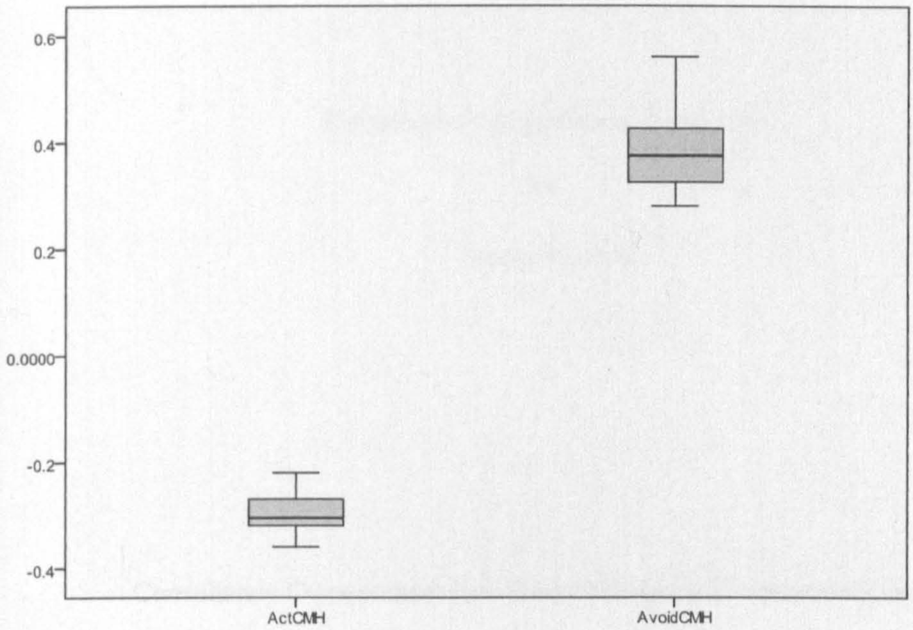
Negative correlations of illness representation dimensions and coping strategies



Pearsons correlation coefficients p<0.01
EmoRepAct - higher reporting of emotional representation lower reporting of active coping variables
IllnesscohAvoid - higher reporting of illness coherence lower reporting of avoidance coping variables

Appendix VI:

Negative and positive correlations of coping strategies and mental health outcomes



Pearson correlation coefficient p<0.01
ActCMH - higher reporting of active coping variables lower reporting of mental health variables
AvoidCMH - higher reporting of avoidance coping variables higher reporting of mental health variables

Consultancy Competence Case Study

by

Joanne Brooke

Consultancy Competence Case Study Submitted in Partial Fulfillment
of the Requirements for the Professional Doctorate of Health Psychology

London Metropolitan University

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Consultancy is one of the competencies necessary to complete the Professional Doctorate in Health Psychology (Stage 2 Training). The process of consultancy enhances a trainee health psychologist's skills and knowledge and develops their competency to practice independently (British Psychological Society 2009). This case study will explore the use of consultancy and psychological theories in the development, implementation and evaluation of workshops delivered for healthcare professionals practicing within the field of stroke in a Kent NHS Trust. I completed this consultancy as a trainee health psychologist and as a senior lecturer for the University of Greenwich. The original aim of the consultancy was to provide a two day workshop for qualified healthcare professionals and a one day workshop for unqualified healthcare professionals, but due to the development of the consultancy relationship with the client and the success of the workshops another two occurrences of each workshop was agreed.

The case study will be structured using the consultancy competencies outlined by the British Psychological Society (BPS) in the Qualification in Health Psychology (Stage 2) Candidate Handbook (BPS 2009). The consultancy models I intend to use to inform my reflection are Flawless Consulting (Block 2011) and the Seven Cs of Consulting (Cope 2003). Flawless Consulting includes the following 5 stages of consulting; entry and contracting, discovery and dialogue, analysis and the decision to act, engagement and implementation, and finally extension, recycle or termination (Block 2011). The Seven Cs of Consulting takes the approach of client, clarify, create, change, confirm, continue and close (Cope 2003).

Assessment of requests for consultancy

The feasibility of a consultancy with a Kent NHS Trust was initiated and assessed through my role as a senior lecturer as I requested to attend a Key Accounts Meeting (KAM). NHS Trust workforce training is discussed at the KAM alongside relevant government targets and initiatives. The Department of Health has recently targeted stroke care and management, producing the National Stroke Strategy (2008) and the Stroke Specific Educational Framework (2010). My presentation at the KAM highlighted the importance of up skilling healthcare professionals working within stroke. A strong element of the proposed workshops involved secondary prevention and informing and helping patients to address and change their own health behaviours (Saco et al., 2006).

Presenting my proposed consultancy at the KAM was commencing Phase 1 of the consultancy process: Entry and Contracting (Block 2011). I had my initial contact with the client and the client's manager. In the discussions at the KAM I aimed to address the client's orientation and their perceptions of their workforce training needs, which is the first dynamic stage of the 7 Cs framework: Client (Cope 2003). I was confident in my proposal for the consultancy as Czerniawska (2002) states consultants are required 'to perform some work that the client does not have the skills to do'. I felt confident I had the required skills, knowledge and experience to successfully deliver the workshops.

A further meeting between the client, relevant ward managers and matrons was organised. The meeting began with me asking questions regarding current and future stroke services with this NHS Trust and progressed with the ward managers and matrons discussing current training needs. The process identified the needs of the client and the workforce and moved the consultancy to the second dynamic stage of Cope's 2003 model: Clarify. During the clarifying process the culture of the organisation needs to be understood (Cope 2003); therefore it was important for me to understand the current training needs of the staff and how workshops are currently implemented and attended.

The client was keen to progress with the workshops and the structure of each workshop was discussed along with the practical technicalities of advertising, recruiting and delivering the workshops. During the meeting I tried to remain authentic, authentic behaviour with the client means putting into words what you are experiencing when working with the client. Both Block (2011) and Cope (2003) state authenticity is an important aspect in building commitment and trust from the client. I felt I had been honest and began the process of building a working relationship with the client.

