

**Making stroke services equitable for minority
groups: the potential role of cultural
competence**

by

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Abstract

Background: In stroke services, providers are challenged to address the needs of people from ethnic minorities.

Aim: This thesis will explore the stroke service needs of people from ethnic minorities, and how stroke services can address them.

Part 1; Methods: Two group interviews with South Asian participants were used to inform an interview schedule. Using this schedule, 23 individual interviews were performed with South Asian participants, some of whom had experienced a stroke and some who had not.

Part 1; Findings: Participants who had not used stroke services held positive expectations about those services. Participants who had used stroke services were negative about their overall experience. Attitudes and behaviour of service providers were seen as poor, and that they lacked an understanding of culturally specific issues. Participants expressed a need to be treated as an individual, to feel cared for and respected, and suggested that staff receive training to address this. Further research was needed to explore the efficacy of training service providers to be culturally competent.

Part 2; Methods: Online databases were systematically searched for interventions evaluating service provider cultural competence training, and papers on theoretical frameworks of cultural competence. Components of theoretical frameworks were compared and evaluated. The training literature was evaluated and synthesised using realist methods. A stakeholder group reviewed the findings and made recommendations for practice.

Part 2; Findings: Three overarching components reflected these theoretical frameworks, which were; cultural awareness, knowledge and skills. The success of

training interventions, underpinned by these components, varied by the type of outcome measured. Where intervention outcomes were based on service providers' self-reports they were perceived to be effective; where outcomes were based on service-user ratings they were perceived to be moderately effective, and where outcomes were based on clinical assessments they were perceived to be ineffective. The few studies with service-users rating their experiences indicated that a more detailed awareness of cultural issues coupled with practice improved ratings. Other studies have demonstrated that service-user ratings and outcomes can be improved by individuals, or teams, with effective levels of cultural skills implementing subject-specific health interventions. Underpinning these interventions were the understanding of service-users' cultural needs, matched with appropriate skill-sets of teams or individuals.

A stakeholder review of these findings confirmed that raising cultural awareness is an important first step in improving staff cultural competence. In addition, translating training into practice and matching the expectations of minority group stroke service-users, requires on-going support at an organisational and leadership level, with which confidence can develop through mentorship and shaping.

Conclusion: The available evidence has shown how to provide cultural awareness knowledge and skills training, but not how to translate this into practical cultural competence. This thesis explores further existing evidence to draw out components and mechanisms that seem to truly deliver cultural competence. Based on a systematic literature search and a realist review, this thesis proposes a model to suggest how true cultural competence can be achieved.

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Chapter 1

Introduction

1.1 Introduction: caveat

As this thesis is concerned with people from a range of ethnic origins from the Indian sub-continent, a decision was made to use the term South Asian; this is consistent with the current norm (Aujla et al. 2009; Banerjee et al. 2010; Bellary et al. 2010; Bennett et al. 2010; Hussain-Gambles 2004), the definition for this thesis is in section 1.2. This thesis examines the issues in stroke care that should be considered to address the cultural health needs of people of South Asian heritage. Both stroke and South Asian minority groups will act as exemplars, as it is acknowledged that the findings and discussions will have relevance for other conditions, and other minority groups. Minority groups in this thesis are defined as groups that make up the sectors of the population that are not white British, irrespective of place of birth, which are estimated at 9% of the UK population (Office of National Statistics (ONS) 2010).

1.1.1 Scale of stroke

Each year approximately 110,000 people in England have a stroke, and 20 – 30 % of these die within one month, making stroke England's third largest cause of death, behind heart problems and cancers (National Audit Office (NAO) 2005). Though not the largest single-factor cause of adult disability, it is the most common cause of complex, or multi-factor disability, resulting in 300,000 people in England living with a moderate to severe disability (Adamson et al. 2004; NAO 2005).

Stroke costs the combined economies of England and Wales, including the National Health Service (NHS), approximately £7 billion a year. This includes direct costs for

the NHS, the cost of home nursing, and indirect costs such as loss of income from reduced production and support costs for disabilities (NAO 2005). Despite the scale of stroke, the population as a whole have limited awareness about what a stroke is, or the risk factors associated with it (Department of Health (DH) 2007). In addition, some groups in society have an increased risk profile for stroke, and associated conditions (Kothari et al. 1997; Pancioli et al. 1998).

1.1.2 Groups at risk of stroke

Risk factors for stroke are well documented (Sacco et al. 1997). These factors fall into two groups, modifiable and non-modifiable. Modifiable risk factors are associated with lifestyle, for example, diet, smoking, and lack of exercise. These are, in turn, associated with other modifiable factors, hypertension, heart problems, high cholesterol, and diabetes. Non-modifiable factors include age, gender, heredity and ethnicity (Sacco et al. 1997).

The presence of multiple risk factors increases the probability of having a stroke several fold. Some minority groups, such as people of South Asian heritage, are at a greater risk of stroke because of multiple risk factors, including elevated levels of non-modifiable and modifiable risk factors, compared to the general population (Banerjee et al. 2010).

1.2 South Asians in the UK

South Asian is a term that includes people from a large geographical area, which includes India, Pakistan, Bangladesh, and Sri Lanka. Each of these sub-groups is not homogeneously populated and comprises many distinct ethnic and religious groups.

This description of South Asian is not the only one, as some include other countries in

the region, such as Afghanistan, or Nepal (Farmer 1993). For this thesis the definition will only include the four countries indicated above as these are the main ethnicities from that region designated in UK census data (Office for National Statistics (ONS) 2003). Though people from South Asia have been migrating to the UK for at least three centuries, the majority of the current South Asian community members have arrived in the last 60 years, mainly from the Indian sub-continent and East Africa (ONS 2010).

According to the last available census data, (2001), the South Asian sub-groups comprise 5.7% of the total population of England. Though distributed throughout the country, the majority live in and around London and the West Midlands, with sizable communities in West Yorkshire and East Lancashire (ONS 2010).

The age distributions of these sub-groups are similar to one another, but different from the general population. The South Asian groups tend to have a majority of younger people, less middle-aged people, and even fewer older people. The general population tends to have similar proportions of younger and older people, but the majority of the population are in the middle-age groups (ONS 2010).

The UK South Asian population differ both within and between sub-groups in a number of ways. For example, though age distribution is similar between sub-groups, this differs between males and females. In addition there are differences within and between sub-groups in language, culture, religion, diet, and environment (Balarajan & Raleigh 1997), as well as standardised mortality ratio (SMR), causes of death and health status (Gill et al. 2005).

1.2.1 South Asians and Stroke

The SMR compares death rates in specific groups in a population, to the majority group in a population, which is standardised, or nominated as 100. For Indian males the SMR for cerebrovascular disease (CVD) is 134 (95% CI 123-147), for Pakistani males it is 149 (95% CI: 127-174) and for Bangladeshi males it is 281 (95% CI: 232-337) (no data found for Sri Lankans) (Gill et al. 2005). The figures indicate an increased SMR for CVD in South Asian groups compared to the general population, and a within group variation, for example Bangladeshi males are 2.81 times more likely to die than white British males (SMRs 281 and 100 respectively).

What is not explained by the SMR is the aetiology of the cause of death, the links with life experiences, and the impact of stroke on the majority of South Asians that survive their stroke event. Yet, the ability to further explore the issues of aetiology, and impact is severely restricted by the lack of a comprehensive and valid ethnicity monitoring system in health care (Aspinall & Jacobson 2005). Ethnicity data recording is not currently mandatory for primary care, and its use is unstandardised, and ad-hoc (Aspinall & Jacobson 2005; Association of Public Health Observatories (APHO) 2005). For secondary care, ethnicity coding is mandatory but in the Hospital Episode Statistics (HES) recording was poorly carried out, making analyses difficult (Aspinall & Jacobson 2005). Even in the regions of the UK where South Asian communities are clustered, there was no relationship between minority group density, and completeness of ethnicity coding, which could indicate organisational issues are responsible for the inconsistency in recording ethnicity data (APHO 2005). For the purpose of this thesis, primary care is seen as taking place in a community setting mostly by general practitioners; secondary care takes place in hospitals, both short and long term. Health care is defined as 'composed of health care systems and

actions taken within them designed to improve health or wellbeing' (Campbell et al. 2000b p1612).

One local study has monitored ethnicity data for strokes (Banerjee et al. 2010). Over a four-year period, this study recorded ethnicity data on a stroke register. They found that, compared to the general population, South Asian people suffered strokes at a younger age, had significantly higher levels of diabetes, hyperlipidemia, and hypertension despite significantly lower levels of smoking.

Thus, South Asian stroke mortality is higher than the general population, and it would seem that these groups have multiple, and raised levels of both modifiable and non-modifiable risk factors. However, because of poor data recording we do not know the part played by a lack of equity in service provision, or the efficacy of that service provision (Iqbal et al. 2009). The impact of inequitable provision of stroke services will become increasingly important for South Asian groups, as not only are the majority of the South Asian population young, but they also have strokes at a younger age than the general population (Blackburn with Darwen Borough Council (BwDBC) 2005; ONS 2010). Thus as the South Asian population ages, the number of people at risk of stroke could rise exponentially.

1.3 Stroke policy and minority groups

The lack of equitable service provision for minority groups has been well documented (Aspinall & Jacobson 2005; Balarajan 1991; Balarajan 1995; Cain & Kington 1991; Cappuccio et al. 1997). For stroke, an attempt to address this disparity was enshrined in policy with the National Service Framework for Older People (Department of Health (DH) 2001). This policy required services to be provided, which proactively

target at-risk minority groups. No guidance on how this was to be implemented was provided, but it would seem that little progress was made, as the same issue was raised in later policy documents (DH 2007; Intercollegiate Working Party for Stroke (IWPS) 2004a; NAO 2005). Re-iteration of this issue in successive policy documents would suggest that there are on-going problems for minority groups in the UK accessing relevant stroke information, as well as prevention initiatives and stroke services. This issue has been highlighted in the literature, for example, when in hospital for stroke, people of South Asian heritage are managed differently from the general population (Bourke et al. 2006; Hsu et al. 1999; Stewart et al. 1998; Wolfe et al. 2002).

People of South Asian heritage are not reluctant to use hospitals, and studies indicate that ethnicity was not associated with a resistance to access primary or accident and emergency care (Adamson et al. 2003). Indeed, the use of primary care by minority groups regularly exceeds that of the general population (Adamson et al. 2003; Smaje 1998; Smaje & LeGrand 1997).

1.4 Health care needs and perspectives of South Asian groups in the UK

Though people of South Asian heritage are not reticent in seeking health care, little is known about the health care needs or perspectives of people from these communities (Payne & Saul 1997). Health care needs are difficult to define (Acheson 1998), but for this thesis need will be considered as what is required of health services to keep or return a person to an optimum level of health, within the restrictions of resources available (Acheson 1998; Donabedian 1993). Further, throughout this thesis the term perspective will be used to describe the point of view, or way of regarding something by a group or individual (The Oxford English Dictionary (OED) 2012).

A preliminary scoping review for this thesis (Hagell & Bourke Dowling 2012), found that the literature describing the health needs and perspectives of South Asian groups were limited, and stroke specific studies were more so. A limited number of hospital services satisfaction surveys have been conducted, and have found a reasonable level of satisfaction, but topics such as lack of information, food and admittance procedures were negatively rated (Madhok et al. 1992; Madhok et al. 1998). The sample sizes in these surveys were small, and to compound the problem, survey methodology used in trans-cultural work is reported to have problems with reliability and validity (Bird et al. 2011; Boniface & Burchell 2000). These problems include low levels of agreement between open-interview and survey item responses (Boniface & Burchell 2000), differential response rates across South Asian sub-groups (Commission for Health Improvement (CHI) 2004), and responders differing significantly from non-responders on confounding factors, such as level of deprivation and education (Boersma et al. 1997).

Two qualitative studies have explored the experiences (what people lived through or participated in), views (their personal perspectives), and perceptions of hospital services with people of South Asian heritage (Clegg 2003; Vydelingum 2000). These studies found that service-users were positive about their clinical care, but negative about their overall experiences. The negative perceptions (or world view) included, issues (or important topic) of dignity, lack of information, poor regard for the context of family, and problems coping after discharge from hospital. Participants claimed they also tried to fit in to an 'English' place and felt like strangers in a crowd (Clegg 2003; Vydelingum 2000). Unfortunately, these studies had small sample sizes, which

makes interpretation unreliable because of the questionable classification of South Asian minority groups (Iqbal et al. 2009; McKenzie & Crowcroft 1996).

1.4.1 Comparison with the general population

There is evidence that the general population also have negative and positive perspectives and experiences of clinical and non-clinical service provision. (Eames et al. 2010; Howell et al. 2007; Jones et al. 2008). A systematic review examined the experiences of acute stroke services of a sample of service-users from the general population (Murray et al. 2003). This review highlighted negative issues such as poor communication, poor general care, thoughtless comments, lack of consideration of the family, and lack of involvement in the discharge process. After the acute phase participants felt abandoned by stroke services. A further study, with a cross-section of the general population, specifically explored stroke service-users' experiences in the acute phase (Morris et al. 2007). The findings indicated similar issues: information-giving was consistently poor; staff attitudes were variable, with a minority holding negative attitudes; clear shortfalls in availability of care/treatment; a failure to treat service-users as individuals; and a failure to see service-users 'in context', which included consideration of impact on the family.

Despite this similarity of negative service perceptions in the general population, a review of the literature in Chapter 4 indicates that, while ethnicity recording in UK health care is generally poor (APHO 2005), where data do exist the worst service-user experiences for all admissions was reported to be in South Asian groups (APHO 2005). This finding may indicate that though the issues reported above may show similarities between groups, people of South Asian heritage continue to receive a lower quality service than the general population.

1.5 Evaluating quality in service provision

Quality of care has been defined by the [US] Institute of Medicine (IOM) as “the degree to which health services for individuals and population increase the likelihood of desired health outcomes, and are consistent with current professional knowledge” (Khon et al. 2000). A model that could help to assess the quality of health care was proposed by Donabedian (Donabedian 1966). The basic approach is to consider ‘Structure’ (the setting and resources where health care is provided), ‘Process’ (what is done to and by the service-user); and ‘Outcome’ (the impact of care on the service-user); and is often referred to as S-P-O. This thesis will use the Donabedian proposals as an over-arching framework when discussing the quality of health care. There are further sub-levels of care; technical care, the level of medical skills; interpersonal care, the quality of the interactions between user and provider; and amenity care, how well the service-user was accommodated during their care.

Assessing the quality of health care is not straightforward: for example clinicians and consumers assess the quality of care from different perspectives, which must be considered when reviewing discussions of care quality (Turner & Poll 2004).

Donabedian discussed care quality assessment in terms of using the S-P-O concepts in isolation, in pairs, or all three (Donabedian 2005). Donabedian was also aware that there was a danger of a focus on outcome as a metric of quality, as he understood that there were relationships between outcomes and structure and process (Campbell et al. 2000b). That said, he concluded that, "outcomes, by and large, remain the ultimate validation of the effectiveness and quality of medical care" (Donabedian 2005 p694); this will be discussed further in Chapter 2. For accuracy and clarity through this

thesis ‘concept’ will be defined as an abstract idea, its root is in conceive, to imagine (The Oxford English Dictionary (OED) 2012).

1.5.1 Health care service need

It is important that an accurate picture of service need is established, as this will be the driver for all other service provision initiatives. Service need is established by using estimates of the incidence and prevalence of illness, as well as other issues such as elevated levels of illness risk, derived from robust studies (Williams & Wright 1998).

1.5.2 Health care service use

This concept is used to describe the incidence of interactions between health services and health service-users and has been described as health care episodes (Hornbrook et al.). The only way of accurately estimating service use is through comprehensive and valid data collection, at all levels of health care provision (APHO 2005).

Unfortunately, there is an incompleteness of ethnicity coding across most datasets and regions (APHO 2005). In addition, different classifications of ethnicity are still being used, which causes a problem for any subsequent analysis. It has also been reported that there is no relationship between the completeness of ethnicity coding and the size of minority populations, suggesting that problems with data recording are at an organisational level (APHO 2005).

1.5.3 Health care information

Information provision problems cover all areas of stroke: primary prevention; signs and symptoms; and the treatments available for people who have a stroke (Smith et al. 2008). In addition, information provision for service-users and relatives at all stages

of a service-user's pathway of care is poor, which prevents people making informed choices about their health (Smith et al. 2008). Unfortunately for minority groups, it has been reported that there is almost a complete lack of evaluated published interventions that target minority groups with stroke information and awareness programmes (Dr Foster Intelligence 2010). Service use, need and information will be defined and discussed in more detail in Chapter 2.

1.5.4 Summary of health care issues for South Asian groups

The lack of research into the needs, perceptions and experiences of minority groups is a cause for concern (Commission for Healthcare Audit and Inspection (CHAI) 2006). It is therefore important to examine what can be done in a pragmatic and appropriate way to ensure that minority groups receive an equitable level of health care service. This thesis will use South Asian minority groups as exemplars to explore inequitable health (stroke) care for minority groups. South Asian minority groups are reported to have the worst health care experiences and outcomes compared to all groups in the UK (APHO 2005). They have higher levels of modifiable risk factors for stroke (Sacco et al. 1997) and a higher incidence of deaths from CVD compared to the general population (Gill et al. 2005).

1.6 Research questions

Thesis Aim

This thesis will explore the stroke service needs of people from ethnic minorities, and how stroke services can address them. This thesis is in two parts, Part 1 addresses research question 1, and Part 2 addresses research question 2.

1.6.1 Part 1

Research Question 1: What are the issues for people of South Asian heritage in accessing health (stroke) services?

Aims:

To establish the context of South Asian minority groups in the UK, the political and clinical observations of these groups and how stroke affects this group. With the context established explore the stroke care experiences and perceptions of South Asian groups in one area of the UK. From these findings develop a tentative hypothesis that proposes the issues for these groups accessing equitable stroke care. Finally review the literature reporting barriers to accessing equitable care in the UK.

Objectives:

- i) Describe the context of stroke and minority groups in the UK
- ii) Describe and evaluate key UK policy documents on health and minority groups
- iii) Discuss and evaluate equity and access to health care in the UK
- iv) Describe and justify the methodological approach to address the first research question
- v) Explore the experiences and perceptions of members of South Asian groups in an area of the UK regarding access to stroke care
- vi) Develop a tentative hypothesis to explain inequitable care for UK South Asian groups
- vii) Review the literature that considers equitable access to health care in the UK for minority groups.

1.6.2 Part 2

Research question 2: What would be the (stroke) service requirements to meet the needs and overcome the issues described in Part 1?

Aims:

To review the literature on the models and frameworks of cultural competence (defined below), and cultural competence training interventions. Using these reviews, propose a new theoretical framework of cultural competence, consider the evidence to support the proposition, and recommend how cultural competence can be developed in practice.

Objectives:

- i) Review the literature of cultural competence theories and conceptual models
- ii) Evaluate the evidence for these theories and models
- iii) Develop a synthesis of a new conceptual model supported with evidence
- iv) Propose a way forward in training health care staff in true cultural competence
- v) Describe how this thesis addresses the research questions on which it was based.

1.7 Outline of this thesis

Part 1 of this thesis (Chapters 2 to 4), addresses the first research question: What are the issues for people of South Asian heritage in accessing health (stroke) services? In this context the word issues includes the factors, barriers, and problems etc. that are perceived by members of South Asians groups to prevent access to stroke services. This part of the thesis explores the stroke care experiences and perspectives of local South Asian groups. The outcome from this part is a tentative hypothesis that proposes the issues that result in inequitable stroke care for minority groups.

Chapter 2 includes a discussion of health care needs from the perspective of ethnic minority groups. UK health care policy, as it relates to minority groups, is also explored. There are discussions of concepts such as ethnicity and culture, as well as the impact these have on the social identity of individuals and groups. The status of minority groups compared to the majority group in the UK will be discussed. This chapter also includes a discussion of the quality of health care provision and the ways this is estimated, because equality of access is a quality issue (Campbell et al. 2000b). Concepts related to equitable access to health care, service use and service need, as assessment metrics are defined and discussed. Chapters 2, 3 and 4 constitute Part 1 and Figure 1.1 indicates how these fit together.

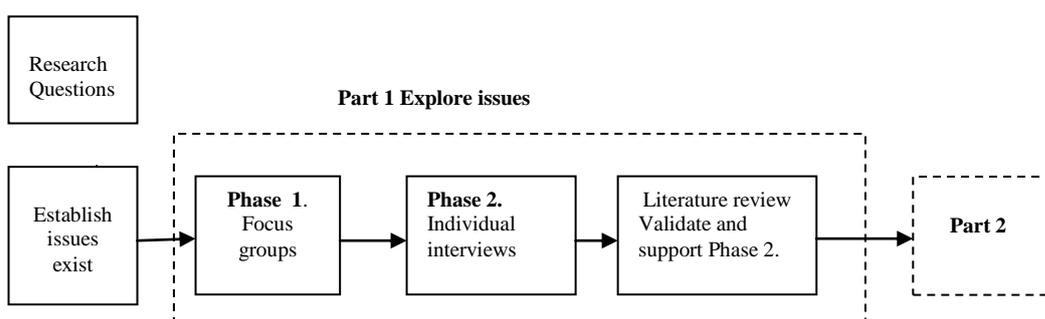


Figure 1.1 Plan of Part 1 of this thesis

Chapter 3 describes the first of the investigative elements of the thesis. In this chapter the collection and analysis of qualitative data is described and the decision to start data collection with limited knowledge of background material is discussed. Focus groups and individual interviews were used to explore the issues that people from South Asian groups perceive as barriers to a culturally appropriate service. The culmination of this chapter is a tentative hypothesis that proposes that people from

minority groups do not receive equitable stroke care. This hypothesis describes two issues, only one of these issues will be the subject of this thesis, the second issue is addressed in separate work (Auton et al. 2008).

Chapter 4 is a review of the literature that looks at equity of access for minority groups in a range of health care situations. Equity, for this thesis is defined as "the absence of disparities in health that are systematically associated with social advantage or disadvantage" (Braveman & Gruskin 2003 p 245). The review is considered with reference to the findings of the previous chapter, as a form of validation. The literature that specifically investigates people of South Asian heritage and stroke is limited. Because of this, discussion of background material and policy documents will focus on 'minority groups' and a range of health conditions, rather than specifically considering South Asian groups and stroke. The chapter commences with a description of how the literature was identified and evaluated. It then describes two recently developed conceptual frameworks that have been used to help make sense of the disparate nature of the literature around barriers to accessing care. Elements of these frameworks are used to classify the results of the review and used as explanatory concepts throughout the thesis.

Barriers to accessing health care could originate with service-users, service providers, or both. The potential barriers that may be located with service-users and providers are considered separately. Comparisons are made with the findings from the empirical work described in Chapter 3. Chapter 4 concludes with a description of how the aims and objectives of Part 1 are addressed.

Part 2 of this thesis (Chapters 5 and 6), explores the current theoretical and practical approaches to cultural competence and training to address the second research question: What would be the (stroke) service requirements to meet the needs discovered in Part 1?

Chapter 5 justifies the methodological approach taken for a review of the literature, which explored the efficacy of training interventions that were devised to develop cultural competence with service providers. Cultural competence has been defined as a "process in which the nurse [provider] continuously strives to achieve the ability and availability to effectively work within the cultural context of a client (individual, family, community)" (Campinha-Bacote 1999). A case is made for undertaking a systematic review of controlled trials that investigate cultural competence training, the review and synthesis are carried out using realist principles (Greenhalgh et al. 2007). Realist work aims to provide a tailored transferable set of recommendations, based on the best available evidence. These recommendations describe what works, for whom, and in what circumstances (Pawson & Tilly 1997). This chapter also briefly considers existing syntheses of conceptual frameworks of cultural competence, and makes an initial comparison of the frameworks (Balcazar et al. 2009; Jirwe et al. 2006). These comparisons are considered in more detail in Chapter 6.

The application of realist principles to a set of retrieved studies is the focus of Chapter 6. Realist principles include estimating what works, for whom in what circumstances and describes these in context, mechanism and outcome configurations (CMO) (Pawson & Tilly 1997). This chapter considers two syntheses of separate frameworks

that describe cultural competence. Visiting the original sources of these syntheses, a meta-synthesis is undertaken and described. The evidence to support this meta synthesis is evaluated using realist principles. The early findings of this chapter were presented to stakeholders engaged in cultural competence training on a regular basis. The recommendations of the stakeholders resulted in a limited scoping review of the literature to retrieve, and evaluate further evidence for the impact of cultural competence interventions. These were problem-focussed, culturally competent interventions for specific conditions.

Chapter 7 is a findings/discussion chapter, where findings and recommendations from all sections of the thesis are discussed in light of the previously evaluated research but where there is still a measure of theory development. A new conceptual framework for cultural competence is proposed from evaluations and syntheses of earlier frameworks. This work resulted in a pragmatic, evidence-based framework that can be used in training initiatives to develop true cultural competence in service providers. An attempt is made to develop a final model of cultural competence that combines the overarching SPO framework with the proposed conceptual elements in stages of development, and the evidence that was found to support them. A further development is undertaken to propose a symbiotic relationship between the SPO and CMO frameworks and the newly developed cultural competence stages of development.

Limitations of the thesis are discussed in this section to augment limitations discussed throughout the work. Recommendations for practice, areas of further research and the contribution to knowledge made by this thesis are presented.

Part 1

Chapter 2

Stroke and people of South Asian heritage

2.1 Introduction

This chapter contextualises both ethnicity and stroke in UK health care policy. It also tracks the development of UK stroke policy as it relates to minority groups. This is to establish what perceptions are held by policy makers of minority groups, especially South Asian groups, in relation to stroke care. This Chapter is intended as a general overview of the context of stroke and (South Asian) minority groups in accessing equitable stroke care. To do this there will be a discussion of the concepts that are associated with equitable health care; need, use, and access (Goddard & Smith 1998; Goddard & Smith 2001). Equity of health care is related to the quality of health care for populations, which will be discussed with reference to the structure, process and outcomes of health care (Donabedian 2005). This Chapter addresses objectives (i), (ii), and (iii) of Part 1 of this thesis and contributes to addressing the aims of Research Question 1, to explore barriers to equitable care for minority groups.

2.2 The context of stroke

Stroke is a clinical syndrome of presumed vascular origin, typified by rapidly developing signs of focal or global disturbance of cerebral functions, lasting more than 24 hours or leading to death (IWPS 2004a). Each year stroke affects between 174 and 216 people per 100,000 population in the UK, and it accounts for 11% of all deaths in England and Wales (NAO 2005). Strokes are caused by the reduction in quality and/or quantity of blood to the brain, either through a blockage, or the rupture of a blood vessel (IWPS 2004a).

Common symptoms of stroke are a sudden onset of neurological loss that leads to new facial asymmetry, weakness, or paralysis on one, or both sides of the body, and new speech problems. If the stroke symptoms last less than 24 hours, the event is termed a transient ischaemic attack (TIA), although the advent of new emergency treatments and classifications of TIA seriousness has led to a revision of practice (Panagos 2011; Rothwell & Warlow 2005). Approximately 35 per 100,000 of the population suffer a TIA each year and, apart from the duration of the event, the symptoms can be the same as a full stroke (NAO 2005).

Until the mid-1990s, the care for acute stroke was mainly supportive (Zerwic et al. 2007). Since then, the developing efficacy of specialist stroke care has had a positive impact on both service-user survival, and the survivors' levels of disability. With the advance of acute stroke care has come the understanding that delays in treating strokes could lead to stroke progression, when the area of brain damaged by the stroke increases, as does the risk of death (Stroke Unit Trialists Collaboration 2002). Thus, in terms of death and disability, accessing hospital care for stroke is increasing in importance. The link between delay in accessing acute care, and stroke progression, when a stroke worsens has led to the current view that stroke, in the acute phase, should be treated as a medical emergency requiring urgent hospital care (NAO 2005). The evidence of effectiveness of thrombolysis, the injection of drugs to reduce blood clots, when given very early after stroke onset, has further heightened the imperative to treat stroke as a medical emergency (Pitcock et al. 2003).

South Asian minority groups are known to be at a greater risk of stroke than the general population and have a disproportionate prevalence of stroke (Aspinall &

Jacobson 2005; APHO 2005; Banerjee et al. 2010; Gill et al. 2005). Because stroke is a medical emergency, and the efficacy of early post-stroke treatment has increased, it would seem important to explore how key UK stroke related policy documents and reports aim to address the stroke care needs of South Asian groups.

2.3 Key reports and policy documents on stroke

In 2001, the Government of the day published a set of standards and service models that targeted specific health concerns in England and Wales. Unfortunately, stroke was not afforded a dedicated framework but was included in The National Service Framework for Older People (NSF) (DH 2001). The NSF set out a ten-year plan to improve the health of older people in England and Wales. The standards were multidisciplinary in approach, and provided milestones for the achievements required. Despite stroke being a sub-category, the NSF did indicate deficiencies in the provision of stroke care for people from minority groups. The NSF report required that services needed to be sensitive to the needs of minority-groups, and not be culturally biased (DH 2001). In addition the NSF required health care services to remedy the current position whereby older people from minority groups suffered a disparity of service, compared to the general population. Unfortunately, the NSF did not set out how these aims were to be achieved or prescribe standards by which improvements could be audited.

A five-year review of the NSF indicated that both stroke clinical care and service organisation had improved: it also indicated that there seemed to be little advancement on the recognition of stroke needs in minority populations (CHAI 2006). The report continued with a call for a greater consideration of the health care needs of minority groups in service provision, and for commissioners of services to consider

such needs in all that they do. Again, no areas of need were specified and no strategies for improvement were proposed. Health care needs in this context are related to available resources, as people can have needs that cannot be met (Oliver & Mossialos 2004). Therefore need can be seen as the capacity to benefit from treatment currently available (Culyer 1998; Culyer 2001).

In contrast, the National Clinical Guidelines for Stroke (NCG) (IWPS 2000) pre-dates the NSF but makes no mention of ensuring the suitability of stroke services for people from minority groups. The NCG do indicate that such services must fit the needs of individuals, and this generalisation is continued through revisions in 2004 and 2008. In later revisions, apart from requiring that African/Afro-Caribbean people have blood pressure reduction intervention at any age (rather than >55), there was no specific mention of the needs of other minority groups at risk of stroke (IWPS 2004a), which was also not explained.

To assess implementation of the guidelines, the Royal College of Physicians publish a biennial sentinel audit. Each iteration of the audit sets out how stroke care has increased in penetration, scope, and quality (Intercollegiate Working Party for Stroke (IWPS) 2004b). These audits have not explicitly assessed the quality of stroke care provision for people from minority groups, which is understandable, as this is not set as a clinical guideline. However, the RCP also carry out audits on the organisational elements of service provision, but to date the assessment of stroke care for minority groups has not been included (Intercollegiate Working Party for Stroke (IWPS) 2008).

A further Government report focussed on the efficacy and efficiency of stroke care, and also discussed the issue of stroke service provision and minority groups (NAO 2005). The NAO reviewed expenditure on stroke care to explore value for money. Although the NAO did note that stroke care had developed in recent years, it also noted that much more could be done within the existing expenditure to save lives and reduce disability. The NAO highlighted instances of good practice, but commented on the inconsistent nature of their cross-national application. One of these inconsistencies was that public health campaigns had achieved modest success in raising awareness about stroke, and the least success was with ethnic minority and deprived groups. This position remained unchanged five years later (Dr Foster Intelligence 2010).

The advances in stroke care and medicine are instrumental in reducing death and disability due to stroke (NAO 2005; Pittock et al. 2003) and contributed to the development of a new 10 year stroke-specific framework in the National Stroke Strategy (NSS) (DH 2007). This document recognised that minority groups continue to be at an increased risk of stroke compared to the general population. Despite challenging service providers to consider how to meet the needs of black and ethnic minority communities, the report still did not suggest how this should be implemented, or how to assess improvements.

The National Institute for Clinical Excellence (NICE) was established in 1999 to promote efficacy and cost effectiveness of health care provision (National Institute for Clinical Excellence (NICE) 2008). It was not until 2008 that NICE published guidelines for stroke (NICE 2008). Like other national guideline documents on

stroke, it recognised that treatment and care needed to be culturally appropriate, but did not go as far as offering implementation guidelines or assessment criteria.

Five years on from the NAO report on stroke care, the House of Commons Committee of Public Accounts published a report on progress in improving stroke care (Committee of Public Accounts (CPA) 2010). This reported the improvements that had been made since the NAO report, and the remaining shortcomings. Although the report covered variation in access to, and quality of, stroke services, culturally appropriate service provision for the needs of minority, or disadvantaged, groups was not discussed.

The range and focus of stroke policy documents in the UK have increased since publication began in 2001. They have described improvements in stroke care and commented that services need to be made appropriate for minority groups. In general, stroke policy and guideline documents have discussed the need for culturally appropriate stroke services but not how this can be achieved.

2.4 Ethnicity, culture, race and nationality

When working with people from different ethnic groups a number of basic errors occur related to ethnicity classification (McKenzie & Crowcroft 1996). These errors are: combining different groups for an arbitrary reason, inventing groups, not considering confounding factors, and not comparing like with like (Bhopal 1997).

One of the reasons for this confusion is that classifications are not simple, but also the concepts that are used in this area of study, such as race and ethnicity, are also used interchangeably (McKenzie & Crowcroft 1996). For these reasons the concepts, as used in this thesis, will be discussed and clarified.

2.4.1 Race

The distinction between ‘races’ must have been rooted in observable biological attributes such as skin colour, or facial features. As science progressed, the distinction between genotypic and phenotypic features became apparent. Genotype is related to an individual’s specific information residing in each cell that makes that individual unique (Hall & Halliday 1992). Phenotype refers to the result of the interaction of an individual’s genotype with the environment. Evolution acts on the individual and not a group, and is driven by phenotypic development, which is generally long term but also can be short term (Hall & Halliday 1992). Hair colour is inherited, and is unlikely to evolve differentially in reaction to the environment in the short term. In the shorter term, socio-economic status can also be inherited, like wealth, and can have major phenotypic impact on health (Champagne 2008).

The project that mapped the human genome discovered that there were no clear distinctions in the genotypes of people from what was perceived to be different races, or of mixed race; and alleles, or versions of a gene, could be present or not present, in one group, and also present or not present in other groups (Duster 2005; Human Genome Program 2007). As such, the differences between distinct populations are better explained by clines that have resulted from genetic drift, that is groups from a clade evolving in differing environments (see Figure 2.1) (Templeton 1998).

Genetically, *Homo sapiens* belong to the same species who are descended from a common ancestor group (a clade), the phenotypic differences (clines), are a result of members of a clade interacting with different environments over time (See Figure 2.1). An example of the development of clines or genetic drift is demonstrated by Darwin’s finches. What Darwin thought of as distinct species of birds that inhabited

separate islands were in fact variations of the same species that had evolved to suit each island's food source (Lack 1947). Thus, any differences between the appearances of humans are due to phenotypic variation, and in turn, this makes the concept of race merely descriptive rather than explanatory, much like the colour of a garment.

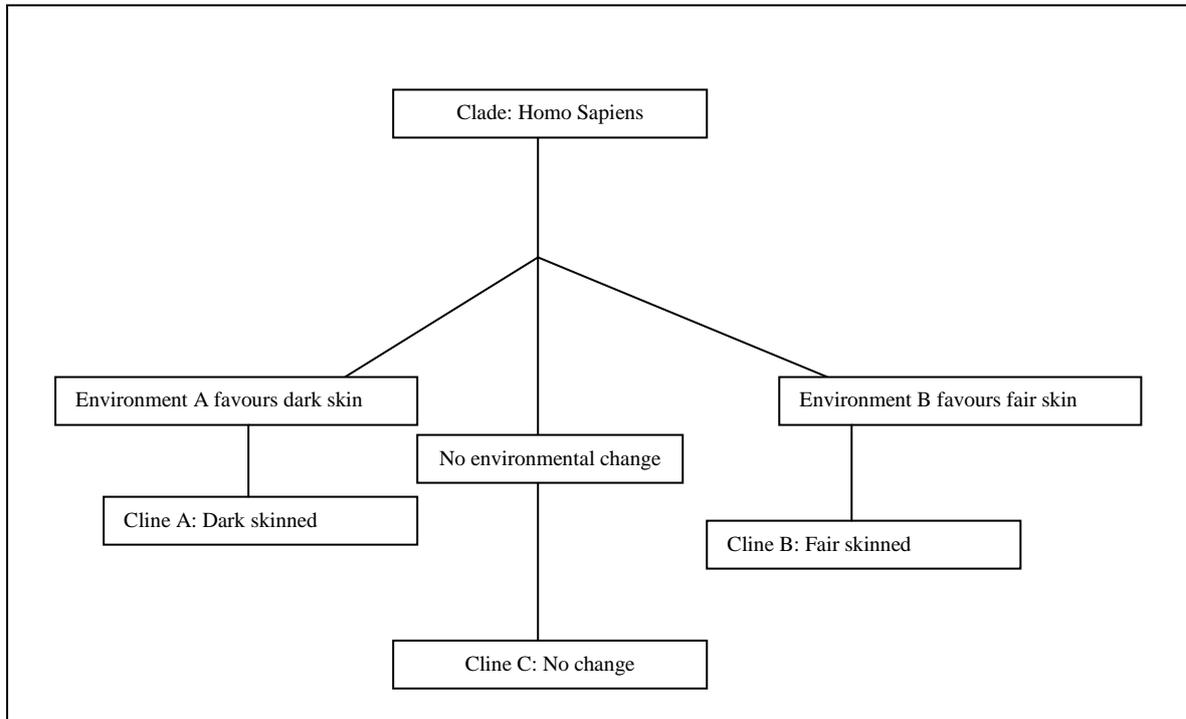


Figure 2.1 Clades and clines impact on physical characteristics of humans

2.4.2 Nationality

Nationality is derived from a person's country of birth, a parent's birth, or nationalisation (The Oxford English Dictionary (OED) 2012). Therefore, a person's nationality can be arbitrarily set, where the boundaries of a nation are positioned, or by nationalisation. For example, a small country like Belgium has at least three distinct cultures, French (Walloons), Dutch (Flemish) and German, one ethnicity (Northern European) but nationally they are all Belgian (See Figure 2.2) (O'Neill 2000). Thus, care should be taken in health sciences when using nationality to

describe populations, as nationality can only be used if the variables considered are related to that nationality. For example, the study of service-users' activities during rehabilitation between European countries (De Wit et al. 2006) is acceptable because the variable under consideration is time spent on activities, which will be determined by the national organisation of health care delivery.

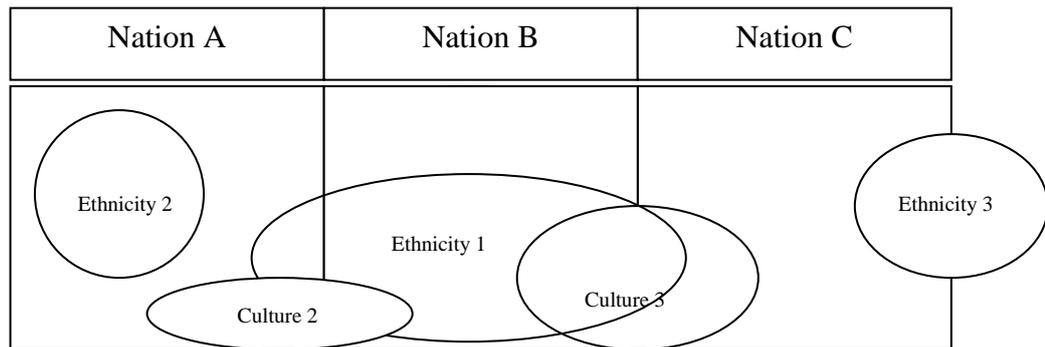


Figure 2.2 Possible interactions between nations, cultures, and ethnicities

2.4.3 Culture

Part of the difficulty defining culture is that the concept is contingent with fashion and politics, and it is dynamic, as such it will be difficult to imagine that a consensus for a taxonomy can be arrived at (McKenzie & Crowcroft 1996). Even though consensus on definition and taxonomy cannot be agreed, this does not prevent progress in research associated with the concept (Jahoda 1984; Rohner 1984). Rohner (1984), defined culture as a highly variable system of meanings, which are learned or shared by people of an identifiable segment of the population. This definition has some problems as there is no definition of population and no criteria are provided for assessing identification. In a more recent work, culture was described as having four major components:

- *Learned from birth through language acquisition and socialisation. From society's viewpoint, socialisation is the way culture is transmitted and the individual is fitted into the group's organised way of life*
- *Shared by all members of the same cultural group. It is the sharing of cultural beliefs and patterns that bind people together under one identity as a group (even although this is not always a conscious process)*
- *It is an adaptation to specific activities related to environmental and technical factors, and to the availability of these*
- *It is a dynamic and ever changing process.*

(Andrews & Boyle 2003 p10)

Unfortunately, not all cultures are learned through birth or language acquisition. In addition, counter or sub-cultures exist in cultural groups that have aims to change, or subvert, the cultural norms of these groups (Jahoda 1984). This demonstrates how difficult culture is to define, and a synthesis of definitions for the purpose of this thesis, may be more appropriate until a definitive version can be established. This definition is: a dynamic, evolving and variable system of meanings, beliefs and values that are shared by, and characterise, a group of people.

2.4.4 Ethnicity

Ethnicity is associated with culture, and the two terms are often incorrectly used interchangeably (McKenzie & Crowcroft 1996). People can be of the same culture, but from different ethnic backgrounds. The defining feature of ethnicity is heredity, or inherited traits, which is why ethnicity should really be self-defined (McKenzie & Crowcroft 1996) although this has been challenged (McAuley et al. 1996).

Despite the challenge the fact is that an individual is the only person that can classify themselves ethnically (McKenzie & Crowcroft 1996). Ethnicity can also involve language, culture and religion and, conversely, people can belong to a minority ethnic group but also belong to discrete cultural groups. Generally, for people who are born or originate from a specific geographical area it is the cultural, or other social construction associated with that origin, that defines a person's ethnicity (Rohner 1984). In addition, a person's ethnicity can only reliably be self-defined, as only an individual can know their affinities (McKenzie & Crowcroft 1996). In this context, ethnicities should be seen as clines, and replace the social construction of race (Serre & Paabo 2004).

Nationality is less complex than culture, race is an outmoded concept, and ethnicity can only reliably be self-classified, which makes classifications for research difficult (McKenzie & Crowcroft 1996). The British Medical Journal (BMJ) issued advice on how to describe minority group populations, but no taxonomy. However, McKenzie (1996) puts forward a more practical approach: that the level of description be related to the hypothesis and, in light of this, to collect as much information as possible to describe what was done. This approach allows the user to estimate the relevance of population classifications to the hypothesis, and potential outcomes. For occasions when classifications are essential, the ONS has provided a guide to considering ethnicity (Office for National Statistics (ONS) 2003). Not only are classifications important for readers, but also to participants and service-users, as nationality, culture, and ethnicity are important constituents of a person's social identity (Boatswain & Lalonde 2000; Ellemers et al. 2002).

2.5 Social identity and group status

During introspection we use inner speech and this has been demonstrated to be part of our self-awareness or inner identity (Morin 2005). This core identity, sometimes termed the ego, the self, or personal identity, is relatively unchanging from situation to situation, and even endures over time (Weatherell 1996). Our social identity, rather than having the dispositional and enduring character of the inner-self, is more situational and ever changing (Tajfel & Turner 1986). The concept of social identity is addressed in the major psychological paradigms (Weatherell 1996). However, a branch of the cognitive paradigm, social cognition, being philosophically positivist, does give the most compelling, and evidence based, explanation.

We rarely expose our inner self or personal identity to the world; this would leave us vulnerable and open to exploitation. The essence of social identity is that we learn through experience ‘what works’ and adapt our social identity to what we consider appropriate to different situations (Terry et al. 1999).

One of the earliest theories of social identity described our social selves as dramaturgical, that is as adopting a ‘character’ appropriate to the current situation, or even demanded by that situation (Goffman 1959). As such, we would have a number of ‘characters’ and associated ‘scripts’. Though compelling, this theory remains at a propositional level as there is limited supporting evidence.

Social Identity Theory is a further development of work in this field and attempts to explain inter-group discrimination (Tajfel & Turner 1986). Tajfel decided that we had a range of social identities, similar to Goffman’s characters, but in contrast to Goffman (1959), he decided that rather than acting out appropriate scripts, we develop

a range of social identities, influenced by the groups we belong to. Typically we describe ourselves by referencing our group memberships: for example, gender, age, relationships, area of birth, nationality, profession (Terry et al. 1999). Furthermore, we derive part of our self-identity and esteem from the value of these groups. If we belong to a highly regarded group, we feel highly regarded. Thus the groups we belong to help to develop our self-concept (Tajfel & Turner 1986). Tajfel (1986) also demonstrated that we would seek to improve and defend the status of our own group (in-group) by lateral inhibition or working to downgrade the status of groups we do not belong to (out-groups) in an attempt to increase the perceived status of our in-group (Tajfel 1970). In addition, depersonalising out-groups, or not seeing them as individuals, would facilitate negative discrimination against them to achieve higher status for an in-group (Allport 1954; Tajfel 1970).

In an early study, Tajfel demonstrated the power of group membership by grouping people together with the minimum of ties (a name e.g. Kandinsky) and observed that members of a group (the Kandinsky in-group) would actively conspire and work to lower the status of other groups (the out-group) (Tajfel 1970). It is not too difficult, therefore, to understand racism, xenophobia and discrimination as attempts to improve in-group status, when one group is not bound to another by shared origin, language, history and interrelationships (Tajfel & Turner 1986).

2.6 Prejudice and discrimination

Prejudice is a negative attitude held by an individual about some other discernibly different groups (or individuals). Discrimination is a negative action taken against a group or individual because of a prejudicial attitude (Allport 1954; Plous 2003).

Evolutionary psychology could postulate that prejudice against out-groups is

beneficial, hence retained in our modern psychology (Hall & Halliday 1992). A suspicion of out-groups, and striving to achieve ascendancy over such, would be sensible when resources are scarce (Plous 2003). Fortunately, in Western Europe we live in societies that are protected from many threats to our 'in-groups', yet prejudice and discrimination still remain and laws have been passed to try to prevent it (Great Britain 1976).

2.6.1 Discrimination and health care

In the case of national health care in the UK, even before anti-discrimination laws were passed, the perception was that race, religion, ethnicity, culture, and nationality were immaterial, and treatment is related to need and not group identity, power or influence (NHS Choices 2012). A search on Medline for articles using terms 'discrimination' and 'NHS', revealed a protracted debate in the literature on discrimination in health care for at least a decade. These findings suggest the NHS is failing to make progress on discrimination issues (Santry 2008; White 2007), resulting in negative evaluations of care by minorities (Mead & Roland 2009). In addition, underachievement of minority medical students was reported (Woolf et al. 2008), as was a lack of progression and deskilling of overseas nurses (O'Brien 2007), and lack of recognition and progression for doctors from minority backgrounds. (Esmail et al. 2003; Esmail & Everington 1997; Esmail et al. 1998; Esmail et al. 1995). Not all claims of discrimination concerned minority groups members, as prior to 1998 the complaints of lack of recognition and progression for doctors were exclusively from white females, and continued after this date (Esmail et al. 2003).

The Race Relations Act 1976 (Department of Health (DH) 2002; Great Britain 1976) established legislation to make any discrimination on the grounds of race illegal. It was not until the amendment to this Act in 2000 that a statutory duty was imposed on public bodies to promote racial equality, and to set in place effective procedures with the aim of preventing racial discrimination (DH 2002). This initiated policy documents to promote compliance with this responsibility. The Race Equality Scheme 2002 – 2005 (DH 2002) set out action plans and responsibilities in this three year scheme. The structure for responsibility for the delivery of health care has changed since this scheme was published; control has become less centralised and the demography of the population is changing and will continue to change (Department of Health (DH) 2005b). For example, over the next 20 years the proportion of people from minority groups in England and Wales will double, and in some areas they will be the majority group (DH 2005b). To address these changes the DH published a revised version of action plans and targets and stated that establishing equity of health care for all would be a key target (DH 2005b). What these documents achieve, together with the policy documents and guidelines above, is to make explicit that the Government and NHS recognises that some members of our society are not treated in an equitable way.

One of the biggest problems in demonstrating the validity of the claims of inequity has been the inconsistent approach to recording ethnicity data (APHO 2005) which could render survey estimates of service use or need invalid. Combined with the problem of inaccurate ethnicity monitoring, many of these reports referenced above are compiled by extracting information from surveys (Aspinall & Jacobson 2005), which tend to be retrospective, and thus affected by accuracy of recall (Pasick et al.

2001). Surveys with populations from different cultures have further validity problems. For example, surveys with minority groups are liable to be confounded by low or differential response rates across minority sub-groups (CHI 2004). In addition, results of such surveys could also be confounded as responders tend to be significantly different to non-responders in terms of age, housing status and cognitive impairment (Boersma et al. 1997), and there is low agreement between open interview and survey item responses (Boniface & Burchell 2000).

Surveys that have been conducted indicate that minority groups, with some exceptions, tend to have worse health and worse health care experiences than the general population (Adamson et al. 2003; APHO 2005; Balarajan 1995; Department of Health (DH) 2005c; Information Centre 2006; King's Fund 2006). Despite political, philosophical, and methodological issues, and although samples vary in size and composition, surveys consistently suggest that there is inequitable health service provision for people from minority groups.

2.7 British minority groups

Ethnicity is most appropriately self-defined as there is no objective measure that can be used, unlike age or gender (McKenzie & Crowcroft 1996). Classifications that are attempted result in an ad-hoc taxonomy that mis-describes classifications as ethnic groupings (e.g. White Other) (Office for National Statistics (ONS) 2003). For example, the taxonomy for the UK 2001 Census groups people into 13 categories that provide little information beyond skin colour and approximate geographical area of origin (see Appendix 1) (Lupton & Power 2004).

Using this system, the 2001 census found that the UK population comprised white (92%), mixed (1.2%), Asian (4%), Black (2%), Chinese (0.4%), and other (0.4%). In a review of the 2001 census data, it was calculated that the UK population growth rate was 0.26% per annum. While this remains stable, in previous decades the majority of this growth was from the indigenous population. Between 1991 and 2001, 73% of the population increase was due to ethnic minority groups (Lupton & Power 2004). This trend for growth is in areas that previously only had small minority populations (Lupton & Power 2004).

Census data has some problems, for example as they only happen every 10 years the data can quickly become dated. Significant changes can occur between censuses and be missed, and the questions used are limited and objective. The greatest validity problem for a census is undercounting; this is estimated to be 2%, but in London, for example it can be up to 20% (Lupton & Power 2004). Undercounting is the number of people missed by the census, and these tend to be young males, recent migrants, and minority groups (Lupton & Power 2004). This is a major issue for accurate population estimates for minority groups. Despite these issues, there is no other regularly collected record of the population on the scale of the census.

2.7.1 Health status variation

Minority groups, as a whole, consistently report poorer health status, and poorer health care experiences, compared to the general population (APHO 2005; DH 2005b). This does mask between-group variations, for example Bangladeshi men consistently report the worst health outcomes and the worst health care experiences of all minority groups. Black African and Chinese report better health status than the average but also report poor health care experiences (King's Fund 2006). Bangladeshi

men have lower than average rates of hypertension, but higher than average risk of diabetes, stroke, and coronary heart disease (Bhopal et al. 2005). Indian men, apart from those at higher risk of diabetes, have a similar risk factor profile to white males, and Bangladeshi females have the highest prevalence of diabetes of all groups sampled (Information Centre 2006).

Health status is positively correlated with socio-economic status (SES) and the effects of low SES can last for the life course of an individual and their offspring; this can have implications for the health needs of generations ahead (Bajekal et al. 2001; World Health Organisation (WHO) 2009). Thus, the effects of deprivation on subsequent generations, though not genetic, can be inherited, like wealth (Champagne 2010). When health outcomes are considered, it can be difficult to attribute differences to a particular factor, but when deprivation markers have been accounted for, deprivation does not fully account for differences between the general population and minority groups (APHO 2005; Nazroo 2003). This finding indicates that deprivation alone does not account for the health care differentials between white and non-white service-users.

In addition, when each apparent between-group difference has been examined, large within-group differences were discovered, indicating that genetic or cultural variables are not a likely explanation (APHO 2005). This suggests that other factors, such as the experience of discrimination, cultural insensitivity or differential care, could be causal factors of differential health outcomes which need further investigation (King's Fund 2006).

The cause of service provision differentials between groups of people is unclear. With differentials reported from a range of sources, it would seem to indicate that structural or organisational factors are responsible. For example, a recent report indicated that the majority of hospital trusts still did not meet their requirements of publishing equality information (Healthcare Commission (HCC) 2009). Despite the drive to eradicate disparities, ethnic minority service-users were still enduring worse experiences and outcomes than the general population and a disproportionate number of NHS staff were experiencing discrimination from staff and service-users, because of their ethnic background (HCC 2009).

The HCC information is derived from literature reviews, surveys of websites, hospital trust reports, and commissioned surveys of approximately 10% of the Trusts in England. The sample may be adequate, but one of the issues with monitoring service use and reports of compliance by Trusts is that for them to be accurate, ethnicity-monitoring data from each source needs to be accurate. The problem with these sources is that up to a third of hospital data is still not adequately coded for ethnicity, and few GP practices routinely collect such information about their service-users (APHO 2005; London Health Observatory (LHO) 2006). An ethnicity health intelligence report stated that the proper recording of ethnic group, birth, and death information was the single most important action that could improve the evidence base and help tackle health disparities for minority groups (LHO 2006).

In 2006, the then government set in place reforms for the health care system. The DH expressed concern in two areas, firstly although there was commitment to equity at the highest levels, it was difficult to get a sense of commitment from other areas of

the NHS (Esmail et al. 2005). In addition, NHS reforms put in place in 2006 had the potential to attenuate drive and progress on matters such as equitable service provision (Race for Health 2006). With the onset of the financial crises in 2008, and the subsequent political changes in 2010, it is unlikely that such issues will maintain or increase in importance (see: Race for Health 2009; Race for Health 2011).

Whether political or organisational, there is a perception that there are barriers preventing people from minority backgrounds experiencing equitable care. The Health Care Trust investigation above tried to discover what these barriers were, but found it difficult to obtain certain information (HCC 2009). This information included the number of minority group employees who had received training or promotion they had applied for, or who had ‘experienced detriment’. The Health Care Trust also found it difficult to provide evidence that the views of service-users and carers had been sought on planning services, or indicate where service-users had found access to services difficult (HCC 2009). As discussed above it does seem that inequitable service provision is a structural issue. If it was how the processes of care were delivered by individuals, it would require complex networking or widespread poor practice to have an effect, both of which would still implicate organisational factors (Campbell et al. 2000b).

2.8 Equity, use, need and access: elements of quality health care

The NHS was established with the underpinning philosophy of equity, in that appropriate and proportionate care and consideration would be afforded to all users, irrespective of their life station (NHS Choices 2012). This section will consider the concept of equity and barriers in relation to health care that may prevent the ubiquity of equity, with reference, where possible, to South Asian minority groups.

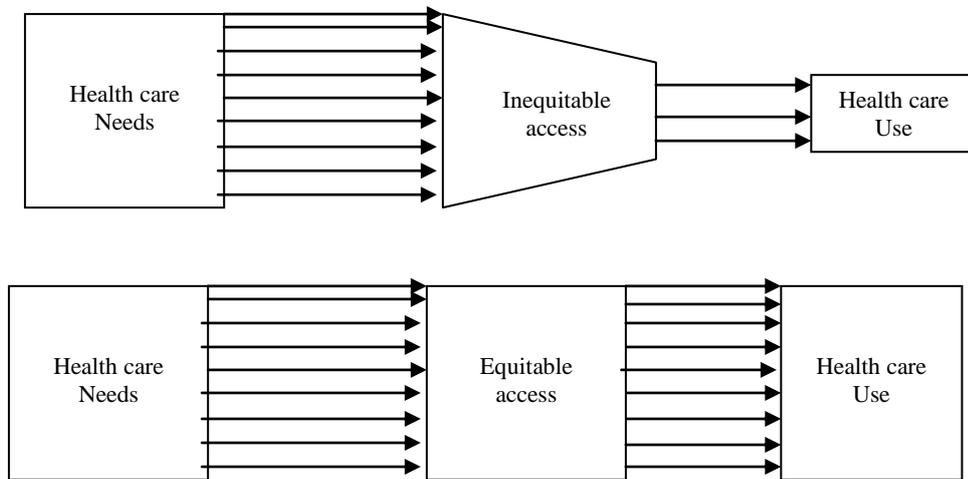


Figure 2.3 Health needs, use and access

Figure 2.3 proposes the interconnection of health care quality, represented by equity, access, need and use in relation to populations for this thesis. The upper diagram indicates a poor quality service where a range of needs of a population are ‘filtered’ by barriers to access, resulting in a lower level of use of a service. The lower diagram indicates a better quality service where access issues cause no barriers to health care use. A further proposition is that the upper diagram represents the position of minority groups and the lower, the general population.

2.8.1 Equity

Equality of distribution of a service means that apportionment will be the same for each recipient and was defined in Chapter 1 (Braveman & Gruskin 2003). If the intention of distribution is ‘fairness’, equality of distribution may not be sufficient. For example, distributing the same printed self-help manual to all is equal, but this is not enough to be equitable if some recipients are blind or cannot read. Therefore, if health care is to be distributed free and according to a person's needs, then that service

must be able to demonstrate an equitable distributive process. However, health care is not the same as health and it could be argued in the case of iatrogenic illness that the distribution of some health care actually deprives people of health and brings into question the NHS equity claim (Culyer 2001; Culyer 2007). For example, there were 86,000 adverse incidents in the NHS in 2007, and medication errors were responsible for 70% of events that caused serious harm (Langford 2010).

In respect of health care, there is no unified theory of equity or what it means to be equal (Culyer 2001; Oliver & Mossialos 2004). This confusion may be a result of the differing philosophical paradigms in existence. For example, there are theories such as the 'Maxi-Min' theory, a system is equitable if it is to the advantage of the most disadvantaged individual in a population; the 'Deontological' approach that stresses the duty of each of us to ensure others are provided for; the 'Entitlement' theory that equitable service provision is available because that is what an equitable and a just society expects (Veatch 1982).

In health care, two different methods of equitable distribution of resources are discussed; horizontal and vertical equity. Horizontal equity refers to like treatment for like individuals (cases), while vertical equity is unlike treatment for unlike individuals (cases) (Culyer 2001). These concepts are a way of describing different equitable applications. The essence of both concepts is to help to distribute finite resources in the most efficient way while avoiding apportionment by some capricious or irrelevant criteria, for example a person's ethnicity (Musgrave 1959).

The most appropriate description of the equitable approach of the NHS is that of horizontal equity, as vertical equity would require value judgments that would be difficult to estimate during a health care contact (Dixon et al. 2003; Goddard & Smith 1998). This would indicate that assessments of equal need are considered value free, or that they are based on objective criteria readily available in a health care contact, both of which are unlikely. It may be beneficial to avoid such divisions of equity and use the definition from Chapter 1 for this thesis, as it has been reported that health care service providers and researchers do not understand the merit or demerit of each or the difference between them (Culyer 2007).

2.8.2 Health service use

The use of health services by a service-user has also been described as health care episodes because of the complex and varied facilities required, and interactions experienced, some of a protracted nature (Hornbrook et al.). As service-user in this thesis describes people who receive health care it makes sense to use the term service use. Service use is the most common outcome measure used to assess service delivery (Goddard & Smith 1998). Unfortunately, in the case of need and equity, it can be the most unreliable. For example, the number of contacts with a GP may be recorded, but this could be a measure of the quality as well as the quantity of service, as repeated visits may result from poor service. Contacts could also be for repeat prescriptions, nonsense or frivolous visits, or sick note requests. Similarly, hospital repeat visits can be a result of poor service delivery and changes to practice. For example, a procedure that took 2 weeks a number of years ago may currently be a day case (NHS Institute for Innovation and Improvement 2008).

Equitable provision of services is a complex issue, but use should be related to need, for example, if a minority group had a high prevalence of an illness, then service use should be greater, proportionately, than for the general population. Therefore, need should be factored into calculations when estimating future service requirements as use alone as an outcome measure will be inaccurate (Culyer 1998; Culyer 2001).

2.8.3 Service-user need

Health care need is difficult to quantify and operationalise (Culyer 1995). An attempt to classify need has resulted in a taxonomy of needs where values could be ascribed to establish 'real need' (Bradshaw 1972). The need taxonomy included: normative need, where an individual was compared to a recognised standard applied by an expert (clinician), for example a Barthel index of function (Wade & Collin 1988); felt need would equate to what an individual wants, assessed by interview; expressed need would equate to a demand and comparative need would be estimated by comparing one service-user's condition with a service-user with a similar condition who is in treatment. Bradshaw (1972) did attempt to include a range of needs that accounted for previously under-regarded elements. In addition, an attempt was made to quantify need, but there was no clarity about the amount of weight each type of need would have in the assessments. For example, an individual may not have expressed a need, or demanded a service, and may compare less well to an existing service-user, but the normative need may indicate threat to life.

Notwithstanding Bradshaw's approach, there is still no generally accepted working definition of need but it is thought that it should contain two components (Culyer 1995). Firstly the state of the individual's pre-treatment health (with a positive correlation between ill-health and greater need) (Oliver & Mossialos 2004).

Secondly, the individual's capacity to benefit from treatment that is currently available (Culyer 1998; Culyer 2001; Oliver & Mossialos 2004). A working definition has been proposed as part of a comprehensive body of work on service-user satisfaction, this is: 'what patients – and the population as a whole - desire to receive from health care services to improve overall health (Asadi-Lari et al. 2004).

2.8.4 Access to health care

When discussing equitable health care, health needs and access to health care are key concepts, and when considering the quality of health care, effectiveness, in terms of clinical and inter-personal care, also needs to be considered (Campbell et al. 2000b).

One of the problems when assessing access is that use of health care is the typical assessment variable (Culyer 2007; Goddard 2009; Goddard & Smith 2001; Oliver & Mossialos 2004). Unfortunately, health care use as a measure can be seen as actual access (those who use it) but tends to omit the people who have need of health care but may not have the opportunity to use it, or those with potential access (Aday & Andersen 1981). This renders studies of equitable access that rely on utilisation data as questionable, and leads to the proposition that equitable access is better defined as all those who need the service get it (Aday & Andersen 1981). Potential access includes people who need health care, but for some reason, e.g. ignorance of the service, do not access it. Potential access goes further than this, and includes those who do not yet need the service but need to know it is there, or the option value of a service (Weisbrod 1964). An option value may be seen as the comfort an individual gains from the knowledge of access being available.

2.8.5 Quality in health care

Health care quality was defined in Chapter 1 as “the degree to which health services for individuals and population increase the likelihood of desired health outcomes, and are consistent with current professional knowledge” (Khon et al. 2000). It is clear from this definition that for a service to be of good quality it must be fulfil the needs of service-users. For minority groups this would not seem to be the case as there have been calls for services to be made appropriate to the health needs of these groups (CHAI 2006; DH 2001; Intercollegiate Working Party for Stroke (IWPS) 2000; IWPS 2004a; IWPS 2008), to be culturally appropriate (NICE 2008), to raise stroke awareness (NAO 2005), and to monitor service use by minority groups more effectively (APHO 2005). It seems apposite to discuss what service quality is and how it is assessed.

When considering equitable care for South Asian minority groups it is the quality of care for populations that needs to be considered rather than individuals. The quality of care for individuals cannot include equity as this requires complex within and between group comparisons (Campbell et al. 2000b). Quality of care for populations has been defined as;

‘...the ability to access effective care on an efficient and equitable basis for the optimisation of health benefit/wellbeing for the whole population’ (Campbell et al. 2000b).

Operationalisation of quality of care has also been proposed by describing the essential dimensions that contribute to a quality health care system (Donabedian 1990), and a conceptual framework in which to explore these components

(Donabedian 1992). The attributes of quality used within the framework are; efficacy, effectiveness, efficiency, optimality, acceptability, legitimacy, and equity.

- efficacy is the ability of a health care system to bring about health improvements
- effectiveness is by how much the improvements (efficacy) in health care have been attained,
- efficiency is the extent to which the cost of health care can be reduced without reducing effectiveness
- optimality is the balancing of cost with improvements,
- acceptability describes how closely aligned the health care system is to the needs of the population
- legitimacy the level of conformity with the current ethical principles and laws of a population
- Equity is the level of fairness in the distribution of care and its impact on health.

A high quality health care service will satisfy all the attributes (Donabedian 1990).

The framework was proposed by Donabedian (1992) who explained that to assess the quality of care we need to examine the structure of the setting where care is provided, by measuring the processes used to deliver the care, and/or by assessing the outcomes of that care (Donabedian 1992). The framework to assess health care quality should be used when considering two equally important care areas, technical (clinical) care and interpersonal (customer care) (Donabedian 2005). However, structure, process and outcome are approaches to assessing quality of care and not attributes of a quality health care system, for example like effectiveness (Campbell et al. 2000b).

Structures of health care

Evaluations of structure refer to assessing the characteristics of the setting in which care takes place, essentially the context. Evaluations of structure might include characteristics of health care staff, physical and organisational infrastructure and increasingly the policies that influence the care process (Castle & Ferguson 2010; Cleary & O'Kane 2011). The rationale for including structure is that the influence of context, be it physical or psychological, is increasingly being recognised as having a major impact on outcome (Greenhalgh et al. 2009; Pawson & Tilly 1997).

One of the positive aspects of structural measures is that they are relatively easy to measure and collect, the data is often routinely available in files, reports or policy documents (Cleary & O'Kane 2011). They also have disadvantages as delivering health care is a complex intervention and as such there are interactions between the elements that need to be considered (Bird et al. 2011). For example, staffing levels are a structural component, and increasing staff levels are thought to be related to increased care quality, but a review found the evidence ambiguous with many studies finding no such association (Castle 2008). Donabedian did indicate that structural assessments are necessary but not sufficient as assessments of quality, as they are rather a blunt instrument (Donabedian 1988). Structural elements have been described as a conduit for care processes, moderating outcomes and at the same time having a direct influence on outcome (see Figure 2.4) (Campbell et al. 2000b). For example, absence of an Acute Stroke Unit in an area can have a direct outcome of reducing a stroke service-user's chances of survival (NAO 2005).

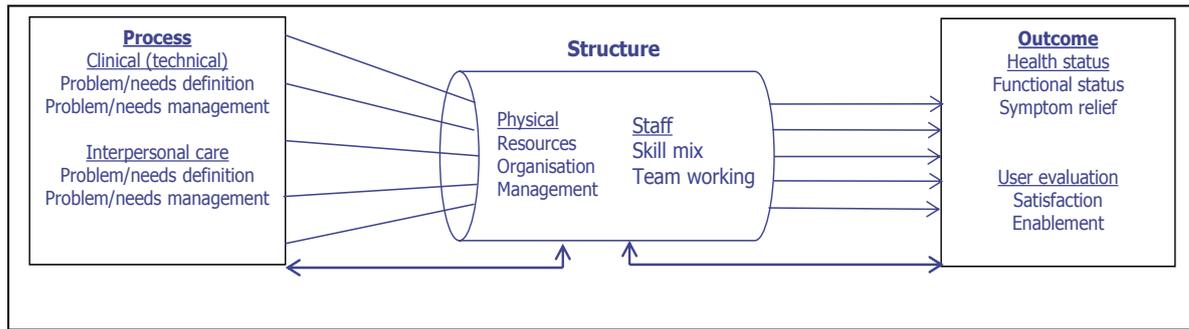


Figure 2.4 Relationships between Structure, Process and Outcome

Process measures

Process measures assess the care that a service-user receives. Process refers to any procedure or interaction, technical or interpersonal, carried out between a service-user and a service provider. These can include clinical procedures, therapies, communication, information and emotional support (Cleary & O'Kane 2011).

Process measures are specific, and generally understandable by service-user and providers. They are more reliable than outcome measures; which is explained in the next section (Donabedian 2005). They can also be used as a comparator between different units that carry out similar processes, and can also indicate if the right procedure is used for a particular service-user (Campbell et al. 2000b).

Process measures also have disadvantages, for example some care is delivered by bundles of actions, any one of which can be responsible for a failure of a process. To make accurate assessments many parts of processes would need to be independently examined for a comprehensive assessment (Cleary & O'Kane 2011). This may not be as difficult as it sounds, for example stroke care has published guidelines and these

are audited on a regular basis, providing documentary evidence for a complex pathway of process (IWPS 2008).

One of the main issues for process measurement is that many of the processes are delivered with limited evidence of effectiveness, resulting in poor or incorrect quality of care assessments (Institute of Medicine (IOM) 2001). Where evidence for the effectiveness of processes does exist there may be two or more different processes for the same procedure that have not undergone comparisons. This is an important point as choosing one instead of others may result in the use of a sub optimal process (Institute of Medicine (IOM) 2009).

Outcome

Outcome refers to measuring the effects on service-users' health status after contact with the structures of health care, or interaction with a process of health care.

Examples of these would be relief of pain, curing an illness, improving functional ability. It also includes service-user satisfaction with, or appraisal, of the structures and processes (Cleary & O'Kane 2011). It is important not to confuse service-user satisfaction, when used as an outcome assessment, with good interpersonal care as a service-user may be satisfied with poor care (Cleary & McNeil 1988).

Positive change in health status or appraisal of a process by a service-user would seem to be the optimum measure of the quality of a health service. Though it may seem that service-user outcome would be the best indicator of the quality of a service, it has some major limitations. These include: the outcome is heavily dependent on the pre-existing health state of the service-user, the results of some processes may take a long time to manifest, outcome data for some processes are not routinely collected, with

service-user surveys there are numerous issues that lead to non-response, and people may be satisfied with a poor service (Campbell et al. 2000b; Cleary & McNeil 1988; Cleary & O'Kane 2011; Pasick et al. 2001). Donabedian was against using outcome as the main assessment of quality and indicated that process was the more reliable metric, but always maintained that to be fully valid, assessment should be linked to outcome wherever possible (Donabedian 1992).

2.8.6 Developments of the SPO framework

Some of these issues with outcome measures have led to the proposal of a new category to make the SPO model more responsive and robust. This is the concept of intermediate outcomes, where the recent impact of health care interventions are assessed (Cleary & O'Kane 2011). For example, the aim of lowering blood pressure to reduce circulatory diseases may take years for the outcome to be apparent. The intermediate outcome, 'blood pressure in optimal range' can be assessed reasonably soon. This intermediate outcome can be used as a proxy measure of effectiveness, where evidence exists between a good intermediate outcome and an original target outcome (Campbell et al. 2000b).

Donabedian never intended that structure, process and outcome assessment approaches were to be used as a whole system and describes using one or more approaches in combination (Campbell et al. 2000b; Donabedian 1992; Donabedian 2005). He also proposed that process in the most appropriate single measure to assess the quality of a service, outcome may be unreliable and structure was necessary but not sufficient (Donabedian 1988). The selective combination approach has been revised by later workers (Campbell et al. 2000b). What needs to be established when using the SPO approach in assessing health care quality, is that variations in what is

measured must relate to differences in health status outcome with reference to contextual issues (Terwee et al. 2003). This relationship has been discussed earlier and recognises the whole system nature of the SPO approach (Campbell et al. 2000b). This integrated approach recognises the complex nature of health care interventions and the interrelatedness of the components of a health care system (see Figure 2.4) where context can mediate or explain a relationship, and moderate or influence an outcome (Greenhalgh et al. 2009; Pawson & Tilly 1997).

2.9 Conclusion

This chapter began by proposing that people of South Asian heritage may not have equitable access to stroke care. The support for this proposition was provided by national policy documents and published guidelines. The chapter then discussed the concepts of race, ethnicity, culture and nationality to clarify the use of such concepts. This led to the discussion of health care service indicators, need, use, access and equity, and proposed that many of the studies employed service use as a metric, when service need would be more appropriate. The discussion of equity led to a further proposition that equity was a key component of what can be seen as the quality of a health care system. This helped to develop the recognition that, as a population, people of South Asian heritage maybe receiving a poor quality of health care compared to the general population. Donabedian's (1992) SPO framework, with a modification to a whole system approach may provide a method of assessing if minority groups do actually receive a lower quality health care. The following chapters will work toward that proposition in an attempt to address the research questions.

Objectives (i), (ii), and (iii) of Part 1 of this thesis have been achieved with this chapter. The context of stroke and minority groups in the UK has been described; UK policy documents on health and minority groups have been evaluated and equity and access to health care in the UK has been introduced. The next Chapter describes a body of empirical work that explored the issues that may be barriers to South Asian groups accessing equitable stroke care.

Part 1 Chapter 3

Stroke care and people of South Asian heritage

3.1 Introduction

Chapter 2 considered stroke health care policy documents and guidelines and found that for minority groups, including South Asian groups, there have been calls for services to be made appropriate to the health needs of these groups (CHAI 2006; DH 2001; ICWPS 2000; IWPS 2004a; IWPS 2008). There were also calls: to ensure that services are culturally appropriate (NICE 2008), to raise stroke awareness (NAO 2005), and to monitor service use by minority groups more effectively (APHO 2005). The conclusion was that stroke care for minority groups was less than equitable compared to the general population. Chapter 2 then discussed concepts related to inequitable care and how care can be assessed in terms of service provision quality, and decided an overarching quality assessment framework of structure, process and outcome (SPO) would be appropriate for this thesis.

This Chapter addresses Research Question 1: What are the issues for people of South Asian heritage in accessing health (stroke) services? The aim of the chapter is to explore the experiences and perceptions of South Asian groups in one area of the UK and, from these findings develop a tentative hypothesis proposing issues for these groups accessing equitable stroke care. The objectives are to (iv) describe and justify the methodological approach to address the first research question, (v) explore the experiences and perceptions of members of South Asian groups in an area of the UK in access to stroke care and (vi) develop a tentative hypothesis to explain inequitable care for UK South Asian groups.

3.2 Phase 1 Methodology and theoretical base

To answer research questions it is essential to know how the information is going to be collected. Approaches to collecting information vary, but tend to include elements of the Theory of Inquiry (Misak 2011). An awareness of the ways of knowledge acquisition will ensure that the correct method is chosen. The aim of this part of this thesis is to explore the expressed needs of local minority groups when accessing stroke care, and their experiences and perceptions of that care.

3.2.1 Theory of Inquiry

There are different processes of acquiring knowledge. Acquisition does not have to involve conscious thought processes: in the case of cadenced movements or automated processes, conscious thought can cause errors of precision and timing (Stroop 1935). This section will discuss the cognitive processes of knowledge acquisition through inquiry. These processes are abductive, deductive, and inductive, reasoning (Misak 2011).

Abductive

Abductive reasoning is formulating a reasoned judgment on an incomplete set of observations. Abductive reasoning forms the basis of daily decision making, for example medical diagnoses or juries' decisions (Misak 2011).

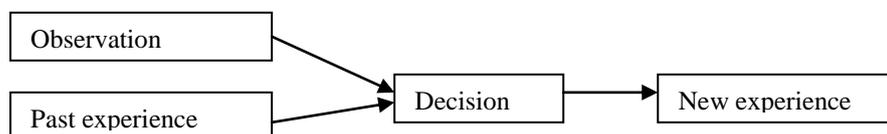


Figure 3.1 Abductive reasoning

Deductive

An example of this is hypothesis testing starting with a theory, followed by iterative testing and hypotheses reformulation until a conclusion is reached (Misak 2011).

Deductive reasoning forms the basis of experimental work (see Figure 3.2).

A theory will be tested by developing a hypothesis, testing the hypothesis provides new information that changes or supports the theory.

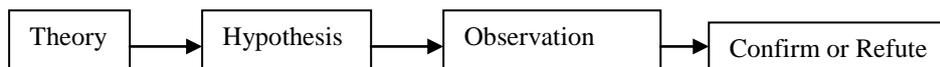


Figure 3.2 Deductive reasoning

Inductive

Inductive reasoning begins with observation, looking for patterns to emerge and then proposing tentative hypotheses and ultimately a theory (see Figure 3.3) (Misak 2011).

Inductive reasoning forms the basis of qualitative enquiry.



Figure 3.3 Inductive reasoning

The utility of these modes of reasoning is to provide a framework with which research can be planned. This study will use inductive reasoning because the aim is to work from the specific, the experience or perceptions of individuals, to the general, a theory of how stroke care can be developed to accommodate the cultural needs of a minority group.

Research approach

For this part of the thesis the perceptions and experiences of stroke care of ethnic minority groups is required, which would be difficult to gather with survey,

experiment or observation methods. Therefore group and individual interviews using an inductive approach was considered to be the most appropriate. A qualitative interview based approach was used and borrowed principles and approaches from ethnography. Though not ethnographic, the work is between cultures therefore the findings will be susceptible to inherent biases of ethnographic studies. For this reason the principles of robust ethnographic investigations will be used to inform the qualitative data collection and interpretation (Im et al. 2004).

Ethnography aims to describe a culture and its interactions with the social world through its writing (Maggs-Rapport 2000). The culture under study can be any identifiable cultural group, for example football supporters, but the essential element is a direct observational element through engaging with the groups (Maggs-Rapport 2000). This study does not have the direct observational element or the unstructured iterations that this brings. However, as the information collected will be from different ethnic and cultural groups, care must be taken to avoid the problems that beset ethnographic study, data collection and interpretation (Hammersley 1992).

The main problems identified in ethnography is the capacity of the ethnographers to accurately represent cultures different from themselves (Woolgar 1988a). Two main critiques have been proposed, a) that ethnographic descriptions are unreliable, and b) that ethnographic texts are social artefacts, or constructs generated by the interaction (Wolcott 1990). Both of these problems are claimed to be caused by ethnographers not operating reflexively and recognising the limits of their representations of 'reality' (Woolgar 1988a). This implies that ethnographers fail to take the context of their investigation into account. By not being reflexive and standing back from their data

and considering how it is located in reality, they are omitting other areas of reality which will impact on their representation (Atkinson 1990).

Qualitative research is premised on an assumption that the small samples worked with are a useful reflection of the real world (Atkinson 1990). In addition, qualitative work relies on the researcher holding three beliefs: recorded fragments can reliably represent a social world or structures of the participant, micro events in everyday life have commonality with a participant's broader social experience, and people try and make sense of their everyday life and offer accounts of this in good faith (Atkinson 1990).

Overcoming these difficulties with qualitative work requires confidence in the writer's integrity and good practice (Stanley 1990). This can be demonstrated by following a set of principles: establish the wider relevance of the setting, identify the reason for choosing the topic, identifying underpinning frameworks, demonstrate the reliability and credibility of the data analysis, explain how the conclusions were derived, and avoiding simplistic suggestions that ignore the context of the data (Im et al. 2004; Stanley 1990).

3.3 Methods

3.3.1 Design

This two phase study collected qualitative data by using focus groups and individual interviews. In Phase 1, focus groups were used to provide information for the development of a reference framework for use in Phase 2. Phase 2 used the developed framework to explore the perceptions and experiences of stroke services

with people of South Asian heritage. In both parts a semi-structured approach was taken, to enable the collection of rich data while facilitating cross case analyses. A detailed plan of both parts can be seen in Figure 3.4.

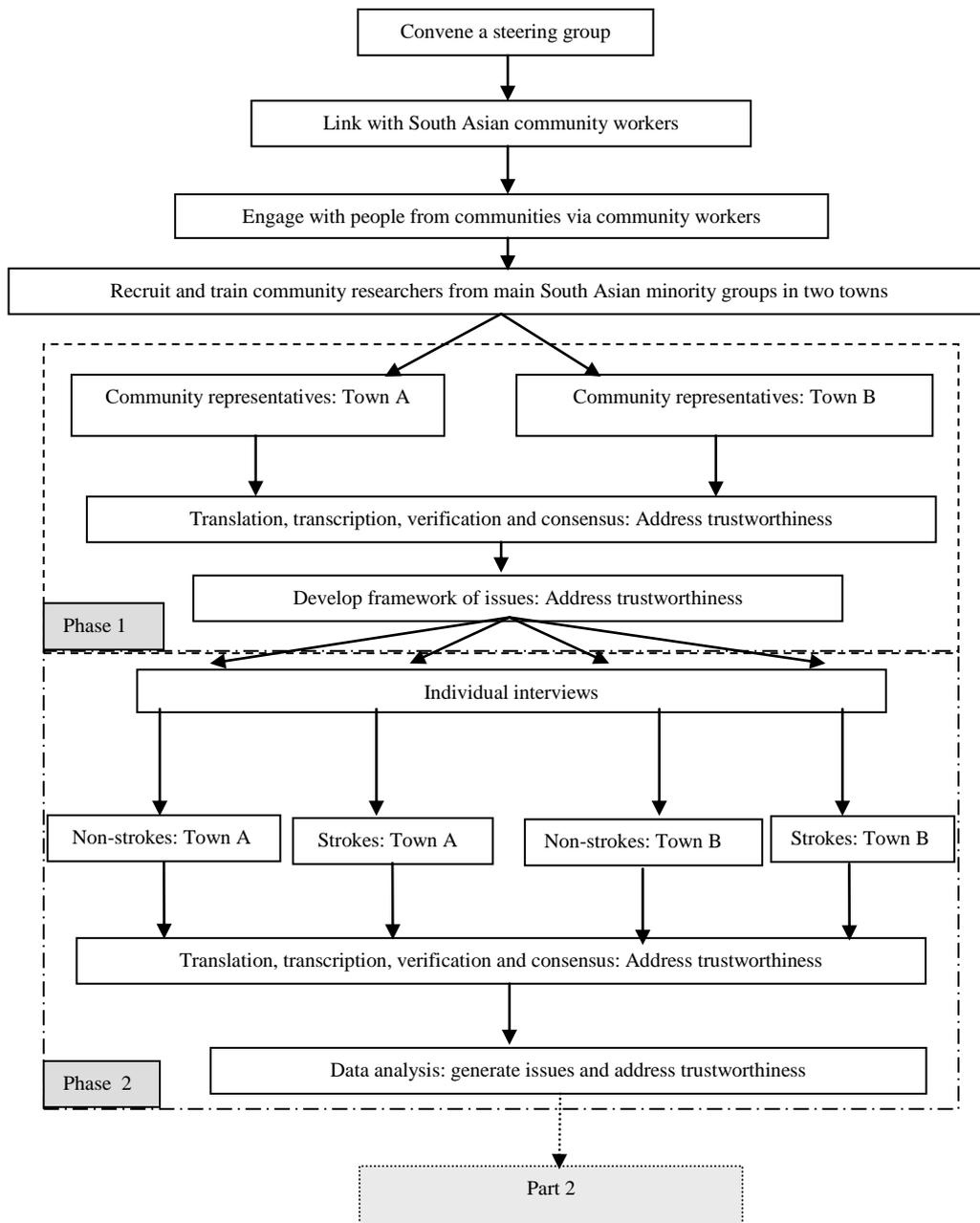


Figure 3.4 Flow chart of investigation for Part 1

Both phases of Part 1 collected data from South Asian communities residing in two towns in Lancashire, North West England. South Asians are the largest minority group in Lancashire (ONS 2010). These two towns were chosen because they have relatively large South Asian communities, the communities are differentially composed, and they are both in the same catchment area of a large general hospital that has an Acute Stroke Unit (ASU).

One of the main strengths of qualitative data is the depth of insight and richness that can be elicited that could not be collected by quantitative methods. Weakness of the methods used to collect qualitative data are the part played by the data collector, and the reliability and validity, or trustworthiness, of the interpretation of that data (Hammersley 1992; Stanley 1990). Trustworthiness is the reliability and credibility of the interpretations and was addressed by member checks, or respondent validation of summaries of interviews, providing a data audit trail, and working with an independent researcher for verification and reliability checks.

Research with groups from other cultures (inter-cultural research) is particularly susceptible to trustworthiness problems that the above strategies do not address (Im et al. 2004). For example, there are layers of meaning that a non-member of the community cannot access; these are constructed from the socio-political context, history, religion, ideology and sub-group epistemologies (Im et al. 2004). These issues are crystallised in the criticisms of ethnography described above: reliability of interpretations and observed events could be social artefacts precipitated by the interaction of different cultures (Hammersley 1992).

3.3.2 Setting

The target populations for both phases were from two towns (A and B) in East Lancashire. These towns were chosen because they have relatively large South Asian populations, but with different demographic profiles. The South Asian minority groups in these two towns have some marked differences. In Town A, the Asian population comprises Pakistani, Indian, East African, and Bangladeshi, and they are part of a sizable sub-group in the town (19% overall), the remainder of the population is white British (80.5%), with black African/Caribbean and Chinese accounting for only 0.5%. This is including a recent growing, but small number of East Europeans (Blackburn with Darwen Borough Council (BwDBC) 2005).

Town B has a smaller and less diverse Asian group (7% overall), mostly Pakistani, the majority living in one ward; the remainder of the population are nearly all white British, with a small (less than 1%) number of Chinese and an increasing number of East Europeans (Leaf 2007). The demographic differences presented an opportunity to explore the similarities and differences between the populations in terms of their perceptions and experiences of stroke care.

3.3.3 Ethics

The two towns (A and B) in this study were served by different primary care trusts (PCTs) therefore this study was reviewed and approved by the appropriate Multi-centre Research Ethics Committee (MREC Approval: BHRV 138). Informed consent was obtained in writing, and participants were assured they could withdraw at any time without giving reasons. The safeguards of the Data Protection Act (1998) regarding participant confidentiality and anonymity were complied with. To protect participant confidentiality, all data were anonymised so that they could not be

identified from paper or electronic records. Data on paper were kept in locked cupboards separate from consent forms and electronic versions stored in password-protected files.

It was a requirement of the ethical approval that a community worker from each town would be the initial contact with people from the South Asian communities, and they would identify potential participants for the study. The rationale for this is that these people already work in the communities, are aware of the social processes and dynamics within these communities, and have existing contacts with people from these communities.

3.3.4 Sampling and Participants

This section will describe the recruitment, training, and functions of the community workers and researchers who worked on this project. Interview participants for each part of this phase will be described in that part. A diagram indicating the phases of the whole of Part 1 is shown in Figure 3.4.

Community workers

Using existing networks, community health workers from each of the towns were contacted and asked to take part in the investigation. A community worker from each town agreed to act as advisor to the investigation, and to help identify potential participants from their respective town. The community workers were both of Pakistani heritage and both spoke three South Asian languages. The Town A community worker was a 41 year old male, and a 28 year old female was the community worker for Town B.

Community researchers

People from the target communities would be best placed to interview the people from those communities. This is because even experienced researchers with a different cultural background could interview the participants but may not understand the subtleties, norms, and mores of a different culture (Im et al. 2004).

To recruit researchers from the local communities, adverts were placed in local newspapers, on the University website, and Jobs.ac.uk. A minimum of two speakers of each major South Asian language were required for translation verification, and to ensure that a specific language speaker was available when a participant was asked to provide consent and be interviewed. As the people would only be required for short periods, and employment would be sporadic, the positions were advertised as 'Community Researchers (Bank)' (CR). The successful applicants were required for training, interviews, and translations on an ad-hoc basis. This flexibility also provided the possibility of people already in full and part time work taking part as well as the unemployed and students.

Terms and conditions of employment were organised by the University Human Resources department, and the community researchers were paid per hour for interviews and associated work. In the person specification, 'essential' elements required candidates to be over 18, bilingually fluent in English and a major South Asian language, and living, or geographically close to, the local South Asian

community from either of the two towns¹. The ‘desirable’ criteria asked for experience in interpreting / translation, fluency in more than one South Asian language, and having experience of working in a research environment.

Sixteen people applied for the positions. After screening the applications against the job criteria, all applicants were deemed suitable and invited for an interview. Each applicant was allocated a time slot. On arrival they were greeted and required to complete a translation test in a South Asian language of their choice. The Stroke Association (SA) had produced a set of leaflets and audiocassette tapes which provided information about stroke, in the major South Asian languages (Urdu, Gujarati, Punjabi, Bengali, and Hindi). The SA donated a complete set for this study. Included with the set was a leaflet in English with the content of the tapes for reference material. Prior to the interview session, a different section of recording was allocated to each language recording. This prevented candidates who speak multiple languages memorising the section content and allowed for cross-case evaluation (see Figure 3.5).

Translation section min.0 -1	Hindi recording	
	Translation section min. 2 -3	Gujarati recording
Bengali recording		Translation section min. 4 -5

Figure 3.5 Test sections from three language recordings of the same text

¹ The author is aware that such ‘communities’ do not exist in isolation. However, it was important that candidates lived or had lived in local areas or the two towns where a large number of South Asian people lived.

When a candidate took part in the task they were asked to listen to a pre-selected section of a recording in a language they were fluent in. They then had to verbally translate this and the translation was recorded and checked against the English version. Two independent South Asian language speakers verified the accuracy and semantic equivalence of the translations. Candidates who spoke more than one South Asian language carried out this exercise for each language. On successful completion of the translation task, a panel of three interviewed the candidates, two males (Community worker and the author) and one female University employee independent of the project.

Eleven of 16 candidates were selected as community researchers. Three candidates were not selected because their language skills were not at a sufficient level and two withdrew because they misunderstood the nature of 'bank' employment. There were two males and nine females with an age range of 24 to 51 years, all were fluent speakers of English and at least one South Asian language. All the predominant South Asian minority languages were represented with a minimum of two speakers of each Asian language. The successful candidates had to supply references and undergo Criminal Record Bureau checks. On completion of these checks, the community researchers attended two sessions of training in the aims of the project, interviewing skills, ethical issues, data protection, and personal safety.

3.3.5 Translations and Verification

Translation is the communication of meaning from a source language to a target language (The Oxford English Dictionary (OED) 2012). The two main problems with translation are fidelity and transparency (Kasperek 1983). Fidelity is the concept of literal or meta-translation, aiming for a direct correlation between source and

translated material. Fidelity is problematic as some words are not directly translatable. Such words or calques tend to become part of the target language for example *zeitgeist* (German) or *bungalow* (Indian). A further problem is idiomatic errors; for example, an idiomatic error would be directly translating ‘kicked the bucket’, rather than died (Cambridge, J 2005). Transparency is where the translation would appear to a native speaker as if the translated message was originally generated in that language, poor transparency results in sentences or phrases that are not syntactically correct (Kasperek 1983).

Though people may demonstrate fluency in a language this does not mean that they would be able translators. In screening the potential community researchers, it was observed that some people would attempt to paraphrase or provide a summary of a conversation, an example of a fidelity error. Other researchers would attempt to metaphrase or give a literal translation and make idiomatic errors. Yet other translations would have transparency error where a direct translation of the original was so faithful that in sections it was unclear. Efficient translations that can address the tension between fidelity and transparency are difficult as there is evidence to suggest that fluent bi-linguists can make major errors even if they are trained in specialist areas such as law (Hale 2002).

As an adjunct to formal training the community researchers were invited to attend a translator seminar provided by the University of Central Lancashire (2005). In a subsequent discussion, the seminar presenter advised on content and scope for a translator’s workshop. The more expert translators from the community researchers, and one community worker helped present the workshop to ensure that all community

researchers could provide translations that addressed the balance between fidelity and transparency.

All interviews (focus group and individual) were digitally recorded. A number of these would require translation. To ensure translated interviews were as accurate as possible, within the restrictions of fidelity and transparency, they underwent a verification process. There are a number of methods for verifying translations. The two most common are forward translation with testing, and back translation. Back translation is when a translation is made from one language to another then back again for checking (Maneesriwongul & Dixon 2004).

Forward translation with testing is where two English translations are made by separate translators from the same original voice file. The two English translations are transcribed and compared, discrepancies are discussed, and consensus worked towards (see Figure 3.6). No verification process is perfect, but back translation is prone to error, typically through reduction of semantic equivalence (Beck et al. 2003; Maneesriwongul & Dixon 2004).

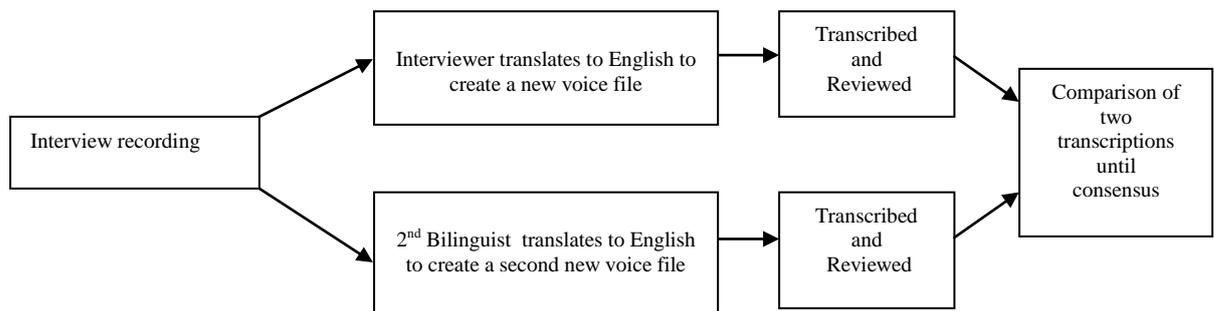


Figure 3.6 Forward translation with testing (Maneesriwongul & Dixon 2004)

For example back translating a questionnaire in one study resulted in 37% of the items not having the same meaning (Lee et al. 1999). Forward translation with testing also

has flaws, for example, two translators from the same background may interpret a text in the same, but erroneous, way. Forward translation with testing was used in this study as it is considered to be the most reliable and transparent method of the two, and the probability of two translators producing the same errors in a translation was considered to be low (Beck et al. 2003; Maneesriwongul & Dixon 2004).

3.3.6 Data Analysis

As both phases of Part 1 employed a structured method of generating qualitative data, aiming to address specific questions, a Framework Approach was considered to be the most appropriate method of analysis (Ritchie & Spencer 1993). This method is specifically for applied policy-relevant research with pre-set objectives, which are typically those of a funding body (Pope et al. 2000). It also has the flexibility to include concepts outside of the pre-set objectives (Srivastava & Thomson 2009).

The Framework Approach employs the following steps:

- Familiarisation: immersion in the raw data; voice files, transcripts, notes etc.
- Identifying a thematic framework: a detailed categorisation of issues from the project objectives and frequently occurring in the data.
- Indexing: systematic annotation of the data.
- Charting: reordering of the indexed data into areas defined by the thematic framework.
- Mapping and interpretation: used to illustrate the range and nature of phenomena, look for associations between themes, and provide an explanation for the findings. (adapted from Ritchie & Spencer 1993)

Framework analysis is a mixture of basic qualitative analysis approaches, predominantly content and thematic analysis. The ‘framework’ it provides to work within does give a structure to the process, in that way essential steps are unlikely to be forgotten or circumvented. In addition, it is flexible enough to not only be used for applied policy research but theory generation as well (Srivastava & Thomson 2009). Other approaches to analysis could have been used; for example, grounded theory or hermeneutic analysis (Silverman 2004). Framework analysis is more advantageous in that appropriate analysis methods can be used with the Framework approach over and above the basic thematic and synthesis approaches. In addition there is the ability to apply straightforward within-case and across case-analysis because of the framework structure (Srivastava & Thomson 2009). Originally this was carried out using a framework drawn on paper, but can now be carried out with computer aided qualitative data analysis software (CAQDAS), though the individual applications require some initial reconfiguring.