During these meetings the ward managers became engaged with the consultancy and began providing proformas currently in use within their service. The provision of information allowed the workshops to be tailored to relevant current practices and organisation needs within this NHS Trust. When an outline of both workshops had been developed and agreed, the client suggested an evaluation of both workshops with the possibility of agreeing further workshops. I felt agreeing to one occurrence of both workshops would allow me to consider the main resource of this consultancy which was my time, my time to plan the workshops from broad outlines to contain in-depth information, to construct worksheets, scenarios and various other teaching materials as well as my time in delivering the workshops when taking into account my existing commitments.

Plan Consultancy

The broad categories for each workshop were agreed, which focused my attention on providing the detail. The element of health psychology occurs within the two day workshop for qualified healthcare professionals I aimed to provide two sessions on: primary and secondary prevention and changing health behaviours. Healthcare professionals are involved with providing patients with information to prevent further strokes, which may include information regarding health behaviours, such as; cessation of smoking, increasing physical activity, change of diet, reducing alcohol intake, weight loss and adherence to medical regimes (Lawrence et al., 2011). The workshops were open to any member of the multi-disciplinary team working with stroke patients. The majority of healthcare professions have a very limited teaching of health psychology or effective communication regarding behaviour change during their training (Kruijver et al., 2000). However as healthcare professionals they would have the ability to understand and possibly even have some knowledge of health psychology models from clinical practice. For the session involving primary and secondary prevention I returned to stroke literature to ensure the most up to date information was provided. The health psychology models I planned to include were; the Health Belief Model (Rosenstock 1974), Protection Motivation Theory (Rogers 1975), Theory of Planned Behaviour (Ajzen 1991), Transtheoretical Model of Behaviour Change (DiClemente and Prochaska 1982) and the Common Sense Model (Leventhal et al., 1984). I also planned to introduce the National Institute for Health and Clinical Excellence (NICE) guidelines regarding behaviour change: Behaviour changes of populations, communities and individual levels (NICE 2007) as I expected all healthcare professionals to be competent and knowledgeable of NICE guidelines. The practical element of these sessions included two scenarios providing secondary prevention advice from within a framework of a health psychology model.

The detailed plans for consultancy included the responsibilities of the client, such as; the distribution of flyers advertising the workshops in both hard copies to clinical areas and online through the NHS intranet. The client and the educational team were responsible for registration of participants, booking of appropriate teaching environments, providing certificates, and collating feedback sheets to form a report. My responsibilities as consultant included; the provision of pre-reading material, contacting the educational team prior to each workshop to ascertain the number of participants and the room allocation, the delivery of the workshop and the collection of feedback. During the agreement of these processes the consultancy process had moved to Phase 2: Discovery and Dialogue (Block 2011), the client's strength of being able to advertise the workshop and influence the managers to encourage their staff to attend and release them from clinical duties had been identified.

Following the agreement of the consultancy and identification or roles and responsibilities a contract was drawn up by myself and agreed with the client. The cost of the workshops was the standard cost per participant for a workshop provided by the University of Greenwich, where a minimum of 10 participants per workshop would be charged, the maximum participants charged per workshop is 20. The client had completed consultancy projects with the University of Greenwich prior to this occasion and was already aware of costing and the implication of the amount of participants attending.

During the planning of the consultancy the client and I designed feedback sheets. Both the client and I are used to creating feedback sheets and a format was quickly identified and applied to the current workshops. The format of the feedback both oral and written was based on theory and evidence and the importance of implementing strategies from this process (Hampton and Reiser 2004). The consultancy moved to Phase 3: Analysis and the Decision to Act (Block 2011) during this process, as further discussion of the objectives of the workshops occurred. The identification of clear objectives allowed for the workshops to be measured against success criteria. The consultancy had progressed from the dynamic stage of clarify to create (Cope 2003), including the creative techniques to enhance the workshop delivery to the mechanisms to measure the success of the workshops.

The main objective of the workshops for the client was to increase staff awareness of the different care and management strategies within stroke, which would then impact on their practice. When constructing the feedback sheet I did not feel 'impact on practice' could be reliably measured. However, the client informed me this is a routine objective when evaluating workshops within this NHS Trust. The objective is measured by a question on the feedback sheet, such as 'Will the current workshop impact on your practice and how'. I had also expected all feedback sheets to be anonymous to encourage staff to report honest feedback. However, the client specifically wanted the clinical unit of the staff to be included to identify which units the workshop was most applicable for. I felt as the client was responsible for training within this NHS Trust and managed all workshops with the same procedures; the attendees on the workshop would be aware of providing feedback which was not anonymous and accept this process.

Establish, develop and maintain working relationships with clients

During the establishment, development and maintenance of the working relationship with the client I maintained good communication, during meetings and with follow-up emails. The client and consultant relationship can be understood through the roles a consultant may adopt depending on; individual differences, management styles and the consultancy to be completed. Schein (1998) identified the expert role; the consultant plans, provides and implements the consultancy and the client responds by evaluating the outcome following the consultancy. The pair-of-hands role; the consultant is viewed as an extra-pair-of hands and the client maintains full control. The consultant is expected to apply their specialist knowledge to the problem defined by the client. The collaborative role; the consultant and the client are actively involved in defining the problem with bilateral decision making, communication is two-way and issues of control are discussed and negotiated. The role of consultant and client within my consultancy changed throughout the consultancy process. The original working relationship could be defined as the 'expert role', as a consultant I delivered the workshops and the client would evaluate the workshops impact on the workforce. During the delivery of the first occurrence of the workshops I felt my role was equitable to the pair-of-hands role, as the client maintained full control. However during the consultancy process the client began to respect my expertise and my commitment to the implementation of the workshops. Our roles within the consultancy process began to change to one of a collaborative role. I felt this occurred due to my inexperience at the beginning of the consultancy process and being led by someone who had more experience and knowledge in delivering training within the NHS, but as the consultancy unfolded and I was involved in this process I was able to contribute further to the client and suggest changes and discuss on-going issues as they arose. From this process I felt the client began to have more respect for my collaboration rather than just my expertise.

Czerniawska and May (2004) identified three broad categories that aid the effective building of the relationship between clients and consultants which included; discipline and accountability, leadership and flexibility. I feel it was my flexibility in providing further workshops and changing the workshops to meet the client's needs, boasted the client-consultant relationship and my role to one of a collaborator.

Conduct consultancy

The confirmation of responsibilities and the implementation of the workshops moved the consultancy process into Phase 4: Engagement and Implementation (Block 2011). However, when I contacted the educational department for the number of participants and the room allocation for the first workshop, it became apparent the workshop had not been organised. Emails had been circulated and dates agreed for the first occurrence of both workshops. I began to doubt the client's commitment to this consultancy. An effective consultancy skill involves creating internal commitment of the client, which is required to enable the client to remove any obstacles and act (Block 2011). I was aware of the huge operational move within the NHS Trust to close one hospital and to open the newly built hospital in the month preceding the first workshop. The client was committed to that process above and beyond the delivery of the training workshops. However, the client was in contact with me and apologised for this oversight and new dates were booked. The consultancy unexpectedly entered Phase 5: Extension, Recycle or Termination (Block 2011) as the workshop failed to be implemented and the consultancy was extended and new dates were organised.

The client was keen to engage the participants prior to the workshop and the agreement had been to send pre-reading material. I provided the reading material to the educational team for them to distribute to the participants. In each workshop I included a reflection on the reading material and discussed the material further. However, this aspect became difficult when participants did not receive the material. I had no control over this aspect of the consultancy and could not become involved in the decision making process to improve the effectiveness of this process.

I implemented the workshops including; a combination of relevant PowerPoint slides, quizzes, case scenarios, YouTube clips and DVDs to encourage interactive participation. I also included small group work and group feedback. For the two day workshop I was able to ascertain interests of the group and tailor the information provided on the second workshop appropriately to that group. The first workshop for qualified healthcare professionals was attending by nurses, physiotherapists and occupational therapists, so I maintained a broad approach. However, the third occurrence of the workshop was attended by qualified nurses working in stroke research rather than providing clinical care, therefore my emphasis was on research skills rather than care and management skills.

During each workshop confidentiality was reinforced with the acknowledgement that information disclosed regarding patients, practices or other colleagues was not to be discussed outside of the classroom by myself or the participants. The participants were reminded of their professional code of ethics regarding confidentiality; which included the Nursing Midwifery Council's (2008) The code; Standards of conduct performance and ethics for nurses and midwives and Health and Care Professionals Council's (2008) Standards of conduct, performance and ethics. The participants' confidentiality was also assured and maintained when I discussed different comments with the client regarding feedback.

The client had requested the workshops to be delivered within the educational training rooms within the Trust, rather than use classrooms at the University of Greenwich. I agreed to this request as it is more practical for me to attend the Trust rather than ask Trust members to travel to London and I felt the Trust members would feel the workshop more relevant to their clinical practice if delivered on site. The client assured me each training room was equipped with the necessary IT equipment and it wasn't until my first delivery of the workshop that I had overlooked to enquire what IT equipment would be available. On the first workshop I had access to PowerPoint and a large screen; however there was no internet access or the ability to play a DVD. I had wrongly presumed the standards of NHS

Trust classrooms would be equivalent to that of a university classroom, where all rooms are to a standard specification. When discussing this issue with the client, it also became apparent if classrooms do have internet access the Trust has blocked some websites such as YouTube. The client advised if I thought it was necessary to use YouTube during the workshops I would need to contact a senior member of the educational team to log in and gain access. I considered the clips were important and following the first occurrence I arrived early for each workshop and worked with the educational team to ensure I had the correct equipment to facilitate the smooth running of each day.

Monitor the process of consultancy

At the end of each workshop I facilitated a discussion with the participants for their feedback and the participants also completed the feedback sheets. On the first two occurrences of the workshop I met with the client to provide feedback information and to discuss how the information would impact on the delivery of the next workshop. The first issue was the inconsistency of the staff receiving the pre-reading material, which the client agreed to address. The second issue was the standard of the pre-reading material as some of the participants' thought the article was too difficult to understand and I agreed to provide an alternative article. The client highlighted that many of the participants had not completed formal studies for a number of years and it is especially important to engage these staff to update their knowledge, current practice and evidence-based care and management for stroke patients. The client's knowledge of the workforce and my specialist knowledge of stroke and health psychology enabled collaboration between the client and I to refine elements of the workshops to ensure appropriate training was implemented. The process of refining the workshops encompasses two elements of the Seven Cs framework: Change and Confirm (Cope 2003). This process continued throughout all occurrences of the workshops.

The workshops were positively evaluated following the first occurrence and two further occurrences were agreed. The consultancy process clearly identifies with Phase 5:

Extension, Recycle or Termination (Block 2011) as the consultancy was extended to include two further occurrences of the workshop. However, the third occurrence of the workshop for unqualified healthcare professionals did not proceed due to the low number registered. In the original consultancy contract the attendance of at least 6 participants had been agreed to ensure the workshops were financially and educationally viable.

Evaluate the impact of the consultancy

The secondary process of monitoring the consultancy was completed by the client and the client would amalgamate all the feedback comments into a standardized report. The report would then be circulated to the client's line manager, the person ultimately responsible for the successful completion of training in the Trust and me, as well as ward managers to identify the applicability of the workshops for their staff. My only comments were regarding the joint responsibility noted of ensuring participants received the adequate reading material, as once I had provided the material I could have no influence over this process. However, the feedback on the workshops throughout all occurrences was very positive, which I felt highlighted the fact the client and I had collaborated to ensure the information was relevant to the staff attending the workshops. All participants' feedback stating their knowledge of stroke care and management and secondary prevention had been improved and the majority of participants stated the workshops would impact on their current practice.