3.4 Phase 1: Focus Group interviews

Focus groups are:

‘A group of individuals selected and assembled by researchers to discuss and comment on, from personal experience, the topic that is the subject of the research.’

(Powell & Single 1996 p499.). The utility of focus groups is that they can draw on the attitudes, feelings, beliefs, and experiences of the group members, which is not possible with other methods such as one-to-one interviewing or questionnaire surveys (Powell et al. 1996). The defining feature and where they differ from group interviews is the intention to develop interaction between the members to generate a greater insight into the topic of discussion (Morgan 1997).

The composition of focus groups is important and members should possess a key characteristic that is important for the study; it should consist of six to ten members who are unknown to one another. This will ensure the group is manageable and they are not influenced by pre-existing relationships, which can result in an atmosphere which fosters candid discussion. Theoretical sampling is advised to collect as wide a range of experiences as possible to prevent sampling bias (Powell & Single 1996).

Other forms of bias can operate in focus groups and an awareness of these can mitigate their effects (Krueger & Casey 2000; Puchta & Potter 2002). For example the outcomes depend on the questions asked and how they are phrased (Krueger & Casey 2009). More subtle biases can also operate and one of these was identified in the early days of focus groups, groupthink. This is a form of unconscious consensus as a result of a failure of group members to resist group pressures (Janis 1982). A second bias is a form of explicit or implicit manipulation by the moderator (Puchta & Potter 2002). The main defence against these biases is a moderator that is aware of how these operate (Janis 1972; Janis 1982). The moderators in this phase were aware of focus group biases and made concerted efforts to negate them.

Aim

The purpose of the focus groups was to collect information about:

- Stroke awareness.
- What people would suggest they would do if they were to experience the stroke symptoms described to them
- What they would advise others to do in the same situation.
- What they would expect of stroke services.

- How they would like stroke services to accommodate their individual religious and cultural needs.

This information was then used to develop a reference framework for the individual interviews.

3.4.1 Sampling and Participants

The characteristics of the focus group members are shown in Table 3.1 and moderator characteristics are described in section 3.34 above. The composition of the two groups was different and this is discussed below. However, this presents an opportunity to explore collect data from two different sources and explore the similarities and differences as a form of verification by triangulation (Begley 1996). The potential impact of the moderators on the focus group process and subsequent analysis was considered. The presence of the author could have had a negative impact as he was an ‘outsider’, in contrast he may have added credibility as he represented a research department. The community worker co-moderators were known to the participants because of their regular work. The community workers reported that during the sessions they did not perceive any change from known behaviour that could have been caused by the interaction (Wolcott 1990).

Town A

The group from Town A were heterogeneous for age, gender, ethnicity, UK born, and religion. All members could speak English and the majority had a close relationship with someone who had suffered a stroke (see Table 3.1). The community worker and the author acted as co-moderators.

Characteristic	Town A: 9 members	Town B: 5 members
Age range: 18-50	62%	0
Age range 51+	38%	100%
Male	56%	100%
UK born	88%	0
Speak English	90 (100%)	1 (20%)
Stated ethnicity	3 Pakistani; 1 Bengali; 5 Indian	All Pakistani
Religion	4 Muslim; 1 Sikh; 2 Hindu; 1 n/a	All Muslim
Had stroke	1 (9%)	1 (20%)
Cared for stroke sufferer	7 (77%)	3 (60%)

Table 3.1 Characteristics of the focus group members

Sampling strategies were difficult to employ in selecting participants. The requirements of the ethical approval were such that a community worker had to make first contact. As this town has a diverse South Asian population, the Community Worker compiled a list of 32 people he considered as representative and knowledgeable of the local South Asian communities. Because of the diversity of the groups attending, English was chosen as the language of the interviews, and associated documentation; translation facilities were available for those who required them. Both community workers and two community researchers together with the author acted as a review panel to avoid selection bias. The panel selected 14 people from the list as representatives of each South Asian group in the town. Although the ideal number for a focus group is approximately six to ten (Powell & Single 1996), 14 were selected in case of refusals. The nominated community representatives were

sent letters inviting them to take part and containing contact details and project information sheets.

Town B

Town B is a smaller town than A. As a result, there are less existing formal or informal community interest groups. The minority group from this town was a smaller and less diverse group than Town A. The Community Worker advised that a snowballing technique would be a more appropriate alternative to mailed out requests (Barendregt et al. 2005; Hartnol 1997) as face to face contact would achieve better results.

The Community Worker identified a primary contact, who recommended a subsequent contact, and this carried on until no other contacts were suggested. Each potential group member was provided with an information sheet in English and this was verbally translated if required. The potential participants were re-contacted two days later and invited to join the focus group sessions.

Five members of the main minority community agreed to attend the focus group. The group were homogeneous for many characteristics, but were significantly different from Town A group members. To a great extent the composition of this group was beyond the control of the author as community workers had to be the first point of contact with the participants and the guide to what would work with that community. The majority of the participants did not speak English, therefore the focus group was held in Urdu, the common language of the participants; the Community Worker acted as moderator and translator for the co-moderator, who did not speak Urdu.

3.4.2 Procedures

The focus group process was the same for both groups, except they were held on different days and at different venues. The community worker from each town arranged for their group to meet at an appointed time in a community centre known to the participants. The interviews were limited to 90 minutes, but terminated when all the issues were covered and discussions completed. Town A lasted for 90 minutes and Town B for 25 minutes. The author and the community worker from the relevant town co-moderated the focus groups, and the discussions from both focus groups were digitally recorded, with the written informed consent of the participants.

All group members agreed they understood the information sheet and were asked to give written consent to take part in the study. After the consenting process and introductions the group were read 4 vignettes related to stroke awareness (see Appendix 2) and included: a) a typical set of TIA symptoms, b) a typical set of major stroke symptoms, c) typical acute treatment processes, d) typical rehabilitation processes and e) post-discharge issues. Paper copies, in English, were distributed to all group members and verbal translations were available if required. These vignettes were developed by a consensus group of stroke researchers with knowledge of typical care-pathway experiences of stroke service-users. The description of 'typical' means that in the opinion of stroke care experts these would be the structures and processes of care that a person from a minority group background would encounter if they suffered a stroke. Vignettes are brief descriptions of situations where participants are expected to react or respond (Polit & Beck 2008). They elicit responses to novel situations that may be unethical to construct or enact, and have been used with minority groups with successful outcomes (La Fontaine et al. 2007; Morrison et al.

2004). However, as peoples' attitude and behaviour are not always concordant, the findings are essentially an estimation of reality (Ajzen 2001).

After each vignette was read out, the group was asked to discuss the content of the vignette, and what they would suggest if:

- This happened to someone they knew, what action they would take?
- If this happened to them, what action would they take?
- What would be the cultural or religious implications if they had to experience any of the processes described?
- How could such processes be changed to make them culturally and religiously acceptable?

The questions asked were to explore what would be required of a stroke service to enable it to suit their specific needs. In addition, to explore the issues around what they would do if it happened to themselves or someone else. The disparity between what is intended and what is actually done has been documented (Ajzen 1991; Ajzen 2001). The use of a focus group facilitated reaching a consensus about these needs in an efficient way. The validity of the reported opinions would be explored later in individual interviews.

3.5 Data analysis

The recording from the focus group in Town A was in English, the recording from Town B focus group was in Urdu, therefore translated and verified using the process described in Figure 3.6. This resulted in an original English voice file for Town A and a translated and verified English voice file from Town B. The analyses were carried out using a qualitative data management application, Atlas-ti (Muhr 2010).

The internal objects (codes, super codes, and quotations) had to be reconceptualised to accommodate the framework approach, as Atlas ti was not specifically designed for this task, but has been used for this type of analysis before (Vermeer et al. 2009) (see Table 3.2).

	Preliminary theme 1 (Code family)	Preliminary theme 2 (Code family)	Preliminary theme etc (Code family).
Town A Focus group (Primary document)	Summary (Code)	Summary (Code)	Summary (Code)
Town B Focus group (Primary document)	Summary (Code)	Summary (Code)	Summary (Code)

Table 3.2 Example of using Atlas-ti (objects) for the framework analysis

Text in brackets indicates the appropriate Atlas-ti objects and the table shows how they relate to framework analysis concepts.

3.5.1 Audio analysis

One of the reasons for using focus groups is that interactions will generate the development of more in-depth data (Puchta & Potter 2002). Transcription of focus groups is difficult and time consuming, in addition transcripts may not capture the nuances, voice tone, volume, and intonations that are evident in focus groups and interviews (Halcomb & Davidson 2006). To investigate the reliability of analysing transcriptions an alternative method was used. This alternative method involves using a six step process (Halcomb & Davidson 2006):

1. Audio record session and make notes (memos).
2. Review memos post interview.
3. Listen to audio file and develop memos.
4. Preliminary content coding.

5. Secondary content coding.
6. Final themes (preliminary framework in this case Table 3.3).

For these focus groups, memos written during the sessions were limited; for both towns, the notes amounted to ideas from co-moderators (steps 1 & 2). These ideas formed the basis of discussion between moderators after the focus groups. The audio files were reviewed with reference to the initial ideas and a preliminary content analysis was undertaken (step 3 & 4). For reliability this process was carried out by the author and an independent researcher separately (step 5) (see Figure 3.7). This resulted in a preliminary framework (step 6) (see Table 3.3).

3.5.2 Transcription analysis (text files)

The two focus group recordings in English (Town A recording and Town B recorded translation) were transcribed and checked for accuracy. Using the preliminary framework generated from the audio files, framework analysis (Ritchie & Spencer 1993) was carried out using a qualitative data management application, Atlas-ti (Muhr 2006).

In the spirit of framework analysis, this textual analysis was not restricted to the thematic framework generated from the recordings, these themes could be adapted, and new themes added as necessary (Ritchie & Spencer 1993). In terms of Atlas objects; primary documents (transcript) were seen as cases, code families were seen as preliminary themes, interconnecting matrix cells (summaries) were seen as codes.

Trustworthiness

For trustworthiness, the coding process was carried out by the author and a second independent researcher who completed the process without using the preliminary

framework from the audio files (Figure 3.7). This was to avoid biasing coding by having the pre-existing codes. The level of agreement between the two outputs was good but required a standardising of the theme names.

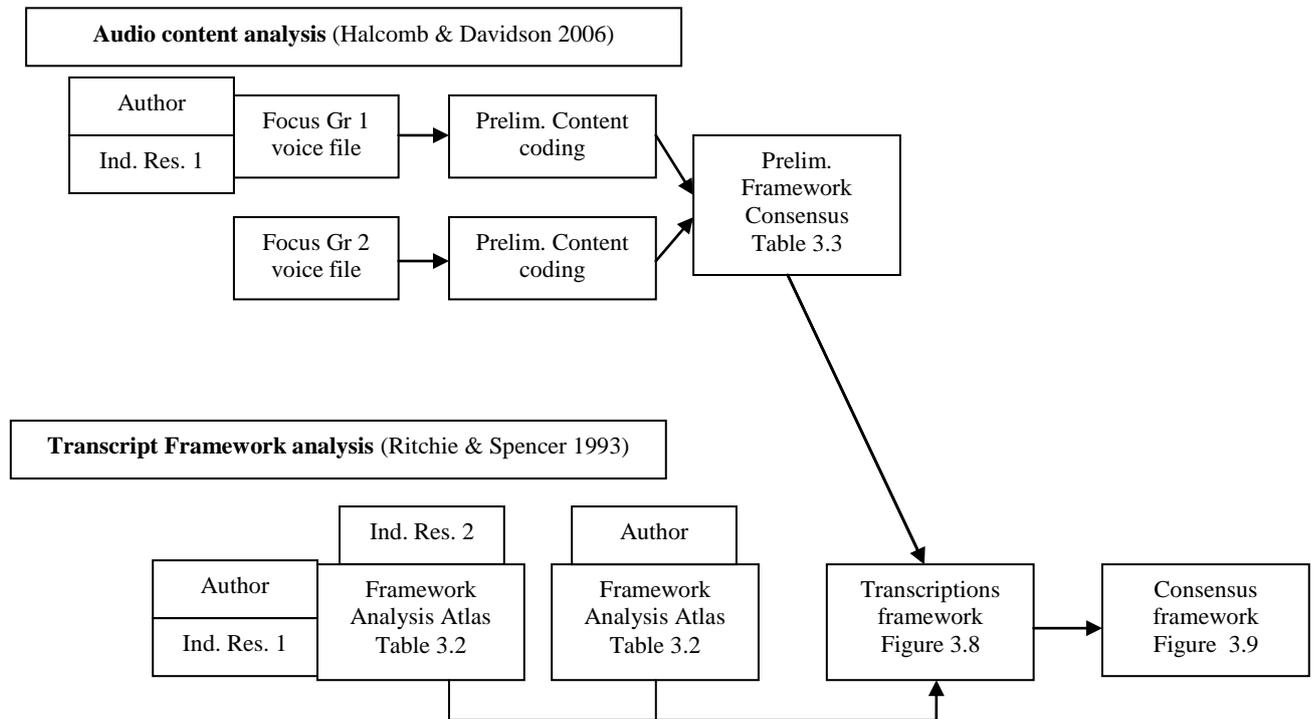


Figure 3.7 Analysis plan to ensure trustworthiness

Community workers from each town took a summary of the findings to verify the content with at least one member of their focus group. Two representatives from Town A and one representative from Town B reviewed the themes and explanations. The community workers indicated that the summaries were a fair reflection as far as the representatives could recall.

3.6 Findings

The preliminary framework from the audio analysis is presented in Table 3.3, and to prevent duplication these themes will be discussed after the findings from the transcript analysis that resulted in the transcript framework (Figure 3.8). The two frameworks are compared in Figure 3.9.

Knowledge of stroke	There was a consensus opinion that there was generally a lack of awareness about stroke issues in the target communities. Awareness alone however might not improve things, as there were other factors that influenced decisions to access services.
Family centred care	In these communities, stroke was a family event, and responses to stroke, and recovery from stroke is set very much in a family context. For example, in the ‘crisis’ phase of acute stroke, people would generally turn to family first, although there are different and sometimes conflicting views about what should be done. Generally having clear plans for what to do in cases of emergency may not be fully established in these communities. Families were described as having an important role in on-going care and rehabilitation, and many examples of where they might help the service-user’s hospitalisation were given. Specific problems of isolation can be found in older people from these communities after stroke
Language barriers	Language appeared to be a major barrier to accessing services, or accessing appropriate care once services are being provided. Communication barriers may also make it difficult for people affected by stroke to contact primary care services, and most especially General Practitioners. The role of the communication link worker was highlighted as having potential to alleviate some of these difficulties, although provision is patchy. Instances were highlighted where family members were used as translators even though this is now deemed unacceptable practice.
Gender issues	Gender appeared to be an important issue, and many women from these communities would be unhappy at being touched by men. This has implications for the management of either acute stroke or rehabilitation at home. There was some agreement that the use of uniforms by male staff would mitigate this whilst the service-user was in hospital, particularly if family members were present.
Service issues	Generally, community leaders thought that the sensitivity of services to cultural and religious needs was improving, although there was still a considerable amount of work to be done. It was deemed important to consider ethnicity issues in all aspects of the service. Certain issues remain problematic including, for example, the provision of alternative meal options. There was general agreement that service-users and family members were not always made aware of what facilities were available (for example prayer rooms). There were some examples highlighted of poor staff attitude, including some from professionals from South East Asian ethnic heritage.
Community changes	There may be a shift away from extended families, and service need to take this on board in long-term planning of stroke services.

Table 3.3 Preliminary framework of issues from audio file analysis

Figure 3.8 represents the mapping from the transcript framework analysis.

The centre table indicates the thematic framework and these are associated with the outer tables that include sub-themes and supporting text extracts.

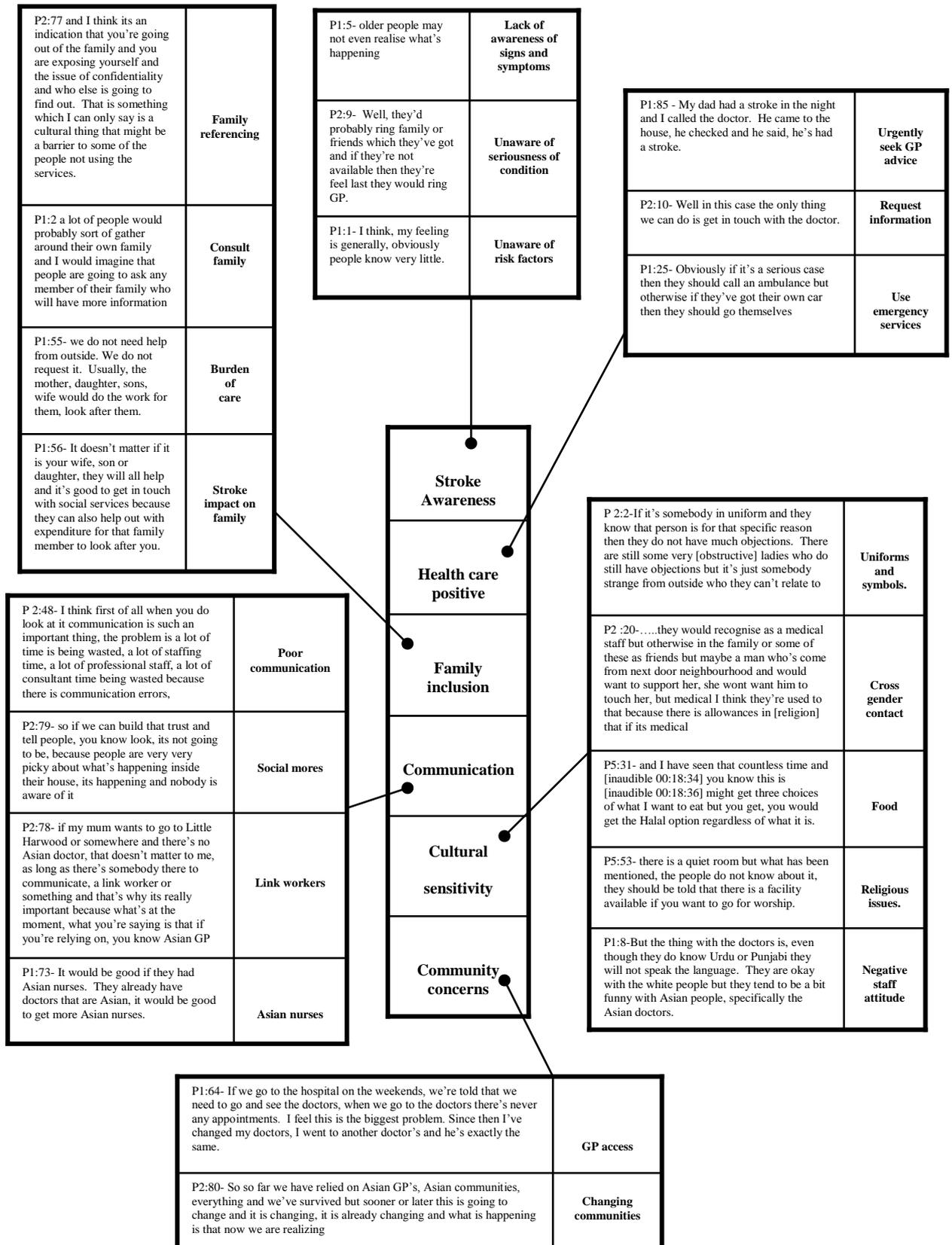


Figure 3.8 Transcription (and Final) Thematic framework (centre panel)

The final stage of the analysis is to compare the two frameworks; they are comparing the same two focus groups, they should result in similar frameworks.

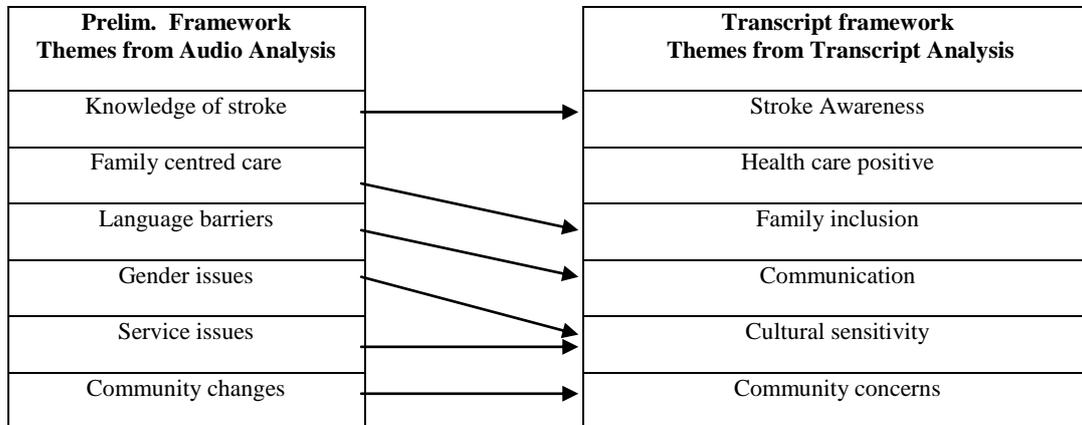


Figure 3.9 Comparison of audio and transcript themes

Six issues were evident from the analysis of the audio files. There was a generalised low level of stroke awareness in both focus groups and knowledge of stroke issues was limited except for those with direct experience of stroke. A new theme of ‘health care positive’ was generated for the transcripts framework, as it was felt on the more in-depth analysis that although the focus groups were health orientated, participants demonstrated that they were keen to access good health care and it was a concern for them.

In the audio file analysis, family centred care was named as a theme as it seemed as though the family was a unit that stroke affected. While this may be true the more detailed analysis of the transcript files indicated that rather than a unit affected by stroke, it was more that respondents required, or rather expected, the family to be included at each stage of stroke care. Language was evident in the audio files framework as a significant barrier, but there were more subtle issues where it was clear that other aspects of communication were discussed, for example non-verbal

behaviour, this resulted in Communication as a theme in the transcript framework. Two separate themes in the audio file framework were combined in the transcript framework. Initially in the audio files analysis, gender and service issues were seen as discrete. However, the transcript analysis brought out other culturally related service issues, and although gender is important, it was decided that the subthemes of both gender and service issues were better reflected by the theme cultural sensitivity. The community theme was altered from 'changes' to 'concerns' as it was the concern the changes were generating that seemed to represent the theme better.

Considering the above, the final consensus framework that represents the analysis of the focus group files is accepted to be Figure 3.8, the transcript framework.

3.6.1 Discussion

Analysing focus group transcripts from voice files in this case was adequate. It does allow the analyst to capture the voice tones and subtleties that a transcript cannot (Halcomb & Davidson 2006). However, on this occasion analysing verbatim transcriptions seemed to facilitate a more detailed and measured analysis, but the differences in the results are subtle. For future work the optimum approach would be analysing transcripts at the same time as listening to the audio file. This feature is starting to be included in computer applications; synchronisation between audio and transcript may also be possible.

Stroke survivors from both towns had access to the same hospitals and South Asian populations from both towns were ethnically different, as were the focus group participants. This was given full consideration during the analyses by looking for differences between the groups. The themes that emerged were similar from both

towns, however they differed in focus. For example in town A, the group members would discuss issues around gender at length whereas in town B the discussion was more limited. Town B talked about GPs and health issues in more detail, where these topics were discussed less in Town A.

This could be a factor of the composition of the groups, Town A had females and the participants were generally younger than Town B. As Town B were male and older, then health and GP issues would be more important (Barendregt et al. 2005).

Unfortunately, because of the requirements of the ethical review choice of candidates was limited as the designated community worker had to identify candidates. For town A the choice was limited to the range of candidates presented by the community worker. For town B the choice was limited to the candidates that the community worker found. This may have presented some form of sample bias. However, the design of the analysis (see Figure 3.7) was such that every effort was made to ensure such bias was overcome (Dixon-Woods et al. 2004). The parallel coding and interpretation by two separate independent researchers, the involvement of the community researchers and use of audio and text strategies increased confidence in the findings (Cutcliffe & McKenna 1999).

The duration of Town A's discussion was three times longer than that of Town B. This is probably a function of the composition of the groups. Town A group, as community group representatives, were more likely to be used to speaking in public on such topics. In addition, some of participants represented groups that focused on a particular issue and would tend to speak for longer on that issue. Most participants wished to speak, resulting in the topic response taking longer than expected (Puchta &

Potter 2002). The group for Town B were older, inexperienced in speaking in public and tended to give much shorter answers and content to let one member speak, then voice agreement. However, it could also be that the CR who conducted the group was not experienced in focus group facilitation and could not get assistance from the co-moderator as he did not speak Urdu.

The groups in both towns were asked to carry out the same tasks and had the same probing questions. However, there was sufficient flexibility in the way the focus groups were conducted to allow individuals or the group to express themselves, in addition the composition of the groups was very different. Therefore, the similarity of responses would seem to indicate a commonality of issues between the two towns unaffected by their differences.

Two focus groups may have been insufficient to explore all the variation in South Asian minority groups (Barbour 2005; Fallon & Berman Brown 2002). This is a problem with focus groups and interviews; however, the commonality of findings from both groups, despite the brevity of one session, is a fair indicator of data saturation (Silverman 2004). The differential composition of the groups, using community researchers as moderators and holding the sessions in places known to the group members, all contributed to the validity of the findings. This increased validity can refute the accusation of the results being a social artefact of the situation (Woolgar 1988a).

These findings suggest that issues surrounding stroke and stroke services are similar for people in East Lancashire from a range of South Asian backgrounds. Again to

avoid duplication, further discussion on this part of the study will take place later in Chapter 7.

This phase described the development of a thematic framework that can be used to inform individual interviews with people of South Asian heritage about stroke care. The literature was not reviewed ahead of this phase. The rationale for this was to avoid researcher or expectancy bias from findings in the literature (Rosenthal & Jacobson 1963).

3.7 Phase 2: Individual interviews

The aim of this Phase is to explore the experiences and perceptions of South Asian groups in one area of the UK using the framework developed in Phase 1. From these findings, to develop a tentative hypothesis that proposes the issues for these groups accessing equitable stroke care. The objectives are to (iv) describe and justify the methodological approach to address the first research question, (v) complete the exploration of the experiences and perceptions of members of local South Asian groups in an area of the UK in access to stroke care and (vi) develop a tentative hypothesis of the source of barriers to equitable care for South Asian groups in the UK.

3.8 Methods: interviews

Semi-structured individual interviews, in the participants' language of choice were used in this part of the study. This was seen as the appropriate method to gather depth and breadth of information required. Surveys are too restrictive and would not capture the level of detail that is possible with individual interviews and focus groups and group interviews may inhibit individuals when recounting their experiences

(Britten 1995; Marrow 1996). Semi-structured interviews have been used in a range of social sciences (Silverman 2004). The strengths are that interviewers and interviews have time to develop a rapport, they are high in validity as the respondent has free expression, and they allow time for clarification and development of issues (Silverman 2004). Interviews do have some weaknesses as the success of an interview depends on the skill of the interviewer, the respondents can give social desirable responses, and the responses may be subject to the accuracy of recall of experiences (Silverman 2004). Awareness of the strengths and weaknesses is important in counteracting these biases (Britten 1995; Field & Morse 1989).

3.8.1 Sampling and Participants

The community workers who collaborated on Phase 1 identified potential interview participants from their contacts within their communities. The names, contact details, gender, preferred language, and ethnicity of the contacts were noted and an appropriate community researcher (CR) was assigned to contact them. All potential participants had to be South Asian, 18 years or over, live in Town A or B and able to communicate in English or a South Asian language.

In each of the towns, two sub-groups of people were recruited. The first sub-group had either survived a stroke, or had cared for a person who had survived a stroke (Stroke survivors), and the second had no personal experience of stroke (Non-strokes). For 'Stroke survivors', their experiences and perceptions of stroke services were explored, as well as their recommendations to develop services to address their cultural needs. For 'Non-strokes', their levels of stroke awareness and expectations of whether stroke services would address their cultural needs were explored.

People who had survived a stroke and / or carers

Nine people from Town A were interviewed in this category, two were carers: one female (40 years), one male (42 years), both of Indian heritage. Of the Stroke survivors, four were male (65 –78 years; two Pakistani, one Indian and one Punjabi) and three female (66 – 81 years; two Indian, one Punjabi). From Town B there were two participants who were both male Stroke survivors (68 and 72 years, Pakistani heritage).

People with no personal experience of stroke:

Eight people from Town A and three people from Town B were interviewed. From Town A there were four males (27 – 41 years, two Pakistani and two Indian) and four females (26 – 65 years, one Pakistani, two Indian, and one Punjabi). From Town B, two were female and from the main minority group (26 - 35 years, Pakistani), the third was of East African-Asian heritage (32 years, Indian).

3.8.2 Procedures

Interview material

A workgroup was convened consisting of community researchers, community workers and the author; they used the thematic framework from Phase 1 to develop materials for the individual interviews. The focus of the interviews for the two groups was different, requiring a set of material for each. One set for ‘Non-strokes’ (Appendix 3), and another set for Stroke survivors or their carers (Appendix 4).

The ‘Stroke survivor’ set included an interview spine with probe questions to explore their experiences of stroke care and how stroke care could be developed to address their religious and cultural needs. For Non-strokes a different interview spine was

included which explored their knowledge of stroke and stroke care. A series of vignettes explored their expectations of stroke services and how they saw these services addressing their individual religious and cultural needs (see Appendix 2).

Although the material for both sets was semi-structured, the CRs were trained to use flexibility in the interview structure allowing sufficient latitude to capture rich accounts (Britten 1995; Field & Morse 1989). In order to support the CRs with stroke related information, they were issued with prompt sheets that linked to sections of the interview spine. These included sheets describing stroke symptoms and risk factors (Appendix 5), a typical stroke care pathway, and stroke/TIA differences (Appendix 6). As an additional training exercise and to pilot test the materials, CRs used the materials to interview one another. This resulted in some changes, these included adding more structural steps to the interview material and the production of a checklist to ensure interviewers did not omit any stage of the process. These changes were a joint response to the pilot exercise and reflected the CRs caution because of limited interview experience. All changes were reviewed by the CRs to ensure they were suitable for use in their communities (Im et al. 2004).

Recruitment

When a potential participant was identified, the appointed CR would telephone to invite the contact to take part in the study. The CR explained that all the paperwork was in English but they would provide translation if required. If the contact agreed to take part, they were sent an information sheet about the study. Three days after sending the letter, each potential participant was contacted to see if they understood the paperwork sent to them and if they would join the study; further opportunity of translation was offered.

Twenty-two people agreed to be interviewed; the CRs arranged a mutually convenient time and location for the interview. The majority of the interviews were carried out in the participants' homes, the remainder at a local community centre. The Community Researcher carried out the consenting process and recorded demographic data, such as age, sex, ethnicity, and languages spoken on a data capture form (Appendix 7).

Interviews were digitally recorded, 14 were in English and 8 in Asian languages (5 in Urdu and 3 in Gujarati). Recordings in English were transcribed and the non-English recordings had to undergo the verification process. Recordings were verified using the forward translation with testing described above (Figure 3.6). Initially the less experienced translators had problems with translating verbatim. Though this is not always possible because of the structure of the languages, it is possible to arrive at a translation that is semantically equivalent. The inexperienced translators were relaying a summary of the discourse rather than a faithful representation. This issue was rectified when a more experienced translator gave guidance. The verification process indicated that the translations were transparent and semantically equivalent (Kasperek 1983), and consensus between the translators and a multilingual community worker was achieved in all these cases.

3.8.3 Data Analysis

The study was never designed to compare one town with another, but rather to see if minority groups in either town had specific needs or expectations. Therefore, based on the similarities found in the focus groups, the transcripts were grouped for analysis into Stroke survivors and Non-strokes, but analysts were aware of the origin of each transcript and were looking for town-specific variation.

Framework Analysis

Analysis proceeded using the framework approach as described in the focus groups analysis above (Ritchie & Spencer 1993). Transcripts from the two groups were read until familiarisation was achieved through immersion. Coding the transcripts proceeded (indexing) using the Transcription (Final) Framework developed in Phase 1 (Figure 3.8). As this continued, other categories emerged and were included by coding segments of text in an ‘open’ manner (open coding) that was not assumption based. The coding and subsequent analysis of the data was facilitated by a computer programme, Atlas-ti (Muhr 2006). This process grouped categories (codes) into code families for each interview (case). By using the multi-layer coding facility in Atlas, a text segment or quotation could be coded with a theme from the framework and other levels of coding, such as inductive coding, to provide deeper levels of analysis (Pope et al. 2000)(Table 3.4).

Framework theme	Code Family	Open coding 2	Open coding 3 etc.
Awareness of stroke	Signs and symptoms	Facial	Sub-codes of Facial
		Limb	Sub-codes of Limb
	Emergency	Yes	Sub-codes of Yes
		No	Sub-codes of No

Table 3.4 Example of multi-level coding

Because of the flexibility of Atlas-ti this multi-level coding could be re-configured to represent framework analysis as described in Phase 1, and shown in Table 3.2 (Ritchie & Spencer 1993).

Recruiting participants and data coding was carried out in parallel, and recruitment was halted when data saturation was achieved. Saturation is achieved when the interviews have been analysed and no further new themes, ideas, or concepts are generated by including additional transcripts (Baxter & Eyles 1997). Because of the time lag between verification/transcription and analysis, more people were recruited and interviewed in excess of the data saturation point; these additional data with no new themes reinforced the decision that data saturation was achieved for this analysis (Bowen 2008). The functionality of Atlas-ti facilitated saturation assessment. For example, when a transcript was coded the codes were counted; as each new transcript was coded the codes were recounted. For stroke survivor interviews, when 11 transcripts had been coded, 98% of the final total codes had been accounted for by transcript 9.

Non-strokes reached saturation at an earlier stage than the stroke survivors. This may have been because of the nature of the interview material. Although expansion on the interview spine was encouraged, responses tended to be restricted to spine items because of the participants' limited knowledge of stroke care pathways. Each stroke experience is unique and thus it was expected that data saturation for this groups would require more participants (Bowen 2008).

Mapping was carried out for both sub-groups; Non-strokes are in Figure 3.10 and Stroke survivors in Figure 3.11. Mapping is the process that illustrates the range and nature of the findings of an investigation (Hoffman et al. 2002; Ritchie & Spencer 1993). It is towards the end of the chain of steps in an inductive inquiry between a tentative hypothesising and theory statement. Extra material from the interviews to support the extracts is in Appendix 8.

A weakness of using the Framework Approach would appear to be that issues in the framework would pre-determine the outcomes and possibly the final theoretical framework. There should always will be good reasons for the concepts in the framework in the first place (Ritchie & Spencer 1993). As long as analysts are aware of this problem, and flexibility is adopted in the approach, then the framework should not pre-determine the outcome. Reliability and transparency are essential to ensuring this (Horsburgh 2003).

Each text extract from transcripts was coded numerically; the first figure refers to the transcript code, and the second refers to the quotation number in that transcript. The extracts placed in the body of the text are preceded by SS for Stroke survivor or NS for Non-stroke. These do not appear in the maps as it is plain what group the extracts belong to. For example, NS 6:32, is a person who has not had a stroke, transcript number six, quotation number 32. Some respondents were interviewed more than once, their interviews were joined in sequence of recording and treated as one case.

3.9 Findings and discussion

The analysis of both groups elicited the similar mapped outcomes onto three super-ordinate themes, 'Willingness to access health care services', 'Stroke awareness', and 'Cultural competence' in providing services to people of South Asian heritage.

These super-ordinate themes were arrived at after analysing data from both Stroke survivors and Non-stroke participants. This adds to the credibility of the findings as two different interview structures were used, and the two groups had different levels of experience of stroke.

The levels of abstraction as a result of the charting and mapping analysis are indicated in Figures 3.9 and 3.10 by different shading (Ritchie & Spencer 1993). Low level themes, or open coding, is represented in the lighter shade, for example, gender, or food. The mid-level or code-families are represented by mid-grey shading, for example cultural sensitivity. The highest level of abstraction is super-ordinate themes which are represented by the darkest shading, for example cultural competence. Each low level theme is supported by a quotation from the transcripts (see Appendix 8 for supporting material).

3.9.1 Willingness to access health care services

As a group, the people of South Asian heritage interviewed in the individual interviews and focus groups were keen to access good health care as a way of maintaining or restoring their health. This may seem to be self-evident but it is important as it provides evidence from a different source that supports the existing evidence that inequity in health care distribution is not from the lack of motivation or need on behalf on these minority groups (Adamson et al. 2003). The knowledge that South Asian minority groups are willing to access health care is a key finding for future public health initiatives. Finally, if a population is willing to access services, it would seem that service provider structural factors are more likely contributors to inequitable access to stroke care.

3.9.2 Stroke awareness

Two mid-level themes comprised this super-ordinate theme, 'Low stroke awareness' and 'Validation'. Across the two groups, there were low levels of stroke awareness. Most people in the Non-stroke group could identify at least one sign or symptom. More strikingly for this group there was a low level of awareness of the risks of

stroke, specific to their own minority groups. The majority were unaware that, compared to the general population, South Asians were more likely to suffer a stroke, and that there are higher than average levels of diabetes in South Asian communities, which is a major risk factor for stroke. Thus, South Asian groups are over-exposed to stroke risk and under-exposed to stroke awareness. The Stroke survivor group had more knowledge because of their experiences. The majority did not recognise that they had suffered a stroke at the time it happened, and post-stroke, although there was evidence of more knowledge than the Non-strokes, it was still limited.

I: so did you have a reasonable awareness of the symptoms of stroke before this?

*R Not really, I've seen brain haemorrhage [before] but not err, of course [a stroke].
(SS_2:2)*

The second mid-level theme was 'Validation'. Though this is related to low level of knowledge (Jones et al. 2010) it was categorised as a theme because of its prevalence. The majority of participants from Stroke survivors did not treat stroke as a medical emergency and rang a GP or other person for validation of their condition (Banerjee et al. 2010).

With the Non-strokes, responses to vignettes, there was an approximately equal division between intent to call 999, or calling someone else if they experienced stroke symptoms. The same was true when asked what they would advise someone else to do who also experienced these symptoms. However, it was discovered that a minority would advise a family member to call 999, but not do this themselves:

R: [I would advise them to] get to the hospital [immediately].

[Section removed for clarity]

I: Okay, what would you do if that happened to you.

R: If that happened to me I think I'd try and contact a family member (NS_4:5).

What is clear is that expressed personal attitude does not always manifest as a behavioural action. This is probably premised on the lack of confidence in symptom recognition brought about by low levels of stroke awareness. The theory of reasoned action tells us that attitude and subjective norms play a part in intent and subsequent behaviour (Ajzen 2001). Although research has shown that attitude is a more consistent behaviour driver than subjective norms, this is dependent upon the strength of attitude (O'Keefe 1990). In this case, a perceived life-threatening stroke will be high in attitude to call 999 and result in action. Where the symptoms are perceived as less life threatening, then attitudinal drivers will be weak and subjective norms will be referred to, and tested by calling referent groups, GPs or families, to validate the subjective norm of calling 999. Unfortunately, there is less robust research on subjective norms or how they are influenced, which is also not addressed in the theory (O'Keefe 1990).

The low level of stroke awareness in minority groups has been previously noted as a concern (Dr Foster Intelligence 2010). It could be argued that if a service exists and it is not used it is a matter of personal choice or personal responsibility. It has also been argued that not mounting awareness raising and screening programmes is failing to address the needs of groups with an increased level of risk (Atkinson et al. 2001; Szczepura 2005). If this is the case then this would seem to indicate that structural factors are responsible for the outcome of inequitable service provision for South Asian groups.

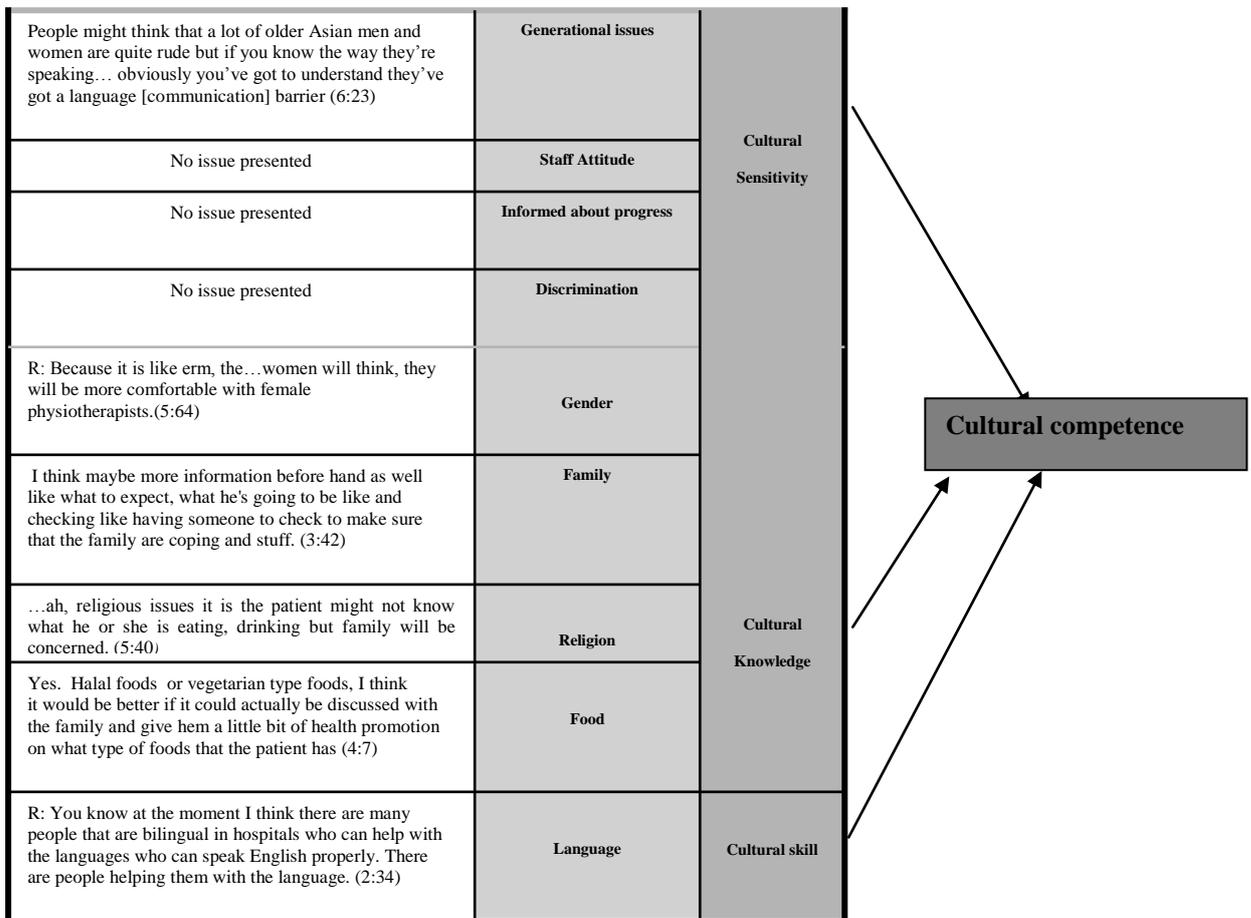
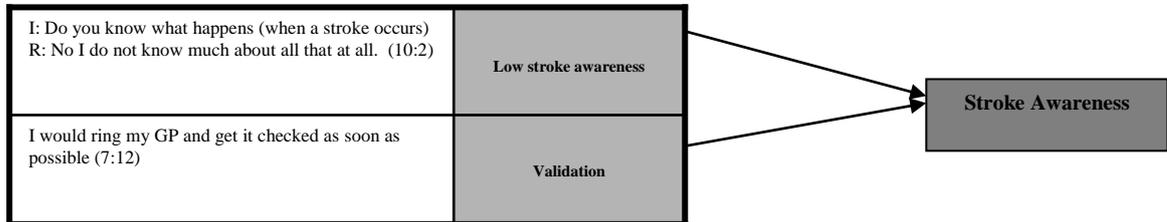


Figure 3.10 People who have not suffered a stroke

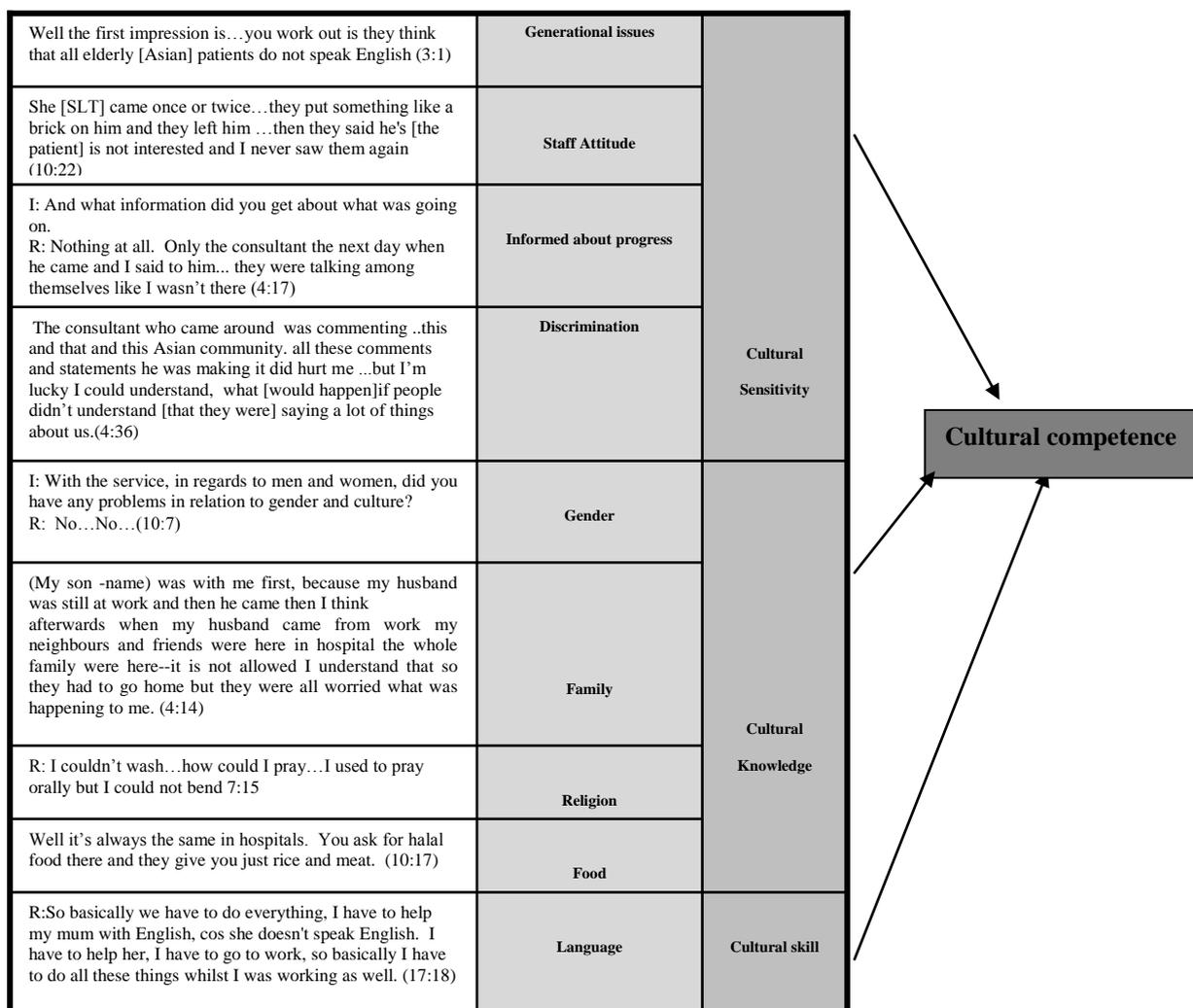
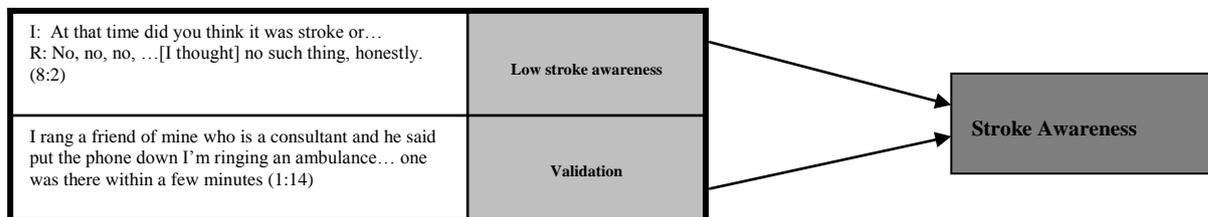
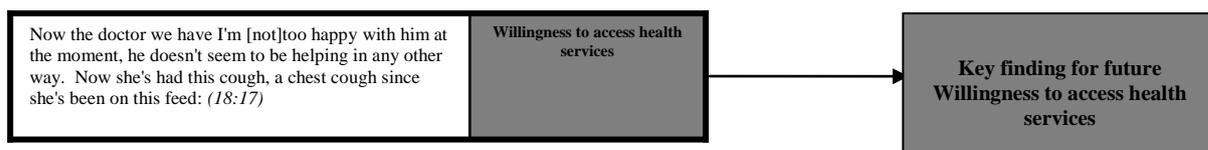


Figure 3.11 People who have had a stroke

3.9.3 Cultural sensitivity, knowledge and skill

The three concepts of cultural sensitivity, knowledge and skill were logically developed from the lower order themes in the analyses. Knowledge and skills are key to levels of competency to carry out a task (Royal College of Nursing 2011). Therefore cultural skill, knowledge and sensitivity or awareness must form part of being culturally competent (Campinha-Bacote 2003).