The consultancy reached the final phase of termination (Block 2011) and the dynamic stage of close (Cope 2003) following the final occurrence of the workshop. The client and I agreed the maximum amount of the relevant workforce had attended the workshops and therefore no further workshops were required at this time. Although this consultancy was closed, my contact with the client remained as we began discussions regarding workshops on dementia awareness, a new government initiative. Through completing this consultancy I feel more confident to engage in further consultancy work and I am now aware of how the process can unfold, develop, progress and close.

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Teaching case study and lesson plan

by

Joanne Brooke

Teaching Case Study and Lesson Plan Submitted in Partial Fulfillment
of the Requirements for the Professional Doctorate of Health Psychology

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Case study and teaching plan

Teaching and training is an important competency for all healthcare professionals, including health psychologists (HCPC 2009). My reflective case study will provide an account of a teaching session involving third year undergraduate psychology students completing a 30 credit module at Level 6 entitled Health Psychology. My reflective case study will include my rationale for discussing this teaching session and how I was able to place my own planning and teaching in the wider context of educational theory and practice. I further aim to identify my own strengths and weaknesses within teaching, which will include my adaptive teaching skills and the need to appreciate the perspective and experience of the students in the classroom.

I am a Senior Lecturer working for the University of Greenwich, and as such I am deployed to teach pre and post registration nurses and paramedics. Some of my deployed teaching involves an element of health psychology, however for my reflective case study I have chosen a session completed with undergraduate psychology students. This session involved the explanation of psychological constructs in coping with and adapting to a long term condition or chronic illness. My rationale for the selection of this session is due to my training as a health psychologist and my experience as a qualified nurse as these two elements become enmeshed in this teaching. I am able to provide knowledge on both psychological constructs and on chronic illnesses. My approach to health psychology is from working within primary and secondary care settings with patients diagnosed with a chronic illness. I have been involved in caring for acute exacerbation of chronic illnesses and empowering patients' to manage their own chronic illness when in remission. Therefore my understanding of health psychology constructs and chronic illnesses would allow me to bring knowledge, experience and insight into this session.

The session I delivered was part of a course and the course coordinator had developed a structure to be applied to all sessions. I therefore followed the set structure of a formal lecture for just over an hour, a short break and then a seminar session lasting an hour. The format provided a clear timetable for certain teaching strategies to be used and allowed the construction of a clear teaching plan (see appendix I). The lecture involved the provision of information including; the definition of chronic illness, prevalence rates and physical, psychological and social problems associated with the disability from a chronic illness. The theoretical models included; Shontz's (1975) coping with a diagnosis, Moos and Schaefer's (1984) coping with the crisis of an illness and Taylor et al.,'s (1983) cognitive adaptation model. The seminar activity involved small group work exploring the role of a health psychologist in primary and secondary care settings, followed by a classroom discussion.

Teaching strategies for the formal lecture were considered as some strategies encourage surface learning rather than deep learning. The definition of learning incorporates three important factors; practice, knowledge and context (Brown et al., 1989). The teaching strategies deployed aimed to address these three concepts and to avoid surface learning which can occur if individual sessions are; delivered without a strategic overview of the course, not relevant to the assignment and which do not require in depth analysis (Biggs and Tang 2007). I therefore met with the course coordinator prior to planning this session to ensure I understood an overview of the course, the assignment and where my session was delivered within the course. Then I was able to design the session to engage students in deep learning by encouraging thinking and relating ideas together and encouraging the understanding of theory to practice (Fry et al., 2003). I aimed to provide the theory in the formal lecture and engage the students to relate theory to practice during the seminar.

I began the planning of the session by identifying relevant learning objectives. Jones et al., (2011) found unclear learning objectives as one of the six common lesson planning pitfalls made by new teachers. The learning outcomes are necessary to inform the student what they should know, understand and the level of understanding required by the end of the session/course/programme. Learning outcomes should be within a time frame and achievable. The level of understanding within learning outcomes can be identified by

Blooms taxonomy (1956), including the categories of; knowledge, comprehension, application, analysis, synthesis and evaluation. The University of Greenwich Learning and Quality (University of Greenwich 2012) provide appropriate terminology depending on the level of the course. This session was a part of a level 6 course and therefore the appropriate terminology was; critically analyse, evaluate and explore. This terminology was incorporated into the learning outcomes under the anagram of SMART, to ensure they were specific, measurable, achievable, realistic and time bound (refer to appendix I for the learning aims and outcomes for this session).

The importance of information provision for all learning outcomes was to address the issue of constructive alignment (Biggs 1999). Two elements in particular were important; the need for the student to construct meaning from what they need to do to learn and to align planned activities with the learning outcomes. Biggs (1999) highlighted the task of the teacher is to engage the student in learning activities, such as what the students have to 'do' to learn and then 'how' do teachers get students to do it. The planned activities need to include teacher-controlled, peer-controlled and self-controlled activities (Biggs 1999). Teacher-controlled activities included the formal lecture of this session. The peer-controlled activities included the seminar small group work and lastly the self-controlled activities depend on individual student's activities in completing pre-reading or further recommended reading or not engaging in any of these activities.

Learning outcomes are linked to the seven factors underpinning successful learning identified by Race (2010), including; wanting to learn, needing to learn, learning by doing, learning through feedback, making sense of things, learning by coaching other students, assessing their own learning and assessing others to make informed judgements. When introducing the learning outcomes to the students I considered these seven aspects to begin the process of encouraging the students to learn.

I had planned and delivered this session before completing my Post Graduate Certificate in Higher Education and therefore hadn't purposely followed a particular learning theory. Learning theories are varied and complex and include the approaches of; behaviourism, humanism, cognitivism, social learning and constructivism. Retrospectively the session demonstrated the applicability of a number of these theories. Johnson (1992) found that less than 2% of university courses were based on theories of education, which was true of this session.

Learning theories identify different processes of how students learn. Behaviourism describes learning as the association between a stimulus and a response, this perspective is concerned with how the association occurs and what strengthens this association (Jarvis, Holford and Griffin 2003). The stimulus response within this session could be described as the provision of the information and then the students response, which was then strengthen by a relevant YouTube clip. However, behaviourism doesn't acknowledge the underlying mental processes, so the students' learning during this session was not restrained or possibly coherent with the behaviourism perspective.

Constructivism defines learning as an active process, an individual is actively involved in obtaining the information and this is interpreted within the individual's perception of their world. Therefore, learning occurs through an individual working through challenging problems and using these mental processes (Fox 2001). The seminar activities aimed to challenge the students' newly acquired information and apply this knowledge to different clinical settings involving the process of problem solving.

Learning, as described by social constructivism, is also applicable to learning on this session as learning is taking place in a social context (Daniels 1996). Vygotsky was interested in social connections and the role of peers within the sociocultural context in which shared experiences and learning occurs (Crawford 1996). The seminar session in the classroom also allowed learning through the Zone of Proximal Development. The students are able to learn, but allowed to make errors with no permanent repercussions. Vygotsky's Zone of Proximal Development is often compared to 'scaffolding' (Fernandez et al., 2001). The teacher provides only the needed support by providing activities that will enable the student to build on prior knowledge and once the stage of proximal development has been reached, the guidance/scaffolding can be removed. The process is designed to encourage students to engage and internalise new concepts. The small group work and the discussion in the seminar session were to aid this process.

The construction of this session evolved using different process of learning. In hindsight this reflects Snelbecker's (1989) acknowledgement you shouldn't restrict yourself to one theoretical learning perspective but investigate all and apply aspects appropriate to your learning environment.

A possible weakness in my planning of the formal teaching element of this session was my conception of teaching as teacher-centred/content-orientated; I was the teacher with information to impart and would transmit structured knowledge (Kember 1997). I planned a formal teaching session with a PowerPoint presentation; YouTube clips and further reading references. However the importance of the students' learning was central to my approach. During the seminar activities, my teaching began to change from teacher-centred/content-orientated to student teacher interaction/apprenticeship (Kember 1997). I was beginning to see the importance of the students' contribution in the teaching and learning process. The discussions I had when I walked round to each group aided this change as students were helping each other to understand the task and contents of the task. The seminar work highlighted a weakness in the planning of this task, as I had not taken into consideration; the students' current knowledge of the topic. One student had worked as a receptionist in a GP surgery and was able to help her group understand the different team members that work in primary care. I should have considered the students prior knowledge in planning the whole session as Ausubel (1986) acknowledged;

"The most important single factor influencing learning is what the learner already knows. Ascertain this and teach him accordingly."

I had considered the student prior learning on their current programme when meeting with the course coordinator and particularly their learning on the current course, so this lecture could be placed appropriately within their learning. However I had not considered prior learning or prior experiences when planning the seminar task. This is a weakness I have identified in my planning of this session, but an element I will remember when planning future teaching.

The classroom discussion following the small group work was interactive as students' engaged in the discussion and as I was able to facilitate rather than lead the discussion. I became involved when questions were asked and no answer was forthcoming from the group or when facts provided where not accurate. The seminar activities addressed many of the seven factors underpinning successful learning, including; learning by doing, learning by feedback, making sense of things and learning by coaching. The seminar activities encouraged deep learning (Skinner and Whyte 2004) as the students did not concentrate on facts, but were applying these facts and solving complex problems within the clinical speciality provided.

I would like to feel my conception of teaching is developing into student-centred/learning-orientated and I am beginning to facilitate understanding and conceptual development (Kember 1997). My conception of teaching has changed due to direct contact with students and the theoretical understanding of teaching provided by the Post Graduate Certificate of Higher Education. When commencing the last academic year I could not have envisaged my conception of teaching changing to such an extent. Through the progression of the last academic year I have replaced formal lectures with group work, scenarios, discussion and presentations of articles by the students.

My strengths involved my multiple theoretical approaches to teaching and the students' learning, my adaptiveness throughout the session to meet the students' needs and a change in my conception of teaching in higher education, although this occurred over an academic year and in a wider context than this one teaching session. My original weakness was my formal lecture approach and lack of student engagement, although this weakness has been addressed over the past academic year. Originally on planning a two hour lecture I would ensure I presented all the necessary information to the students and this would include around 60+ PowerPoint slides. However, I am more confident in providing the background information for students to continue their own learning with private studies and provide discussions and group work during the lectures. This is a weakness I continue to work on as I occasionally find myself wanting to provide the students with all the necessary information although I am aware this will not engage the student to understand and internalise new concepts.

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Appendix I

Lesson Plan

University:	Greenwich	**Room:**	S011
Course Name:	Health Psychology	**Date:**	
Lesson Name:	Chronic Illnesses	**Time:**	9 – 12
Lecturer Name:	Jo Brooke		

AIMS
The aim of the lecture is to: To develop an awareness of psychological models in coping and adapting to a long term condition, their purpose and how they can be utilised in clinical practice.

Learning Outcomes
By the end of the session the student will be able to:
1. Discuss long term conditions/chronic illnesses
2. Critically analyse psychological models in coping with and adapting to a chronic illness
3. Explore the role of a health psychologist in primary and secondary settings

Session Outline			
Structure	Teacher activities	Learner activities	Resources
1st Part 10 mins	1.Introduction to the structure of the session and long term conditions/chronic illnesses		Power point presentation
2nd Part 20mins	1.Complete a 10 minute task of defining a chronic illness and naming as many chronic illnesses as possible. 2. Discussion following the 10 minute task	Working in small groups, making notes, listing conditions	Power point presentation
3rd Part 30mins	1. Completion of the formal lecture 2. Question and answer session on information provided	Listening, making notes, answering	Power point presentation

		questions	
4th Part – seminar 45mins	1.Working through seminar task in small groups 2. Classroom discussion of seminar work	Working seminar activity in small groups and then participating in a classroom discussion	Power point presentation and handouts

Teaching Evaluation

by

Joanne Brooke

Teaching Evaluation Submitted in Partial Fulfillment

of the Requirements for the Professional Doctorate of Health Psychology

London Metropolitan University

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Teaching Evaluation

Evaluation of teaching is important in the quality assurance process in higher education. The UK Quality Code for Higher Education (2012) outlines important elements for effective learning and teaching, including the promotion of equality, diversity and equal opportunities, and learning facilitated by enthusiastic and capable staff. The importance of evaluation of teaching in quality assurance is highlighted in Indicator 4 of the code:

"Higher Education providers assure themselves, everyone included in teaching or supporting students learning is appropriately qualified, supported and developed."