Service provision competency: Non-strokes

Some issues were not discussed by the Non-stroke participants, which could be because participants were not recounting experiences, but discussing hypothetical cases. Discrimination or staff attitude was not raised in this group when talking about services. This could be because the interviewer did not raise it directly, it is a sensitive area, or even that they genuinely did not expect to experience such treatment.

Generational issues were discussed occasionally and when they were mentioned, they tended to be from the point of view of the respondent:

R:just put down Gujarati my English is not very good....(she) I go to learn English at the temple they come from the college.... what am I going to learn at my age now (NS_7:24).

These issues were also discussed when the participant referred to staff attitude towards 'older Asians', there were no mention of staff attitude toward younger minority group members.

The overall impression of the remaining issues is that there is no major perceived problem in accessing acute stroke care. The majority of comments for *Gender*, *Family*, *Religion*, *Food*, or *Language* were that these will be 'taken care of' or that if

they had to they would cope with the situation when it arose. The quotations in the Non-stroke map (Figure 3.9) are some of the few that commented in detail. Typical responses would be more in line with the quotation for *Language*, that is, people would be available or that the issues would be 'taken care of'. To prevent an impression that all the opinions were positive, the Non-stroke map was populated with a range of responses to provide a more complete impression of the data.

Service provision competency: Stroke survivors

The Stroke survivor responses are in contrast to the optimistic responses from the Non-strokes. These participants have direct experience of acute hospital stroke care and the overall impression is negative. Clinical care was not directly addressed in the interviews; the intention was that participants would raise the issue if they saw fit. When clinical care was discussed, it was usually positively regarded. Non-clinical or inter-personal care was the major focus of the issues raised. Although clinical processes were not discussed, non-clinical processes are still a major consideration for service quality (Campbell et al. 2000b).

In the cultural sensitivity themes, there were instances in every case of poor staff attitudes, perceived discrimination, and lack of consideration. These categories may have been even more negative as many of the people who had suffered the stroke did not speak English. People who do not speak English would find it difficult to successfully acculturate, or adopt and understand the social norms and mores of the dominant culture (Berry 1997). In these cases the participants would not be attuned to the verbal and non-verbal behaviour of the staff (Vega & Rumbaut 1991), and this is supported by two participants (one male and one female) who, despite being older

adults, were well educated, spoke fluent English and had lived in the UK for a long time.

I was taken to the operating theatre in Town B Hospital and the porter said, "oh what a strange animal I'm carrying" because of my beard [00:13:32] at that time I was not yet unconscious and I heard it, anyway I didn't say anything at the time [but he complained to the consultant later] (SS 2:27).

...and to be honest one thing he said was, it was nothing to do with the stroke, he said I've got vitamin D deficiency...and he said, these people cover up in the sun...so the sun cant get at them that's why they have vitamin D deficiency that is why they get osteoporosis easily because they cover up...and at that time he though I couldn't understand English (SS 4:18).

Both participants could understand the verbal and non-verbal behaviour of the staff, were more negative about their experiences and spoke about the negative issues at greater length.

In the cultural knowledge themes, there were few comments on gender issues. This may be because of a lack of issues, or the health status of the participants in the early phase of stroke care reduced this issue in their personal hierarchy of concerns. The finding is similar to the views of the Town B focus group, which were pragmatic about gender issues, when in the context of a high state of anxiety and need. The Town A group placed more importance on gender, but this may have been because this group were more 'politicised' in their views, as they were members of groups organised around specific issues. This stresses the importance of understand the wider contextual issues in cross cultural interactions (Stanley 1990) as gender issues may have been a social artefact of that focus group situation (Wolcott 1990).

The majority of family issues were regarding the lack of information that families were given, and the amount of family members who wanted to be with the service-user. Information about a health care situation is important for service-users and their families, but it may not be easily or readily available (Turton 1998). People who are

not at ease in situations like hospitals may find it difficult to press staff for information.

This is one thing that the nurses or the doctors do not do, they do not tell us what is gonna happen next, they do not tell us what they're gonna do next, they actually tell us after the next day what they're gonna do (SS 17:11).

When people are from minority groups, with language and cultural issues, the problem getting information must be more difficult, as is having to leave a confused elderly relative alone and go home:

so going into a hospital where it will be the general population is a scary thought for them, women and men, I mean the men could be slightly...slightly less but women especially because they've never lived anywhere apart from in the family a lot of Asian women do not tend to go out to work... (NS 6:57).

There seemed to be no clear policy on the number of visitors a service-user can have.

The data indicates that some nurses would allow a large number of people to the bedside, and even let some family members stay overnight, whereas others were quite strict and limited numbers for visits as well as the duration of visits:

...We have problems going to the visiting times because at that time [there are] people from work, its quite hard for us to [meet] in time, the visiting times, so sometime so do suggest [if it's possible] you know, a bit later...a bit early. Some of the nurses allow it some of the nurses do not allow it (SS 17:12).

For religion, the main criticism was that although prayer rooms were set aside for followers of faiths, participants described either not being provided with the information, not being able to get to the room, or only finding the room as they were leaving. This type of information would seem to be basic service-user information, and not just for visible minorities that may be perceived as being religiously orientated. If such basic information is not disseminated then it could indicate a lack of some form of information-giving protocol. It could also indicate either a process of health care had failed in these cases, or the structural approach to information giving on the ward was causing the problem.

There were issues with hospital food, and these were raised by approximately half of the sample. Poor hospital food is a perennial problem despite a range of initiatives. A recent report has described the poor state of hospital catering and the impact on service-users (The Soil Association 2011). Although the authors of the report may have their own agenda, food was treated as a generic issue as minority groups of any kind were not mentioned in the report. Food and its preparation and provenance means as much, or more, to some minority groups as nourishment (Reimer-Kirkham 2009).

Participants mentioned halal food provision as an example of good practice at one hospital, but the provision of one type of food preparation does not address the other cultural issues with food. Muslim Stroke survivors appreciated the provision of halal food and others appreciated the vegetarian option, maybe as a substitute for non-availability of culturally appropriate food. Even these options were reported to be poorly prepared or unavailable. In some cases, participants' families had to bring food in when visiting or the service-users would not have eaten. This is a clear structural issue; service providers at a ward level can have little impact on the choice or quality of food. Though this problem is not confined to minority groups, the type and preparation of some foods has an increased significance for some minority groups and needs to be accounted for to provide an equitable and ethical service (Reimer-Kirkham 2009).

Most Stroke survivors discussed language issues, but it was not one of the issues that preoccupied participants more than other issues. Families were concerned for relatives in hospital who could not speak English, as they would have communication

difficulties when alone. It seemed a common perception that service providers assumed that older South Asians could not speak English. For example, two older Stroke survivors (noted above) reported that staff dealing with them were surprised when they found that they spoke fluent English. Link workers/translators were not common; there were some Asian nurses that tried to help, but they or the link workers did not speak all the required languages. In a large proportion of non-English speakers, family members were used as translators despite this being officially discouraged (Bischoff et al. 1999):

I: .. was there anyone in the hospital that could speak Konkani² or not...

R: we were there day and night.

I: so you had no problem?

R: we were there day and night. (SS 10:5).

In common with the Non-stroke group, the Stroke survivors were willing seekers of health care to restore or maintain their health, but tended to have limited stroke knowledge at the time of their event and at the time of interview. The perceptions of their non-clinical care were generally negative in direct contrast to the perceptions of the Non-stroke group. The stroke survivors described experiencing poor levels of accommodation of language problems, minimal staff communication with the family, limited understanding of cultural differences, and instances of discrimination or xenophobia.

Key Findings

The research question that this section investigated was, *what are the issues that prevent people of South Asian heritage accessing equitable (stroke) care services?*

² A language of Western India and Goa.

The answer to this from the results of this study, with the qualification of transferability (see below), indicate:

- People of South Asian heritage are willing consumers of health care.
- Knowledge of stroke and stroke care are limited.
- People who have not experienced acute stroke care have positive expectations of culturally appropriate care.
- People who have experienced acute stroke care have negative perceptions of the non-clinical aspects of that care.
- The professional development of health care staff requires review in areas that require competencies dealing with people from other cultures.

The findings from this part of the thesis can be summarised as a tentative hypothesis that there may be the lack of equitable provision of health (stroke) care for South Asian minority groups.

Figure 3.12 is a schematic representation of what can be proposed from the findings and policy/guideline documents in Chapter 2, in the form of a tentative hypothesis. Both the left and right hand sides illustrate the components of structure that are in existence that can either increase or decrease equitable service provision and thus quality of health care. On the left hand side, anti-discrimination laws, policy documents etc. set out directions and requirements for equity of service provision. Discrimination laws prevent overt discrimination, but seem to have little effect on supporting policy documents that in turn have had little effect on equitable provision. Willingness to access health care is a population structural factor, which also has little impact on equitable provision because this does not seem to translate into actions or actions with sufficient impact to make a difference. On the right hand side

organisational (structure) issues (ineffective discrimination policies, poor awareness raising strategies and low levels of staff inter-cultural competencies) have produced a strong effect that prevents equitable provision, partially contributing to a poor quality service outcome for South Asian minority groups.

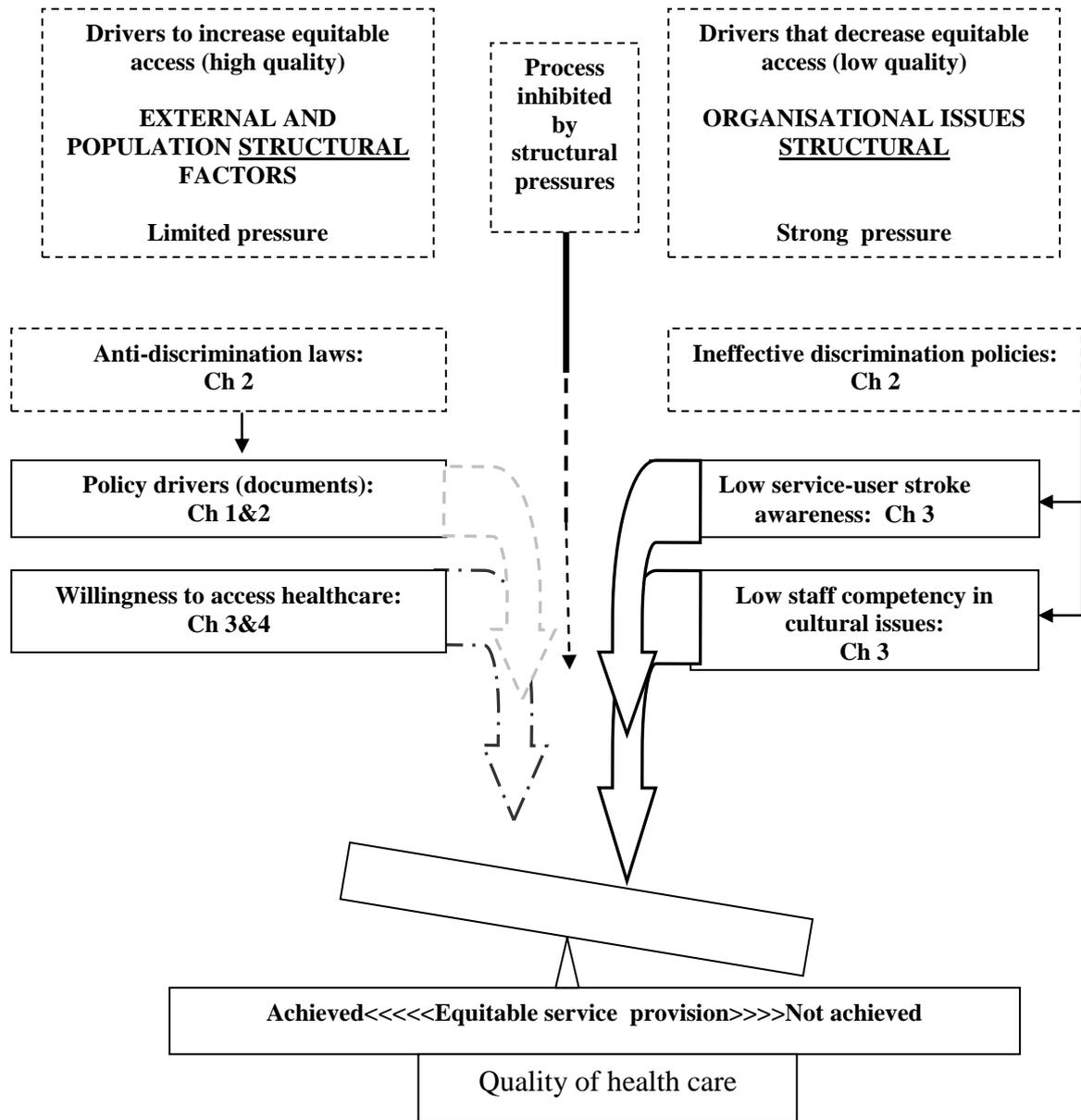


Figure 3.12 Tentative hypothesis: factors involved in equitable health care

To address part of the right-hand side of the hypothesis, a targeted and appropriate education campaign is needed to raise stroke awareness (addressed in parallel work).

In addition, it would seem that health care staff at all levels do not have the

appropriate skills to provide care to people of South Asian heritage that matches their specific cultural needs. Though structural issues are at the root of the problem, the process issues cannot be ignored to achieve a high quality equitable outcome for South Asian service–users. As described above, the consideration of individual assessment components of a quality care system is outmoded, and a whole system approach of structure process and outcome needs to be considered (Campbell et al. 2000b). What seems to be required is a comprehensive approach that will ensure that service providers can interact with people from cultures different from their own in an effective way.

It is necessary here to state the tentative hypothesis derived from Figure 3.12.

For people of South Asian heritage, anti-discrimination laws, health care policy aims and a willingness to access health care are insufficient to overcome ineffective anti-discrimination initiatives, low levels of stroke awareness, and poor service provider cultural competence: this may lead to an inequitable service provision compared to the general population.

3.10 Meta discussion

When taken out of context, the themes elicited from the focus groups, and subsequently crystallised in the individual interviews, are similar to issues that the general population have raised in a number of studies. The general population are willing to access services (Pound et al. 1995) if they realise the seriousness of the condition, this is in spite of a fear of hospitals (Calnan et al. 2003). Low levels of stroke awareness and validation of stroke symptoms with others have occurred in the

general population in the UK (Parahoo et al. 2003). A common theme in studies that look at service-user experiences is poor communication between staff and service-users. Stroke is no exception: lack of information about progress (Murray et al. 2003) and being heard (McCabe 2004) are two facets of communication that stroke service-users in the general population have regarded negatively. Others include poor or negative staff attitude (Morris et al. 2007), family issues (Morris et al. 2007), gender specific differences (Madhok et al. 1992; Rhodes et al. 2003) and food presentation and content (Madhok et al. 1992).

South Asian stroke survivors experienced discrimination. While there is no intent to negate or diminish these inappropriate instances, groups in the general population also experience discrimination for example service-users with HIV (Schuster et al. 2005), obese service-users (Kaminsky & Gadaleta 2002), and aged service-users (Kinrade 2003).

However, although these issues can be similarly categorised, the experience and perception of these issues will undoubtedly be different for people of South Asian background. There are fundamental reasons for this, including lack of understanding of dominant cultural mores; inherited colonialism, exploitation, and unequal social relations (Silveira & Ebrahim 1998). To compound these problems, members of a visible minority, or their descendants, are readily identifiable as a minority and belonging to such groups is associated with deprivation and barriers to accessing appropriate health care (Wu et al. 2005). Having immigrant status or heritage and belonging to a visible minority, together with increased levels of social deprivation (APHO 2005), could contribute to multiple jeopardy, where the combined effects of

belonging to multiple stigmatised groups are greater than the partial effect of belonging to one (Silveira & Ebrahim 1998).

Reviewing the literature in this area found only one study on multiple jeopardy. This reported no evidence of such a phenomenon between black and non-black service-users on levels of age related functioning. Although black service-users had consistently poorer function, when income and education were controlled for, the difference was still not significant, indicating other explanations (Clark & Maddox 1992). However, income and education may have been adequate only for the generation that was assessed but they may still suffer the effects of trans-generational deprivation which can be inherited like wealth (Champagne 2008; Champagne 2010). This may still disadvantage the black participant despite the education and income improvements. A later study found evidence that multiple jeopardy was associated with poor self-rated health for immigrants in Canada (Veenstra 2011).

Reliability and Social artefacts

When researchers from the general population work with ethnic minority groups there is a potential for reliability and validity, or trustworthiness, problems (Im et al. 2004; Woolgar 1988a). These are the accuracy and credibility of the descriptions provided (representativeness), and the likelihood that the descriptions are a result of the research interactions (social artefact). There is a set of criteria to evaluate the accuracy and credibility of descriptions in ethnographic work (Stanley 1990). Though this work is not ethnographic, it is cross-cultural and potentially beset with similar credibility issues (Im et al. 2004; Woolgar 1988a). These criteria have been used to evaluate the processes and findings of Part 1 (see Table 3.5). A review of these

criteria indicated that the empirical work in Part 1 of this thesis has demonstrated trustworthiness, in the form of accuracy and credibility.

Reliability criteria	Response
Establish the wider relevance of the setting and topic including demonstrating their representativeness.	There has been a national policy initiative and a local hospital based initiative to develop health services in general to make them sensitive to cultural and religious differences, see Chapter 3.
Identify the features of the topic addressed and why these have been chosen.	Supply side features were selected for investigation. These have been highlighted in policy documents and the literature, see Chapters 2&4.
Identify any theoretical frameworks that underpin the study and any associated values.	The underpinning theory used is the theory of inquiry. It was decided that an inductive approach was the best way to work from observation to proposed theory.
Establish integrity by: i) Justifying grounds on which knowledge is claimed, ii) Clarifying of all experiences in the research iii) Identifying strengths and weaknesses of research strategy.	The knowledge is claimed by: i) The rigour and comprehensiveness of the study design, see Figure 3.4 ii) Comprehensiveness of methods, see Chapter 3 iii) Strengths and weaknesses - see this section.
Establish authority of the data by: i) Explaining any coding system and how they were arrived at ii) Discussing rival explanations and ways of organising the data, iii) Providing sufficient data extracts in the text to allow reader evaluation iv) Discussing power relations in the research.	Authority of the data was established by: i) Initial coding generated from theme generation from focus groups, flexibility to account for new themes included. ii) Rival explanations discussed findings see Chapter 3. iii) See findings and maps, Chapter 3, iv) The underpinning philosophy of the study was collaboration, community workers and community researchers from the target communities collaborated with the participants to produce the data, minimising any power differential.
Avoid suggestions of simple fit between the target culture and representation of it: i) Discuss deviant cases ii) Show any participant's multiple or contradictory descriptions iii) Reference the contextual nature of the data and any features that may impact on the data from the context	Deviant cases noted and discussed with community workers and researchers. Context referenced on a regular basis through discussion with community researchers and workers.

Table 3.5 Trustworthiness evaluation criteria by Stanley (1990)

Limitations of the study

Two focus groups may not have been sufficient to explore the issues on this topic and similarly the samples for the individual interviews may have been too small.

However, in the case of the focus groups, the samples were markedly different from one another in ethnicity mix, age and gender. The moderators were also different for both groups. For individual interviews saturation was achieved and was estimated qualitatively and quantitatively. Participants either had or had not had a stroke and in some cases carers were interviewed; and interviews were conducted by different CRs. These factors, and the trustworthiness measures undertaken, combine to indicate that the descriptions provided are trustworthy, credible and representative of the populations under study.

An inherent limitation of the design was the use of CRs. The CRs had a short time in training and across the group there was a range of levels of skill at the task. The CRs with more experience and better skills assisted the CRs with less experience. In addition, although collaborating with community members like this may have provided a greater insight into the different cultures, it could have confounded the study. It could be argued that using people from the same community could have prevented the participants from being as candid as they could be, to maintain the privacy of a family from other members of the community.

However, these inherent weaknesses are limited compared to the inherent strengths of using community researchers. They proved to be a valuable and indispensable part of the research process with their language skills, understanding of their communities, and interpretation of the data.

Areas of further research

Though the participants of this study who had no experiences of a stroke held positive expectations of future care, the people who had suffered a stroke reported negative experiences of their interpersonal care. The findings from this part of the thesis, and policy documents described in Chapter 2, contribute to a growing body of evidence that people from minority groups experience an inequitable level of care. A way needs to be investigated that can address this disparity.

Conclusion

Service-users of South Asian heritage who had suffered strokes viewed their experiences of stroke care as being a factor of their ethnicity rather than being a factor of them being a service-user. A first review of the issues raised by people of South Asian heritage seemed similar to those raised by the general population. People from South Asian groups may experience and perceive these experiences differently and it is a task for service providers to re-think the structures and processes of care to take account of these sensitivities (Atkinson et al. 2001). From the findings of this chapter, apart from stroke awareness issues, it appears to be a lack of ‘inter-personal care’ or specifically cultural competence (Papadopoulos 2003), that is the root of the problem of inequitable service provision for minority groups.

Service-users were asked for solutions to the problems with service provision they described. In response, many of the participants indicated that they wanted to be considered and treated as an individual rather than a member of a minority group:

everybody that has an illness may want to be treated differently while making it more individualised and by asking me as an individual if there's anything I would expect them to do, actually being involved in the care that they're going to deliver. (SS 4:24).

People who had not used stroke services held positive perceptions about the service and did not perceive any potential barriers to access:

Most hospitals nowadays have halal food ... (NS: 1:26)

People who had used stroke services reported negative hospital experiences:

... because when I went to the hospital and they left me for so long before a doctor came to see mesomebody came to give me an injection, an injection so my blood pressure can come down...I think that all that procedure took so long...that err. I think that is where I got this. [disability]. (SS 4:7).

What is required is a way of working with people from different cultural backgrounds, to treat them as individuals, and to maintain the earlier positive perceptions through to positive hospital experiences. Training for staff is needed to facilitate the development of ways of treating each service-user as an individual; staff should have the appropriate level of competency for working with people from other cultures in a competent, values-based manner (Fulford 2008; Fulford 2011).

Three super-ordinate themes were found in this body of work, two of these themes are related to the direct aspects of quality of health care. These are low levels of stroke awareness and poor levels of competency when working with minority groups. Both of these involve elements of the processes of quality of care, but for these issues the organisational or structural element is dominant. The structural elements of health care include writing policies, organising budgets, providing facilities, estimating staff numbers, instigating training programmes, and require the processes of care to be organised. Raising stroke awareness with minority groups requires structural changes to be effective and will need to be dealt with by work outside of this thesis. Cultural competency levels of staff are also structural as they rely on policy that influences

training. Aspects of developing service providers in cultural competence will be the focus of subsequent chapters.

This chapter has addressed the relevant objectives: (iv) describe and justify the methodological approach to address the first research question, (v) explore the experiences and perceptions of members of South Asian groups in an area of the UK in access to stroke care, and (vi) develop a tentative hypothesis to explain inequitable care for UK South Asian groups. It has also addressed the first research question about the nature of the barriers to accessing good quality health care. Early in this Chapter it was stated that a literature review on barriers to access would not be undertaken prior to the empirical work, to prevent expectancy bias. Now the empirical work has been completed it is necessary to review the literature and compare the findings of that to the findings of the investigation.

Part 1: Chapter 4

Minority groups and access to health care

The previous chapter explored the perceptions and experiences of people of South Asian heritage. Local South Asian community workers collaborated to recruit a team of South Asian community researchers from the local groups. This team and the author conducted focus groups and developed a thematic framework to inform subsequent individual interviews. The interviews were conducted with South Asian group members who had not had a stroke, who reported positive perceptions of what they expected from stroke care. Interviews with South Asian stroke service-users reported negative experiences of stroke care. Both groups had low levels of stroke awareness, but were willing to access health care. The conclusion was that South Asian minority groups were not receiving equitable processes of stroke care because the interpersonal processes of care were poor. This could be linked to low levels of cultural competence, and the lack of an effective programme of cultural competence development is a structural issue.

To validate and amplify the findings of the empirical work in Chapter 3, this chapter reviews the literature that considered barriers to equitable health care for minority groups. This is a wider remit that specifically South Asian groups accessing stroke care. This new remit is a result of the limited specific literature, and an assumption that findings from the general body of literature will be applicable to South Asian service-users accessing stroke care. The objective (vii) of this Chapter is to review the literature that considers equitable access to health care in the UK for minority

groups. This review marks the end of Part 1 of this thesis and addresses Research Question 1, which is to elicit the barriers for people of South Asian heritage accessing equitable health (stroke) care.

4.1 Introduction

The Health Care Commission's latest report has indicated that despite legislation and statutory requirements for minority groups, there is still inadequate access to some areas of health care, poor experiences and inadequate data monitoring, compared to the general population (HCC 2009). The issues relating to inequality in health care have been discussed in policy and guideline documents since legislation changes nearly two decades ago, and improvements have occurred, but not enough to claim equity (HCC 2009). A review on access to health care for minority groups in the UK identified three dimensions that need to be considered for health care to be regarded as equitable for the whole population (Atkinson et al. 2001 p3):

- Having equal access via appropriate information
- Having access to services that are relevant, timely, and sensitive to a person's needs
- Being able to use the health service with ease, and having confidence that you will be treated with respect.

Thus, equitable services should not be seen solely in terms of their existence, or how much they are used. Rather, services should be known about, appropriately delivered, and accessible by all (Atkinson et al. 2001). If the three points above are accepted then they indicate that barriers are related to the structure and process of health care delivery, rather than with the service-user. Chapter 3 addressed this question and found that for the local South Asian minority groups the barriers were also related to

structure and process. Essentially the groups did not have accessible appropriate information about stroke and when they did access stroke care they were not treated appropriately. The latter point is supported by the policy and guideline documents discussed in Chapter 2, with the call for services to be made appropriate. This chapter will explore some of the research that has considered equity of access and where the barriers to equity, perceived or real, could be located. This will enable the findings of Chapter 3 to be validated, and set in the context of the equitable access to health care for minority groups in the UK.

4.2 Background

There is a small but increasing pool of research that looks at the lack of equitable service provision for South Asian minority groups. Therefore, the literature on barriers to accessing health care for minority groups in general will be subject to a targeted and contemporary review of studies after 1995. Considering publications from 1995 is seen as appropriate, as this was the period when legislation making racial discrimination illegal was introduced, and when major health reforms were introduced (Chahal & Julienne 1999). If evidence exists of barriers to accessing services for minority groups as a whole, then it would be reasonable to contend that South Asian groups accessing stroke services would suffer a similar fate. Care will be taken in the analyses to ensure that specific issues relating to a particular group are not generalised to all groups.

Searching the literature

Online electronic databases, including Medline, Cinahl, Embase, Psycinfo, and Google Scholar were searched. In addition the reference sections of retrieved papers were manually searched for appropriate papers. The search was for articles published

after 1995, other search terms were ethnicity and variations on this term, and access to health care and variations on this term, in English (see Table 4.1). No study designs were excluded, as long as there was an element of inquiry, e.g. reviews, and both qualitative and quantitative studies were included.

Adapt strategy to suit search engines, (this example Medline), * = wild card
Published after 1995
AND
Ethnic* OR Cultur* OR Minority OR Minority group* OR race OR vulnerable OR depriv*
AND
Access* OR barrier* OR discrimination OR divers*
AND
Health* OR healthcare OR health service* OR NHS OR service prov*
AND
English language

Table 4.1 Search strategy for Medline

This strategy is less specific than it could to be, this is to ensure as many articles with variants of the search terms are retrieved. In total 1698 studies were retrieved, after removing duplicates (148). The 1698 were screened for UK and Republic of Ireland studies (Great Britain OR United Kingdom OR England OR Scotland OR Wales OR * Ireland), which left 278 articles. Screening by title and abstract using the criteria of minority groups accessing or barriers to accessing health care, reduced this to 47 articles (see Figure 4.1). An independent researcher also screened the initial batch of retrieved papers and the two results were compared as part of a reliability assessment. There was a good level of agreement and any disputes were resolved by consensus. The next procedure was to assess the credibility of the articles by a quality review.

The UK studies of equity of access to health care are limited in quantity and quality, which has been previously noted (Dixon-Woods et al. 2006). The aim was to find a balance between excluding an article for some design weakness and retaining it when it may have had something important or interesting to add. For both qualitative and quantitative articles it was decided to use a criteria set, adapted from those used by the NHS National Electronic Library for Health, for evaluation of qualitative articles (Dixon-Woods et al. 2004). If the papers did not meet these criteria, they were judged to be fatally flawed, and rejected (see Table 4.2).

Are the aims and objectives of the research clearly stated?
Is the research design clearly specified and appropriate for the aims and objectives of the research?
Do the researchers provide a clear account of the process by which their findings were produced?
Do the researchers display enough data to support their interpretations and conclusions?
Is the method of analysis appropriate and adequately explicated?

Table 4.2 Criteria for judging quality of papers (Dixon-Woods et al. 2004)

Approach

Because of the poor quality, the methodological variety, range of foci and presentation style of the studies meeting the inclusion criteria, an approach was required that was flexible enough to accommodate this variation. An adaptation of thematic synthesis was used on this sample (Campbell et al. 2003). Thematic synthesis enables

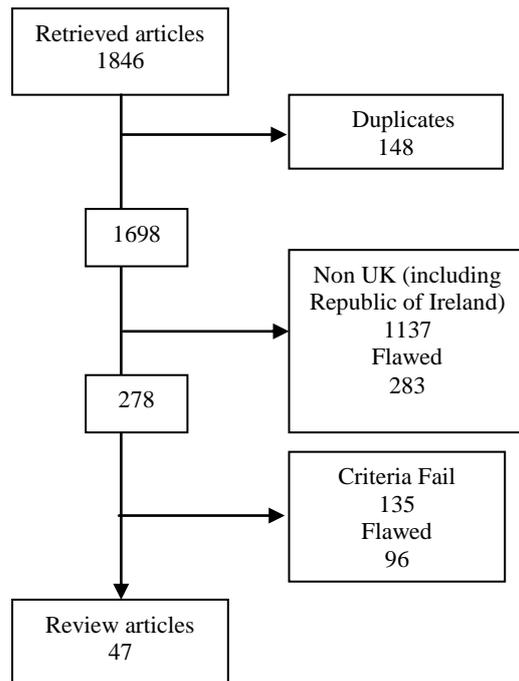


Figure 4.1 Flow chart from initial sample to review articles

the identification of key concepts which can then be synthesised into themes which can be used for evaluation (Thomas & Harden 2008).

The intention was to only consider articles that specifically discussed minority groups. Many of the articles concerned with barriers focussed on socio-economic status and as minority group members are amongst the most deprived in the UK (APHO 2005), these would be included if they made specific reference to ethnic minority groups. Electronic copies of each article were retrieved (PDFs). These were imported into a quantitative data management programme, Atlas-ti. A coding scheme was then entered to the application. The coding scheme consisted of: author(s); date; sample size; design; minority group(s) of interest; disease/condition of interest; identified barrier (service-user); identified barrier (service provider); outcome measure(s); author conclusion; and comments. The articles were read and coded using the code scheme.

Using the search facility of Atlas-ti themes could be synthesised to suit the structure of the review with the added facility of hyperlinking from concept or code to the image of the article for contextualisation.

Because of the structure of the findings for this chapter and the nature of the articles, some articles are used in different sections as they inform different divisions of the findings. For example, a study by Robb et al (2008) is cited in four different sections, because aspects of the study relate to those sections. The articles relating to service-user barriers are displayed in Table 4.3, and service provider in Table 4.4. Though some are cited in a number of sub-sections of this Chapter, the first instance of citation decided the location in the table. The two tables do not include the two reviews (Dixon-Woods et al. 2006; Szczepura 2005).

The aim of this review is to examine contemporary literature that explores barriers to minority groups accessing equitable health care. It has been proposed that barriers are located with service-users and service providers (Goddard & Smith 2001), that is both parties are at fault. It could be argued that if a service exists, and it is not used this is a matter of personal choice or personal responsibility. Although this may be correct, it has been proposed that failure to implement and maintain awareness/screening strategies for at risk groups is part of inequitable service provision (Atkinson et al. 2001; Szczepura 2005). It is a proposition of this thesis that problems can arise from omission as well as poor or inappropriate commission with service awareness and delivery.

Two recent reviews of equity of access to care, retrieved for this literature review, have developed conceptual frameworks to identify barriers to accessing health care (Dixon-Woods et al. 2006; Szczepura 2005). Both of these reviews reported the low to moderate quality of the literature, and the limited amount. In addition the reviews themselves had methodological problems; these were not serious enough to remove them from this review.

Barrier		Reference	Minority group
Service-user (Candidacy)	Newness	<ul style="list-style-type: none"> • Adamson et al. 2003 • Bowes & Wilkinson 2003 • Elkan et al. 2007 • Hayes 1995 • Iqbal 1997 • Jones et al. 2010 • Lindsay et al. 1997 • Mukadam et al. 2011 • Robb et al. 2008 	<ul style="list-style-type: none"> • Minority groups • South Asian • Minority groups • Minority groups (Females) • Black, Ethnic • Minority groups • Asian Gujarati, White Elderly • Ethnic Elders • Ethnic minorities
	Ethnicity	<ul style="list-style-type: none"> • Atkinson et al. 2001 • Dhar et al. 2010 • Lawrence et al. 2008 	<ul style="list-style-type: none"> • Minority groups • South Asian • Black Caribbean, South Asian. White British.
	Linguistic factors	<ul style="list-style-type: none"> • Assn.of P. H. Observatories 2005 • Carr-Hill et al. 1996 • Crane 1997 • Gill et al. 2009 • Merrell et al. 2006 	<ul style="list-style-type: none"> • Minority groups • Minorities with no English • Minorities with no English • Black and minorities • Bangladeshi carers

Table 4.3 Studies used in the service-user barriers section

The first review (Dixon-Woods et al. 2006) found that the literature on this topic was low to moderate quality, conceptually different, in different settings, with different disciplines, and different foci. In an effort to make sense of this, Dixon-Woods et al. (2006), carried out a critical interpretive synthesis (CIS) of the literature that looked at equity of access for all deprived areas of society. This is a method of integrating qualitative and quantitative material and providing an interpretation via a synthesising process. The review claimed that because of the disparate nature of the studies, the

aim was to look for underlying mechanisms that could be responsible for barriers.

The logic of using this method was, whatever the service area or the issue, one of the proposed barriers could be attributed to particular instances of access problems.

However, this novel method suffers from the same constraints as qualitative thematic analysis and requires similar demonstration of trustworthiness and transparency, which it does not fully comply with (Harrison et al. 2001; Horsburgh 2003).

Barrier		Reference	Minority group
Service provider	High Permeability	<ul style="list-style-type: none"> • Ben-Shlomo et al. 2008 • Goddard & Smith 1998 • Goddard 2009 • Hamaad et al. 2006 • Hargreaves et al. 2006 • Kontopantelis et al. 2010 • Shah & Cook 2008 • Smaje & LeGrand 1997 	<ul style="list-style-type: none"> • Ethnic minorities • Minority groups • Minority groups • Ethnic minorities • Minority sub-groups at a London A&E • GP service-users ('Asian' sub-group) • Minority groups • Minority groups
	Health care screening	<ul style="list-style-type: none"> • Austin et al. 2009 • Greenlund et al. 2003 • Moser et al. 2009 • Patel et al. 2007 • von Wagner et al. 2009 	<ul style="list-style-type: none"> • Ethnic minorities • General population (minority sub-groups) • General population (minority sub-groups) • Ethnic Inner City • General population (minority sub-groups)
	Long-term conditions (Navigability)	<ul style="list-style-type: none"> • Banerjee et al. 2009 • Christopher & Kendrick 2004 • Garduno-Diaz & Khokhar 2011 • Gholap et al. 2010 • Gray et al. 2007 • Nazroo et al. 2009 • Roderick & Armitage 2002 • Rudge et al. 2007 	<ul style="list-style-type: none"> • South Asian • South Asian • South Asian • South Asian • South Asian • General population (minority sub-groups) • General population (minority sub-groups) • Ethnic minorities
	Ethnicity data recording	<ul style="list-style-type: none"> • Day et al. 2010 • Jack et al. 2006 	<ul style="list-style-type: none"> • General population (minority sub-groups) • All ethnic groups
	Transcultural service provision	<ul style="list-style-type: none"> • Cortis 1998 • Gerrish 2001 • Kalra et al. 2009 • Vydelingum 2000 • Vydelingum 2006 	<ul style="list-style-type: none"> • Pakistani • South Asian • Black, Ethnic • South Asian • South Asian

Table 4.4 Studies used in the Service provider sections

These mechanisms proposed by Dixon-Woods et al. (2006) have been set out in a framework in Table 4.5. Despite the issues with this review it does present a logical interpretation of the underpinning data that resulted in a potentially useful framework. A component of this framework that is applicable to service-users is candidacy. Candidacy can be seen as how much a service-user perceives themselves to be a candidate, or have rights, to receive a service. Regarding service providers, the framework describes two further concepts. Firstly permeability, or how easy it is to access a service, and navigability, how easy it is to negotiate barriers once access is gained to a service (see Table 4.5). These concepts will be described in more detail in the appropriate section.

The second review developed a conceptual framework that looked exclusively at barriers for people from minority groups, as these groups have specific properties that may cause access issues (Szczepura 2005). The service-user components of this framework that could be seen to prevent accessing appropriate health care are Newness, Linguistic factors and Ethnicity issues (Szczepura 2005). Newness relates to service-user ignorance of a health care service, generally related to new migrants, but can also relate to issues with minority groups that isolate them from mainstream society. Linguistic factors relates to poor English speaking, and lack of interpreters, but also poor accessibility to information in appropriate media. Finally, ethnicity factors relate to those aspects that are identified as specific to a minority group.

This framework was developed from a major report for the London NHS Executive on minority access to health care in London. It became evident that what Szczepura called intrinsic or personal factors were regularly occurring in the literature that went

into her systematic review. However, the framework was not developed as part of the review but described in a paper subsequent to the report. No validation work seems to have been carried out with the framework and the supporting evidence was limited

4.3 Findings

The findings from the literature review for this chapter are structured as service-user barriers and service provider barriers, and the references for the articles are in Tables 4.3 and 4.4 respectively. For service-user barriers ‘candidacy’ will be used as the overall theme to explore the literature investigating service-user barriers to assessing equitable services. In addition the concepts of newness, linguistic factors and ethnicity (Szczepura 2005) will be used as sub themes. These themes were chosen as they directly relate to service-user characteristics, whereas permeability and navigability involve service provision characteristics. Service provider barriers will be sub divided into concepts that emerge from the thematic synthesis, high permeability services, health care screening; long term conditions, ethnicity data recording and transcultural service provision. Candidacy, permeability and navigability will be used as overarching analytical concepts (Dixon-Woods et al. 2006).

4.3.1 Service-users barriers

Newness

Newness or user ignorance, as a distinct theme has not been widely addressed in the literature, although individual components that contribute to this theme, such as lack of service knowledge, have been reported (Robb et al. 2008). The evidence for this component included the lack of awareness of services such as midwifery (Hayes 1995), and palliative care (Iqbal 1997; Lindesay et al. 1997).

As an illustration, two studies indicated that in South Asian minority groups, carers of dementia sufferers felt it was their responsibility to care for their relative (Bowes & Wilkinson 2003; Mukadam et al. 2011). They also felt that a diagnosis was purposeless as nothing could be done, and they had a distrust of psychiatric services. The carers did not call for help until it became unbearable to carry on. These are hallmarks of a lack of candidacy as a result of 'newness': the carers believed that it was their responsibility and were not informed by agencies of the type and amount of support that was available.

The studies of dementia above indicate a problem of 'newness'. The carers were unaware that support was available for their relatives and cared for their relatives unaided, as they were under an impression that little could be done to help. This is supported by a similar pattern in cancer care (Elkan et al. 2007) and stroke care (Jones et al. 2010). In both of these cases qualitative data indicated that people from minority groups, who are at a higher risk than the general population for these particular conditions, have limited awareness of the signs and symptoms. In the case of cancer care, the minority groups tend to present at a much later stage than they should, usually when the symptoms are advanced (Elkan et al. 2007).

Newness may not be an ideal descriptor for this theme as it implies that people are 'new' to interactions with the health care system. The majority of the people in these studies are not new migrants, but new to a particular service. However, the same underlying mechanisms exist for this; the interface with a service is new for them whoever they are. Lack of awareness of a condition does not necessarily indicate that

ethnic minorities will not seek out help. Participants from a cross-section of the population were given scenarios describing two sets of symptoms, chest pain, and lump under the arm. There was no difference between minority groups and the general population on decisions to seek help (Adamson et al. 2003). However, attitudes and behaviour do not always correlate (Ajzen 1991), and reactions to scenarios will be different to real life situations. Accessing services will depend on service-users' self-perceived level of candidacy (Dixon-Woods et al. 2006).

Ethnicity (Cultural factors)

A report on accessing health care by minority groups in the UK found that belonging to a minority ethnic group may cause members of that group to respond differently to a health care interaction, compared to the general population (Atkinson et al. 2001). This may be because of health beliefs and behaviours that are different from other groups. The report was based on a systematic review of qualitative and quantitative studies and the authors found that specific cultural factors may affect accessing health care in a number of ways including religion, females not wishing to deal with male clinicians, fatalism, shyness, and family dynamics (Atkinson et al. 2001).

Revisiting the studies of dementia, could also illustrate cultural factors. In this study families saw it as a duty to care for family members with the illness, and would only call for help when a crisis point was reached (Bowes & Wilkinson 2003; Mukadam et al. 2011). Another dementia study illustrates how a cultural divide may prevent candidacy. This qualitative study interviewed dementia carers from South Asian, Afro-Caribbean, and white populations in the UK. They found that nearly all the South Asian, half of the Afro-Caribbean and few of the white carers held a traditional view of caring for dementia service-users. Traditional views of caring include

regarding caring for a family member as a duty, and a privilege. The remainder had non-traditional views that included seeing caring as a burden, an interruption to a career, and something to be tolerated (Lawrence et al. 2008). The families' beliefs in being responsible for caring for their relatives is an important barrier that needs to be considered when designing/promoting services.

Other culture related issues include shyness or embarrassment (Atkinson et al. 2001). Two large survey studies investigated reasons for non-attendance at screening clinics. In the first study South Asian service-users represented 5% of 4600 new attendees at a genito-urinary medicine service (GUM). Compared to the other ethnicities the South Asian groups were no less likely to have sexually transmitted diseases but were less likely to attend, and cited embarrassment within their community as the main reason (Dhar et al. 2010).

In the second study 875 minority group members were interviewed for a monthly nationwide surveys of ethnic minority communities (Robb et al. 2008), which included a comparison group of 125 white British respondents. Items on screening for colorectal cancers were included in the interview schedule. All respondents showed a significantly low level of awareness of the cause of colorectal cancers, but it was more pronounced in the minority respondents. Interest in attending screening sessions was high but amongst the ethnic minority groups the main barrier to attending screening was cited as embarrassment.

Service provision can only be considered as equitable if it takes account of minority groups' needs. The dementia studies could help to inform the provision of support for

carers of these service-users. The screening studies indicate what needs to be considered when developing education programmes. However, what is shown here is that minority groups may have specific issues that need to be considered to facilitate their equitable access to good health care.

Linguistic factors

Less than 30% of individuals from South Asian minority groups have a proficiency in English that enables them to function independently, with the lowest frequencies being in older adults (Carr-Hill et al. 1996). Just over a third of Bangladeshi and Pakistani older females, and less than two thirds of older men, can read English (Rudat 1994). Even when material is translated into the major South Asian languages, in some minority groups there are still illiteracy levels of approximately 50%. To compound the language problem, some South Asian languages have no written form, Sylheti for example, which is a common language of older Bangladeshis (Rudat 1994).

A review of the Health Survey for England (HSE) revealed that just under 300,000 people from the four main minority groups spoke no English (Gill et al. 2009). These figures were collected to inform the provision of interpreters in GP consultations. This number of people would equate to approximately 2.5 million consultations needing interpreters. This indicates the scale of potential communication difficulty for service-users and providers, which could result in inequitable or inappropriate care. These estimates are likely to be an underestimate, as accurate estimates of the actual number of people in the UK who cannot speak English are hampered by inaccurate, or un-standardised data recording methods (APHO 2005). Additional problems include the logistical difficulty of accessing people who do not speak

English (Rudat 1994), and the unreliability of survey responses when working with people of other cultures (Pasick et al. 2001). If these are underestimates, then the importance of finding ways of interacting with people who do not speak English is even more pressing, as actual figures will be higher.

Ineffective communication is plainly a barrier to accessing effective health care and this is highlighted in a study of Bangladeshi informal carers (Merrell et al. 2006). This qualitative study interviewed twenty Bangladeshi carers of relatives with long-term conditions. The findings indicated that the carers had limited knowledge of what was available from Health and Social Services, their main sources of information were GPs and hospital doctors, and both of these were affected by limited proficiency in English. The service-user or the carers were not receiving equitable access to appropriate care, as professional interpreter services had not been offered, which prevented comprehensive needs assessments. For service providers the provision of communication support is not optional or related to availability of funds, as it is a requirement under the Race Relations (Amendment) Act 2000 and the Human Rights Act 1998 (Department of Health (DH) 2005a).

Effective communication includes more than just spoken English, as people find it difficult to retain what was said in a medical consultation (Ley 1979). In a more recent study in the USA, an exit interview was conducted at a paediatric emergency department. Service-users with good English could correctly identify 60% of the instructions they were given (Crane 1997). For people who used English as a second language the retention was considerably less. A similar exit interview was held at a UK children's emergency facility. Parents wanted additional health information but only leaflets were available. This presented a difficulty for the illiterate and non-

English speakers. Although service-users would prefer to have additional information from service providers, the majority found additional information from friends and family or the Internet, which may be inappropriate (Cline & Haynes 2001).

The studies in this section relating to ‘ethnicity factors’ indicate that people from ethnic minorities find it difficult to obtain appropriate information, and to retain guidance after a consultation. In addition, people from minority groups seek information from alternative sources. The language related difficulties with information and communication is a clear indicator that those who have difficulties with English are not receiving equitable service provision.