My role of senior lecturer within the department of Health and Social Care at the University of Greenwich is regulated by the professional body Nursing Midwifery Council (NMC) who state any person teaching pre or post registration nurses must have a formal recognized teaching qualification (NMC 2010). The qualification must be recognized by the NMC and commenced within one year of commencing a teaching appointment.

Since being appointed as a Senior Lecturer I have successfully completed a Post Graduate Certificate in Higher Education and have meet the requirements of the UK Quality Code for Higher Education (2012) and the regulations of my current professional body (NMC 2010). I aim to complete a reflective evaluation of a teaching session which occurred whilst undertaking my teaching qualification and one which was formally reviewed by a Principal Lecture from the University of Greenwich.

The teaching I have chosen to evaluate occurred during the delivery of a lecture as part of a course entitled 'Hyper Acute Stroke Care and Management'. The students undertaking this 30 credit module at Level 6 or Level 7 were qualified nurses working on a hyper acute stroke unit. The lecture concerned primary and secondary prevention within the field of stroke. I have chosen this aspect of my teaching to evaluate as an important element of secondary prevention in stroke concerns the modification of certain health behaviours (Kernan et al., 2010; Greenlund et al., 2002). The modification of health behaviours is central to health psychology and nurses are provided with limited information regarding health psychology during their training. Another aspect of choosing this lecture for my teaching evaluation is my specialist interest in stroke and being a qualified nurse. I am once again able to enmesh my knowledge of health psychology and my knowledge of stroke nursing to provide knowledge, experience and insight into this session.

For a systematic teaching evaluation I intend to use the Framework for Teaching Evaluation Instrument (Danielson 2011). The framework includes four domains; planning and preparation, classroom environment, instruction and professional responsibilities. I will expand on each domain under sub-headings to structure the evaluation. I will also refer to the formal teaching practice evaluation completed by a Principal Lecturer (refer to Appendix II).

Planning and Preparation

Planning and preparation encompasses knowledge of content, knowledge of the students, setting learning outcomes, knowledge of resources, designing coherent instruction and designing student assessments (Danielson 2011).

Preparation is an important first process to inform the planning of a lecture. Preparation by a teacher has been aligned with higher student achievement (NCATE 2006). I began my preparation for this lecture by ensuring my knowledge and skills were current and accurate, this involved researching current evidence based practice and the outcomes of recent clinical trials.

The second aspect of planning this lecture was the consideration of the students' current knowledge, experiences and skills. All students were working on a hyper acute stroke unit and involved in secondary prevention on a daily basis. I therefore had the opportunity to provide in depth specific information regarding secondary prevention to ensure I challenged the students' current level of understanding. An important element of influencing learning is the understanding of what the student already knows and to teach them from this starting point (Ausubel 1986).

Once I had completed the preparation for this session I constructed the learning aims and outcomes (see teaching plan Appendix I). My aims for the lecture were broad and the learning outcomes specified what the student should understand by the end of the lecture and the level of understanding they should attain. My learning outcomes were defined with the terminology 'discuss' as I thought it would be important of the nurses to be able to discuss secondary prevention with patients and their families. However, following the lecture and the discussion with the principal lecturer who had completed the teaching practice evaluation I found my aim was overly complex and the outcomes did not reflect the level of the course. When re-visiting my aim I found I had added multiple concepts into the one aim, rather than breaking the concepts into different aims. Furthermore I had not considered Bloom's taxonomy of learning domains (Bloom 1956), I was aware the students' were completing this course at Level 6 or Level 7 and yet I defined the learning outcomes using the terminology of 'discuss', when 'analyze' or 'evaluate' would be more appropriate. In future I plan to re-visit the course specification before writing the aims and outcomes for a session as this will help me to keep the outcomes at the correct level for the course. Prior to delivering this lecture I had understood the importance of the course learning outcomes to match the level of study being undertaken, but I hadn't applied this to individual lectures within a course. I found this process both challenging and helpful, so in the future I will be able to plan the information to be delivered at the correct level.

Following the construction of learning aims and outcomes, I developed a teaching plan for the session and the amount of time I would spend on each activity including; a PowerPoint presentation, question and answer session and two scenarios.

Classroom environment

The classroom environment involves creating an environment of respect and rapport, establishing a culture for learning, managing classroom procedures, managing students' behavior and organizing space (Danielson 2011). Some of these factors I had already addressed as I coordinate this course and have taught these students on various occasions. There are only 12 students completing this course and as qualified healthcare professionals an environment of respect, confidentiality and professionalism was created at the beginning of the course. The students' all worked on the same hyper acute stroke unit and were existing colleagues before commencing this course, this aided a good rapport, but occasionally limited discussions. An aspect beyond my controlled was the allocation of the classroom, the classroom allocated was small and allowed for no movement or structure to the students seating. The students' only option was to sit around the edge of the classroom with their backs against the walls. According to McGregor (2004) the space in a classroom has implications for the interaction between physical and social spaces. I felt the size of the classroom and the allocation of the seating limited social interaction between different students and possibly affected learning opportunities. An observation by the Principal Lecturer completing the teaching practice evaluation was the interaction between particular students and how this influenced group discussions.

Instruction

Instruction encompasses communicating with the students, questioning and discussing techniques, engaging students in learning, using assessment in instruction and demonstrating flexibility and responsiveness (Danielson 2011).

I commenced the lecture with an introduction and proceeded to the main delivery of the information with the PowerPoint presentation. During this process I included two five minute tasks for the students to complete, the purpose of the five minute tasks was for the students' to demonstrate their current knowledge on the next subject to be explored. From the information the students' provided I was able to base my discussion on their current knowledge and challenge some of their beliefs with more in depth information. I felt this process was successful, however, due to the students' experience in working within stroke they were keen to discuss practical experiences and although these discussions were informative I hadn't allowed enough time for this element of the session.

The five minute tasks were important to ensure an interactive lecture and to avoid a traditional lecture as these are often unpopular with students. Maloney and Lally (1998) recorded a 40% absence rate among third year undergraduate students for formal lectures, and Sander el., (2000) found formal lectures were ranked amongst the least favorite teaching methods. I have spoken to the current students when they were half way through there course and gained feedback from them regarding their experiences. The students completing this course found the discussion of practical elements of nursing stroke patients the most beneficial and I therefore recognized the importance of the students' interaction in each session I delivered.

Due to the time frame I had allowed, the more formal aspect of the lecture had taken too long, I decided to work through only one scenario with the students' and provide the second scenario for them to complete outside of the session. On further discussion with the Principal Lecturer an option was presented that I had not considered, and that was omitting the activity of working through the scenarios to concentrate on the topic that was taking more time, which in this incidence was relating theoretical concepts to practice. When delivering sessions in the future with more than one element I will concentrate more on the students' needs and if this means omitting an activity, the activity can be added to their moodle shell for further information.

The teaching practice evaluation highlighted my effective communication skills with the students and I clearly communicated the structure of the session and the individual components of the session. However, an aspect I was surprised was my challenging of the students and the Principal Lecturer was under the impression I could have challenged the students further. When completing this particular session I was still a relatively new lecturer and although I was confidant to ask the students questions I had not developed the skill to encourage the students to explain their thoughts or understanding in more depth. I feel this is a skill I have begun to acquire through the experience of teaching and teaching a variety of students.

Professional responsibilities

Professional responsibilities encompass reflecting on teaching, maintaining accurate records, participating in a professional community, growing and developing professionally and showing professionalism (Danielson 2011). In the delivery of this session I reflected on my teaching during the session in discussion with the students and asking for feedback to gauge their understanding of the information I had provided, but also following the session with the formal teaching practice evaluation. I found the both forms of reflection helpful to understand my teaching practices and my communication skills with the students.

The teaching practice evaluation is a process of peer observation of teaching, which is a common process in the UK higher education sector for both enhancing teaching and learning and evaluating teaching skills for a formal qualification (Hammersley-Fletcher and Orsmond 2004). Martin and Double (1998) identified six aims of peer observation teaching including; to enhance and extend teaching techniques and styles of presentation through collaboration, to engage in and refine interpersonal skills through the exchange of insights relating to the review of a specific teaching performance and to expand personal skills of evaluation and self-appraisal. I have completed the process on four different occasions, across different settings and students. I have found the discussions following peer review helpful and insightful. The discussions have involved practical ideas for small group working in a large lecture hall, how to address any disruptive behaviour and the specialist skill of teaching in a nursing skills lab with manikins. The discussions have also highlighted strengths of my teaching including the relation of information to evidence based research, my ability to engage the students in an interactive lecture when teaching in a lecture hall and my communication skills with the students with my informal approach. I have found discussing all these aspects of my teaching important to confirm my strengths, but also to highlight my weaknesses and how I can work and improve upon these.

On conclusion I have found completing my Post Graduate Certificate of Higher Education and the teaching competency for my Professional Doctorate of Health Psychology has improved my teaching skills and has changed my approach to teaching and learning. I have had the opportunity to teach a wide range of students completing a wide range of qualifications and through this process have deepened my understanding of addressing the students' needs. I have found the process of peer observation in the form of teaching practice evaluation helpful and insight with discussions with peers that I would not otherwise have engaged in.

References

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Appendix I

Lesson Plan

University:	Greenwich	**Room:**	G101
Course Name:	Acute Stroke Care and Management	**Date:**	22/11/2011
Lesson Name:	Primary and Secondary Prevention in Stroke	**Time:**	11am
Lecturer Name:	Jo Brooke		

AIMS
The aim of the lesson is to explain the differences between primary and secondary prevention within the field of stroke and to examine the importance and implications of secondary prevention, including the evidence base from randomized controlled trials

Learning Outcomes
By the end of the session the student will be able to:
4. Discuss secondary prevention in stroke
5. Discuss the evidence for secondary prevention in stroke
6. Discuss the importance of secondary prevention and adherence to secondary prevention to patients and relatives

Session	**Outline**		
Structure	Teacher activities	Learner activities	Resources
1st Part (10 mins)	1.Introduction of primary and secondary prevention 2.Modifiable risk factors of ischaemic stroke	Taking notes	Power point presentation
2nd Part (30 mins)	1.Main body of lecture explaining secondary prevention 2.Introducing clinical trial evidence to support secondary prevention	Taking notes, answering and asking questions	Power point presentation
3rd part (20 mins)	1.Introduction of 2 scenarios identifying secondary prevention and information	Working through	Power point presentation

	provision 2.Initiating discussion on issues in practice with delivering secondary prevention	scenarios and contributing to discussion	and handouts

Self Evaluation		
Strengths	Areas for development	Action and improvements required
I planned an interactive lecture relating to the students clinical practice expertise, so I was able to change some of their knowledge and work towards expanding their knowledge from the approach of evidence based nursing.	I planned to deliver a lot of information during this session, as I was also challenging the students and discussions were happening this meant the time frame I had allowed for certain aspects of this lecture were soon used up and I was running over time. I was aware of this during the lecture, so I change the lecture around to work on only one of the scenarios after ensuring all relevant information was given, and I gave them the second scenario to take away and think about individually.	I need to be more realistic in the amount of information I can provide to the students and how I should begin this process and allow them to do self-directed study to complete this process. In future I would probably not rush the last section, to ensure at least one scenario discussed, but allow the discussion during the giving of information and then provide the students with both scenarios to take away.