The issues of newness, ethnicity and linguistic competence, explored as service-user barriers to equitable care, contribute to a person’s level of candidacy when interacting with service providers. Candidacy is a property of the service-user and it would be reasonable to see these barriers as service-user barriers. However, it is incumbent upon the service providers to understand and accommodate these issues, and if they do not, then in reality these barriers reside with service providers as these are structural and process aspects of quality health care (Atkinson et al. 2001; Campbell et al. 2000b).

The issues here can be related to the empirical findings in Chapter 3. The Non-stroke participants, despite a proportion validating their symptoms with others, would call emergency services and seek acute care. The Stroke survivors all eventually gained access to acute stroke care and as such both groups claimed candidacy. This is also demonstrated in the ‘willingness to access health care’ concept from Chapter 3 This

indicates that candidacy for the empirical study sample in Chapter 3, was not a barrier, despite some ‘newness’ issues such as not understanding stroke as a medical emergency (Szczepura 2005). As hypothesized at the end of Chapter 3, barriers to accessing equitable health care are located with the structures and processes of health care.

4.3.2 Service provider barriers

It was demonstrated above that even though a service-user is a valid candidate for services (candidacy), there still may be barriers to accessing them. In this section, the related concepts of permeability and navigability of health care systems (Dixon-Woods et al. 2006) are explored to examine the part they play in potential barriers to equitable service access.

After reviewing the literature on access to health care systems, Dixon-woods et al. (2006) carried out a Critical Interpretive Synthesis (CIS) to make sense of the disparate studies that investigated equitable assess to service provision. CIS is similar in approach to a thematic analysis; the included studies are treated as transcript data, and explored for reoccurring themes. The outcome of the CIS proposed that barriers to access could be classified into six components of a conceptual framework (see Table 4.5). In addition to the three components discussed above, Dixon-Woods et al. (2006) proposed that ‘appearance’, ‘adjudication’, and ‘offers’ were further components that could explain barriers to equitable service. Reviewing the three additional components it was considered that ‘appearance’, was a sub-theme of permeability, and ‘adjudication’ and ‘offers’ were sub-themes of navigation, and will be treated as such for this thesis.

Synthetic Variable	Description	Findings
Candidacy	Ability to claim health care	Candidacy is more evident in deprived individuals in times of crisis, with lower use of preventative services.
Navigation	Ability to negotiate access to services	Deprived individuals lack awareness of services, have resource issues in accessing services, are less inclined to use 'optional' services
Permeability	Ease of Access to services	High permeability services (A&E, GP) are heavily used by deprived groups, Less permeable services are less well used, these are typically those that require referrals and appointments
Appearance	Ability to obtain and maintain health care by the ability to appear at health service	Disadvantaged people feel intimidated by health professionals, more advantaged people are more likely to get referrals
Adjudication	Working with the requirements and judgment made by health care providers	Providers make judgments on the typicality of a service-user, influenced by local conditions
Offers and resistance	Use may be refused or not offered	Deprived individuals are more likely to refuse referrals and refuse medication

Table 4.5 Concept for access to health care services (Dixon-Woods et al. 2006)

The three components used as analytic concepts in this section are not independent or mutually exclusive, therefore, candidacy indicates the right a person can claim for access to a service, permeability is the measure of the ease of passage through any initial access barriers, and navigations are the actions that are needed to negotiate the permeability of a service, and any further barriers beyond initial access (Dixon-Woods et al. 2006).

4.3.3 High permeability services

Accident and emergency departments in hospitals (A&E) and emergency ambulance probably have the highest permeability of all services. GPs are regarded as high permeability, but there are some restrictions, which could include opening times, availability of a GP and enrolling on their list. Low permeability services could

include some elective surgery and some therapies, for example psychological services (Goddard & Smith 1998; Goddard 2009).

Once candidacy has been claimed then highly permeable services like GPs present few barriers to initial access (Smaje & LeGrand 1997). These services still need to be navigated to receive optimal service provision. In a satisfaction survey for GP services, nearly 5 million questionnaires were distributed and nearly 2 million returned. The most dissatisfied groups were young white adults and adult Asian service-users (Kontopantelis et al. 2010). There are reported to be differentials between responders and non-responders to surveys (Boersma et al. 1997), therefore these findings need to be treated with caution. Though, when socio-economic status and the size of practice were controlled for, the outcome was unchanged.

Attending work and distance to work were related to high levels of dissatisfaction. It would seem that not only were the service-users dissatisfied with the service, but one of the contributing factors was they had difficulty accessing the service because of work patterns and commitments.

For some minority groups, the low satisfaction with access to GPs could contribute to the increased 'light use' of A&E by minority groups (visits not resulting in admittance or follow-up treatment or investigations) (Petersen et al. 2011), and indicate that even a high permeability service like GP practices have navigation issues that may introduce a barrier to equitable access to services.

Data from the General Household Survey (GHS) (N=20,421) indicated that people from low socio-economic groups used A&E more than other groups (Shah & Cook 2008). However, they also found that these groups, and notably minority groups, also used NHS Direct less than the general population. This suggests that A&E is a highly permeable service, where attendees know they will be treated, whereas NHS Direct may be a low permeability service that requires good communication and negotiation skills to navigate to the required support (CHI 2004).

Care must be taken with interpreting survey methodology with minority groups. Surveys are not seen to be reliable as it has been shown that there is low agreement between open interview and survey item responses (Boniface & Burchell 2000), differential response rates across South Asian sub-groups (CHI 2004), and responders differing significantly from non-responders on confounding factors such as level of deprivation and education (Boersma et al. 1997).

To avoid the problems of survey methodology, two studies of A&E use by different ethnic minority groups analysed hospital and ambulance records, and found distinct 'navigation' issues (Ben-Shlomo et al. 2008; Petersen et al. 2011). In a study to verify high usage of emergency departments by minority groups, Peterson et al. (2011) found that ethnicity classifications were inadequate. This inadequacy required them to resort to a name-based categorisation of London A&E 'light' usage by different ethnic groups. Computer applications were used to analyse service-users' names for the classifications, and found there was no differential access rate across all user groups. These results challenge the common perception of such a differential

(Hargreaves et al. 2006), and add further support to the issue of poor classification of minority groups in the UK.

One problem with this A& E study is that non-light use was not analysed, the results of which could support the common perception of a differential use by minority groups. A second issue is that London has a highly transitory population that include tourists from all backgrounds. The transitory nature of the population could also explain the additional finding that service-users from Asian backgrounds also had lower rates of GP registration than the general population group (Hargreaves et al. 2006).

The lack of a differential in emergency health care use could be explained in part by the patterns of use by different groups. In the second A&E study Ben-Shlomo et al. (2008) analysed patterns of people arriving at A&E departments across England and Wales with acute chest pain. South Asian groups used ambulances at a rate of 40% less than the general population, regardless of the diagnosis on admission (Ben-Shlomo et al. 2008). These findings highlight a problem of ‘navigating’ high permeability emergency services (Dixon-Woods et al. 2006) and further work needs to be undertaken to find out why these different patterns of access occur. The lower use of ambulances is of concern, as an audit of UK A&E sudden deaths records, found that service-users of South Asian background are more likely than any other group to suffer a cardiac arrest in transit to A&E, irrespective of mode of transport (Hamaad et al. 2006).

Frontline services such as GP, A&E, and NHS direct should be the most permeable health care services. What these studies have shown is that even these services have barriers on initial contact that must be 'navigated' to access equitable health care for minority groups. The seemingly minor problems with access to GPs (Kontopantelis et al. 2010) up to the disproportionate number of South Asian service-users suffering a cardiac arrest in transit to A&E (Hamaad et al. 2006), contribute to the evidence of problems for minority groups accessing equitable health care. The quality of care problems in these cases would seem to be mainly structural, for example services seem to be making assumptions that patterns of use are similar across minority groups and instigating the process of audits is a structural issue (Campbell et al. 2000b).

4.3.4 Health care screening initiatives

Illness prevention initiatives aim to address the awareness issue and encourage people to be screened for potential health problems (Greenlund et al. 2003), and in effect develop candidacy. There is an established significant low rate of screening for breast, cervical, and bowel cancer in ethnic minority groups (Austin et al. 2009; Moser et al. 2009; von Wagner et al. 2009). These differences could not be explained by poor health or socio-economic factors. The possible reasons for not accessing or attending screening for colorectal cancer were explored using focus groups (Austin et al. 2009). Afro-Caribbean, South Asian, and white participants took part in nine focus groups, where it was found that limited awareness of the risk of disease was the main barrier to taking part in screening. Language difficulties, religious sensitivities, and a mismatch with culturally influenced health beliefs were discussed but low levels of awareness were evident across the ethnic minority groups (Austin et al. 2009). Focus groups do suffer from validity problems such as pressure to conform (Janis

1972), and moderator influence (Puchta & Potter 2002) but trustworthiness issues such as these were not discussed.

Lack of awareness of the availability of screening was also cited as the barrier that prevented attendance in a large study with minority groups (Robb et al. 2008). Using face-to-face structured interviews, 875 participants expressed a high level of interest, but embarrassment about colorectal cancer was more prevalent in South Asian minority groups. Face-to-face interviews can have (demand characteristics) issues that may alter the usual behaviour of a respondent, such as socially desirable responses and the reported embarrassment by South Asian respondents may have inhibited accurate responses.

A further study of colorectal screening tried to remove the barrier of awareness by posting information and home sampling kits to a large cross sectional sample of the population. A typical response was that they had not been screened previously because they were unaware of the problem. Even with this targeted campaign and screening with self-administered home kits, people of South Asian background had significantly lower response and return rates than white or other minority groups (Szczepura et al. 2003). No clear explanation was discovered for the low response, but it could be language related as the kit and information were in English and needed to be read; or embarrassment, which has been cited in other studies (Austin et al. 2009; Robb et al. 2008).

It could be the processes of colorectal cancer screening that was causing the reticence rather than the fear of getting bad news. When data were collected at 10 health

screening events for cardiovascular risk factors, the study found no reticence in minority group members volunteering for screening (Patel et al. 2007). The events took place in a medium sized town with a diverse range of minority groups. The attraction was that a health check and subsequent diagnoses were on a 'walk in' basis in community settings with immediate feedback or referral from physicians. There was a high level of undiagnosed or un-managed risk factors, mainly high blood pressure, abnormal glucose, and raised total cholesterol. Of the 824 people who took part just over a quarter were white European, and the remainder from South Asian or Arabian minority groups. From the total sample, 470 were referred to their GP for primary or secondary health care; there was no difference across the groups for hypertension, and raised cholesterol, but South Asian and Yemeni service-users were diagnosed with significantly more diabetes and unregulated blood glucose levels.

The outcomes of the referral and thus the accuracy of the screening were not discussed. One of the features that may have facilitated the high level of volunteering was the availability of dedicated interpreting facilities, the walk-in design, and the location. However, there could have been sampling issues as the events were held on weekend mornings and many of the South Asian residents work in the restaurant, or taxi trades. In addition, estimates of attendances by ethnic group were made based on the demographic information of the town. The white British were over represented, Pakistani and Bangladeshi attendance was under represented and other South Asian groups were close to expectation. Despite these issues, the proportions of South Asian groups that had undiagnosed conditions was greater than projected (Patel et al. 2007).

Poor uptake of screening could be seen as an indicator that health related messages are not received by minority groups. With one exception (Patel et al. 2007), what these screening studies have shown is a barrier to minority groups taking up screening offers. What is needed for a truly equitable service is to explore barriers to access and seek to remove them. In the previous section embarrassment about certain conditions was cited, and here lack of awareness was cited. The successful screening study indicated that a problem focussed intervention will work but even this was still not fully used by some groups (Patel et al. 2007). Issues such as embarrassment and lack of awareness seem to lower permeability for some screening initiatives. The fact that screening services are not taking these into account indicates structures of care are responsible for the lower permeability, rather than the service-users lacking candidacy.

4.3.5 Long term conditions

The services that may be less permeable and require informed 'navigation' are those that involve the management of long-term conditions (Dixon-Woods et al. 2006). The high prevalence of diabetes in South Asian populations has been well documented for a number of years (Garduno-Diaz & Khokhar 2011). Despite this an unexplained difference in the diagnosis and management of the disease still exists between minority groups and the general population (Atkinson et al. 2001).

The UK Government's agenda for quality improvement in chronic conditions (DH 2005c) sets targets for diabetes management. These targets include numbers of screening attendances, and minimum clinical outcomes for blood pressure, cholesterol, and blood glucose measurements. One of the difficulties with assessing equitable care is the way the processes of care are assessed can present equivocal

findings. For example, a secondary analysis of the Health Survey for England (HSE data) looked at hypertension, raised cholesterol and diabetes in white and South Asian groups over four years (Nazroo et al. 2009). The analysis indicated that between 1999 and 2003 any inequalities between minority groups and the general population in clinical outcomes such as hypertension, blood pressure, and diabetes were minimal.

Other studies, independent of HSE data, have also investigated attempts to reach the Government's targets for diabetes management. A cross-sectional study looked at 7605 electronic records in 32 primary care practices in one UK city (Gray et al. 2007). On analysing screening attendances and clinical outcome measurements, it was found that while there were no significant differences of attendance rates between Black, South Asian, and white service-users, there were differences in clinical outcomes. Black and South Asian service-users were significantly less likely than white service-users to meet the national diabetes targets for blood pressure, cholesterol, and blood glucose.

There is clearly a mis-match between these two sets of outcomes. One difference was the methodology: survey methodology such as the HSE, has been shown to be unreliable when used with minority groups (Boersma et al. 1997; Boniface & Burchell 2000; Pasick et al. 2001). In addition to these issues, the HSE does not just include those with diabetes in their survey. The physical assessments were taken for the survey in the service-user's home, whereas in the second study (Gray et al. 2007), the data was collated from GP records of consultations.

A further cross-sectional retrospective study analysed GP and clinic records of service-users with diabetes (Christopher & Kendrick 2004). Eight hundred and thirty-nine records of diabetes treatments were examined, 671 had received formal diabetes management, of which 125 were classed as South Asian. For either GP or clinic management, South Asian diabetics were significantly less likely than white service-users to have their blood pressure and serum creatinine checked. There was also some evidence that they were less likely to have their feet examined, or their body mass index recorded.

There seems to be a contradiction between survey results and audits of medical records, but the validity of the former is questionable (Pasick et al. 2001). Disparities like this can impact on decisions made for evidence-based practice, and may eventually lead to inequitable care for minority groups (Atkinson et al. 2001). If diabetes is not detected or managed, it can lead to serious complications in later life (UK Renal Registry 2001). Even when actively managed, differences still exist in management and outcome between South Asian service-users and the white general population. (Christopher & Kendrick 2004).

Poorly managed diabetes can lead to diabetic nephropathy, which can result in end stage renal failure, the most common cause of kidney failure for service-users accepted for transplant (UK Renal Registry 2001). There has been an increase in the number of people requiring transplants, which is in part due to policy changes for eligibility, but there is a growing unmet need for transplants with an associated shortage of donors (Roderick & Armitage 2002; Rudge et al. 2007).

Unfortunately, there are significant imbalances between the general population and black and South Asian service-users in kidney transplantation. Asian and Black service-users will wait for transplant at least twice as long as a white service-user. Black recipients have a shorter survival period than whites or South Asians, and tissue matches are more difficult for Black and South Asian service-users (Rudge et al. 2007). In 2006, the U.K. National Kidney Allocation Scheme was instigated to achieve greater equity of access to transplantation for all service-users, irrespective of where they lived, their blood group, or their ethnicity. There has been no explanation for the disparity of distribution, or outcome (Rudge et al. 2007).

Cases described in this section are indicative of structural quality of care failures. Even if there were process issues that prevented an equitable service, structural initiatives would need to be in place to ensure these were overcome. This situation is related to the research questions, as in general there seems to be a discrepancy between the general population and people of South Asian origin. In addition diabetes is a major risk factor for stroke and TIA, making it even more important that this condition is detected and managed (Banerjee et al. 2010; Gholap et al. 2010).

4.3.6 Ethnicity Data recording

Poor ethnicity data coding and recording have been cited as one of the major barriers to making accurate estimates of issues for people from minority groups (APHO 2005). The following studies highlight the problems this poor data recording can cause.

In a glaucoma mapping exercise it was discovered that there was a clear mismatch between areas of deprivation and access to optometry services; individuals from

deprived areas tended to get treatment at a significantly later stage of the disease (Day et al. 2010). Although there is an association between minority groups and deprivation (APHO 2005), the study could not make accurate estimates of the problem for minority groups alone, as ethnicity data was poorly recorded. Ethnicity data was only available through the Patient Administration System (PAS) but only 9% of the sample had ethnicity recorded. Poor ethnicity recording has been a theme that has been discussed in this and the preceding chapter and must be considered a major threat to equitable access for minority groups, as accurate levels of risk or service provision cannot be estimated. It has been suggested that, as a result of a lack of a standardised approach and appropriate classifications, clerical staff are not properly equipped to record ethnicity (Petersen et al. 2011).

Even in areas where such recording would be considered as essential, the problem persists. An example of this is recording ethnicity data for malignant cancers. The Hospital Episode Statistics (HES) records this data nationally and for a local initiative it is recorded on the Thames Cancer Register (TCR) (Jack et al. 2006). The HES had recorded ethnicity data for 81.1% of the entries and the TCR had recorded 22.7%. This is despite the TCR receiving data from a range of sources, including the HES directly. There needs to be more research to explore the difficulties in recording ethnicity, however until the current situation is resolved the veracity of both data sets is in question. With a situation like this, accurate estimates for cancers in minority groups cannot be calculated, which could result in cancer service provision for minority groups being less than equitable.

A reoccurring theme in this part of the thesis is the poor recording of ethnicity data. This can be seen as both structure and process based. That a unified definitive recording classification or process is not in place is clearly structural. However, where unilateral systems exist these may be inadequate or poorly maintained, both of which can be seen as process issues.

4.3.7 Trans cultural service provision

The NHS has a policy to recruit staff at all levels from minority groups. A study was conducted to explore why such a policy has not resulted in the appropriate staff ethnicity profile. The information was collated from advertisements for staff, job descriptions, HR records, interviews, and a literature review. The findings demonstrated that despite years of equal opportunities legislation, NHS senior management still does not reflect the diversity of the wider NHS, or the population as a whole (Kalra et al. 2009).

In the UK there have been a limited amount of studies that explored the service providers' perspectives of working with ethnic minority service-users. A qualitative study of district nurses' interactions with South Asian service-users and carers found that psychological support and follow-up treatment was severely restricted (Gerrish 2001). This was suggested to occur because of language barriers, as district nurses relied on family members for translations. The restricted communication resulted in processes of care quality failures, as nurses were unable to gain a full understanding of situations, which resulted in follow-up assessments being less than adequate.

A second paper from the same study data described structures of care issues that led to process of care failures. Participant observation and an organisational audit

indicated that small single-handed practices with large minority group service-user lists had less district nursing resources than single-handed practices in predominantly white areas (structural). By some manoeuvring of staff and appointments, the caseloads were covered in the minority group practices, but this was at the expense of the quality and quantity of district nursing input (process) (Gerrish 1999).

Participant observation data of processes were collected as part of the approach of these studies, but this may have limitations, as the nursing teams may not exhibit their normal behaviour, under observation. Furthermore, using qualitative interviews for such sensitive topics may prevent respondents being candid; both of these issues may lead to an underestimation of the problems they found.

A further qualitative study was undertaken in a general hospital (Vydelingum 2006; Vydelingum 2000). This study used focus groups to explore caring for South Asian service-users. The participants were nurses of all grades from six medical wards, 90% were white. The participants believed that they were culturally fair in their approach; treating all service-users the same. Horizontal equity or equal treatment for minority group service-users may not be appropriate treatment, and they may need to be treated differently in order to receive equal levels of care (Culyer 2001) and avoid a process of care failure. In addition to this false consciousness of equity, other themes included evidence of ethno-centric practices and victim blaming (Vydelingum 2006), process of care failures fostered by structural deficiencies. If these issues are taken together, then the staff displayed poor levels of cultural competence. Cultural competence is the ability to interact with service-users in a way that service-users see

as appropriate (Papadopoulos 2003). This lack of cultural competence did not support the nurses' perceptions of treating everyone the same.

It can be imagined that concerted or extra efforts would have been made by service provider participants, in hospital or community studies, to present their interactions in the best way possible, or risk breaching NHS policy. Despite this, the conclusions of the studies in this section indicated that there were concerns about the quality of care, but because of a lack of awareness by staff and management, these structural and process quality shortfalls enable practices to continue with the result that minority group service-users receive less than equitable care.

Service-users' perceptions of nursing staff were explored in an earlier study in northern England. This study used service-user focus groups, followed up by single individual interviews with a focus group member as a validation exercise. The study found that nursing staff held stereotypical views, and had a lack of understanding about the needs of ethnic minorities. This led to a mismatch between the service-users' expectations and service-users' experiences (Cortis 1998).

Currently there are few studies that explore South Asian service-users' experiences or perceptions. In addition, a recent review indicated that the literature on raising awareness of stroke in minority communities was rare (Dr Foster Intelligence 2010). The few studies that have been carried out tend to be small and have methodological issues. Many of the studies with non-English speaking groups use translators with no or inadequate validation which can result in error from inadequate translation and

insensitivity to cultural norms (Hunt & Bhopal 2004), and often fail to demonstrate that their descriptions are valid and not social artefacts (Woolgar 1988a).

For example, the study with South Asian focus groups above used translators and only recorded the translator responses and not the actual interaction (Cortis 1998).

Because of this there was no way of validating the accuracy or validity of those responses. In the validation interviews, the same translators interviewed members of the focus groups, rather than independent service-users, risking contamination; again only translator responses were recorded.

A targeted and contemporary literature review considering barriers to accessing care services has resulted in 47 studies that indicated barriers to accessing equitable care in a number of health care areas. In Chapter 3, stroke service-users experienced a number of issues that collectively were seen as poor levels of cultural competence. Service providers do not seem to possess the necessary skills and knowledge to provide care to people from minority groups, which suggests their care was not equitable. Therefore the findings in Chapter 3 have been supported by the review in this Chapter.

Table 4.6 shows a framework of the concepts used to evaluate the findings of this review and compare these with the finding of the empirical work in Chapter 3, and indicates the main location of barriers for South Asian service-users in accessing equitable service provision.

Barrier		Review finding	Phase 1 & 2 finding	Quality issue
Service-user (Candidacy)	Newness	Service-users unaware of range or existence of services	Willing to access health care but low stroke awareness	Structure
	Ethnicity	Minority groups specific issues impact on service access	Negative experiences by Stroke survivors, specific needs not addressed (Cultural competence)	Process
	Linguistic factors	Inadequate response to statutory duty	Variation of experience, limited translation services. Some issues with South Asian doctors who would only speak English (Cultural competence)	Structure
Service provider	High Permeability	Frontline 'High permeability' services have navigability issues. .	No issues of low permeability services, lack of knowledge of higher permeability services (Cultural competence/low stroke awareness). Some issues with small practice GPs, appointments and referrals	Structure
	Health care screening	Some services need high level navigation skills that people with low candidacy may not have	Limited knowledge of risk or diabetes, stroke and heart problems.	Structure / process
	Long-term conditions (Navigability)	Diabetes more prevalent in South Asian minority groups but inadequate differential provision	No major issues discussed, some difficulty with appointments, few referrals to rehabilitation (Cultural competence)	Structure
	Ethnicity data recording	Ethnicity classifications and data recording unsystematic and irregular	Not an issue that would surface in Part 1 study	Structure
	Transcultural service provision	Ethnocentric, inadequate levels of skill and knowledge to work with minority groups	Perceived low levels of competency dealing with minority groups, instances of discrimination (Cultural competence)	Process

Table 4.6 Comparison of literature review and Phase 1 and 2 issues

4.4 Limitations

The main limitation of this section was that a full systematic literature search was not used. By not using such a search policy there could be accusations of selection bias, which could occur by partiality in the papers selected for the review. However, an attempt was made to retrieve as full a set of papers as possible. The purpose of the

methods for this section were not to collate every article that has been published on the topic, but rather to present an illustration of the work in this research area, to both contextualise and validate the findings from Chapter 3. Extended searching strategies, such as targeting salient authors or journals, and hand-searching reference lists were not undertaken. These would have been attempted if there was a shortage of material, or the retrieved material seemed to be biased in some way.

It has been acknowledged that the literature in this field is low to moderate quality (Dixon-Woods et al. 2006; Goddard & Smith 1998). The studies are mostly observational, survey or qualitative, the majority are small in scale. This is not to say that the evidence is not there or what is presented is incorrect, but conclusions will always be tentative or propositional. When taken together, and with such a broad range of disciplines, health issues, methodologies and samples, it is sufficient to propose that service provision for minority groups is less than equitable. It can also be proposed that the issue is not if there is inequitable service provision, but rather the scale of and reasons for it.

4.5 Conclusions

In Chapter 3, using focus groups and interview methods it was reported that there were low levels of stroke awareness, despite the fact that South Asian groups have an increased risk of stroke (Chiu et al. 2010; Kothari et al. 2002; Patel & Punekar 2010). Participants who had not used stroke services held positive expectations about those services. Participants who had used stroke services were negative about their experience of the interpersonal processes of care. Attitudes and behaviour of service providers when working with South Asians were seen as poor, and that they appeared to lack an understanding of culturally specific issues. Participants expressed a need to

be treated as an individual, to feel cared for and respected, and suggested that staff receive training to address this. Further research was needed to explore the efficacy of training service providers to be culturally competent, to enable them to provide equitable stroke care for people of South Asian heritage.

The evidence described in this chapter supports the findings of Phases 1 and 2 of this thesis that there is a disparity in health care provision for people from minority groups in general. There were also specific instances demonstrating lack of equitable care for South Asian groups in particular. These disparities can be subtle, for example, in some cases candidacy does not materialise until a critical point in a condition is reached (Bowes & Wilkinson 2003). Services, for which most people have good levels of candidacy (such as A&E), are also seen as having high permeability. Front-line services are perceived to have high permeability but as the evidence has shown these have navigation issues (Kontopantelis et al. 2010). Lower permeability services, such as screening initiatives and long term conditions, have navigation problems that may be related to 'gate keeping' or referral practices (Rudge et al. 2007). Services such as these require a high degree of navigation skill to obtain appropriate care (Goddard 2009). The problems with candidacy, permeability, and navigation highlight the barriers that prevent people from minority groups accessing equitable health care (Goddard 2009). To date policies that have been put in place to reduce or remove these barriers have been ineffective and may even have made some worse. The main problem has been that policy initiatives failed to identify the source of barriers faced by some minority groups (Goddard 2009).

The problem of access to equitable care has the potential to become more urgent. For example in the case of South Asian minority groups, demographic evidence indicates that nationally the South Asian population is relatively young, with an increasing number of people aging into the 50+ age group each year (Blackburn with Darwen Borough Council (BwDBC) 2005). There is also a marked increase in the risk of stroke at age 55 for South Asian groups, and this risk increases with age (Gill et al. 2002). Therefore, an increasingly greater number of people of South Asian heritage will be at risk of stroke and related conditions year on year and at an earlier age.

4.6 Reflection on the aims of Part 1

This chapter has addressed the final objective for Part 1 of the thesis: review the literature that considers equitable access to health care in the UK for minority groups. Part 1 was designed and executed to address the first research question for this thesis: What are the issues for people of South Asian heritage in accessing health (stroke) services? The aims of this part were: To establish the context of South Asian minority groups in the UK, how stroke affects this groups and what the existing literature describes. In addition, to explore the experiences and perceptions of South Asian groups in one area of the UK and develop a hypothesis that addresses the issues for these groups accessing equitable stroke care.

Part 1 has fulfilled the aims and objectives set out in Chapter 1. It has established that there is a need for equitable service provision by exploring UK policy documents and guidelines, the existing literature and carrying out local empirical work. This part has contributed to knowledge in this area of health research by developing a robust, collaborative approach to working with hard to reach groups.

The outcomes of Phases 1 and 2 culminated in the tentative hypothesis in Figure 3.12. The hypothesis draws on all areas of Part 1 and proposes that structural issues are the context where health care processes operate and these are inextricably linked and may contribute to the outcome of poor quality health care for minority groups in the UK. Part 2 aims to propose ways of addressing the issues elicited in Part 1.

PART 2

Chapter 5

Realist principles and evaluation of methods

5.1 Background

The findings from Part 1 of this thesis indicated that there was little reticence on behalf of people of South Asian heritage accessing health care. The lack of reticence is borne out by the literature for both primary care (Smaje & LeGrand 1997), and secondary care (Adamson et al. 2003). The participants in Part 1 who had not used stroke services held an optimistic perception of future care. This optimism seems to be reversed when people have direct experience of hospital stroke services. The participants who suffered a stroke reported negative experiences. This dichotomy of positive perceptions and negative experiences has been reported in a similar study in Northeast England (Cortis 1998).

If this health care-positive approach of people of South Asian heritage is contextualised in their experiences and perceptions of stroke care, then it would seem that any barriers to equitable access to health care rests with service providers. As described in Chapter 4, people from other cultures can have problems that may prevent them accessing the services they need. One of these problems could be candidacy, or the perception of the right to access health care (Szczepura et al. 2003). Chapter 4 proposed a robust case that barriers to accessing equitable health care do exist, and that the majority are as a result of structural issues, for example, lack of targeted screening or awareness programmes for groups that have an elevated risk of health problem.

What service providers can do is to remove structural barriers, such as making information, and services as accessible as possible, and ensuring processes, such as care delivery, are culturally competent. These issues are complex, but not impossible, for example there were instances in Part 1 where service-users were cared for in such a way that they felt that nothing more could be done:

I...Does anything come to mind where you think they could have done this better. Can you think of any instance at all, are you happy with everything?

R: no I can't think of anything. (SS 16:13).

A number of service-users in Part 1 indicated that staff needed to be trained to work with people from other cultures effectively. Such training already exists and this training is supported by theoretical models and frameworks (Campinha-Bacote 1999; Papadopoulos et al. 2004).

The application of new skills by staff is part of the process of health care, and they can be assessed for quality by a S-P-O quality framework (Donabedian 2005).

Processes of health care can be easily measured, but they are usually delivered in bundles of processes (Cleary & O'Kane 2011) and are moderated by the structures within which they are practiced (Campbell et al. 2000b). Structural elements described in Chapter 2, such as policy and guidelines, indicate that it is policy for services to address the needs of minority groups (CHI 2004; CHAI 2006). Cultural competence training for individuals and organisations already exists (Crandall et al. 2003). The calls for services to address the needs of minority groups and the evidence from Chapter 4 indicate that health care service provision is not culturally competent. If and when health care services begin to ensure that staff and services are culturally competent it would be useful to consider the existing cultural competence theoretical

models and frameworks, the efficacy of training models, and the relationships between theory and practice (US Office of Minority Health 2001). This part of the thesis will explore conceptual frameworks of cultural competence and the evidence that may support them, then propose a model to suggest how true cultural competence can be achieved in practice.

Chapter 2 explored the context of culture and difference between concepts such as ethnicity, race, and culture, and how the lines between them are less than clear. One 'cultural context' is religion and, for example within Islam there are differences between Muslims that are extreme and numerous (Sheikh & Gatrad 2007). When the issue of religion is combined with other contexts like language and ethnicity, the contexts become challenging to isolate and address.

What is needed is an approach to enable service providers to work with people of any background; to do this requires a set of inter-cultural competencies that are generic, theoretically sound and evidence based. Generic, to enable the skills to be applied no matter what intercultural interaction is encountered. Theoretically sound, as an approach based on a theory will provide a framework or set of principles that can be applied across different situations. Finally, being supported by evidence indicates that the application has worked in the past, and can be tested continually in new contexts to further evaluate efficacy.

Research Question 1 is: what are the issues for people of South Asian heritage in accessing health (stroke) services? This was addressed in Part 1, where it was proposed that barriers to access were located with service providers and needed

structural alterations to services. These alterations were that a) service providers needed to be culturally competent and b) minority groups needed information about stroke and the risk of stroke (addressed elsewhere).

The proposition for Part 2 is to address research question 2: what would be the (stroke) service requirements to meet these needs and overcome the issues described in Part 1? The aim was to achieve this by reviewing the literature on cultural competence and cultural competence training. Realist principles were used to synthesise findings from the literature review to evaluate the theoretical approaches to cultural competence and evaluate and synthesise the evidence to support components of existing and proposed conceptual frameworks. Finally to make recommendations for the development of true evidence based cultural competence in practice. This Chapter will address part of objective (i) for Part 2 which is to review the literature on cultural competence theories and conceptual models; this will be completed in Chapter 6.

5.2 Introduction

The United States of America (USA) have recognised the issue of inequitable health care for a number of years, and to address this disparity have established a specific office within the Department of Health and Human Services. The Office of Minority Health (OMH 2011) was opened in 1986 with the aim of helping to eradicate health disparities for minority groups in the USA.

The OMH funds research and collaboration programmes, rather than carrying out work directly, and has decided that the most effective way to ensure that access to health care is equitable is to make health services as a whole culturally competent

(OMH 2011). To this end, OMH has produced a set of fourteen ‘Culturally and Linguistically Appropriate Standards’ (CLAS), that service providers can use to establish if their services are appropriate (The Office of Minority Health (OMH) 2011). The USA has taken a quasi-mandatory structural approach to providing culturally competent health care to ensure an equitable approach (OMH 2011), but in the UK, equitable access is treated differently. For example, the discourse about ensuring stroke services suit the needs of minority groups has changed little since it was initially mentioned in the National Service Framework for Older People (DH 2001).

Chapter 2 described how good quality health care for a population needs to include equity of provision (Donabedian 2005), and therefore equitable health care can be assessed by considering structures, processes, and outcomes of health care (Campbell et al. 2000b). Chapters 3 and 4 describe both empirical and literature-based evidence which indicates that people from minority groups were not receiving equitable service provision in a number of areas. Though some processes of health care were poor, in the majority of cases it was the structures of health care provision that either mediated or moderated the process and this resulted in less than optimum service. It would seem that the USA has recognised that services and the people who work in them need to be culturally competent and are trying to address this by putting in place structural requirements (US Office of Minority Health 2001).

The effectiveness of the OMH CLAS initiative is difficult to assess. Despite a search of the CLAS website and Medline, only three studies could be found for either the evidential basis of CLAS, or the effectiveness of their endeavours. A systematic

review considered the evidence to support the standards that directly affect service-users, and for some of these standards found no studies at all. For the remainder of the standards considered, the evidence was inconclusive (Anderson et al. 2003).

A second article directly assessed the effectiveness of one element of the CLAS standards and found positive evidence (Pacheco 2007). This investigation used a mixed methods approach, and looked at online training modules for 2245 physicians. After the online intervention, there was an increased level of self-reported cultural competence, and a higher regard for translators. The report was commissioned by the OMH, and used a single group pre- and post-intervention assessment design, with no control group. The findings were also supported by data from focus groups and interviews. However, the single group method used was not the most robust, there was no service-user impact assessment, and no association was explored between the online participation and any reduction of health disparities in minority groups.

A final study conducted a review of the evidence for CLAS in health care in the USA (Tawara et al. 2006). The review reported findings similar to the studies above (Anderson et al. 2003; Pacheco 2007), and concluded that the evidence was limited, weak, and inconclusive. Despite this, they reported that the body of evidence was growing and recognised that the development of a body of evidence in programmes that aim to change organisational and individual behaviour are inevitably slow (Tawara et al. 2006).

Although the focus for the above is the USA, it is suggestive of the potential problems for the UK. The USA has invested large resources into the OMH and associated

institutions, such as the National Centre for Cultural Competence (NCCC), and although they have devised standards, there is limited, unsystematic, and unarticulated evidence for the theoretical underpinnings of CLAS, and the impact of their work on reducing health care disparities. The NCCC (2006) report discusses this limited effectiveness and claims that when they looked for the evidence it was too early to evaluate such programmes, and added that the situation is exacerbated by short-term funding practices (NCCC 2006).

Part 1 of this thesis proposed that, from a structural perspective, culturally competent services are essential to providing an equitable service for minority groups. To provide such services the training of service providers using effective theories and methods is required (Leininger 1993). Although the focus is on service providers, the ultimate desired effect of this training should be either a positive service-user clinical outcome or experience of care for service-users. It would seem appropriate, therefore, to carry out a review of work that has been previously undertaken, and make recommendations on the results of the evaluation. This review is reported here as an important step within this thesis. The next section will discuss the various approaches to performing a review, and will explain why the particular approach ultimately used, was chosen.

5.3 Reviews

In 2010, the Public Library of Science (PloS) published its 10,000th article (Gemert 2010). The electronic database for medicine and related professions, Medline, currently holds just under 21,000,000 citations (PubMed 2011a) and one more is added every minute (PubMed 2011b). With such a large number of articles available

it is unrealistic for practitioners, who may also not have the time or skill, to review them (The Cochrane Collaboration 2012).

Even with sophisticated search engines, the resulting numbers of articles that can be retrieved are typically large and can be daunting to filter through and review. To reduce the burden on practitioners, publications of secondary research studies (called reviews) retrieve, screen, grade, and synthesise the articles and place the output into accessible formats (The Cochrane Collaboration 2012). The range of style, methodology, and even underpinning philosophy, has dictated that different approaches to reviews can be considered.

5.3.1 Systematic reviews

A systematic review poses a particular research question, then identifies, selects, evaluates, and synthesizes all the relevant high-quality primary research evidence it can find, and then uses this to answer that question (Cochrane 1999).

Systematic reviews, like all reviews, are a tool and a useful resource when used for the purpose for which they are designed. Traditional systematic reviews are at their most efficient when used with meta-analysis to combine a number of studies that address the same question with the same intervention and the same outcome. When meta-analysis is not possible and a narrative approach is used, the reviews are starting to move away from their original purpose, but still useful if carried out and described well (Delfini Group 2003; Eyesenck 1994).

A systematic review is a literature review that aims to answer a specific research question and should include:

- Clear inclusion/exclusion criteria
- An explicit search strategy
- Systematic coding and analysis of included studies
- Meta-analysis (where possible) (Crombie & Davis 2011).

When carried out proficiently, these reviews provide a sound synthesis of current evidence of a declared standard and tend to come with recommendations for practice.

Unfortunately there are problems with systematic reviews, especially those that include a meta-analysis (Eyesenck 1994), for example:

- Regressions are often non-linear, assumptions are often made that regressions are linear. Non-linear regressions are as common as linear, and if not accounted for will return a meaningless result (Eyesenck 1994)
- Effects are often multi-variate rather than uni-variate; without knowledge of how meta-regressions work, a common assumption is that the interventions are homogenous, which is not the case in trials with a human intervention (Eyesenck 1994). In these cases random effects models need to be considered, but often these are decisions for skilled statisticians (Jackson et al. 2011)
- Bad studies may be included; despite quality control, poor studies can be included and skew overall effects (Eyesenck 1994)
- Data summarised may not be homogeneous (Eyesenck 1994)
- Grouping different causal factors may lead to meaningless estimates of effects (Eyesenck 1994)
- A theory-directed approach may obscure discrepancies (Crombie & Davis 2011).

Originally, meta-analyses were used to combine the findings of a number of smaller studies that used the same outcome measure into one synthesised output. This has been further developed to combine studies with different outcome measures, and different levels of data, by converting all outcome scores into z scores or standardised effect sizes (*subtract measure 1 from measure 2 and divide by standard deviation of measure 1*). Although this may be statistically correct, it ignores the context of the studies and may be prone to subjective judgments made about the variables entered (Crombie & Davis 2011).

5.3.2 Narrative reviews

Narrative reviews are an overview of the current evidence base (Delfini Group 2003). Although meta-analyses are essentially hypothesis testing and deductive, narrative reviews can test hypotheses, but also can be used inductively to build theory.

A systematic review (meta-analysis) has a binary outcome; the intervention works or does not work, as it is looking for net effects. In contrast, a narrative review can have four outcomes which can be: accept the null hypothesis, the intervention does not work; the alternative hypothesis correct, the intervention works; the alternative hypothesis is the current best guess on the available evidence; and finally, no evidence to support or refute the null hypothesis (Crombie & Davis 2011).

The outcomes of robust narrative and systematic reviews can be useful for evidence-based medicine. This is not always the case, for example it has been claimed that the majority of narrative reviews are less than robust (Delfini Group 2003). Those that are not carried out well make a number of common mistakes, and it is the number, and combination of these mistakes that determines if these reviews are useful

(Baumeister & Leary 1997). These mistakes include: inadequate coverage of the evidence; focusing on preferred studies; poor critical appraisal of the material; lack of synthesis, with no ultimate conclusion; selective or partial review of the evidence; and finally presenting assertions as evidence (Baumeister & Leary 1997).

It can be seen that either type of review has strengths and weaknesses. The rigour, transparency, and reproducibility of systematic reviews are valued, but the readability, lucidity, and multiple possible outcomes of narrative reviews are similarly appreciated (Collins & Fauser 2011). For some topics the narrow scope of the systematic review, and the individuality of the narrative review are not suitable and other approaches need to be considered (Collins & Fauser 2011).

Situations where neither review approaches are suited are reviews of complex interventions (Pawson & Tilly 1997). Complex interventions have many components that can act on the intervention in singular and combined ways (Medical Research Council 2000). The Medical Research Council (MRC) has set out what makes an intervention complex and what issues need to be considered (see Table 5.1).

Dimensions of complexity	Number of and interactions between components within the experimental and control interventions
	Number and difficulty of behaviors required by those delivering or receiving the intervention
	Number of groups or organizational levels targeted by the intervention
	Number and variability of outcomes
	Degree of flexibility or tailoring of the intervention permitted
Implications for development and evaluation	A good theoretical understanding is needed of how the intervention causes change, so that weak links in the causal chain can be identified and strengthened
	Lack of impact may reflect implementation failure (or teething problems) rather than genuine ineffectiveness; a thorough process evaluation is needed to identify implementation problems.
	Variability in individual level outcomes may reflect higher-level processes; sample sizes may need to be larger to take account of the extra variability, and cluster- rather than individually randomized designs considered.
	Identifying a single primary outcome may not make best use of the data; a range of measures will be needed, and unintended consequences picked up where possible.
	Ensuring strict fidelity to a protocol may be inappropriate; the intervention may work better if adaptation to local setting is allowed.

Table 5.1 Dimensions of complex interventions (Craig et al. 2011)

5.3.3 Complex interventions

Table 5.1 indicates the range of issues that need to be considered when working with complex interventions. The premise of Table 5.1 is the revelation of a causal link; it does concede a number of possible causal links and flexibility around local settings, but it is still successionist. A successionist approach is when one person or event (must) follows another person or event. A typical successionist approach is illustrated in Figure 5.1, Y succeeds X, and a causal link is evident (Pawson & Tilly 1997). Events A to G are confounding factors, or other explanations for Y occurring, and are what the experimenter hopes are controlled or eliminated (see Figure 5.1).

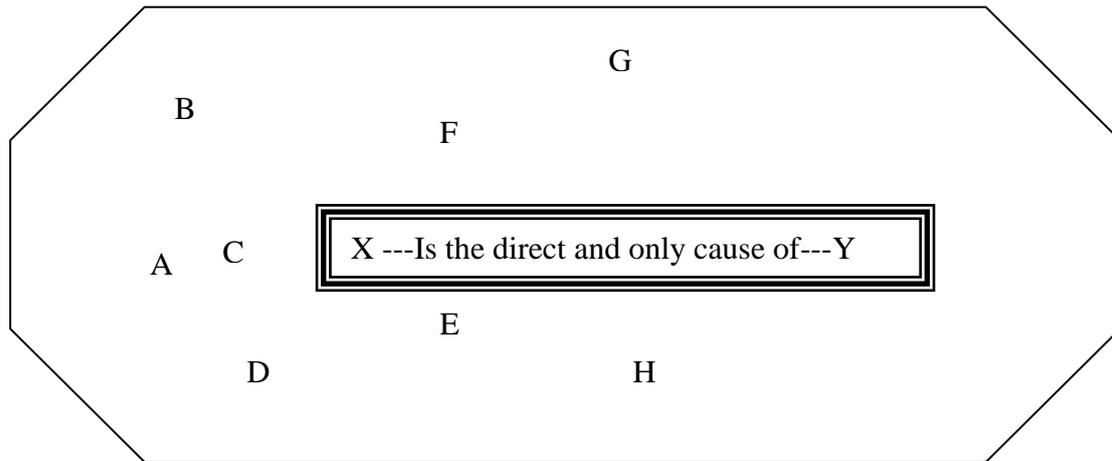


Figure 5.1 Positivist / successionist view of an ideal causal link

This process is only practically possible in a laboratory environment and even then, in this conceptually simple experiment, variation in outcome could occur (Woolgar 1988b). Health research that is involved with practice, involves working with people, as such these interventions are complex (Craig et al. 2011). Each person involved in the intervention is a confounding or biasing variable. A typical response (see Table 5.1) is to call for larger sample sizes or to cluster the sample into units and analyse the data at the level of the unit not the individual. In fact, what happens is the larger the sample, and the more complex the design, the more complexity is introduced (Craig et al. 2006; Pawson 2001).

Rather than a successionist approach, a generative approach may be more appropriate for working with complexity. With complex interventions, no matter how well controlled, what cannot be ignored is that causation is generated out of the interactions of the intervention, the context, and the mechanisms (Pawson 2001; Pawson 2009; Pawson & Tilly 1997).

5.4 Realism

It may seem that this section is working towards a critique of positivism and its fixation with a successionist view of causation. This is not the case, and an argument will not be made for a dualist approach to science, where two fundamentally different approaches exist separately from one another (Marcum 2008). It will be argued that a pragmatic approach is considered where some approaches are more appropriate than others, and outcomes are context dependent. In Chapter 3, a short description of realism was provided. This section will reiterate these points and explain how, and why, this realist philosophy and its applications are better placed to evaluate complex interventions than some of the more traditional alternatives (Pawson et al. 2004).

Realistic synthesis is a relatively new scientific approach, but its roots go back to the eighteenth century enlightenment, when there were debates about what reality actually is. For example, David Hume offered a challenge to his readers to show him the reality behind experience, which is not possible, nor is it possible for you to demonstrate that you are not dreaming now (Hume 2003).

A realist position is that, until it can be proved otherwise, anything that exists outside of our minds is real. Naive realism accepts that reality exists outside of our consciousness, but this is ontologically on a basic level (Mingers & Willcocks 2004). Critical realism goes further and claims that in ontology, or the study of being, there are three domains of existence (Bhaskar 1989). Bhaskar proposed that the three domains are the real, the actual and the empirical. The domain of the empirical is contained in the domain of the actual and this in turn is contained in the domain of the real. This is demonstrated in Figure 5.2.

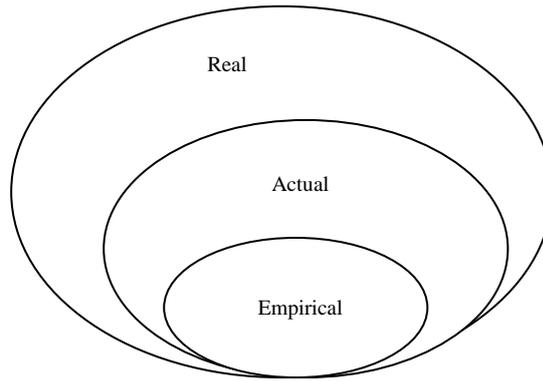


Figure 5.2 Bhaskar's proposition of ontological domains (Mingers & Willcocks 2004)

The domain of the empirical is the observation of an event, the domain of the actual is the event and the domain of the real contains the mechanism that brought the event about (Mingers & Willcocks 2004). As an example, a person throws a rock and breaks a window. An observer only has the experience from the domain of the empirical, the window breaking is in the domain of the actual, it actually happened, but the mechanism that caused the rock to be thrown is in the thrower's mind, and is in the domain of the real. Critical realism proposes that this causal mechanism is as real as any physical entity, because of the real manifestations, in this example the broken window.