Appendix II

Teaching Practice Evaluation

Practitioner Name:	Joanne Brooke		
Venue:	University of Greenwich		
Date of assessment:	22/11/2011		
Time:	11.30	*to*	12.30
Course being taught:	NURS1400/NURS1401 Hyper Acute Stroke Care and Management		
No. in Class:	6		
Type of session & Topic	Classroom. Primary and Secondary Prevention in Stroke		

Personal tutor	Julie Bowden
Assessor's name	Julie Bowden

Commentary	This lesson was for qualified nurses undertaking Continuing Professional Development in the topic of hyper-acute stroke care.
Preparation:	Jo had prepared a PowerPoint presentation and additional prompts for herself. The presentation was clear and focused. Jo demonstrated substantial subject knowledge and expertise during the session. The session aims and outcomes had been produced by Jo and were shared with the group. The session aim was overly complex and the outcomes did not reflect the level of the course.
Planning: *<u>Lesson Plan</u> checklist* • *Resources & Materials* • *Activities & timings* • *Monitoring learning* • *Links to pre/post*	Jo had produced a lesson plan breaking the hour long lesson into 3 parts. The timing of the lesson did not run to plan with each aspect taking longer than anticipated. The activities were clearly communicated to the group but could have been more challenging. The students were encouraged to ask questions and offer observations throughout the lesson. Jo set the lesson into the context of previous learning within the course and their professional practice.
Delivery:	Jo has a relaxed style of delivery and is confident in front of the students. She was able to adjust the session to ensure most of the material was covered as planned.
Relationships:	Jo has a friendly manner with the students and encouraged them to participate. The students responded to Jo's teaching style very well.

Practitioner Evaluation & Reflection	*The Practitioner writes:* Overall I felt the session went well, I realize I planned the session with a large amount of material to cover, however felt the topic dictated this

	approach. All the students engaged with the tasks without much prompting from me. I realized on re-reading my aims and outcomes for the session, my aims were confusing with some outcomes included. Also the outcomes were not written at the level of study the students were undertaking. Revisiting the course specification before writing the aims and outcomes before each session should help me to keep the outcomes at the correct level for this course. I began to challenge the students during the session, but due to the heavy content of the session I should have considered giving the students the 2 scenarios to take away and prepare a discussion for next week as this may have produced more in depth discussions. I found this assessment very useful as the discussion afterwards with Julie Bowden led to ways to keep the student engaged and challenged throughout the length of the course and also how to introduce some formative assignments to aid toward their summative assignment.
Tutor evaluation & conclusion	Following the lesson Jo and I discussed the following issues / areas for improvement: 1. Aims and outcomes. These need to reflect the level of the course and include high level intellectual skills for students such as these studying at level 6 and 7. Revisiting them at the end of the lesson will help the students to focus on their learning. 2. The activities within the session need to be challenging to the students. If time does not allow then such activities can be set as individual study within the framework for the course. 3. If a lesson is not running to time as per the plan the teacher must decide whether to omit an activity or try to do the intended activities in a different time frame. Omiting an activity and concentrating on the topic that is taking more time to cover is an acceptable strategy.

DVD of teaching and reflective commentary

by

Joanne Brooke

DVD of Teaching and Reflective Commentary Submitted in Partial Fulfillment
of the Requirements for the Professional Doctorate of Health Psychology

London Metropolitan University

January 2013

DVD of teaching and reflective commentary

The attached DVD is an example of my teaching, this is only one of the teaching styles I use in practice and is in a large lecture theatre, with 150 students in attendance. The example I have attached is an introduction of a course I coordinate, the course is a level 5, 30 credit course for 2nd year students completing an Adult Nurse BSc. The course is called 'Hospital and Home: Care of the Client in the Community and Surgical Setting".

I feel the introduction lecture is extremely important as the students' need to understand the course, what is expected of them and what they can expect from the course, the course coordinator and other lectures who teach on the course.

The aims and learning outcomes of this session are to ensure the students understand the content of the course, the relevance of the course to practice and assessments to successfully pass the course. I begin the session by asking the students why they think they need a course linking hospital and home. The students discussed the discharge process and the importance of continuation of care in the community. The students have been in practice for 18 months, both in hospitals and in the community, so had an understanding on the emphasis of the importance of short hospital admissions and intense care in the community.

Following the brief discussion of the necessity of the course I introduce safe and effective discharge. I highlight the importance of safe and effective discharge by providing examples of when healthcare professionals failed to provide this process and the consequences for the patient and their family. The two examples are from the Parliamentary and Health Service Ombudsman 2011 report and are audio files of family members speaking about their distressing experience and the complaints process. The two audio files engage the students in a discussion regarding current practice. The students in the current session engaged in a discussion of discharge processes they have recently been involved with. The two examples I introduce are recent and true stories I am therefore aware that some of the information is sensitive and could by upsetting for some of the students. However on this occasion the students were indignant with the care the patients had received.

The course introduces the importance and relevance of national policies and how these are implemented by local NHS Trusts. The course aims to provide the students with a strategic overview of national policies and local NHS Trust initiatives and the implications for the students when they become qualified healthcare professionals. The exam of the course requires the students to understand national policies relevant to decreasing hospital stays and care in the community and how these are implemented in the NHS Trust they are attached to.

The session is in a large lecture theatre, although only three students are seen within the DVD, 150 students attended this lecture. The students are not identified to maintain their confidentiality. The lecture theatre has a capacity for 200 students and due to the size of this teaching environment I use the microphone attached to the AV system to ensure all students can clearly hear my voice. However, I am aware that this then restricts my movement around the lecture theatre. I am also aware during discussion I need to repeat the students question or comment as other students may not have heard. I feel over the past two years I have gained confidence in teaching in large lecture theatres and I am more relaxed and engage the students in discussions. I have also developed my teaching style as to not rely on PowerPoint slides, although I still structure my lecture with slides, I ensure I use other mediums such as audio or video clips as well as group and individual discussions.

The current session was interactive and the students were able to ask questions concerning the course to ensure all aspects were understood. This occurrence is the fourth time I have introduced this course to students and on each occasion I include information students have previously asked. I have developed the session to include more discussion and the included the two audio clips to engage the students. I feel this process of continually developing this session has ensured the session is relevant for the students and the information they want to know regarding the course rather than the information I think they should know.