Critical realism can be applied to the natural and social sciences, but the application and interpretation are different. The laws of nature are universal and as such critical realism can have explanatory and predictive power. Social settings result from human activity and as such are not constant and thus may only apply for certain situations at certain times. In these situations critical realism has only explanatory power and explains the mechanisms behind complex events (Archer 1998). This explains the

importance of the contextual element of an event for realism and its applications (Pawson & Tilly 1997).

	Real	Actual	Empirical
Mechanisms	Yes		
Events	Yes	Yes	
Experiences	Yes	Yes	Yes

Table 5.2 Bhaskar’s three domains, populated by entities (Bhaskar 1978 p13)

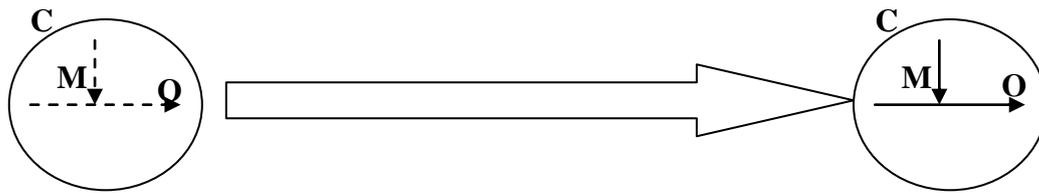
Therefore, when a cultural competence education programme is considered, a successionist approach would aim to say that it worked, and aim to produce an effect size to show by how much it worked. A generative approach would look at what made it work, with whom and in what circumstances (Pawson et al. 2005). It is the latter which is a fundamental to the approach to analysis, and to synthesis, within this thesis.

5.5 Realist reviews

One of the key drivers in improving health care is that of evidenced based practice (Michie et al. 2005). Employing a realist approach to review evidence to inform practice has been used successfully in sociology, psychology and evaluation science (Pawson 2001). In recent years it has also been used successfully in health care (Rycroft-Malone et al. 2010; Wong et al. 2010). Realist review differ from other types in terms of theory development, sourcing literature and developing conclusions (Pawson et al. 2005). They are suitable for complex interventions because of the approach and rather than providing simple answers to complex situations will make a series of recommendations supported by the best available evidence (Pawson et al. 2005). This style of review has been described as providing an “*explanatory analysis aimed at discerning what works for whom, in what circumstances, in what respects*

and how. The results of the review combine theoretical understanding and empirical evidence, and focus on explaining the relationship between the context in which the intervention is applied, the mechanisms by which it works and the outcomes which are produced” (Pawson et al. 2005).

Evidence for practice is collated from interventions conducted in the real world, although not perhaps in real situations. Realist philosophy sees real world programmes as complex interventions in complex situations (Pawson & Tilly 1997). As such, three important elements should be considered: context, mechanism, and outcome. For example context can be: a stroke unit clinical team; mechanism could be the focus of the training (e.g. develop empathy) and outcome could be service-user satisfaction. Realist synthesis sees interventions as theories in their own right, and main programme theories as general intervention approaches. An example for this thesis could be the proposition that theoretically supported interventions, to train staff to be cultural competent, are effective (Pawson & Tilly 1997). The basic building block of realist evaluation is the context-mechanism-outcome configuration (C-M-O). Although these may appear simplistic, C-M-Os do not work in isolation, rather they operate as part of a chain of C-M-Os (Pawson & Tilly 1997). In the example above, the mechanism was suggested to be increased level of empathy a service provider displays. That mechanism was arrived at by an earlier C-M-O chain, where the mechanism could have been ‘feelings of inadequacy’ when dealing with people from other cultures. At a practical level, the mechanism that brings about the required outcome for a given context is as far as the C-M-O chains need to be explored (see Figure 5.3 for a C-M-O configuration and transformation).



Dashed arrows indicate a programme theory. By applying the CMO analysis to primary studies, a revised and applicable theory is developed (solid lines)

Figure 5.3 C-M-O interactions and transformations

One of the problems with context currently is the limits and content of context. For example some contextual constituents must be more important, or rather relevant, to a particular situation than others. What is proposed in this thesis is that not only are the mechanisms important in a C-M-O configuration but the direct influencing contextual factors are of equal importance.

Current realist work began in criminology and social policy (Pawson et al. 2004).

However there is a resonance with health service quality research, as described in Chapter 2 (Donabedian 2005). Structure will always have a contextual element as health structures such a policy, physical facilities, training organisation, are contextual when processes take place. Mechanisms are indirectly associated to process of care. For example in the context of culturally competent practice, leadership and protocols are structural and the application in practice is a process. The mechanisms underlying the application decide the outcome. The symbiotic, or interdependent, relationship between C-M-O and SPO will be revisited later in the thesis.

In the context of interventions to develop cultural competence, there are many contextual elements; location, reasons for attendance, group composition, time and

duration of the course and educational/intervention component. What this thesis contends as a contribution to knowledge is that though all of these elements have a bearing on the context, the intervention component must be singled out for extra consideration because of its salience in the context of the teaching environment.

In the following chapter, the salience of the intervention components will be explored, together with the link with mechanisms of action. Ideally, a direct component-mechanism- outcome link will become apparent. For the present it is proposed that the C-M-O configurations are re-formatted to include components (C_p), (see Figure 5.4), and consider the configurations in terms of C_o - C_p -M-O. The component (black disc C_p) in interventions is proposed to be directly associated with the mechanism that brings about the outcome, but is part of the context.

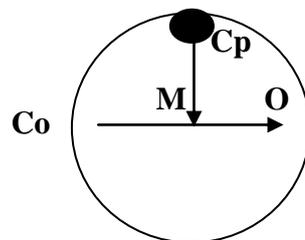


Figure 5.4 Proposed inclusion of component as an element in C-M-O

Realist evaluation is an emerging science, and as such when the principles are applied in new areas an amount of flexibility is essential (Pawson & Tilly 1997). This was recognised by the originators of the approach who provided a set of steps that they propose will bring about a successful realist evaluation (Pawson et al. 2005) (see Table 5.3). The steps, set out in Table 5.3, are not prescriptive but advisory; these

steps enshrine a set of guiding principles, as realist work has to be adaptable to different disciplines.

The realist pathway through reviews is similar in many respects to that of a traditional systematic review, what does differ are the methods used at the different stages. For example, the search strategy used in realist work is purposive, compared to the strategy in a traditional review, which is typically exhaustive (Pawson et al. 2005). Study appraisal is also different; in a traditional review, clear and rigid inclusion criteria are set out that look for threats to the internal validity of a study (Greener & Langhorne 2002). In realist work, the criteria are more concerned with the extent to which the study addresses the theory (intervention) under investigation and how well the study can support the conclusions, rather than the robustness of the execution of the study (Pawson et al. 2005).

Although the focus on the quality of papers in realist review is different from that of a traditional review, it does not mean that fatally flawed (see Table 4.2) (Dixon-Woods et al. 2004) studies are included, as a proposition cannot be put forward based on evidence that is fundamentally suspect. It is more that there is an understanding that no study or design involving humans will ever be flaw free (Dixon-Woods et al. 2006). However, even in studies that may fail because of design problems, there may be some benefit to be gained from analysing what did, or did not, work for some participants in a particular context made from the findings (Pawson et al. 2005).

Define the scope of the review	Identify the question	<ul style="list-style-type: none"> • What is the nature and content of the intervention? • What are the circumstances or context for its use? • What are the policy intentions or objectives? • What are the nature and form of its outcomes or impacts? • Undertake exploratory searches to inform discussion with review commissioners/decision makers
	Clarify the purpose(s) of the review	<ul style="list-style-type: none"> • Theory integrity – does the intervention work as predicted? • Theory adjudication – which theories about the intervention seem to fit best? • Comparison – how does the intervention work in different settings, for different groups? • Reality testing – how does the policy intent of the intervention translate into practice?
	Find and articulate the programme theories	<ul style="list-style-type: none"> • Search for relevant theories in the literature • Draw up 'long list' of programme theories • Group, categorise or synthesise theories • Design a theoretically based evaluative framework to be 'populated' with evidence
Search for and appraise the evidence	Search for the evidence	<ul style="list-style-type: none"> • Decide and define purposive sampling strategy • Define search sources, terms and methods to be used (including cited reference searching) • Set the thresholds for stopping searching at saturation
	Appraise the evidence	<ul style="list-style-type: none"> • Test relevance – does the research address the theory under test? • Test rigour – does the research support the conclusions drawn from it by the researchers or the reviewers?
Extract and synthesise findings	Extract the results	<ul style="list-style-type: none"> • Develop data extraction forms or templates • Extract data to populate the evaluative framework with evidence
	Synthesise findings	<ul style="list-style-type: none"> • Compare and contrast findings from different studies • Use findings from studies to address purpose(s) of review • Seek both confirmatory and contradictory findings • Refine programme theories in the light of evidence
Draw conclusions and make recommendations		<ul style="list-style-type: none"> • Involve commissioners/decision makers in review of findings • Draft and test out recommendations and conclusions based on findings with key stakeholders • Disseminate review with findings, conclusions and recommendations

Table 5.3 Steps of a typical realist review (Pawson et al. 2005)

Realist review and evaluation are not proposed as an alternative to traditional review methods, but as complimentary. Each review approach has properties that are more suitable to synthesise some material more than others. Figure 5.5 indicates the strength and utility of each type of review. By considering this configuration, it is proposed that they fit together as a triad of methods that can be used individually to summarise disparate sets of material.

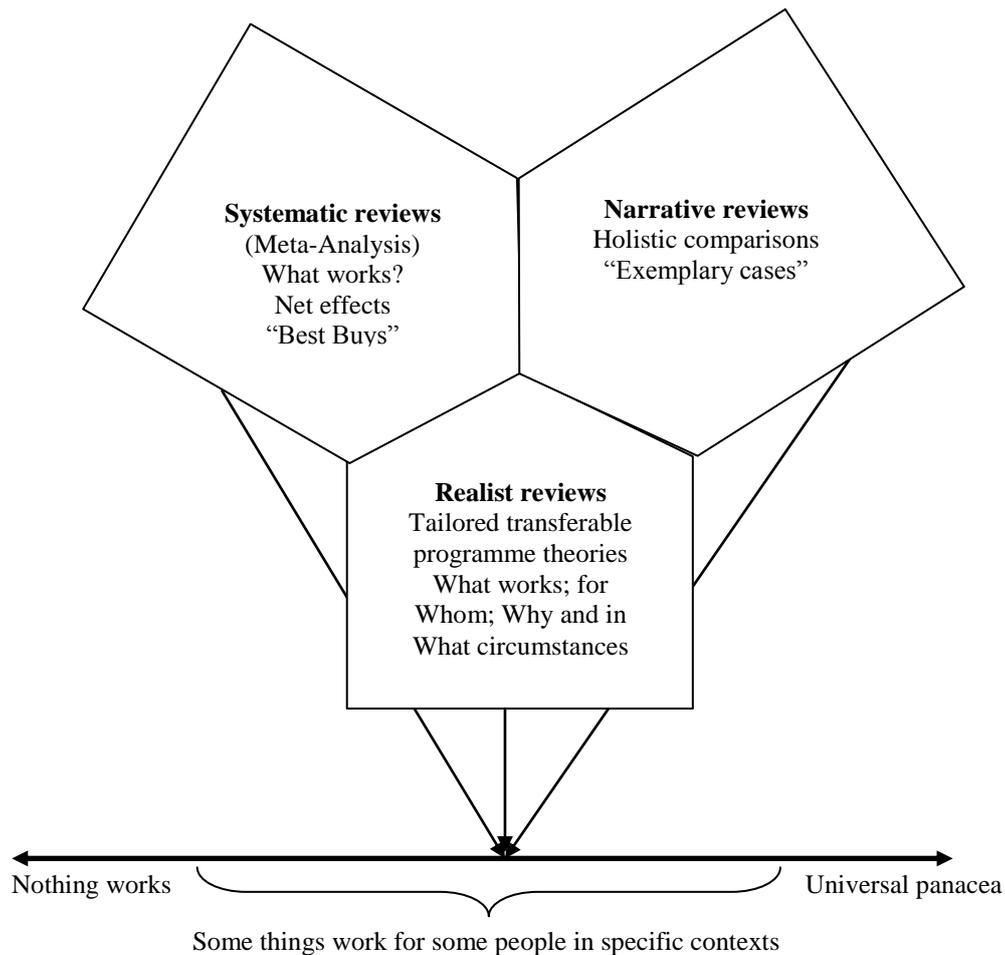


Figure 5.5 Suggestion for how the three types of review work together

5.5.1 Rationale for the search

Searching for articles in a realist reviews work is different from the strategies used in systematic reviews. In a systematic review, a search strategy is established that aims to collect every article published, and unpublished, that fulfils the search criteria.

With a realist review an exploratory search is undertaken (see Table 5.3); from the articles retrieved from this search incipient 'theories' will be developed, a search for more evidence then takes place that will either confirm, refute or refine these 'theories' (Pawson et al. 2005). A realist approach recognises that not all of the available material can be collected, and uses the concept of saturation, that is halting the search when no new 'theories' are becoming evident (Pawson et al. 2005).

The strategy for this review was to combine the best elements of both systematic and realist reviews. The exhaustive search strategy from traditional review was combined with the pragmatic approach of realist reviews. To explore the feasibility of this approach a scoping review (Hagell & Bourke Dowling 2012) was carried out to retrieve any systematic reviews of cultural competence interventions, as this would indicate the amount and quality of material available. If the approach was feasible, a systematic search would be used to retrieve as many articles that matched the suggested criteria as possible.

5.5.2 Rationale for the approach

When evidence is being assessed in a traditional systematic review, there is usually a reference to a hierarchy of evidence. At the top of the hierarchy are the designs that provide the most robust form of evidence, i.e. those demonstrating cause and effect, randomised controlled trials (see NICE 2008). Randomly assigning participant to an intervention or treatment group and a control or comparison group is seen as the most efficient way of achieving groups that are similar in characteristics (Gore 1981).

Moving down the hierarchy are controlled, non-randomised or quasi-experimental trials, where random allocation to intervention, or control groups is not possible.

Lower down the hierarchy are designs with no control or comparison group, and at the lower end are qualitative studies and expert opinion (NICE 2008).

Realist reviews do not consider this hierarchy as applicable to realist principles (Pawson & Tilly 1997). For example, an RCT seeks to control all aspects apart from the intervention in anticipation that this will demonstrate causation. Other variables that can affect the outcome are seen as confounding the study and strategies to control

these are employed (see Figure 5.1). Realist work accepts that in complex interventions, such as health research, these confounders are part of the context of the study and as real as the intervention. A positivist approach would attempt to negate or control these confounding variables or by making the samples larger, with the hope that these confounders will be balanced out, as they should occur equally in intervention and control groups. However, with complex interventions this is not the case. Every time a study is carried out in a different location, with different people it is a unique event, not part of a continuum of the same events (Eysenck 1994; Pawson & Tilly 1997).

The realist approach to evidence is to explore the context and elicit the mechanism that brought about an outcome (Pawson et al. 2005). In realist terms controlled trials, by their nature, aim to negate context by using control groups and stratification strategies (see previous paragraph). In complex interventions, such as development studies, this is difficult because of the large number of variables that are integral parts of training interventions (Craig et al. 2006). Despite this view, this thesis, in the first instance, will attempt to find controlled trials as they eliminate many problems with uncontrolled designs. There is a precedent for this as controlled trial evidence has been used as source material for realist reviews (Greenhalgh et al. 2007; Pawson et al. 2005). There are other benefits of using trial evidence as they are less prone to subjectivity than interpretive studies, and this style of evidence is preferred by health professionals (NICE 2008).

The main issues that these designs control are threats to validity. Validity is essential in trials as it is the extent to which measurement of a variable measures what it reports it is measuring (Michel 1989). If a control group is not used in a design, there is always the possibility that an outcome was unrelated to the intervention. Threats could be related to a design issue, such as a testing threat, using an inappropriate instrument, or a selection threat by biased sampling (Gliner & Morgan 2000). A further design threat is the Hawthorne effect, when participants operate differently from their normal mode because of the intervention context (McCarney et al. 2007). Validity threats from secular (external) sources are also a problem, for example, confounding events between measurements (history threat) or temporal changes within the sample may have an effect on outcome (maturation threat) (Gliner & Morgan 2000).

Realist reviews are not without critique. A realist approach is not a formulaic approach and is inherently flexible. Thus, the outcomes will depend on the credibility and trustworthiness of the reviewer who must give a clear explanation about findings (Pawson et al. 2005). Unlike other types of review, realist work will never produce net effects or generalisable effect sizes, as the work is inherently contextual. Neither are the outputs ‘hard’ evidence, as philosophically realist work is not premised on such thinking. What they will provide is a set of supported recommendations for example, ‘X seems to work well for Z in context Y’, or ‘avoid trying A with B if you want Z’ (Pawson 2001).

An issue with realist work in health research is the limitations present in primary source material. Primary source materials tend not to describe interventions or

outcome data in sufficient detail; this leads to a lack of precision when looking for mechanisms of action (Wong et al. 2010). For example, a recent realist review of computer based medical education studies found that details of the interventions were limited (Wong et al. 2010). Because of this it was difficult to link a specific intervention, or component of an intervention package, with a specific outcome (Wong et al. 2010). This inevitably leads to more hypothesising about causal links with outcomes than would normally be desirable.

5.6 Previous work on cultural competent training interventions

To establish the practicality of a review, an exploratory search was undertaken for systematic reviews. The existence of systematic reviews would indicate if suitable trials existed. Medline and the Cochrane library were searched using appropriate forms of the search terms below. Medline is one of the largest and most comprehensive databases of medically related articles online (PubMed 2011a). The Cochrane Foundation commissions, or adopts, systematic reviews on health issues, and is highly regarded for the application of rigorous review design and evaluation standards (Naylor 1995).

This was a scoping exercise to assess the size and quality of the existing body of literature, not to retrieve articles for the review proper (Hagell & Bourke Dowling 2012). The outline search terms were (* = wild card): Cultural competence OR cultural sensitivity OR cultural congruence AND Systematic review OR Meta analysis AND Training OR Education* AND Health* AND [Publication Year] 1995 to 2008.

This would establish if there were existing recent systematic reviews reporting on cultural competence training interventions. The search was restricted to articles after 1995 as policy documents reviewed in Chapter 2 indicate that it was a time when the focus on problems of equity in health care provision was increasing (Balarajan 1995).

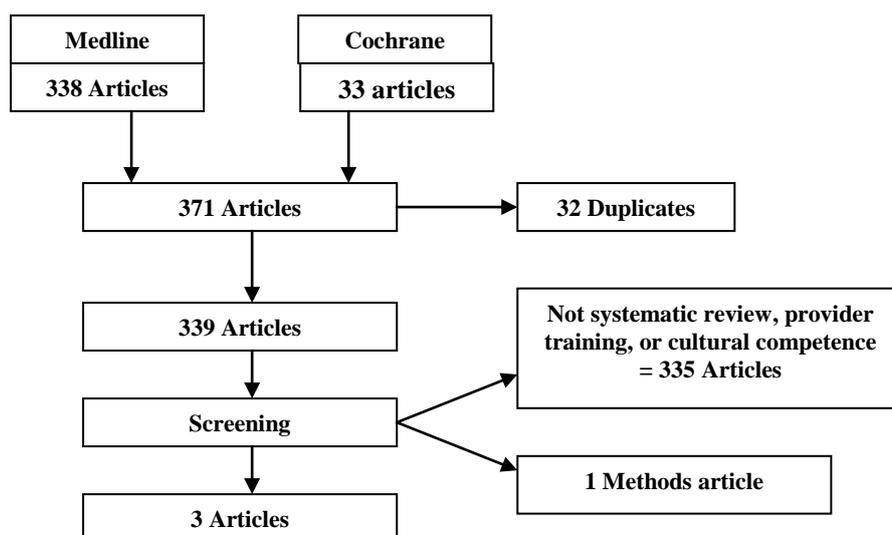


Figure 5.6 Screening for systematic reviews of cultural competence

The search of the Medline database returned 338 articles, and the search of the Cochrane database returned five Cochrane reviews, and 28 ‘other’ reviews (see Figure 5.6). Cochrane reviews have been commissioned or adopted by the Cochrane organisation if they meet their strict criteria of quality and robustness, ‘other’ reviews do not meet their criteria but are included in the library for completeness. None of the Cochrane commissioned or adopted reviews were concerned with cultural competence training interventions. After screening the articles using a set of pre-designed criteria, three articles were retained. The criteria were: the article must describe a review of primary research studies, the primary research must include a culturally competent training intervention with health care providers, the review itself must not have any fatal flaws (Table 4.2).

The reviews will be considered in chronological order. The first review was looking for evidence for the effectiveness of culturally and linguistically appropriate methods of training (CLAS) (Anderson et al. 2003). This review considered studies up to 2001 and is a fair example of a review using strict systematic review criteria. The review looked for cause and effect, and only included randomised controlled trials (RCTs) that met strict criteria (see Zaza et al. 2000).

The review considered three aspects of the CLAS initiative but only the initiative on training staff to be culturally competent is relevant to this thesis. One study was found that met the inclusion criteria (Wade & Bernstein 1991), but as the benchmark of 'sufficient evidence' for this review was set at two appropriate RCTs, the review reported that there was insufficient evidence to support the efficacy of cultural competence training interventions for service providers (Anderson et al. 2003). As discussed above this is a problematic position for complex interventions and shows the inadequacies of the rigid systematic review process. A benchmark of two or more positive studies is understandable, but a realist approach would be to use any reasonable evidence that is available and seek out confirmation from alternative sources rather than disregarding evidence because of a rigorous screening approach (Pawson & Tilly 1997).

The second article described a narrative review, which considered studies up to 2003 (Beach et al. 2005). This study was also looking for cause and effect but took a less rigorous approach to screening the articles. A range of designs were included, and this resulted in 34 studies. The review did include controlled trials but most of the

studies used a weaker design, for example, assessing participants before and after a training intervention, with no control group. Two of the studies reported positive service-user effects, and the remainder reported an overall improvement in service-users' self-assessment of their perceived level of cultural competence (Beach et al. 2005).

The final article considered studies up to 2006 and searched for controlled trials using an approach of similar rigour to the first review, but without the benchmark criterion of good evidence (Chipps et al. 2008). The aim of the review was to estimate the effectiveness of training service providers in cultural competence, by assessing service-user outcomes and experiences. Six studies were evaluated, and concluded there was a lack of consistent and confirmatory evidence that cultural competence training had an impact on service-user outcomes.

The three reviews had one trial in common (Wade & Bernstein 1991). In the Chipps et al. (2008) review one new trial was found (Thom et al. 2006). Overall, the reviews varied in methodological quality and range of inclusion and assessment criteria and were equivocal about recommendations for practice. This reflects the discussion above about the suitability and the utility of using systematic or narrative style reviews with complex interventions. This indicated that there is sufficient material to warrant using a realist review premised on source material from controlled trials of cultural competence training for service providers. In addition to assessing the training effect on service providers, some had also assessed the effect on service-users, and some described theoretical frameworks that structured interventions. The

next step was to carry out the systematic search for source material for the realist review.

5.6.1 Literature Search

The scoping exercise indicated that there were two RCTs and a number of controlled quasi-experimental trials that investigated cultural competence interventions.

Therefore sufficient material was available to warrant a systematic search for articles which would then be reviewed using realist principles. This approach has a precedent in that studies identified in a systematic review, for another purpose, were used in a realist review and evaluation to try to understand the efficacy of a school feeding programme (Greenhalgh et al. 2007).

A search strategy was designed for Medline and this was adapted for all other databases (see Appendix 9). The strategy was designed to retrieve articles on cultural competence (including all variants) AND education (including all variants) AND trial designs (including all variants). The databases searched were: Medline, CINAHL, AMED, Embase, British Nursing Index, Psycinfo, Cochrane, IBSS, Health Management Consortium, and Theses Index; some of these databases contain multiple databases that were searched in parallel. The number of articles from each database is listed in Table 5.4, as well as the number of duplicates and the net results.

Using the screening criteria in Appendix 10, the author and a second researcher independently screened the articles using titles and abstracts. The articles were screened in batches of 1000. After each batch, a meeting was arranged to compare the screening results. Any lack of agreement was discussed and resolved. Initial reliability assessments achieved an average percentage agreement of 93%; the 7%

disagreement was resolved in the meetings. Articles deemed relevant were allocated to one of three categories, Controlled Trial, Theory, or ‘Other designs’.

Database	Retrieved	Duplicates	Net
Medline	10540	444	10096
Cinahl	1370	235	1135
AMED	11	1	10
Embase	1350	301	1049
BriNusIndex	7	0	7
Psychinfo	519	12	507
Cochrane	5	0	5
IBSS	2096	105	1991
Health Management. Info consortium	50	7	43
Theses Index	1		1
Totals	15949	1105	14844

Table 5.4 Articles retrieved from literature search

The reference sections of the controlled trials articles were searched for further trials, other designs, or theory papers. From the initial 15949 articles, 1105 were duplicates, leaving 14844 articles. After screening, there were 32 controlled trials, 27 Theory papers, and 230 ‘Other ‘designs. Searching the reference sections, and other strategies, such as contacting salient authors and target searching salient journals, resulted in a further five controlled trials, making 37 in total. A final screening of the 37 articles resulted in a number being removed for not complying fully with the screening criteria, or because of design flaws. Two articles assessed existing levels of cultural competence but not linked to an intervention (Magee et al. 2004; Schim et al.

2005), one was a culturally competent intervention and not training (Miranda et al. 2003), two had inappropriate designs (Broder & Janal 2006; Pruegger & Rogers 1994). Finally three were unpublished PhD theses that were either unobtainable at the time or were an inappropriate design (Barise 1998; Cameron 2000; Law 1998). This resulted in 29 trials for review, and the number of theory/other designs was unchanged.

5.7 Data extraction

For clarification purposes this may be an appropriate point to define terms used in this thesis. A theory is a proposition that has yet to be developed into a law, and has been described as having a number of levels (Dickoff et al. 1970a). Models and frameworks are also theoretical but they are at an early propositional stage and usually at the lowest level of development (Dickoff et al. 1970a; Dickoff et al. 1970b). The terms are used interchangeably and sometimes both terms are used to describe the same proposition (see for example Balcazar et al. 2009). In this section the articles reviewed use different descriptors, theories, theoretical models, conceptual frameworks etc. For this thesis the term framework will be used to represent the propositional level of work. A framework can be considered as a collection of concepts or variables that interrelate, for a particular application that seeks to predict or explain. A model can be developed from a framework to be used in an application or intervention.

For the sake of simplicity the term cultural competence will be used to include concepts such as transcultural, multicultural intercultural and cultural safety etc. Though these terms may have specific meanings in specific instances, for this aspect

of the thesis they are taken to relate to satisfactory interactions with people from other cultures.

5.7.1 Conceptual frameworks of cultural competence

Theories review

One of the aims of this review was to retrieve theories of cultural competence. A test of the search criteria indicated that articles describing theories or frameworks were being retrieved. When terms relating to theories were included in the search terms an extremely large number of references were returned. As the aim was to find interventions underpinned by theory, the decision was made to omit the theory terms and examine trials and other retrieved articles for references to cultural competence theories. This approach would have the advantage of retrieving applied theories or ‘theories in action’.

Recent syntheses

The screening of articles for the theories group (see appendix 10) produced one systematic review (Balcazar et al. 2009) and one narrative review (Jirwe et al. 2006). There were other articles in the theory group that included theories, models or frameworks but these were already included in the two reviews mentioned above. In addition both of the two recent reviews had used their findings to synthesise conceptual frameworks of cultural competence (Balcazar et al. 2009; Jirwe et al. 2006). The rationale for the first synthesis of separate frameworks (Jirwe et al. 2006) was to explore the common and superordinate themes that would be component concepts of a synthesised model. The review concluded that the resultant framework could be used in training and research.

The second synthesis also explored the components and this was the result of a narrative review (Balcazar et al. 2009). This framework was also proposed for use in research and training. The synthesised framework was used in a training intervention with physical therapists and the outcome assessment was used in a factor analysis to test the original synthesised framework (Balcazar et al. 2010; Balcazar et al. 2009; Suarez-Balcazar et al. 2009).

This thesis proposes to develop a meta synthesis of the two syntheses discussed above. For a preliminary synthesis of these frameworks, a mapping exercise was attempted to explore what components were common between the frameworks, for completeness relevant standards from CLAS (OMH 2011) have been included to see what they can add to the new synthesis (see Appendix 11). The two synthesised frameworks were based on different sets of articles retrieved with similar sets of criteria. It would seem appropriate to explore the articles upon which these frameworks were developed. Firstly to examine the feasibility of the proposal new frameworks by Balcazar (2009) and Jirwe et al.(2006), and secondly to support the proposal of a meta synthesis for this thesis; this is undertaken in Chapter 6.

Evaluation and synthesis of source material

The references from each of the syntheses (Balcazar 2009; Jirwe et al. (2006), were used to retrieve the constituent articles and books. The 24 items were read and re-read and data were extracted using the headings from Table 5.5. The data was entered into a spread-sheet where data from each article were checked and refined. By using a data management computer application, Atlas-ti (Muhr 2010), concept maps were developed and will be discussed in Chapter 6.

Data extraction concepts for syntheses source material (Appendix 13)	
Synthesis	Indicates what framework(s) the article was included in
Country	Country of origin of the article
Author / date	Author(s) and publication date
Discipline	If the frameworks was targeted to a particular discipline, Nurs(e), Coun(selor), Diet(ician), Soc(ial) W(or)k, and VR is vocational rehabilitation.
Rationale	Why the framework was developed
Context	Was the context of the minority group or individual considered (values based)
Journal / book	Type of publication JA = peer reviewed article, BK= book and some were both.
Component	The conceptual elements of the framework
Explanations	An interpretation or explanation of the component
Measure	Has an assessment tool been developed specifically for the framework
Comments	Overall comments on the framework
Evidence	Has any evidence to support the utility or efficacy of the model been cited

Table 5.5 Explanation of data integration table in Appendix 13

5.7.2 Realist principles and data extraction

Justification: realist principles

It is important to remember the differences between the types of review (as set out in Figure 5.5). Traditional reviews have sought to synthesise the findings of articles and present a coherent answer. In the case of cultural competence training interventions using traditional review methods have failed to provide conclusive answers. From the scoping review in section 5.6.1, three traditional reviews into cultural competence training reported mixed findings (Anderson et al. 2003; Beach et al. 2005; Lie et al. 2010). A fourth traditional cultural competence training review was retrieved in the systematic search for this Chapter (Lie et al. 2010).

Anderson et al. (2003) carried out a systematic review with strict study quality inclusion and evidence claims criteria. This review reported that there was no good evidence to support the effectiveness of cultural competence education programmes for service providers. A more inclusive set of criteria were used by Beach (2005), who included less robust research designs which ranged from single group post-test only studies to RCTs. Beach et al. (2005) concluded that there was good evidence for the effectiveness of cultural competence education programmes for provider education. However, the majority of studies were too poor quality to meaningfully support the conclusions (Horvat et al. 2011) and the conclusions were limited.

A third review of cultural competence training programmes considered the evidence from a South African perspective and concluded that the evidence was inconclusive and not applicable in countries like South Africa (Chipps et al. 2008). Chipps et al. (2010) only reported on five studies as they had excluded the remainder on methodological issues.

The final review of cultural competence training interventions was the most recent and also the only review that focused on the impact of cultural competence training on service-user outcomes (Lie et al. 2010). This resulted in eight studies, four of which were single group studies. The review concluded that the quality of the studies were such that they could make no clear recommendation for the impact of cultural competence training (Lie 2010). However, this review also had methodological issues, mainly in the completeness of its descriptions and evaluations (Horvat et al. 2011).

All the reviews had similar recommendations in their conclusions. These included that: this was an important area of research; the existing evidence was of poor to moderate quality; the existing studies are indicative of a trend indicating the efficacy of cultural competence training; and the need for more robust and high quality studies. The utility of undertaking a further traditional systematic review is doubtful, as without new high quality studies the result would be similar to that described above (Horvat et al. 2011). Until such studies are undertaken what is needed is a pragmatic review of the existing material using realist principles, that can make recommendations for what is likely to work for whom and in what circumstances (Pawson et al. 2005).

Procedures

The systematic search (section 5.6.1) retrieved every cultural competence education intervention trial included in the four reviews described above, and others that were not. All the studies were controlled trials, this avoids some of the criticisms of previous reviews where single group designs were included (Horvat et al. 2011). Realist reviews would not normally exclude studies because of the design, but see designs such as controlled trials as attempting to negate the contextual element of an intervention, which is important in realist work (Pawson et al. 2005). However, context can never successfully be negated in complex intervention trials such as cultural competence training (Hawe et al. 2004; Medical Research Council 2000). As such it is calculated that contextual factors can still be considered. This strategy has been previously used successfully in reviewing the efficacy of school feeding programmes (Greenhalgh et al. 2007). In this study a systematic review found that school feeding programmes operated across five continents and over eight decades

and had significant positive effects on growth and cognitive performance (Greenhalgh et al. 2007).

The trials retrieved in the systematic search for cultural competence training interventions in section 5.6.1 were used as source data for a review using realist principles. This was an attempt to propose what would work and in what circumstances. This approach will be used in the following Chapter to review and synthesise the trials retrieved in a systematic review described above. The search and screening for the systematic review for this part of the thesis retrieved 29 controlled trials. All these trials trained service providers in cultural competence, but they differed in outcome assessments. Eight of the trials assessed service providers with service-user outcomes, and twenty-one trials assessed service providers on self-report outcomes. A summary of the details of these trials is in Appendix 14; the trials have been grouped by the outcome assessments they use. For service provider outcomes the sub-groups are self-efficacy training (Appendix 14.1), cultural knowledge, skills and awareness education, or part of those three (Appendix 14.2). For service-user outcomes they are sub grouped as communication skills (Appendix 14.3), clinical outcomes (Appendix 14.4), or satisfaction ratings (Appendix 14.5). The groups the studies were allocated to are shown in Figure 5.7.

To extract the data in a systematic valid and reliable way, a published set of forms were used. These are from a guide to systematic reviews for the social sciences (Appendix 12) (Rutter et al. 2010). These forms were modified and used to develop a relational database. The database included the fields from the forms, a list of all the

framework components extracted from the synthesised set of theories and a table for recording intervention components (teaching and learning strategies).

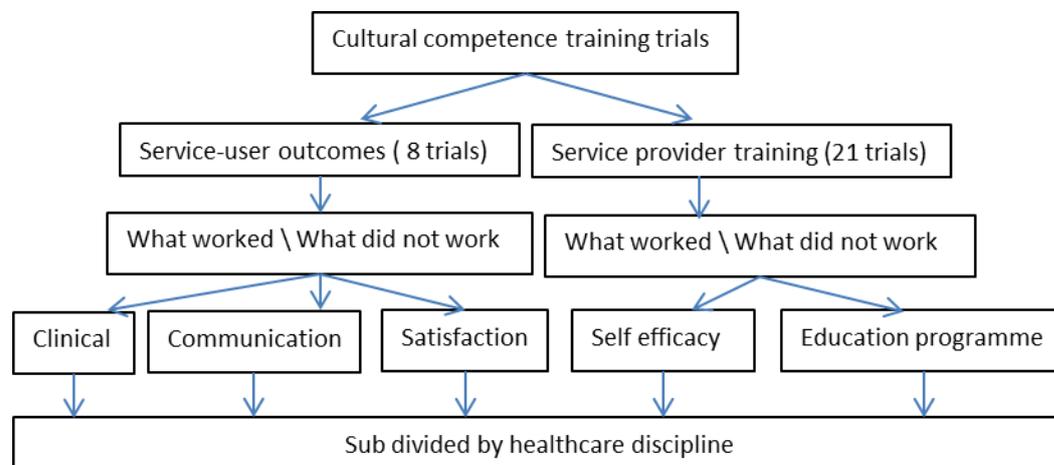


Figure 5.7 Cultural competence training interventions by outcomes

As a reliability exercise, an independent researcher used the data extraction forms (Appendix 12) with lists of teaching interventions, and framework components, to extract data from a batch sample of ten papers chosen at random. The batch sample data was compared with the controlled trial database entries. There were some inconsistencies in the uses of theory components, which were resolved and there was a good level of agreement between the two researchers.

5.8 Conclusion

The first chapter of Part 2 of this thesis has evaluated and explored appropriate methods of reviewing literature on cultural competence. In Part 1, it was established that the quality of health care provision for minority groups may not be equivalent to the general population. When stroke care for local South Asian minority groups was explored it was found that one of the two salient issues was related to the cultural competence of health care providers. It was also established that a method of appraising the quality of health care was to consider health care structures, processes

and outcomes (Campbell et al. 2000b; Donabedian 2005). It was proposed that structural failures, including poor service provider cultural competence, were a major part of the problem. It was deemed appropriate to investigate the effectiveness of training service providers in cultural competence and how this can be incorporated into the structures of service provision. This chapter has discussed a body of research that investigated conceptual frameworks underpinning cultural competence training as well as both the process and the outcome of cultural competence training interventions.

This Chapter has addressed the part of the first objective for Part 2, (i): Review the literature of cultural competence theories and conceptual models. Research Question 2 requires the exploration of what would be the (stroke) service requirements to meet the needs and overcome the issues described in Part 1. To do this, the next Chapter will describe the proposition for a new meta-synthesis of cultural competence frameworks, and evaluate the evidence that can be used to support this framework. A stakeholder review was undertaken and further evidence was sought as a consequence of this. From these findings this thesis will propose a pragmatic, theory based model of cultural competence training that is based on the best available evidence.

Part 2

Chapter 6

Cultural competence: Conceptual frameworks and evidence

6.1 Introduction

Part 1 addressed the first research question for this thesis by exploring the barriers to equitable health (stroke) care for South Asian minority groups. In Part 1, local South Asian minority groups were asked about their stroke care experiences and perceptions. The findings were that those who had not experienced a stroke had positive perceptions of the care they would receive, whereas, those who had experienced a stroke reported negative experiences. Overall two super-ordinate themes emerged from the analyses; low levels of stroke awareness for a population that was overexposed to stroke risk factors and underexposed to stroke information. This information issue is the subject of a parallel investigation.

The second super-ordinate theme was low levels of service provider cultural competence. The approach of Donabedian to health care quality assessment, considering structures, processes and outcomes of care, was chosen as the overarching framework with which to review this issue (Donabedian 2005). Considering the empirical evidence and the literature, a tentative hypothesis was proposed for this thesis. This stated that (stroke) health care for South Asian minority groups was sub optimal, and to improve this, health care structures and processes would need to develop to address low levels of service provider cultural competence.

Part 2 of this thesis started to investigate ways of addressing the deficiency in cultural competence. In the previous Chapter the first step was to undertake a systematic search of the literature for conceptual frameworks and models of cultural competence, and controlled trials of cultural competence training interventions. Data was extracted from these sets of literature and these are reviewed using realist principles in this Chapter. This led to a proposition of a new conceptual framework of cultural competence, supported by independent evidence and reviewed by stakeholders. The stakeholder review led to a subsequent review of problem focussed cultural competence interventions to expand the evidence base. These processes will, in part, address the second research question of this thesis: what needs to be done to ensure an equitable stroke service for people of South Asian heritage. This was achieved by addressing three of the objectives for Part 2: (ii) evaluate the evidence for these theories, models and frameworks, (iii) develop a synthesis of a new conceptual model supported with evidence, (iv) propose a way forward in training health care staff in true cultural competence.

6.2 Theories models and frameworks

The systematic literature search described in Chapter 5 retrieved 27 articles that proposed theoretical (also described as conceptual) frameworks or models of cultural competence (see section 5.6.1). When these articles were screened, eight were removed as they duplicated frameworks described in other articles; two papers were systematic reviews of existing cultural competence frameworks, and 17 described cultural competence models or frameworks. The two systematic reviews both proposed new conceptual frameworks, synthesised from frameworks that they had reviewed (Balcazar et al. 2009; Jirwe et al. 2006). Between these two syntheses they

included the 17 frameworks or models that the literature search above had retrieved, plus seven additional frameworks. It seemed appropriate therefore to examine the articles upon which the two syntheses were established as this was the most comprehensive data set of these articles.

The first synthesis article was a literature review that provided a narrative synthesis of nine publications describing cultural competence conceptual frameworks (Jirwe et al. 2006). The second paper was a systematic review that included 18 conceptual frameworks or models (Balcazar et al. 2009). From the two reviews, there were 24 unique cultural competence frameworks, models or theories. The two reviews had three models in common (Campinha-Bacote 1999; Leininger 2002; Papadopoulos et al. 1998). The authors used different screening criteria, which may explain the difference in retrieved papers. Jirwe et al. (2006) only included papers that had: their own unique definition of cultural competence; were specific to nursing; and had cultural competence and theoretical frameworks in their titles. In contrast, Balcazar (2009) only included papers that were: in English; published from 1991 – 2006; and included a conceptual framework of cultural competence. Both authors used appropriate search and analysis methods, Jirwe (2006) searched health related databases, and Balcazar (2009) searched some health, but also psychology and education databases.

Jirwe (2006) and Balcazar (2009) independently carried out a synthesis of the frameworks that resulted in two separate conceptual frameworks with considerable overlap of components, (see Figure 6.1 and Appendix 11). Both authors had developed their frameworks in similar ways, by synthesising the components using a

form of thematic analysis. The new frameworks that were proposed included cultural awareness, knowledge and skills as components of cultural competence, but they presented these in different ways (see Figure 6.1 and Appendix 11). The expressed purpose of Jirwe's (2006) framework was to explore the components that are required for a valid conceptual framework of cultural competence. This synthesis was not proposed as a developmental model, but it was proposed that it would be useful for training, practice and research.

The original framework proposed by Balcazar (2009) was a four-component framework with awareness, knowledge, skills, and practice/application as separate components (see Figure 6.1). In an evaluation study, the original framework was used to generate items for a tool that could be used to assess self-reported cultural competence. The Cultural Competence Assessment Instrument-University of Illinois Chicago (CCAI-UIC) was a 49 item scale which was administered to a sample of occupational therapists (N=477) (Suarez-Balcazar et al. 2009), and the scores were subjected to a factor analysis. Examining the data indicated that this procedure was appropriately undertaken, and that there was an acceptable item to sample size ratio (Reise et al. 2000).

As a result of the factor analysis, Balcazar (2009) combined 'awareness' and 'knowledge' into one component, as they both loaded onto one factor. An examination of the items used in the CCAI-UIC scale for knowledge and awareness indicated that they had similar characteristics, which explains the factor loading.

Figure 6.1, shows the second framework after the reconfiguration.

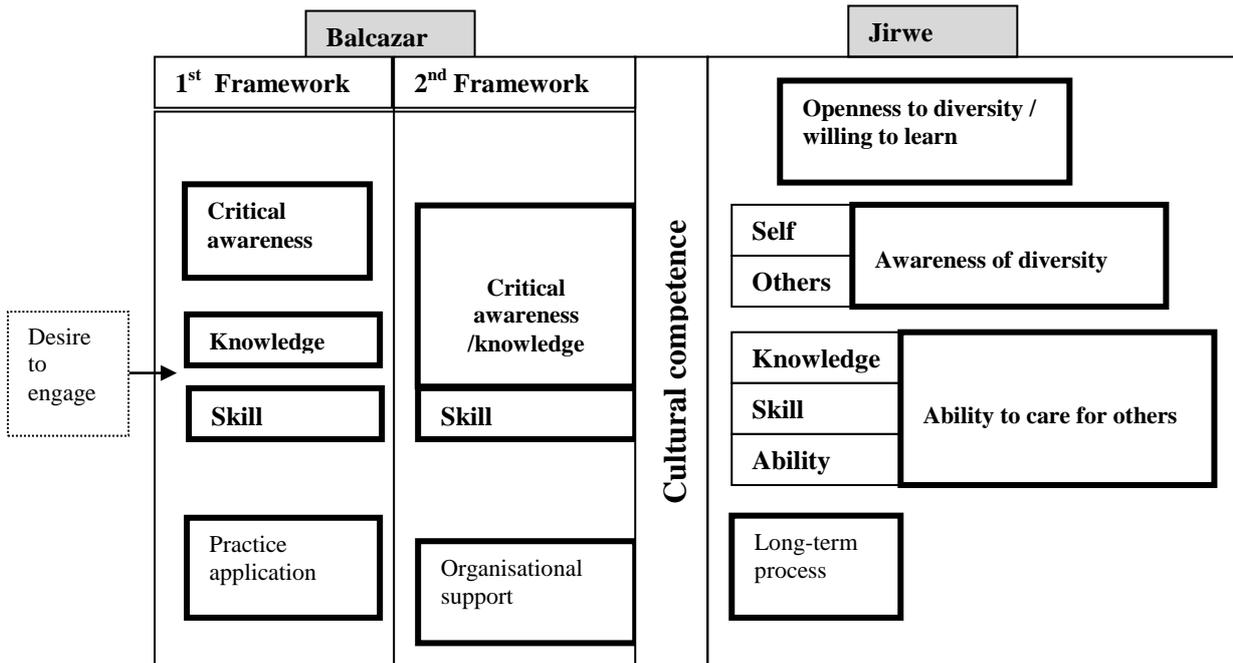


Figure 6.1 Balcazar (2009) frameworks compared to Jirwe (2006) framework

In contrast, Jirwe (2006) retained awareness concepts as part of the component of ‘awareness of diversity’, which included two further sub-components, ‘awareness of self’, and ‘awareness of the other’. Knowledge and skills were retained as sub-components together with ‘ability to address cultural needs’ in an ‘ability to care for the others’ main component. In Figure 6.1, the main components of the two frameworks are in boxes with bold frames, and Appendix 11 illustrates all the concepts and how they are grouped, as well as a comparison with CLAS (OMH 2011).

The main components that differed between the two frameworks included openness /willingness to learn, in which Jirwe (2006) included six sub-components; willingness, openness, sensitivity, a drive for equality and reducing ethnocentrism, or when individual does not appreciate that there are other world views than their own.

Balcazar (2009) was aware of these components as they were component parts of some of his constituent frameworks, such as Transcultural Nursing (Leininger 2002), but decided to remove them from his framework. Balcazar (2009) claimed these were all constituents of a component called 'Desire to engage' and proposed that this is a pre-requisite of undertaking a cultural competence training programme, but not a constituent part. This omission reflects an assumption that attending a course indicates a willingness to engage. It has been demonstrated that individuals can successfully complete such a cultural sensitivity course while holding views that were not congruent with the course philosophy, as well as questioning the utility of the course (Beagan 2003).

Both Jirwe (2006) and Balcazar (2009) initially included components that considered the extended development of newly acquired skills, beyond a cultural competence training course. Both authors took a different approach to this developmental concept. Balcazar (2009) proposed in his initial framework that new skills acquired on training programmes should be developed in practice and included a component 'practice /application'. As a result of the earlier factor analysis this component was removed; it was implied that the employing organisation would provide opportunities for this (Balcazar et al. 2009) (see Figure 6.1).

Jirwe (2006) retained the developmental component of her framework and called it 'cultural competence as a long-term process'. This component contained two sub-components that had been adopted from other frameworks. The first sub-component, 'a step by step process', was from a cultural safety programme (Wepa 2003). Cultural safety is a politicised programme that aims to 'protect' the cultures of indigenous

people from the damage that may be caused by non-indigenous dominant cultures. Developing cultural competencies was described as a step towards that aim. The other sub-component is that cultural competence is an 'on-going process'. This is adopted from a framework that advocates that skill in cultural competence develops as new challenges are dealt with in practice (Giger & Davidhizar 2007).

Both authors did not provide much detail on the components concerning development of skills. Balcazar (2009) seemed to downgrade the significance by removing it from the framework, implying it was part of an organisational brief. Jirwe (2006) retained this in the framework, but on-going development was given limited consideration, which could be related to the rationale for the framework, i.e. identifying the components (Jirwe et al. 2006).

A new component was added to the redeveloped framework of Balcazar (2009). The factor analysis described above indicated that organisational support was a significant component of his cultural competence conceptual framework. Organisational support is seen as the contribution an organisation can make to the development of cultural competence for an individual. Neither of the two initial frameworks by Balcazar (2009) and Jirwe (2006) included this component. This is understandable as they were both derived from syntheses of frameworks that focused on care. However, Balcazar (2009) included organisational support items into the CCAI-UIC scale because of the emphasis placed on these by the CLAS standards (OMH 2011). This is the first occurrence of a 'structures of care' component being included in either of these syntheses, despite some constituent frameworks including them (Leininger 2002; Spector 2004). What Balcazar (2009) did not discuss is what the structural

issues should be. The framework focus was more concerned with the processes and outcomes of care, rather than structural elements and ignoring the potential effects of structure (Campbell et al. 2000b).

The two syntheses have included all the frameworks, models and theories of cultural competence retrieved in the literature search for this chapter. The methods used by both authors are appropriate; but a review of the original constituent articles was still required. Firstly, to explore the validity of the claims of Jirwe et al. (2006) and Balcazar et al. (2009), and secondly to investigate the possibility and practicality of a meta-synthesis of these two earlier syntheses.

6.3 Reviewing the original articles

The details extracted from the 24 articles can be seen in Appendix 13. This section will summarise the findings and evaluate validity of the components of the two earlier syntheses and then propose how the meta-synthesis for this thesis is supported.

Twenty one of the articles were frameworks from North America, mainly USA with one from Canada (Moffat & Tung 2004), the remainder were from the UK (Glockshuber 2005; Papadopoulos et al. 1998) and New Zealand (Wepa 2003). As described earlier the USA has been investigating cultural competence longer than the UK, and their government has taken action at a structural level in an effort to ensure to that it is implemented (US Office of Minority Health 2001). In the UK, at the structural level of Government there are calls for service providers to address the needs of people from minority groups (NICE 2008). Despite these calls, improvements at the structural level of service providers and at the level of process

and outcomes of care for minority groups are still limited (Committee of Public Accounts (CPA) 2010).

One of the original framework dates back to 1981 (Sue 1981) but the remainder have been published between the 1990's and 2006, with the majority between 2000 and 2006. This could be because of the increase in interest in the topic, or the political climate in UK and the USA. Both Jirwe (2006) and Balcazar (2009) completed their literature searches before 2007. A literature search was carried out, using similar criteria as those used by Jirwe (2006), to find any reviews or proposed models published after 2006. Four publications describing cultural competence frameworks or models were retrieved. Two were extrapolations from Leininger's theory (Lancellotti 2008; Schim et al. 2007), and one was a synthesis of four existing theories that were already included in the work of Jirwe (2006) and Balcazar (2009), (Wikberg & Eriksson 2008). The final framework published after 2006 was based on a factor analysis of a cultural competence questionnaire; this questionnaire was based on an assessment tool devised by an 'expert panel' used to assess students who had completed a cultural competence module (Tulman & Watts 2008). The factor analysis findings indicated that the final factors were closely aligned with a model that is already included in the Balcazar (2009) framework (see Campina-Bacote (1999)³. The frameworks and models retrieved since 2006 are based on earlier works that are already included in the frameworks synthesized by Jirwe (2006) and Balcazar (2009). After a review of each of these papers, it was concluded that nothing new had been proposed and thus they were omitted from the component mapping exercise (Hoffman et al. 2002) (Figures 6.2 – 6.7).

³ The work of Campina-Bacote (1999) was also referenced in the introduction to this paper.

All the articles from the Jirwe (2006) synthesis were from books on nursing with people from different cultures. The majority were related to practice, with some, limited, reference to theory. The articles from Balcazar (2009) were mostly from nursing but four were from counselling (Glockshuber 2005; Jezewski & Sotnik 2001; Steenbarger 1993; Sue 1981), two from social work (McPhatter 1997; Poole 1998) and one from dietetics (Harris-Davis & Haughton 2000). The style of publication may have driven the choice of analysis method. The articles used by Jirwe (2006) were all nursing education books that focussed on providing information that could change behaviour in intercultural interactions; as such these focused more on practice than theory. Due to this there were a number of articles that provided no framework and thus required the use of a thematic approach to generate themes from the qualitative data. These themes provided Jirwe (2006) with the core components for the framework as well as a collection of sub-themes that could be used for training or research. However, Balcazar (2009) purposively screened for articles that provided a framework, and his method was more related to a concept mapping approach used to collate the components into a new synthesised framework for this thesis (Hoffman et al. 2002).

All the frameworks included cognitive components, knowledge and awareness, and behavioural components, skills. Cognitive and behavioural components relate to individuals and are process factors. Only six of the frameworks included structural-contextual elements, such as organisational considerations or policy initiatives (Kim-Godwin et al. 2001; Leininger 1993; Poole 1998; Spector 2004; Wells 2000), and only one described the importance of workplace leadership but did not include this in

the model (Willis 1999). Leadership requires a structural approach if it is to be effective, it also implies a developmental approach (Damschroder et al. 2009; Rycroft-Malone et al. 2002b). Developmental components are only evident in five further frameworks and tend to be described as an on-going process or step by step process (Purnell & Paulanka 2003; Salimbene 1999; Sue 1981; Wepa 2003). The importance of a developmental approach will be discussed in the following chapter, but it is not clear why it has not been considered in the remaining frameworks. It could be that some of these frameworks were designed specifically to train individuals and development is seen as the remit of others.

Although the focus of all the frameworks is to change the behaviour of professional practitioners in their interactions with other cultures, only four provided specific tools to evaluate their models (Doorenbos & Schim 2004; Harris-Davis & Haughton 2000; Kim-Godwin et al. 2001). Three of these were developed and then tested on professionals, but only assessed their pre-existing levels of cultural competence, rather than any training informed by the framework (Doorenbos & Schim 2004; Glockshuber 2005; Harris-Davis & Haughton 2000). This method does not assess the impact of training with the framework. The fourth developed a measure and tested this after a training intervention with nursing students; this article also described structure, process and outcome in culture competence training (Kim-Godwin et al. 2001). This framework proposed that health care systems moderated the effects of cultural competence training on outcomes, such as structure, process, and outcome assessments of quality were described in Figure 2.4, but this was not further developed. Though a limited number of articles describe assessment of practitioners

none of the articles describe the impact of cultural competence training intervention outcomes on service-users.

A number of frameworks describe an evidence base, including the most widely cited (Campinha-Bacote 1999; Giger & Davidhizar 2004; Leininger 1993; Purnell 2000), but fail to cite the evidence, and none cited independent evaluations. The independent evidence for the efficacy of cultural competence training interventions exists but is mixed. Three systematic reviews found contradictory evidence, one reported insufficient strong evidence (Anderson et al. 2003), a second reported inconclusive evidence (Chipps et al. 2008), and the third reported that training interventions improved practitioners cultural knowledge, skills and awareness and some impacted on service-user satisfaction (Beach et al. 2005). One of the barriers to such evidence is the lack of a standardised, reliable measure of cultural competence (Gozu et al. 2007).

Some frameworks included other components that were not evident in the majority of the frameworks; this could be because they were either assumed to exist, or were seen as part of another component. These are cultural desire (Campinha-Bacote 1999; Hart et al. 2003), cultural encounters (Campinha-Bacote 1999), and cultural safety (Wepa 2003). Cultural desire is a 'want to engage' attitude and could be assumed to exist in practitioners who deal with the culturally diverse (Campinha-Bacote 1999). Cultural encounters are the drive to actively engage with service-users from other cultures (Campinha-Bacote 1999; Suh 2004). It has been argued that these are pre-cursors to undergoing training or working in transcultural environments and are not elements of a cultural competence framework (Balcazar et al. 2010; Balcazar et al. 2009).

The final singular concept is cultural safety; this concept gained recognition in post-colonial countries with a dominant ex-colonial population but where the indigenous population still co-exist (Williams 1999). Essentially cultural safety is the process of respecting and including the health beliefs and practices of indigenous people into their health care as a method of safe practice and cultural preservation (Wepa 2003). As cultural safety is specific to indigenous people it will not be included in any further framework development for the UK, but consideration of health beliefs⁴ of other cultures will not be ignored.

What is now needed is to consider the reliability of the claims of the two earlier independent syntheses and undertake a meta-synthesis for the development of a new framework and subsequently find evidence to support the components.

6.4 Exploring syntheses and a new meta-synthesis: methods

To explore the original source materials for the proposed meta-syntheses, it was necessary to use methods similar to those used in the original work. For the articles in the Jirwe (2006) synthesis, sections of the books were identified that discussed the frameworks, models, or theories they proposed or used. These data were recorded in the spread-sheets shown in appendix 13. The articles in the Balcazar (2009) synthesis were retrieved and data were extracted and also recorded in the spread-sheet. In appendix 13 the articles are split into three sections, exclusive to Balcazar (2009) (Ref IDs 1 – 15), common to both syntheses (Ref IDs 16 – 18) and exclusive to Jirwe (2006) (Ref IDs 18 – 24).

The data from the spread-sheet were then imported into a qualitative data management application for analysis, Atlas-ti (Muhr 2010). The component and explanations were categorised or coded. The codes were the concepts from the framework of Jirwe (2006) and Balcazar (2009), however if other codes were identified these were included as well.

Concept maps were prepared using Atlas-ti (Muhr 2010) that collated the concepts from each source relating to a specific framework component (Hoffman et al. 2002). They were also sub-grouped within each concept map to indicate which synthesis they originated from (see Figures 6.2 – 6.7). For Balcazar (2009) the concepts are unshaded, for Jirwe (2006) they are shaded dark grey, those included in both are shaded light grey.

On these maps the different articles are indicated by the reference identification number (Ref ID) from the data integration spread-sheet (Appendix 13), main authors and publication date; attached to these are the explanations of the concepts. For example, figure 6.2 indicates all the concepts from the 24 articles that support the proposed core concept of Cultural Knowledge. A contributory component of this map is an article by Hart et al. (2003), this is Ref ID 4 and the data extracted from this article can be seen in appendix 13 by examining Ref ID 4. In addition it can be seen in the concept map that this article contributed to the synthesis of Balcazar (2009) alone, as it is un-shaded.

6.4.1 Propositions

Both Jirwe (2006) and Balcazar (2009) proposed core components of cultural competence as being Cultural Knowledge, Skills, and Awareness. The meta-synthesis of the data from the contributing articles of the earlier syntheses supports the inclusion of the core concepts. These will also be used as core concepts for the meta-synthesis as well as ancillary concepts that have lesser support. In the concept maps the term ‘host’ system is used, this refers to the main healthcare system available in a state, commonly used by ethnic minority or non-indigenous groups.

Cultural Knowledge (Figure 6.2)

All contributing articles from original sources (24 cases) included some form of knowledge acquisition of other cultures or of the existence of diversity, as essential to cultural competence. For example, Hart et al. (2003) ‘Seeking to establish a sound knowledge base about target minority groups will help to develop equality for other cultures’ (Ref ID 4), is a summary of cultural knowledge as proposed in that article and this can be contextualised by referring to Ref ID 4 in appendix 13.

Cultural Skills (Figure 6.3)

All contributing articles (24 cases) also indicated that the development of skills and abilities to work appropriately with other cultures was key to cultural competence. For Hart et al. (2003) this was summarised as ‘A critical approach to how disadvantage and inequality are constructed and the ability to make assessments and deliver culturally appropriate interventions in healthcare’ (Ref ID 4, see Appendix 13).

Cultural Awareness (Figure 6.4)

Similar to the above core concepts Cultural Awareness was also evident in all 24 cases and seen generally to be the base upon which cultural competence can be built.

From Doorenbos and Schim (2004) (Ref ID 1, see Appendix 13) cultural awareness was summarised as ‘The recognition that cultural diversity exists and is the basis for other components of culturally competent care’.

Other components of cultural competence were also suggested by the meta-synthesis for this thesis:

- Cultural competence is on-going (Figure 6.5)

From the 24 cases, 13 cases suggested that cultural competence should be seen as developmental rather than a discrete learning event. This was summarised in a contributing article by McPhatter (1997) as ‘Cumulative skill proficiency developed by working with families from other cultures in a sincere manner and equality based approach (Ref ID 7, see Appendix 13). It may not have been addressed directly in 11 cases because of the focus of some of these articles as they ranged from mid-range but expansive theories (e.g Lieninger 1993), to little more than propositions (e.g Poole 1998).

- Organisational or external factors (Figure 6.6)

Seven out of 24 cases described cultural competence as encompassing organisational or external factors. This is in accordance with the extension of the work of Donabedian (1966) by Campbell (2000b), where the structures of healthcare moderate the processes used in approaches such as cultural competence. For example, a summary from Spector (2004): ‘For culturally appropriate care there needs to be an understanding of the host healthcare system and its interactions with the culturally diverse. In addition an appreciation of local and global structures and constructs and the influence they can have on care’ (Ref ID 23, see Appendix 13).

- Cultural Desire, Cultural Encounters and Cultural Safety (Figure 6.7)

These three concepts have been included for completeness and between them comprise 6 cases; Cultural Safety is only discussed in one article (Wepa 2003) and will be discussed later. The other two concepts (Desire, 2 cases and Encounters, 3 cases) are seen differently by Balcazar (2009) and Jirwe (2006) and will form part of the discussion of the new cultural competence conceptual framework for his thesis.

This section has examined the propositions of the two earlier syntheses (Balcazar et al. 2009; Jirwe et al. 2006). For Jirwe (2006) all the components of the framework that were proposed can be accepted. Jirwe (2006) has produced a chart that presents all the different concepts that were collated into the components of the framework. This was Jirwe's (2006) aim and the concept map in the article provides a useful reference for teaching, research and training. For example, the map can be used to ensure the essential components of a programme are included and therefore inform the processes of care for cultural competence. Jirwe (2006) recognises the on-going nature of developing cultural competence but does not develop this further as a concept. This could be because Jirwe's (2006) aim was to identify the components that contribute to cultural competence, rather than how it is developed (Jirwe et al. 2006). This would also explain why structural or contextual components are not included in Jirwe (2006)'s framework, despite these being evident in the source material for the synthesis.

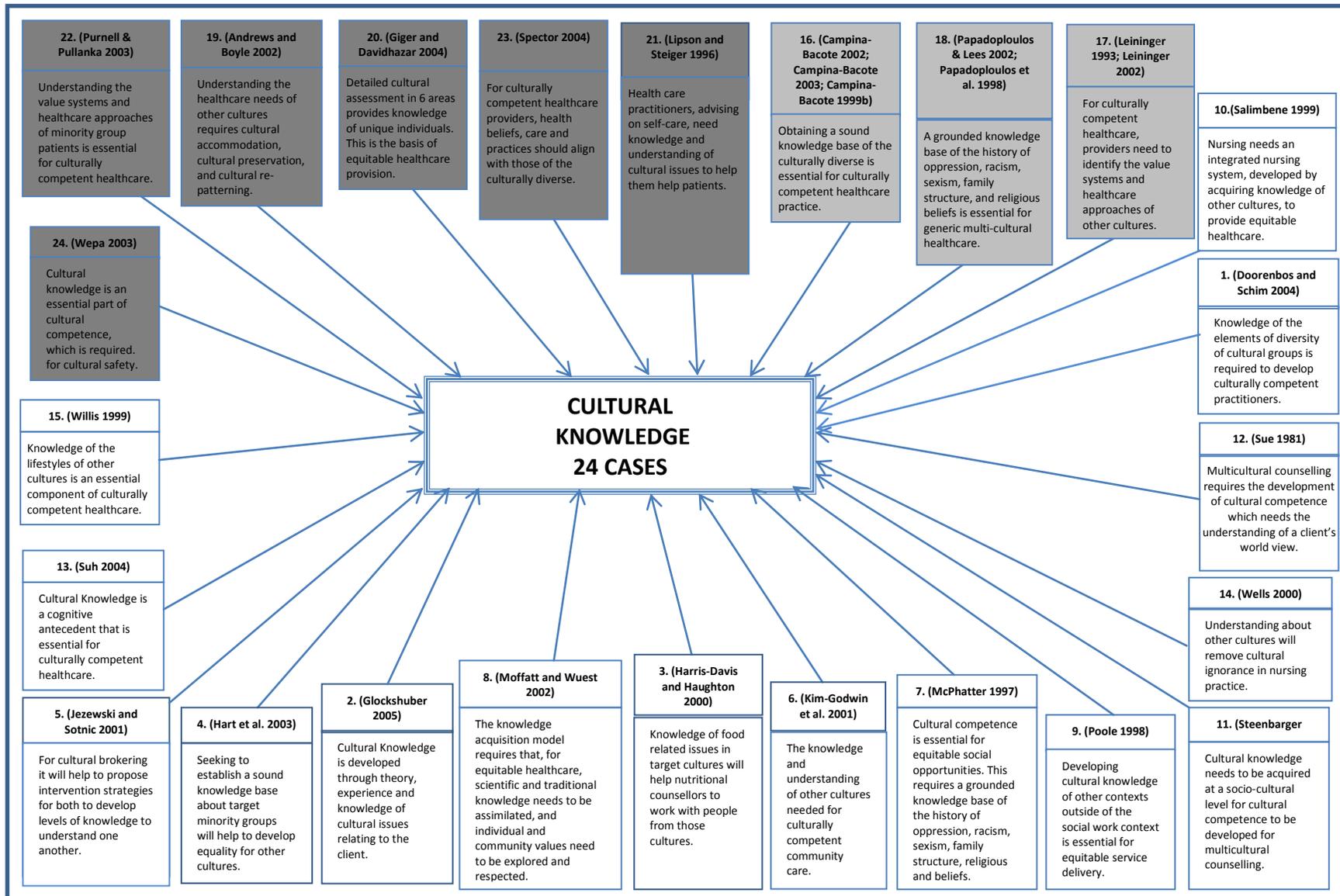


Figure 6.2 Cultural knowledge synthesis of original sources

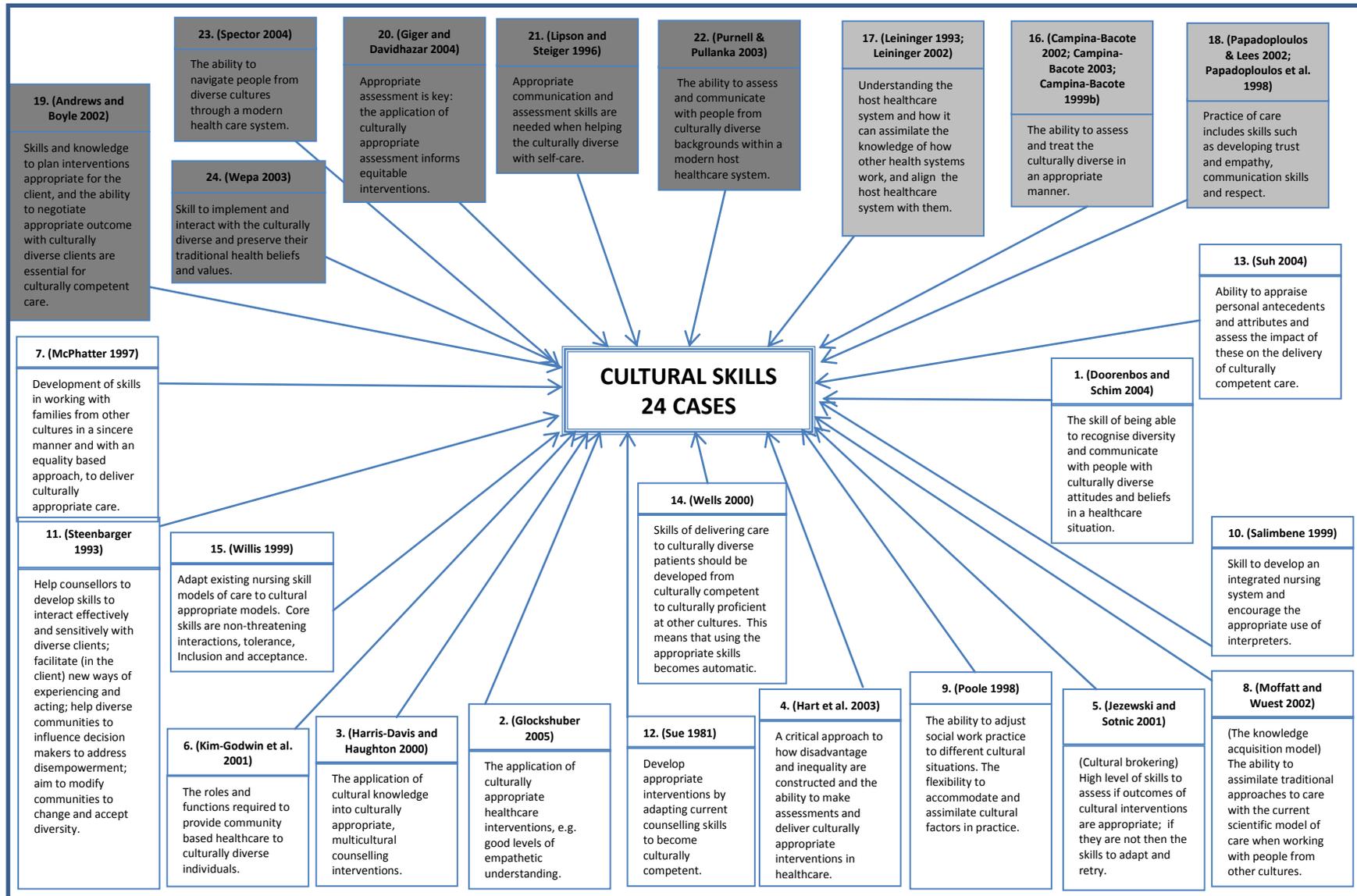


Figure 6.3 Cultural skills: synthesis of original sources

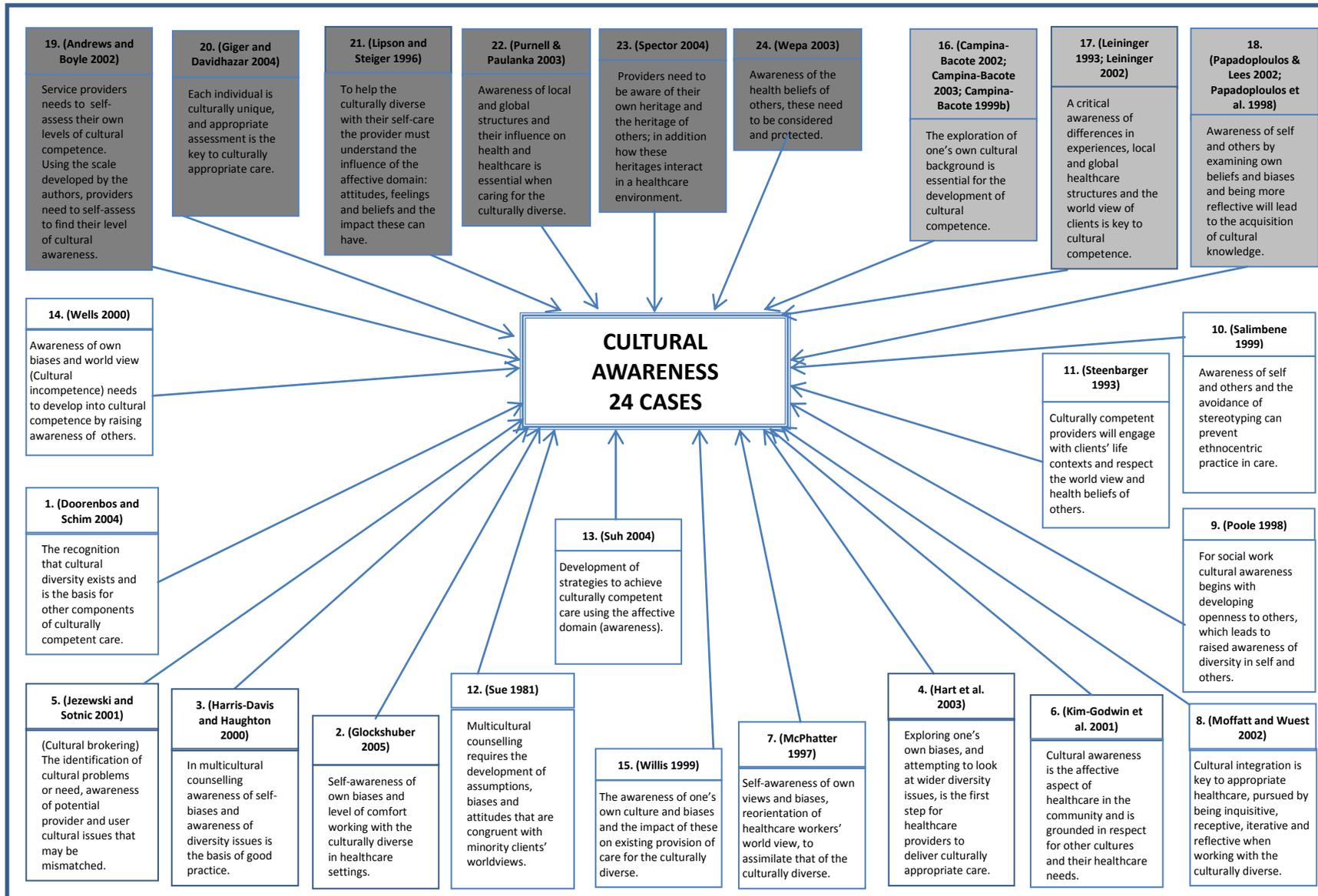


Figure 6.4 Cultural awareness: synthesis of original sources

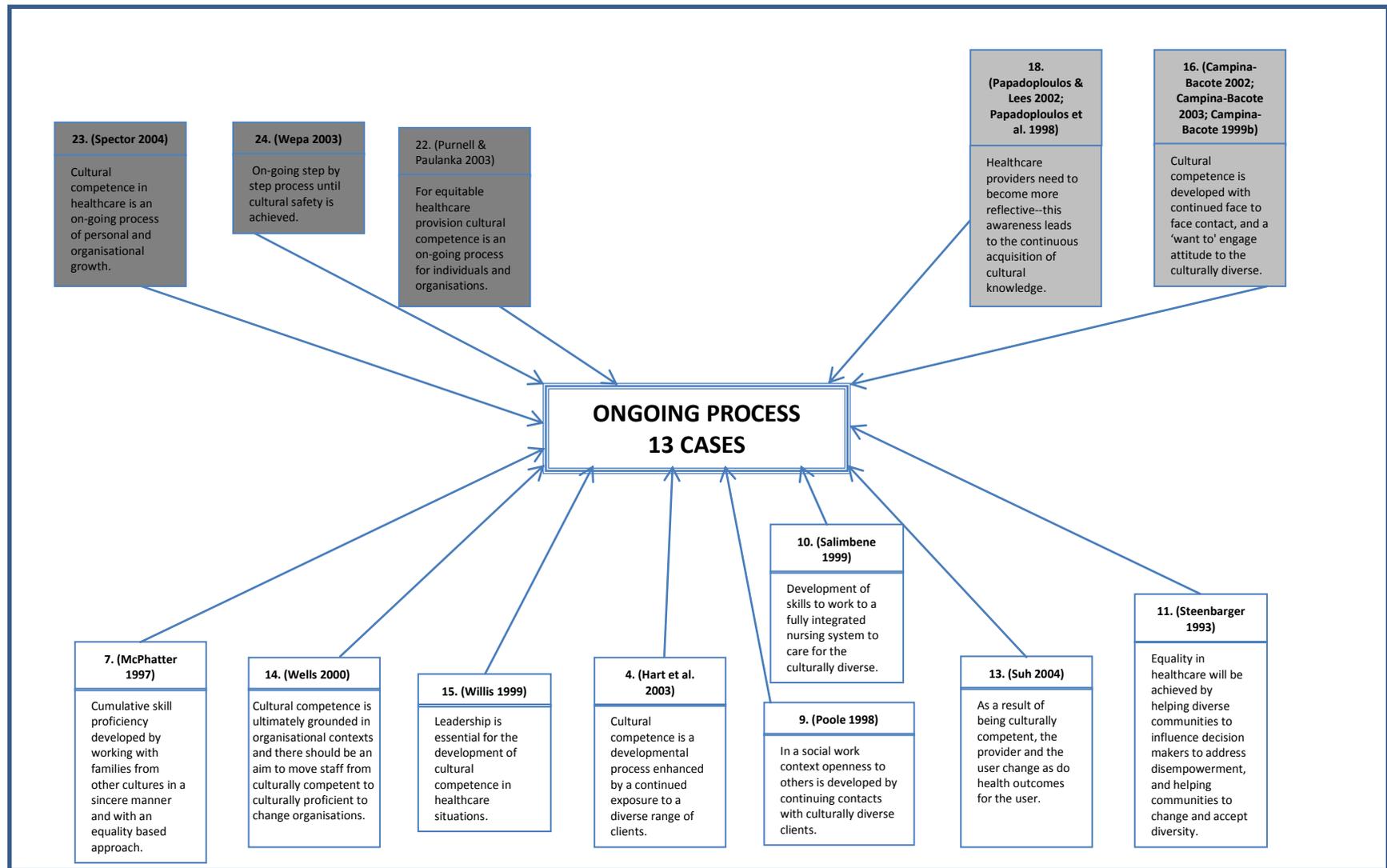


Figure 6.5 Cultural competence as an on-going issue: synthesis of original sources

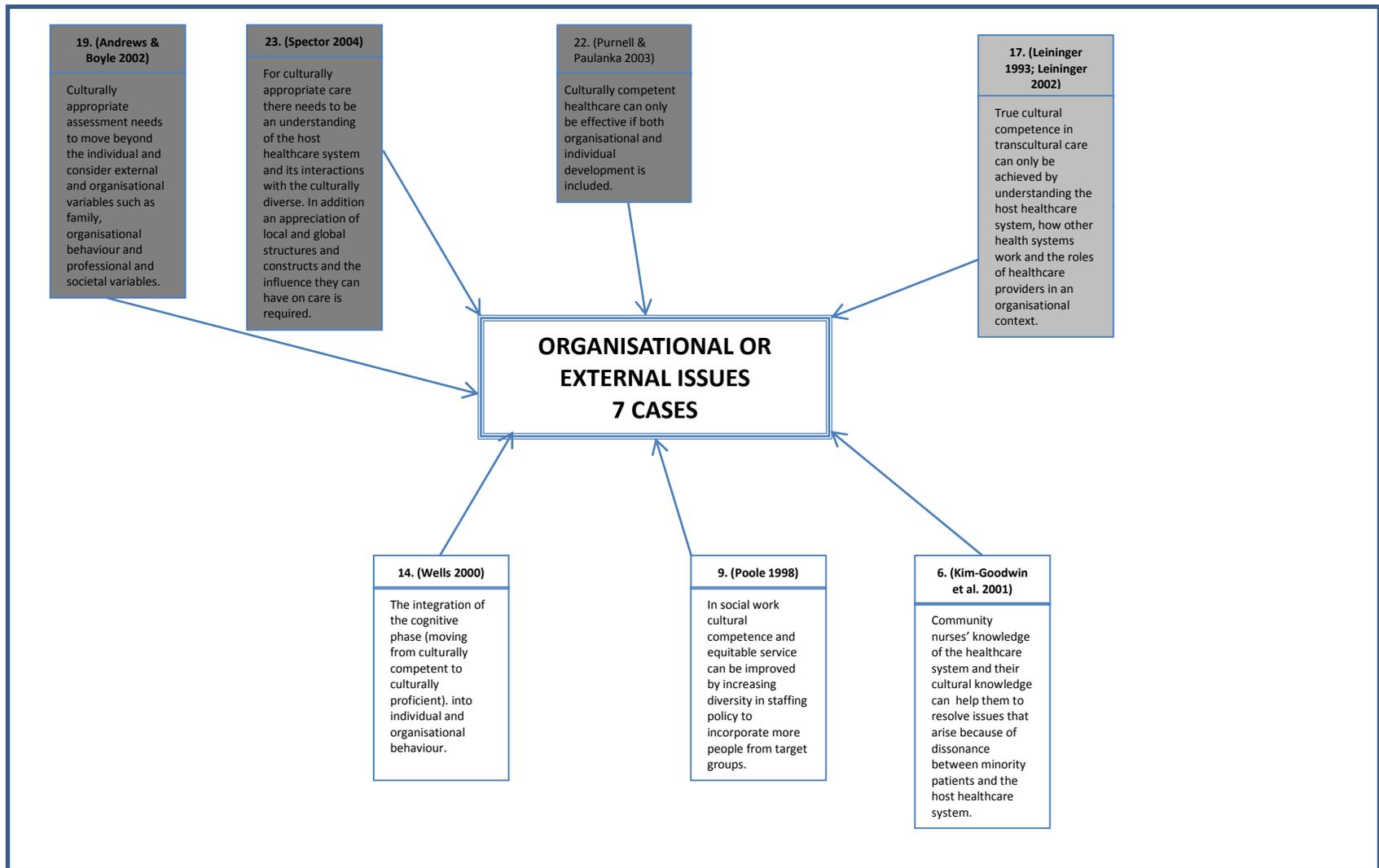


Figure 6.6 Organisational/External issues: synthesis of original sources

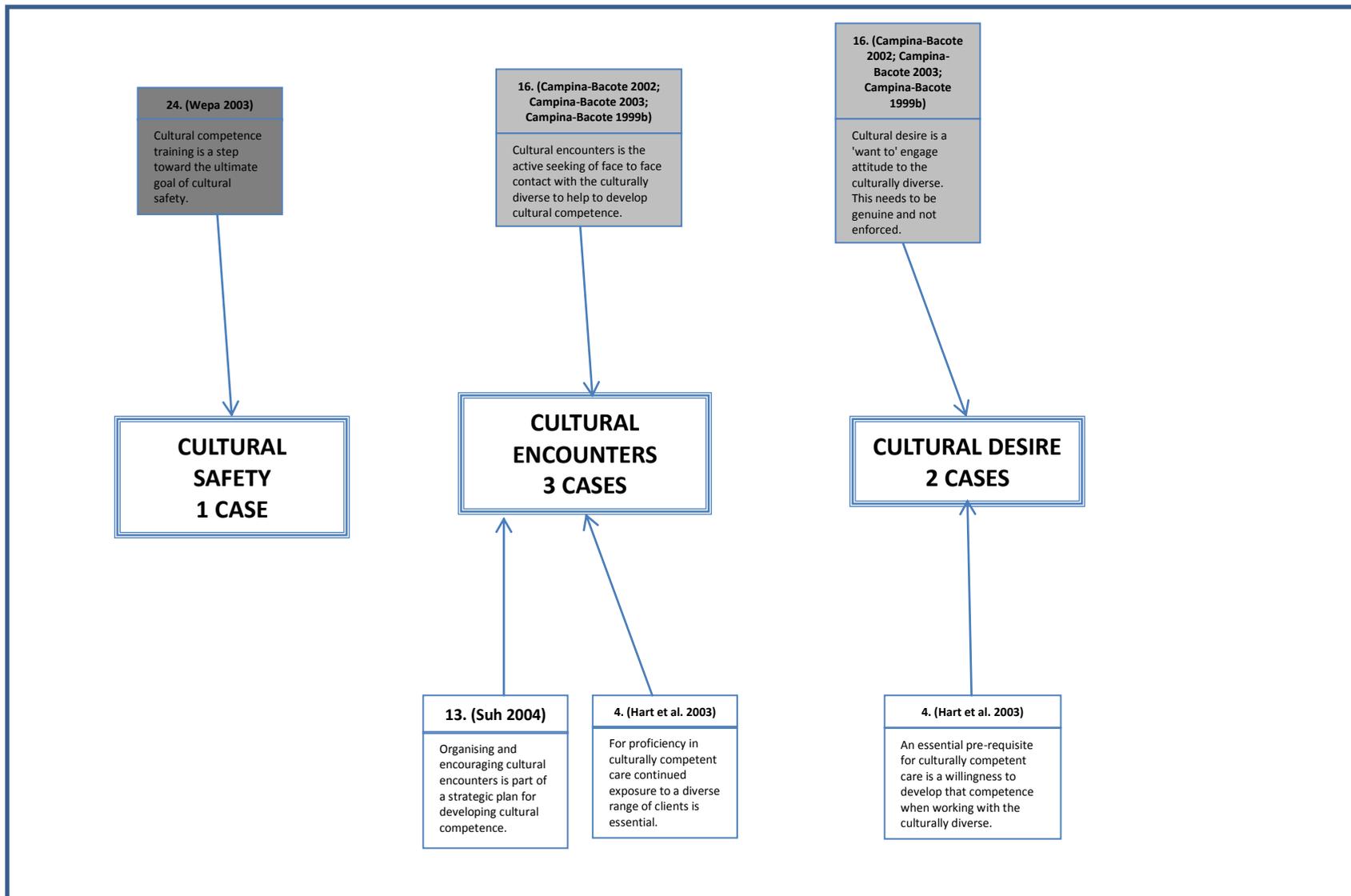


Figure 6.7 Cultural safety, encounters and desires: synthesis of original sources

The main components of the framework from Balcazar (2009) are supported by the concept mapping (Figures 6.2 -7). In the original framework (Balcazar 2009) it was suggested that concepts such as cultural desire were necessary precursors and not a component of a cultural competence framework; additionally organisational components were not included. Balcazar's (2009) suggestions about concepts like cultural desire may be valid as they only appear in two of the original constituent articles. As all the frameworks discussed up to now are at a propositional level, it may not be wise to omit such concepts from a framework without good reason. The impact of not having cultural desire (not wanting to engage) is not clear, but it has been demonstrated that attending a cultural competence course may not change attitudes (Beagan 2003; Kumas-Tan et al. 2007).

In the original framework organisational issues were not included but practice application was. Practice application was supported with 'on-going process' and there was also evidence for organisational support. As a result of the factor analysis, Balcazar (2009) altered the framework to remove practice application, and include organisational support (Suarez-Balcazar et al. 2009) (see Figure 6.1). However, considering the items in the assessment tool on which the factor analysis was based, practice application was not well represented, whereas organisational support was, which could explain practice application's removal (Balcazar et al. 2009 p1157).

The independent development of the two frameworks were conducted for different purposes and from source material that differed in; number; 18 compared to 9; target groups, mixed compared to all nurses; and format, peer reviewed articles compared to books on trans-cultural nursing. Despite this they are both recommended by the

authors to support teaching research and practice. Though the position of having two frameworks is an improvement on 24, there still needs to be further rationalisation.

6.5 Conceptual framework meta-synthesis

Between the two proposed frameworks it would seem that one further level of synthesis is required that will combine all the proposed components of cultural competence that can be used for all applications. The conceptual framework in Figure 6.8 is a further development of the essential and insightful work of Jirwe (2006) and Balcazar (2009). Figure 6.8 shows the approach to cultural competence that this thesis proposes as an explicit part of its contribution to knowledge.

In stage 1, there is a pre-requisite of 'willingness to engage'; Jirwe (2006) includes this in her framework, and Balcazar (2009) removed it claiming it should be a pre-condition to attending training. Figure 6.7 indicates limited but valid support for this concept and it would seem to be limiting in scope if it were omitted from this meta-synthesis. Stage 2 contains two components typically included in cultural competence development initiatives. The first of which is 'critical awareness', and is seen as essential for real engagement with cultural competence training (Campinha-Bacote 1999; Leininger 1993; Papadopoulos et al. 1998). Critical (cf. Balcazar (2009) was chosen as the name because 'awareness of diversity among human beings' (cf. Jirwe (2006)), could be seen as passive and awareness in this context should have a questioning aspect. The development of critical awareness of self and others seems more appropriate for a dynamic form of cultural competence. The concept of awareness, of self and others, was evident in all the constituent frameworks and is therefore well supported for the new synthesis (Figure 6.4).

Figures 6.2 – 6.4 show the range of descriptors and explanations of concepts in the 24 frameworks that contributed to the concept mapping. These have been categorised as cultural knowledge, skills and awareness respectively. The next core component in Stage 2 is ‘culturally able’ when cultural knowledge and skills are acquired.

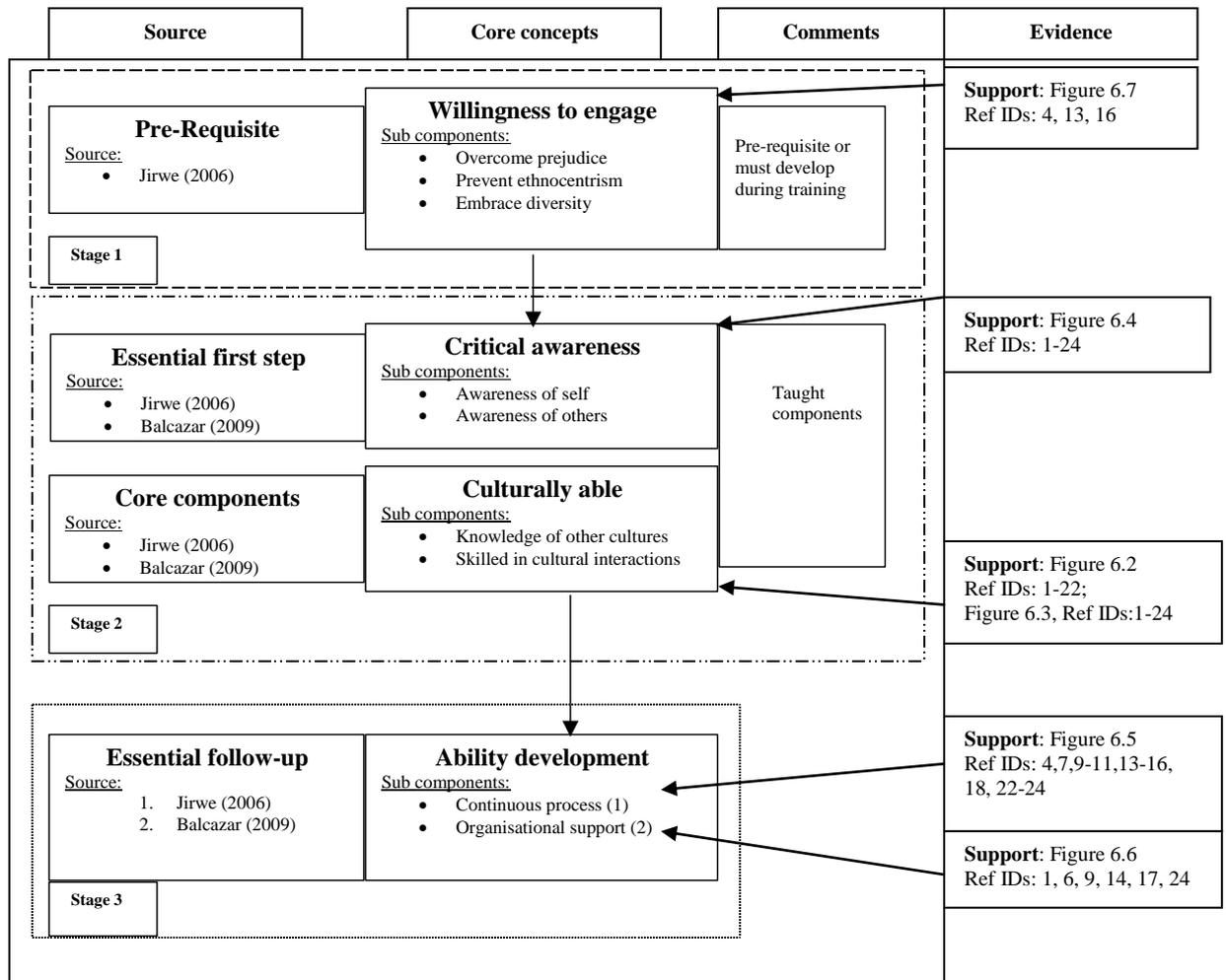


Figure 6.8 Provisional synthesis of new cultural competence conceptual framework

As would be expected these concepts were included in all of the constituent frameworks (Figures 6.2 & 6.3). Competence in general will include knowledge and skills, as these are defining factors of a competence (Kane 1992), and in the case of

cultural competence an awareness of cultural diversity would seem to be essential (Campinha-Bacote 2002; Leininger 1993).

Stage 2 would generally be the end of a formal cultural competence training course and where a form of cultural competence assessment would take place. Stage 3 is 'ability development'; despite having the knowledge and the skills in cultural competence, this thesis proposes that development needs to be seen as an on-going process, where organisational support of some kind will be required. Figure 6.5 illustrates the support from 13 of the 24 contributing frameworks. 'Ability development' could have been omitted from some frameworks as on-going development was not seen as an issue for that particular development situation, or the developers may have removed it because they regarded it as outside of a training remit (see Suarez-Balcazar et al. 2009). However, there is a strong case to include ability development in the meta-synthesis because of both the quantity and the contributions that each of the 13 cases make.

Organisational and external issues are one of the least supported concepts. Balcazar (2009) included this in his later version and CLAS (US Office of Minority Health 2001), prioritise organisational issues in most of their standards. Considering the importance of structural issues in health care quality and the holistic approach to health care quality (Campbell et al. 2000b) (see Figure 2.4) it would seem essential to include organisational and external issues (Figure 6.5) into a framework that is describing a complex developmental concept like cultural competence (Campbell et al. 2000b; Craig et al. 2011).

Reviewing the work of Jirwe et al. (2006) and Balcazar (2009) led to 24 unique conceptual frameworks being proposed for a meta-synthesis of the components required for cultural competence development. There has been limited independent evaluation of these frameworks by people unconnected with the developers.

Independent evidence is essential to control testing biases such as expectancy or experimenter effects (Rosenthal & Jacobson 1963), but measures to counteract these biases are rarely used (Sheldrake 1999). The limited evaluations that have taken place used weak study designs, such as assessing a single group of service providers before and after training interventions (NICE 2008). In addition, when evaluations did take place, the framework authors devised their own unique assessment instrument and few of these have provided statistical data on the reliability and validity of these instruments (Gozu et al. 2007).

Until Jirwe (2006) and Balcazar (2009) undertook the syntheses of their frameworks, there had been no attempt to rationalise them into a single entity. Moreover, until this thesis, these two frameworks have existed independently with no attempt to make a single framework that encompasses all the possible and logical components.

Furthermore, there seems to be scant exploration by framework developers of independent evidence for the core components, notably awareness, knowledge and skills of cultural competence. This thesis has taken a further step in theory development as it proposed a framework that includes stages involved in the development of cultural competence which can be applied to organisations and individuals alike. Cultural competence development is indicated as stages from when an individual is willing to engage with the process, through to the application of skills in the workplace. The next phase of this Chapter makes a further contribution to

knowledge by considering the evidence to support the contribution of the core concepts of this new framework. This knowledge will be combined with the new framework, and refined to a final proposed conceptual framework of true cultural competence.

6.6 Cultural competence: process and outcome of care

The previous chapter described how a systematic literature review retrieved articles reporting controlled trials on training service providers in cultural competence. The following sections of this chapter will describe a review and synthesis of those articles using realist principles. The next sections will review service provider training, assessed by two types of outcome, service provider (section 6.7) and service-user (section 6.8). Section 6.9 evaluates a stakeholder review of the findings of sections 6.7-6.8, which is followed by a review of problem-focussed interventions that informed further development of the proposed cultural competence framework (see Figure 6.8).

6.7 The process of cultural competence: service provider outcomes

Articles investigating cultural competence training in the UK are limited and the majority of studies are from North America (Lie et al. 2010). Although there are differences in health systems between the countries, any available research in this area will be considered, unless some element of the study renders it incomparable to the UK situation (Ham 2005).

Service-user – provider interactions are complex and more so when cultural differences are included (Craig et al. 2006). The findings in Chapter 3 indicate that, people of South Asian heritage have positive perceptions of potential stroke care, but

those who had experienced stroke care described negative experiences. These findings have been supported in the literature with issues such as: poor communication (Johnson et al. 2004), less active engagement in provider - service-user interactions (Cooper et al. 2006), lower ratings of satisfaction (Taira et al. 2001), and perceptions of not being treated with respect (Collins et al. 2002). These experiences related to what could be termed inter-personal care, and cultural competence training for staff was seen as a solution to this issue (US Office of Minority Health 2001). It would seem that self-reported cultural competence levels are important, as a primary care study in the USA demonstrated that the level of cultural competence that a service provider self-reports is associated with service-user satisfaction, trust, and perceived respect (Paez et al. 2009).

Perceptions of a service and satisfaction levels are related to processes of care which are seen as the most reliable indicators of health care system quality (Campbell et al. 2000b). Though service-user outcomes could intuitively be seen as a better metric of health care quality, these tend to be protracted, difficult to measure, and attribute accurately to a specific health care event (Campbell et al. 2000b; Donabedian 1996). Assessing process can be a more accessible and attributable metric as they can be compared to a reference standard for the best available evidence based care to assess health system quality. However, where possible a link to improved outcomes is always desirable (Campbell et al. 2000b; Donabedian 2005).

It would seem appropriate to consider the efficacy of training service providers in the process of cultural competence. It is also desirable to explore the impact of such training on clinical and non-clinical service-user outcomes. These issues are the focus

of the following review of trials of cultural competence training using the principles of realist review and synthesis (Pawson et al. 2005).

Processes of care related to cultural competence will be considered first. When assessing the quality of health care, processes are seen to include the clinical needs and their management as well as inter-personal needs and their management. For this reason cultural competence and its training are necessary processes for effective clinical and interpersonal aspect of quality health care (Campbell et al. 2000b; Donabedian 1996; Donabedian 2005).

In typical realist work, it is usual to describe Context-Mechanism-Outcome configurations (C-M-Os) (Pawson & Tilly 1997). This thesis has proposed a new contribution to knowledge by highlighting the importance of intervention components when considering investigations, in particular with controlled trials, as the estimated effect of the component can be compared to a control condition. In this review, Context-Component-Mechanism-Outcome (C-C-M-O) configurations will be provided in appropriate places, to indicate what these important elements are.

6.7.1 Cultural competence training: Awareness, Knowledge and Skills

It is a necessary first step to establish if cultural competence courses are effective in improving the core competence concepts of cultural knowledge, skills, and awareness of service providers. Training service providers on cultural competence courses, and assessing them on course completion, only indicates the ability of the candidate to complete the assessment and such assessments are subject to response bias (Hays et al. 1089; Schwarz 1999). In addition it is unknown if success on a self-report assessment translates into change in behaviour (Ajzen 2001). A single study has

demonstrated a relationship between self-reported cultural competence in service providers and positive perceptions by service-users (Paez et al. 2009). What is more difficult to estimate is the impact of such training on service-users' clinical outcomes (Beach et al. 2005; Lie et al. 2010).

The systematic search carried out for this thesis (Chapter 5) retrieved 21 articles of controlled trials that investigated cultural competence training for service providers, assessed by self-reports. The studies have been grouped by the type of training that was used and sub-grouped by service provider discipline, which allowed the evaluation of what works and for whom. The studies were judged as having no fatal flaws that would exclude them at the screening stage by using the criteria set out in Table 4.2.

The conceptual frameworks described above were synthesised for this thesis into a single new conceptual framework (Balcazar et al. 2009; Jirwe et al. 2006). The core elements for this framework are cultural knowledge, skills and awareness; this was supported by a re-analysis of the original sources of the two recently synthesised frameworks (Balcazar et al. 2009; Jirwe et al. 2006). It would seem appropriate therefore that training service providers on these core concepts would be an appropriate place to start to develop a culturally competent workforce (Anderson et al. 2003; Office of Minority Health 2009).

Eleven studies used training programmes that aimed to develop cultural knowledge, skills, and awareness for service providers. Seven of these studies had significant outcomes on cultural awareness, knowledge and skills; all were conducted in North

America, mostly USA, with practicing nurses (Caffrey et al. 2005; Lasch et al. 2000), counselling students (D'Andrea et al. 1991; Wang 1998), and medical students and doctors (Godkin & Savageau 2003; Majumdar et al. 1999; Paul et al. 2008). An additional trial has been included, also from North America, from the service-user outcomes group as this reported the outcomes of training nurses in cultural knowledge skills and awareness (Majumdar et al. 2004) (Appendix 14).

Nurses / nursing students: trials that demonstrated an effect

Three trials were successful in training nurses/students on the core triad of knowledge, skills and awareness (Caffrey et al. 2005; Lasch et al. 2000; Majumdar et al. 2004). The size of the samples ranged from 32 to 575 participants, split between control and intervention groups, which were rarely equivalent in size. The three trials used self-report outcome measures specifically designed for each individual study (Appendix 14.2).

Two studies were RCTs with practicing nurses, the first of these used a two group design with small sample sizes ($n/n_1 = 54/60$), these groups were reported to have equivalent characteristics. The intervention was a specially designed course, but few details were provided, and the control group was not trained (Majumdar et al. 2004) (Appendix 14.2).

The second RCT also used an untrained control group, but two intervention groups, both much larger than the controls; but the allocation process was not described (Lasch et al. 2000). The two intervention groups both attended the same one day workshops, but one intervention group was later 'enriched' by experiencing practical sessions with a cultural specialist. There was no difference in outcome between the

two intervention groups but both performed better than the controls on a final cultural competence assessment.

The third trial used a quasi-experimental design (Caffrey et al. 2005). The sample comprised 32 student nurses taking a cultural course, and additionally 7 of the students experienced cultural immersion by assisting clinicians working with minority groups. Though the controls scored well on cultural knowledge, the immersion experience seemed to have a positive impact on the small intervention group resulting in higher scores on a final cultural competence assessment.

The studies above considered cultural competence training in terms of knowledge, skills and awareness. Further trials ($n = 6$) were carried out that trained and assessed samples on one cultural competence core component, pairs of core components or one component in combination with another construct, for a particular training programme (Appendix 14.2). Two of these studies were successful with student nurses in the USA (Naphoiz 1999; Scisney-Matlock et al. 2001). Both used quasi-experimental designs with control groups, were relatively small in scale, and used different intervention methods. In these trials the intervention and control groups both received the same cultural training, but in both cases the intervention group received additional input. In one study 16 out of 65 students who received the cultural training also had six hours with a specialist cultural advisor (Naphoiz 1999). Both groups were then tested on their perception of cultural skills, with the intervention group scoring higher on a skills assessment. In the second trial, the variation for the intervention group was that cultural training was delivered using a novel, theory based teaching approach (Scisney-Matlock et al. 2001). As a result of this variation the intervention group

were more comfortable in cultural interactions and had higher levels of knowledge of cultural diversity than the controls on a post-intervention knowledge assessment.

Nurses / nursing students: trials that did not demonstrate an effect

One trial with practicing nurses did not work (Berlin et al. 2010) (Appendix 14.2).

This trial was a cluster RCT in Sweden with practicing child health nurses. In this trial 51 nurses were allocated by geographical clusters to two groups. Twenty four nurses received a cultural competence education programme based on an established cultural competence model (Campinha-Bacote 1999), and 27 nurses received no training and acted as controls (two dropped out). Both groups were assessed using a published measure, the Multicultural Awareness Knowledge and Skills Scale (MAKSS) (D'Andrea et al. 1990). The final assessment indicated a significant improvement for the intervention group for the domain of cultural skill but not for the domains of cultural awareness, and knowledge. It was reported that lectures and discussions (no more detail) were used for all domains except skills (Berlin et al. 2010). Skills training included a four week clinical practice element, working with minority group service-users, as well as lectures and discussion groups. When knowledge and awareness were taught in other trials, activity-based components were used such as workshops, role-play etc., which may have engaged the participants better. This trial may also have suffered from sampling issues as the samples were small and may not have had sufficient participants in each cluster, related to the number of clusters; this could undermine the power of the statistical tests to detect differences (Hemming et al. 2011). However, the authors claim that four weeks clinical work may not be enough time for the knowledge to become established. This has not been the case in other trials employing shorter periods of consolidation time.

Medical staff / Students: trials that demonstrated and effect

Three trials used cultural knowledge, skills and awareness training with medical staff or students in North America (Appendix 14.2). The three trials had outcomes that supported the experimental hypotheses using small, quasi-experimental trials with controls (Godkin & Savageau 2001; Majumdar et al. 1999; Paul et al. 2008).

One study, with medical students, asked for volunteers to take a 'Multicultural Track' (Godkin & Savageau 2001). Twenty-six volunteers were recruited onto the 'track' and the remainder of the cohort acted as controls (n=104). The track intervention was bi-monthly specialist cultural seminars, and a cultural immersion programme working with minority groups at home and abroad. At the final assessment the intervention group significantly increased assessed aspects of cultural knowledge, skills and awareness, by an average of 25% from baseline, compared to the control group.

In a reverse of the typical cultural competence training trial format, foreign born medical graduates who wished to practice in Canada, took part in cultural competence training or acted as controls with no training (Majumdar et al. 1999). Twenty four intervention group participants undertook training over two weeks with workshops, role-play and support material. There were no statistical differences reported between the two groups on participant characteristics, but the details provided were limited. By the final assessment, attrition had reduced the groups by approximately 20%, but the intervention group scored significantly higher on cultural knowledge, skill and awareness.

Finally, ninety-one paediatric medical students were trained on a standard cultural awareness module (Paul et al. 2008). Twenty-two of these students were assigned as an intervention group to a separate community site, and experienced working in a high density migrant environment, as well as coaching, workshops and role-play. The intervention students significantly increased their levels of cultural knowledge, skills, and awareness at the final assessment. The allocation process was not described, nor were the characteristics of the students. As in the other two trials in this section, the students were assessed on self-report measures specifically devised for each individual trial.

Additional trials were retrieved where medical personnel were not trained on the usual cultural competence triad (Appendix 14.2.). One RCT with medical students in the USA had an overall sample size of 109, with 62 taking part in the intervention and the remainder acting as a control group (Genao et al. 2009). The intervention group undertook a cultural competence course and the controls a module on clinical skills. The intervention consisted of workshops, role-play and working with vignettes in discussion groups. The intervention group significantly increased knowledge of cultural issues compared to the controls on post-intervention multiple choice assessments devised for the study (Bussey-Jones et al. 2005).

Medical staff / student: trials that did not demonstrate an effect

This computer and internet mediated study was the only one that was not successful on a self-report assessment after delivering cultural knowledge, skill, and awareness training online (Appendix 14.2). A sample of 122 family residents in the USA responded to an invitation to take part. Fifty-eight family residents took the computer course and the remainder acted as controls, and completed pre and post intervention

assessments online (Kutob et al. 2009). The group characteristics were reported in detail and the groups were similar in most of these. As with many of these studies, the assessment was developed for the study. Overall the intervention group significantly improved their cultural competence scores while the controls remained similar from baseline to the final assessment. However, the author provided subgroup analysis data and it appeared that for the intervention group, cultural awareness and some of the cultural skills items did not improve and cultural knowledge and some non-verbal behaviour items were responsible for the majority of the improvements.

Counselling: trials that demonstrated effectiveness

Two trials carried out in the USA with counsellors, taught the cultural knowledge, skills and awareness core triad of concepts (D'Andrea et al. 1991; Wang 1998) (Appendix 14.2). These were quasi-experimental studies with control groups, both used small samples, 96 and 62 respectively, and both reported a significant increase in cultural knowledge, skills and awareness for the intervention group as assessed with the MAKSS (D'Andrea et al. 1990).

The first study used three intervention groups and two control groups (D'Andrea et al. 1991). Because the total sample size was small this resulted in small sub-groups making internal validity a problem (Schulz & Grimes 2002). The three intervention groups were trained in cultural competence using lectures, workshops and small group work. The difference between the groups was the duration of the training. On a post-intervention assessment the three intervention groups' scores were approximately twice that of the controls, with minimal differences between the intervention groups.

In the second trial a cohort of 32 first year students took part in a purposely designed module of five, two - hour sessions with multicultural content (Wang 1998). A second year cohort of 30 student counsellors acted as controls. The intervention cohort significantly improved from baseline in the MAKSS, compared to controls post intervention, and at a six month follow-up. The intervention group increased MAKSS scores by approximately 10% at both follow-up time-points when the controls remained unchanged. As a validation exercise the control students experienced the multicultural course after the six month follow-up. When the control group completed the course there was no significant difference between the two cohorts assessed by the MAKSS.

One further trial investigated cultural awareness alone (Parker et al. 1998). Two separate cohorts were used, one was trained on a multicultural counselling course over 15 weeks, and the other acted as untrained controls. No group characteristics were provided apart from sex and race, but the article reported that there were no significant differences. The intervention was delivered with lectures, workshops, role-play and mentoring. Both groups were assessed at baseline and post intervention, with scales that assessed racial consciousness and inter-racial comfort. The intervention group significantly increased their scores (8%) compared to the controls (no change) on racial consciousness, and interracial comfort by 10%.

Counselling: trials that failed to demonstrate effectiveness

A quasi-experimental trial from Canada did not report a significant outcome for training on the single concept of cultural awareness (Brooks & Kahn 1990) (Appendix 14.2). This study trained counselling students on an ethnicity awareness course; it had a small sample size (< 23 in each group), and reported no significant difference in

the characteristics of the intervention and control groups. The programme was 13 weeks at two and a half hours a week, and the intervention was lectures, set readings and small group work including role-play. There was no significant difference between the intervention and control groups at a post-intervention assessment. Telephone interviews with a sample of the intervention group indicated that the course had sensitised them to cultural issues in their current practice, which could indicate the assessment scale was at fault. This indication was supported in the article as it was reported that the outcome measure had failed to demonstrate internal consistency or reliability (Wayne 1981). However, there was also a serious issue with sample size, as there was an attrition rate of approximately 50% for both groups which was not discussed in the article. This could have resulted in two biased groups which could make the final statistical analysis problematic (Schulz & Grimes 2002).

Non-providers: trials that failed to demonstrate effectiveness

Two trials were retrieved that trained and assessed cultural knowledge, skills, and awareness in groups of workers unrelated to health care and counselling. One trial trained students from a range of social science disciplines in the USA (Robinson & Bradley 1997). The second trained social workers in Canada on a multicultural skills course (Williams 2005) (Appendix 14.2).

In the first study, two independent cohorts were the sample for this quasi-experimental trial (Robinson & Bradley 1997). One cohort was trained on a multicultural issues summer school course. The remaining cohort acted as a control group and attended an unrelated course. Limited information was provided about the groups, but they were all under 25, and the majority born in the USA. The intervention was over the three weeks of the summer school and consisted of

workshops, group work, open learning and written assignments. Both groups completed the MAKSS at the start and end of the training sessions. There was no significant difference between the groups at baseline, but at the end of the training the intervention groups scored significantly higher on cultural knowledge and awareness, but not skills.

In the second study 47 experienced social workers in Canada volunteered for a multicultural skills course (Williams 2005). Eighteen volunteers who could attend four scheduled three hour sessions were classed as the intervention group; those who could not attend were placed on a waiting list and acted as controls. There were no statistical differences between the groups on collated characteristics and the training session used lectures and group work with case studies and role-play. The groups were tested pre- and post- intervention using the Multicultural Counselling Inventory (Sodowsky et al. 1994) and the Multicultural Case Conceptualisation test (Constantine & Ladany 2000), which reported no difference between the control and intervention groups. This may have been due to sampling issues, as 90% of students, in both groups had received prior diversity training; in addition, the control group had access to 'diversity materials'. Qualitative data indicated that at six months the intervention group reported a perceived benefit of the training.

Synthesis of self-report outcome studies

Table 6.1 summarises the context, component, mechanisms and outcomes for this group of trials. All but one of these trials was conducted in North America. The sample sizes ranged from 32 to 575. The majority of trials that trained participants on a form of cultural competence programme had successful outcomes. Most of the trials had design or sampling issues. A limited number were based on recognised

cultural competence theories or models and the majority used cultural competence assessments that were either designed specifically for the study, or had little in the way of reliability and validity data. The lack of a valid, reliable and uniformly accepted instrument to assess cultural competence has been discussed as a cause for concern (Gozu et al. 2007).

Despite the design and assessment problems a number of issues have become clear. Cultural competence training, whether as a triad of core components (knowledge, skills and awareness) or individual components, can be taught in a number of contexts, by a number of methods, and a variety of durations. It would seem that active elements are beneficial but the duration of the intervention is not critical. For example, counsellors have attended four days of workshops (Lasch et al. 2000) and been successful in a similar way to a semester of training (D'Andrea et al. 1991). In the latter case three intervention groups, each of a different training duration, were used, but there was no significant difference between the groups on outcome. In some cases trainees did not physically attend training sessions. For example, family residents completed a one hour computer mediated online course (Kutob et al. 2009) and successfully increased their cultural knowledge and non-verbal behaviour scores, but not their skills and awareness, compared to controls.

In relation to training intervention components, there was an approximately equal split between what could be called a standard teaching approach of lectures, workshops and small group work, including role play, and those that included an extra experiential element. The experiential elements were either forms of cultural immersion, working in a mainly minority environment at home or abroad, or

mentoring by a cultural specialist in a work based situation. Unfortunately there were few reports of trials that provided sufficient detail to estimate the association between intervention components and outcome, which is a concern for realist work (Wong et al. 2010).

All trials except one (Brooks & Kahn 1990), had at least one measure that showed improvement and taken together the conclusion must be that knowledge skills and awareness training shows some benefit (it works). Trials that showed no improvement in measures tended to have a number of small issues that could have combined, and been responsible for the outcome or inappropriate intervention components were used. For example, the intervention (context) components may not have been suitable for the topic. Kutob et al. (2009) used online courses which may not be appropriate for skill and awareness training but fine for knowledge, whereas didactic lectures (Berlin et al 2010) may not be appropriate for knowledge and awareness teaching. However the principles of andragogy describe mixed methods, including negotiation and activity, as more appropriate teaching components for adults; a lack of these may be the root of the poor performance (Reece & Walker 1997).

Context	Intervention component	Mechanism(s)	Outcome
Training service providers in cultural competence with formal training courses USA, Canada, and Sweden Training practitioners and students from medicine, nursing, counselling, and social work	Lectures Workshops Role-play Coaching Cultural immersion Open learning Writing assignments	Increased awareness of self and others Increased cultural knowledge and cultural skills Aware of own biases	Increased scores on end of course assessment compared to control groups Increased cultural knowledge, skills and awareness

Table 6.1 CCMO for cultural competence training courses

6.7.2 Cultural competence training: Self-Efficacy

Self-efficacy: trials that demonstrated effectiveness

Three trials reported training groups of nurses and nursing students in cultural self-efficacy and assessing them on self-efficacy scales (Shellman 2007; Smith 2001; St Clair & McKenry 1999). The four trials used quasi-experimental designs, and had relatively small sample sizes (Appendix 14.1).

All four trials used the Cultural Self Efficacy Scale (CSES) (Bernal & Froman 1987; Bernal & Froman 1993). The trials were all carried out in North America, and two of the four were based on published cultural competence theories (Shellman 2007; Smith 2001). The duration of the tuition ranged from 2 hours to approximately 40 hours, and used a range of teaching components.

Two trials did not use conventional training models but forms of cultural immersion to develop cultural self-efficacy with student nurses. The first successful trial was a quasi-experimental design with control groups (Shellman 2007). The groups were two separate student nurse cohorts from separate training years. The intervention group was small, with 43 students and the control was smaller with 21 students.

There was only limited information on the group characteristics, but by the final assessment attrition had reduced both groups by approximately 30%. The intervention consisted of each student nurse holding one two-hour reminiscence session (recalling past experiences) with a minority-group elderly adult; the controls had no intervention. Both groups were assessed pre- and post- intervention on the CSES (Bernal & Froman 1987), and the intervention group significantly improved 12% compared to the controls improvement of 8% on the pre-intervention scores.

The second study was also a quasi-experimental design with controls (St Clair & McKenry 1999). This has a large sample of 200 student nurses and the two groups were self-selecting. The intervention group opted to engage in placements working in the UK, Jamaica and Ghana, the controls worked with minority groups in the USA. The two groups were described as demographically similar but no details were provided. This trial also used the CSES to assess the groups' pre- and post-intervention levels of cultural self-efficacy. The intervention group scored significantly higher on the CSES than the controls.

The final trial was an RCT in which 48 nurses were allocated to complete a transcultural assessment course (Giger & Davidhizar 2004), and 46 to complete a health informatics course; both were held for one day. The allocation was described as random but no details were provided; the groups were stratified for race, which meant that each group should have a balanced racial composition. The intervention used standard components of lecture, small group work and role-play. At the final assessment the intervention group scored significantly higher than the control group on the CSES and a cultural knowledge scale.

Self-efficacy: trials that did not demonstrate effectiveness

The study that found no improvement (Alpers & Zoucha 1996) was with nursing students and also assessed students on the CCSE. One student cohort was used as the intervention group and a cohort from the following semester acted as controls (n=32, 31). Students in the intervention group had cultural sensitivity classes, and then 10 weeks of local cultural immersion. Controls were assessed before taking classes or immersion. Failure could have resulted from a number of small design and sampling

issues that separately were insufficient to exclude the study but may have combined to deliver the neutral result (Appendix 14.1). The issues included dissimilar groups, small sample sizes (<33), and multiple significance tests (> 80). The author attributed the lack of difference in outcome to the intervention group losing confidence when they appreciated their ignorance of minority groups, and the overconfidence of the control group who were still in a state of cultural ignorance (Howell 1982).

Synthesis of self-efficacy trials

The four trials used different designs; short (one hour), to longer (a semester) intervention periods; and different intervention designs. All used the same outcome assessment and had samples that ranged from 63 to 200 participants. They engaged registered nurses and nursing students, and all but one were successful in increasing the intervention group scores compared to controls. The study that failed had a number of design and analysis flaws, and is the only study from the self-efficacy and knowledge skills and awareness training groups that used cultural immersion and still failed. The evidence seemed to indicate that training nurses to increase their self-efficacy working with minority groups demonstrates a degree of effectiveness and intervention components or duration are not critical (Table 6.2).

Context	Intervention component	Mechanism(s)	Outcome
Training service providers in cultural self-efficacy and cultural knowledge with formal training courses	Lectures Workshops Role-play Coaching Cultural immersion	Increased self-efficacy when working with minority groups Aware of own biases	Increased scores on end of course assessment of self-efficacy related to minority groups
North America			
Training nurses			

Table 6.2 CCMO for cultural self-efficacy training courses

6.7.3 Conclusion

Cultural competence training courses are successful in training participants to pass a self-report assessment at the end of a course (see Table 6.1 for details). The mechanisms that bring this about are difficult to elicit, as the papers provide limited detail of the intervention components, and therefore any link between an intervention component and an outcome was difficult to establish. For example, the part played by lectures, role-play etc. cannot be assessed as these studies are not reported in sufficient detail (Wong et al. 2010).

The majority of interventions used multiple intervention components and most of these were activity based for example, role-play. Few studies did not have a positive outcome for intervention groups. However, 7 out of 21 used some form of experiential component, mostly a form of cultural immersion. For one study this was combined with other components and compared to controls with no training (Lasch et al. 2000). For the remainder it was the only difference between the intervention and controls (Caffrey et al. 2005; Godkin & Savageau 2001; Naphoiz 1999; Paul et al. 2008; Shellman 2007; St Clair & McKenry 1999).

It could be concluded that two approaches were effective. One was a 'standard' approach using an array of teaching strategies and the other was experiential learning. Both of these approaches are core andragogic teaching practices, that is teaching adults by negotiation and dialogue rather than a didactic approach (Reece & Walker 1997). However, cultural immersion always seemed to 'add value' to training interventions and showed improvements when it was the only difference between study groups. It has been suggested that cultural immersion should be routinely used with 'standard' teaching to improve cultural competence training (FERENCE & BELL

2004), and this has tentative support from these findings. This also demonstrates the utility of applying realist principles, as what works and for whom has been demonstrated, where other reviews may have failed to note this (see Beach et al. 2005).

Less than half the courses were explicitly based on a cultural competence model or framework. The most cited was the Campinha-Bacote framework (Campinha-Bacote 1999). Initially it would seem as though such frameworks are redundant. However, all the interventions were based on the core components that are evident in the majority of cultural competence models. The utility of a model goes beyond the design of a course; this will be discussed in Chapter 7.

The possible effective mechanisms of action and associated intervention components for teaching cultural competence can be suggested, but these need to be re-visited as the journey of this thesis progresses. Raised awareness would seem to be a key mechanism, which is supported in the cultural immersion literature (FERENCE & BELL 2004). When awareness is raised, a participant has *to face their own biases*⁴ and explore cross-cultural events in the past where these may have operated. The *raised awareness* must develop a level of *anxiety than needs to be assuaged*. The raised anxiety can become a drive to develop the ability to deal with uncomfortable cross-cultural interactions in the future.

Although two types of assessment instrument were used, there was little difference between the training intervention components used. In addition, self-efficacy scales

⁴ Suggested mechanisms are printed in italics

were similar to the knowledge, skills and awareness instruments. Where they differed was the way the items were phrased. In self-efficacy scales, they tend to ask how confident a person is on a concept rather than asking the person to rate their knowledge or ability levels on the same concept.

One of the main problems across all the trials was with the assessment instruments. The self-efficacy scales and the MAKSS did report reliability data, but the remainder were untested. This problem with non-standardised or untested scales has been reported previously (Gozu et al. 2007). In a study of theoretical frameworks for cultural competence, it was found that many of the framework authors devised their own unique assessment instrument and few of these provided statistical data on the reliability and validity of these instruments. It is difficult to see how research and training can progress without a recognised, standardised, and validated measure of cultural competence (Gozu et al. 2007).

Therefore there is evidence to suggest it is possible to equip service providers with a set of cultural competencies to carry out the processes of care with culturally different service-users. As described above, processes of care are a reliable metric by which to assess quality of care but if possible they should be linked to outcome (Campbell et al. 2000b). Thus, to assess quality of care, the impact of the process of cultural competence needs to be linked to the experience and outcomes of minority group service-users, and that has not been demonstrated in these studies. Service providers can be successfully trained in perceived cultural competence; the challenge is to translate this into improved service-user outcomes and experiences.

6.8 The outcomes of cultural competence: service-user outcomes

For the assessment of service quality, service-user outcome is assessed on more than health status, such as the level of practical functioning and the relief of symptoms, but also user evaluations such as satisfaction with service, level of enablement and quality of life (Campbell et al. 2000b; Howie et al. 2004). Outcomes also include service-users' expectations of a service and the extent to which individual needs have been addressed (Stott et al. 1997). This section will report on eight controlled trials where service providers were trained in cultural competence, and then assessed on their cultural competence efficacy by service-user ratings, or clinical outcomes. The trials were evaluated for study quality using the criteria in Table 4.2. Although each study had design or sampling issues, they were not serious enough to exclude them from the review. Two of these studies were informed by cultural competence frameworks or models (Thom et al. 2006; Wade & Bernstein 1991). The studies have been split by the following type of outcome assessment: communication skill (6.8.1), clinical (6.8.2), and satisfaction (6.8.3). In some cases more than one service-user outcome was assessed, in these cases trials are discussed in more than one outcome section.

The eight trials were reviewed and evaluated using a realist approach, and later sections will synthesise the findings. The final part of these sections will be used to suggest mechanisms of action, facilitated by intervention components that could have been responsible for the outcomes. Three of these trials assessed the service providers' cultural competence using service-users' ratings of experience of care and clinical outcomes (Harmsen et al. 2005; Majumdar et al. 2004; Thom et al. 2006).

6.8.1 Communication and sensitivity

In Part 1 of this thesis people from minority groups were asked about the barriers to a culturally appropriate service. An issue that was consistently discussed was poor communication. This included respondents who spoke English, as well as those who did not. Problems with communication have also been discussed in the literature (Jones et al. 2008), it is therefore appropriate to consider trials that aimed to improve service providers' communication ability.

Communication and sensitivity: effective outcomes

Four trials used communication skills interventions and assessments, all four showed an improvement for the intervention groups. Two trials investigated communication problems in a primary care setting in Holland (Harmsen et al. 2005; Schouten et al. 2005). The trials report different aspects of the same study, which focussed on intercultural communication in consultations (see Appendix 14.3).

In this cluster RCT, nineteen primary care physicians in the intervention practices received two days training using intervention components including self and cultural awareness, as well as sensitivity and communication. As part of the training, each physician completed a problem-based learning (PBL) project on a specific minority group communication issue of their own. After two weeks, the PBL projects were discussed with a trainer, who gave further advice.

The primary care physicians had over 900 consultations split between the intervention and control clusters. The sample consisted of both western and non-western service-users in two separate cohorts, one cohort rated the service providers before, and a separate cohort rated them after, the training component. Before each consultation,

non-western service-users were invited to view a language appropriate video about direct communication with physicians.

The initial study (Harmsen et al. 2005), found that both mutual understanding during physician-service-user interactions, and service-user satisfaction increased for non-western service-users, in the intervention group clusters. The second study (Schouten et al. 2005) analysed a sample of the consultation transcripts and found that the intervention GPs increased their number of consultations, and the amount doctors talked in those sessions.

Two further trials in Taiwan assessed the effects of cultural competence training on medical students' communication when eliciting standardised service-users' (SP) perspectives and social factors (Ho et al. 2008; Ho et al. 2010). The two trials related to one study and used the same sample and data set; one is the study proper, and the second is a 12-month follow-up assessment. Ho et al. (2008) investigated the efficacy of cultural competence training with non-western samples (see Appendix 14.3).

Fifty-seven medical students in Taiwan were allocated to a control, or to one of two intervention groups. The intervention components for both intervention groups consisted of two two-hour, 'basic training' workshops. The workshops included cultural awareness and cultural knowledge training, as well as video clips demonstrating how to use communication skills to elicit service-user perspectives and social factors. In addition, half of the initial intervention group attended an 'extended' intervention component, which was a further two-hour workshop including role-play to practice communication skills. All students in the samples were assessed

using Observed Structured Clinical Examination (OSCE) with SPs (McGaughey 2004).

After the OSCE, the students' performance was rated by the SPs. There was no difference between the groups on assessment of basic communication skills.

Although both intervention groups performed better than the control group on exploring social factors, the extended group was rated better than the basic ($\eta^2 = 0.40$)⁵. The extended group was also rated better than the basic group and the control group on eliciting service-users' perspectives ($\eta^2 = 0.2$). At the twelve-month follow-up, the assessment skills had diminished from the original scores, but both intervention groups were still rated more highly by the SPs than the controls on communication skills, although the distinction between the intervention groups had decreased (Ho et al. 2010).

Synthesis

The four (two) studies above indicated that communication training, with the addition of cultural sensitivity training, improves communication between service providers and users from different cultures. In the studies in Holland not all communications were successful and those with more traditional (less Westernised) service-users were less successful, but still improved compared to controls (Harmsen et al. 2005; Schouten et al. 2005). The Taiwanese study was more problematic; this used Taiwanese standardised patients using a script to represent people from other cultures (Ho et al. 2008; Ho et al. 2010). It is difficult to imagine that interactions such as these can relate fully to real world interactions with culturally diverse groups.

⁵ A measure of effect size, proportion of the variance explained by the intervention.

Communication is an integral part of cultural competence training (Campinha-Bacote 1999). Communication barriers are known to have a negative effect on medical interactions (David & Rhee 1998). The range of possible service-user ethnic origins, added to the nature and relatively short duration of interactions, increases the importance of clear communication (Cooper & Roter 2002). There are a number of studies that have highlighted the problem, describing clinicians encountering difficulty with services-users who do not speak English (Elkan et al. 2007; Gerrish 2001).

Learning a language is difficult, and using that language in technical situations like medical consultations is more complex (2005; Cambridge 1999). It could be that people from minority groups who do not speak English understand this difficulty, and therefore appreciate the effort involved by the service providers to learn to communicate effectively with them. Increased service-user satisfaction when providers speak the same language as service-users has further support. Single group studies have shown that when emergency room paediatricians learned a language to communicate with service-users, satisfaction with consultations increased significantly (Mazor & Billings-Gagliardi 2003; Mazor et al. 2002).

In the studies above (Harmsen et al. 2005; Schouten et al. 2005), the primary care physicians could not learn all languages as their client groups were so diverse. Instead, their intervention component was attending communication classes where they learned new skills, and had opportunities to practice these skills. After using the communication techniques, the physicians received higher satisfaction ratings from

service-users, and communicated more than the control group physicians in consultations.

In a similar way, the Taiwanese medical students who completed a basic cultural awareness and communication course were more successful in eliciting information in consultations than control students (Ho et al. 2008). In addition, the students who had the extra intervention component, where they could practice their skills, outperformed the students with basic training. It would seem that intervention components that include a practice element contribute to improved performance on communication skills. A 12-month follow-up indicated that, despite a decrease in eliciting information, both intervention groups performed better than the controls, and the extended group performed better than the basic group (Ho et al. 2010).

In the studies above, it was suggested that service-users appreciated the efforts physicians had taken to try to communicate effectively with them. A '*positive regard*' mechanism could be a potential mechanism that encouraged the service-users to rate these physicians more highly than physicians who did not try to communicate effectively. However, it could be that because of the increased level of communication other mechanisms were able to surface. In the earlier sections, mechanisms were suggested that encouraged service providers to engage in, and complete cultural competence courses. The studies in this section suggest additional mechanisms that may be needed to increase the service-users' perceptions of the quality of their care, for example *confidence in communication ability* could be such a mechanism. These are facilitated by the intervention components (see table 6.3).

However, other mechanisms must be operating with the service-user to bring this change about, for example *appreciation of effort* or *increased positive regard*.

What these trials do show is that it is possible to use communication training with cultural competence training of a relatively short duration to improve inter-personal outcomes for service-users from other cultures, which is a potential area for further work.

Context	Component	Mechanism(s)	Outcome
Primary care in Holland With diverse non-western service-user population.	Communication skills sessions PBL projects	Raised awareness Confidence in skill	Mutual understanding increased Increased interactions
Medical students in Taiwan assessing OESC as 'foreign' service-users.	Awareness workshops and role- play to practice skills. Techniques to modify existing skills, to work with culturally diverse clients.	Positive regard (service provider)	More information elicited from consultations

Table 6.3 CCMOs as a result of communication and awareness training

6.8.2 Clinical outcomes

Three trials looked at service-user clinical outcomes (Majumdar et al. 2004; Sequist et al. 2010; Thom et al. 2006). Apart from moderate success on two items of a questionnaire (Majumdar et al. 2004), none of the trials had positive outcomes. They were all RCT or cluster RCT trials conducted in North America, and training involved workshops, lectures and role-play (see Appendix 14.4). Two trials had mentoring and performance feedback during the treatment period. One trial provided the feedback to intervention and control groups (Thom et al. 2006) and the other to the intervention group only (Sequist et al. 2010) and overall the training element lasted for two days. The third trial trained the intervention group for 36 hours using a specifically

designed experiential course, of which minimal details could be found (Majumdar et al. 2004).

Clinical outcomes: trials that did not demonstrate effectiveness

Considering nurses have more interactions with service-users than any other provider, there is a paucity of evidence for service-user outcomes, or service-user ratings of nurses who have undergone cultural competence training (Lie et al. 2010). The systematic search described in Chapter 5 could find only one randomised controlled trial. In this trial, a sample of 114 nurses and homecare workers from Canada were assigned to control and intervention groups (Majumdar et al. 2004). The service providers worked in either hospitals or community agencies, and the intervention component was experiential workshop training on cultural sensitivity (no further details were available from the author). All the service providers and their service-users completed a battery of measures before the intervention component and at three, six, and twelve months post-intervention.

The outcomes of this trial reported an increase in service-users' overall functioning capacity, but not activities of daily living, health or mood, and an increase in the use of social resources at 12 months after the intervention, without an increase in costs. These outcomes related to single items on a scale, which means each item on the scale must have been tested for significance and the increase was not evident at any earlier time period, plus it had a small effect size. This finding could have been a statistical artefact related to multiple hypothesis testing; this was acknowledged in the conclusion of the article (Dixon & Pennello 2001). Simply put, if a trial assesses outcome at a 5% (1 in 20) significance level, and there are over 20 tests conducted, one can be a false positive by chance alone.

The trial described above failed on all the outcome measures except for two scale items described above (Majumdar et al. 2004). This failure was despite a relatively intensive training programme of 36 hours experiential training. In this study the ‘minority’, groups were mainly white immigrants to Canada; the majority could speak English, had originated from Europe and stated their ethnicity as English, Canadian, or European. These immigrants had been in Canada for up to three years and for a group similar in many characteristics to the general population assimilation may have been more straightforward than for visible minorities, for example people of South Asian heritage. The sampling could have also had an impact on the ineffectiveness of the programme. There was a large attrition rate because of service-user deaths and service provider relocations. The positive outcomes of this trial will need to be treated with caution until supporting evidence is available.

Two trials investigated diabetes management in a primary care setting (Sequist et al. 2010; Thom et al. 2006), and both used a similar design. The two studies were conducted in the USA and used a cluster randomised controlled design, with large and diverse samples. In both cases physicians and practice nurses attended a brief cultural competence training course, but in both cases attendance by physicians was low. The intervention components in these studies included lectures, discussions, and community engagement sessions, with a focus on collecting culturally relevant data. The studies differed in the way service-user data were collected; one used interviews and medical records to collect the process and outcome of care data (Thom et al. 2006), the other collected process and outcome data from service-user records (Sequist et al. 2010).

In both studies, there was an additional intervention component of feedback to the physicians from the research team. The periodic feedback included service-user clinical data, physician prescribing performance and targets, and advice on how to improve future performance. In one study, the physicians were also informed how they had been rated by service-users and the control physicians received the same level of feedback on performance and ratings as the intervention physicians (Thom et al. 2006).

Clinical outcome data for both studies included achieving targets for blood pressure, cholesterol, blood sugar and weight management. The trial designs differed on the process of care measures, for example, one study asked service users to rate their physician on cultural competence and consultation satisfaction (Thom et al. 2006). The other study asked physicians to rate the level of disparities in quality of care by ethnic groups on their list, their practice, and their group (Sequist et al. 2010).

At twelve months follow-up there was no significant difference between control and intervention groups for the target clinical outcome measures in both studies. In the study where physicians had to rate the equity of care by ethnicity, the intervention group physicians significantly increased recognition of inequitable care for black service-users. Despite this and the feedback on prescribing performance; overall statin therapies and cholesterol control for the black service-users was unchanged from baseline, remaining lower than white service-users (Sequist et al. 2010).

Synthesis

The three studies described above are the only trials that could be found that trained service providers in cultural competence and then sought to estimate the impact of this training on the clinical outcomes of their service-users. These trials failed to demonstrate any impact on clinical outcomes. The failure has been described in the literature, as it is recognised that the causal link between a trial intervention and the reduction of service-users' symptoms is not direct and is mediated and moderated by a number of factors (Bird et al. 2011). A lack of understanding of this complexity and the sampling issues described above could have been responsible for the failure of these trials. It has been noted that clinical outcome measures are the most desirable, but not the most ideal assessments of service quality because of the protracted nature of some service-user symptom changes and the lack of attributable cause and effect (Campbell et al. 2000b; Donabedian 2005).

The design problems with one study have been discussed above (Majumdar et al. 2004). The remaining two studies, Sequist et al. (2010) and Thom et al. (2006) failed to find an improvement on clinical outcomes for diabetes management programmes. The areas where these two studies could have failed are the sample, the intervention component, the service providers, the measures, the design, or multiple confounding variables (Kobak et al. 2007).

Both studies were carried out in the USA, one in Massachusetts (Thom et al 2006), one in California (Sequist et al. 2010), and they were conducted approximately three years apart. In Massachusetts there were in excess of 7000 service-users and in California (Sequist et al 2010) just less than 500, making sampling unlikely to be responsible for the failure. Measures were objective medical data, and surveys and

unlikely to be responsible for such significant failures. The studies were of similar designs; Thom et al. (2006) gave feedback to the intervention and control groups, which could have been a confounding source, but Sequist et al. (2010), did not, which would seem to eliminate feedback as both studies failed. Both studies presented and analysed the data in different ways, but both approaches would have indicated an improvement in one of the groups unless it was marginal; the design is unlikely to be responsible for failure.

There were 144 physicians across the two studies, no physician characteristics were supplied by Sequist et al. (2010), but in Thom et al. (2006) they were nearly 80% white and 3% black. Service provider training was short and not well attended by the physicians (not all attended). Both studies were cluster trials therefore whole practices were either intervention or control, reducing the risk of contamination. Contamination is where intervention elements are known about or adopted by the control group. This was possible with Sequist et al. (2010), as all the practices belonged to one organisation. However, Thom et al. (2006) included 53 physicians and did not describe any form of association, but they were spread across the city. Despite this, both the intervention and control groups received feedback on performance, which could have acted in the same way as contamination.

Thom et al. (2006) concluded that the service provider training may have been insufficient, and a more intensive intervention component may be required. Sequist et al. (2010) noted that not all of the primary care team attended training. However, other trials discussed above have used very brief interventions with positive outcomes. In addition to that, an earlier study by one of the authors found that:

“Patient socio-demographic factors explained 13% to 38% of the racial differences in these measures [clinical diabetes outcomes], whereas within-physician effects accounted for 66% to 75% of the differences” Sequist et al. (2008) p1145.

It would seem that there is a high possibility that some physician effect has occurred in both samples, which may be related to either the limited amount, or quality of the intervention component, physician inertia or lack of engagement with the training. However, in Sequist et al. (2010) it is also difficult to explain that even with receiving feedback on prescribing rates and clinical data, and reporting an increase in the awareness of treatment differentials, black service-users were still not at an acceptable level of statin therapy, or cholesterol control, by the end of the trial.

An indication of physician attitude to sensitivity and diversity training may be evidenced in a qualitative study with medical students who were required to attend a module on social and cultural issues. Although they completed the module, they indicated that the module content would make no difference to how they practiced on their clinical rotations (Beagan 2003).

It would seem that in the case of Majumadar (2004) failure was due to design issues and in the cases of Sequist et al. (2010) and Thom et al. (2006) the failure was at a structural or contextual level. It would seem that unless structural interventions are associated with process interventions to bring about a change in service-user clinical outcomes the interventions are likely to fail.

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6.8.3 Service-user satisfaction

Four trials included service-user satisfaction ratings of providers who had also been trained in cultural competence (Harmsen et al. 2005; Majumdar et al. 2004; Thom et al. 2006; Wade & Bernstein 1991). Service-user satisfaction is an important concept in assessing quality in health care, and one of the most consistent findings is that the better 'personal' or inter-personal care is perceived, the higher satisfaction ratings are (Cleary & McNeil 1988). It is also one of the most difficult to assess as there are numerous issues that lead to non-response, and people may be satisfied with a poor service (Campbell et al. 2000b; Cleary & McNeil 1988). In addition, there are extra considerations when working with surveys with minority groups that can cause reliability and validity problems (Pasick et al. 2001).

Satisfaction: trials that demonstrated effectiveness

Only one study resulted in improved satisfaction ratings for service providers (Wade & Bernstein 1991). A randomised controlled trial aimed to assess if mixed ethnicity counsellor/client dyads were as effective as same ethnicity dyads. To test this hypothesis four white and four black female counsellors counselled a sample of 80 black females in a college counselling service (Wade & Bernstein 1991). Two white and two black counsellors were randomly allocated to receive the intervention component of four hours of cultural competence training. The intervention component focussed on problem articulation with minority group clients, followed by practicing skills using role-play.

Black female clients rated counsellors on session satisfaction, credibility, and trustworthiness. The intervention group counsellors were more highly rated than the control group counsellors, and although race was not a factor, same ethnicity dyads

(client/counsellor pairs) suffered less attrition than mixed ethnicity dyads. This study found that cultural competence training contradicts the perception that same ethnicity dyads are more effective than mixed (Atkinson & Schein 1986; Vontress 1971).

Although there was less attrition in same ethnicity dyads the counsellors' ethnicity did not affect the positive ratings of the counsellor, or the counselling process.

Satisfaction: trials that failed to demonstrate effectiveness

Three trials described training service providers on cultural competence courses and assessing the efficacy of this process with service-user ratings and all failed to report an improvement for intervention groups (Harmsen et al. 2005; Majumdar et al. 2004; Thom et al. 2006). It has been demonstrated that this is achievable with a short training course of four hours (Wade & Bernstein 1991). A more recent but less robust study has reported the opposite, and claimed that the association between self-report ratings for cultural competence and client satisfaction ratings is uncertain (Constantine 2002).

Details of these studies are provided above; one was with nurses in Canada but had some design problems (Majumdar et al. 2004), for example a high rate of sample attrition. Nurses in both groups worked with one service-user, resulting in strong emotional bonds developing over the period of the study. As a result of these bonds, levels of satisfaction could be the same for control and intervention groups.

A second trial found that primary care physicians in Holland trained in cultural competence had higher service-user satisfaction ratings than the untrained control group, but this was not significant (Harmsen et al. 2005). This is despite the intervention group being rated higher on quality of care and mutual understanding. It

is feasible that there could be increased mutual understanding and good quality care without improved satisfaction. This outcome could be related to the physician effects described above (Sequist et al. 2008).

Finally, a trial involving diabetes management failed to find a difference in satisfaction ratings between the control and the intervention groups (Thom et al. 2006). The design of the study could have confounded this outcome: the physicians in both groups received performance feedback and therefore both groups could have acted on this, resulting in similar ratings of satisfaction.

Synthesis

Effective communication is just as important in same language consultations.

However, it was suggested that although people speak the same language, if they are from a different culture communications could be impaired (Atkinson & Schein 1986; Sue 1981; Vontress 1971). Wade and Bernstein (1991) demonstrated that this is not the case. Ethnicity was not a factor that influenced client's ratings of counsellors who had undergone cultural competence training. The counsellors in this study were experienced and they received a minimal intervention of four hours. What the counsellors needed was an intervention component that would facilitate the acquisition of client-specific knowledge, and an opportunity to practice the necessary modifications to their existing skills to make them appropriate for the sample of clients. The intervention component worked and the counsellors who received the training were rated more highly than those who did not (see Table 6.4).

Wade and Bernstein (1991) found that attending a cultural competence course increased clients' ratings of counsellors on satisfaction, trustworthiness, and skill, as well as increasing adherence levels for the clients.

Two correlation studies have looked at rating of counsellors by ethnic minority group clients (Constantine 2002; Fuertes et al. 2006). In one study, students from minority groups who had withdrawn from counselling were asked to rate their ex-counsellors from their sessions (Constantine 2002). Most of the counsellors were white, but it was found that there was a strong positive association between the students' ratings of counsellors' skills, and ratings of counsellor empathy, trustworthiness, and warmth. In the second study, a multicultural sample of current counselling clients returned similar associations but in addition these were also strongly associated with counsellors' own self-rating of counselling skills. In general, as counsellors' skills self-rating scores increased, satisfaction scores increased, as did perceptions of empathy and trustworthiness.

For cross-cultural counselling relationships to be successful they seem to require a combination of client confidence in the service provider, developed from a regard for levels of skill, and perceived levels of counsellor empathy and trustworthiness.

Context	Component	Mechanism(s)	Outcome
Counsellors, USA mixed ethnicity dyads.	Techniques to modify existing skills, to work with culturally diverse clients.	Raised awareness, increased skills, increased knowledge Confidence in skill Positive regard (service provider)	Increased satisfaction with consultations

Table 6.4 CCMO for service-user satisfaction ratings

The greater the skill the greater the client confidence: this provides more support for a *confidence in skills* mechanism for service providers and *positive regard* for service-users (see Table 6.4).

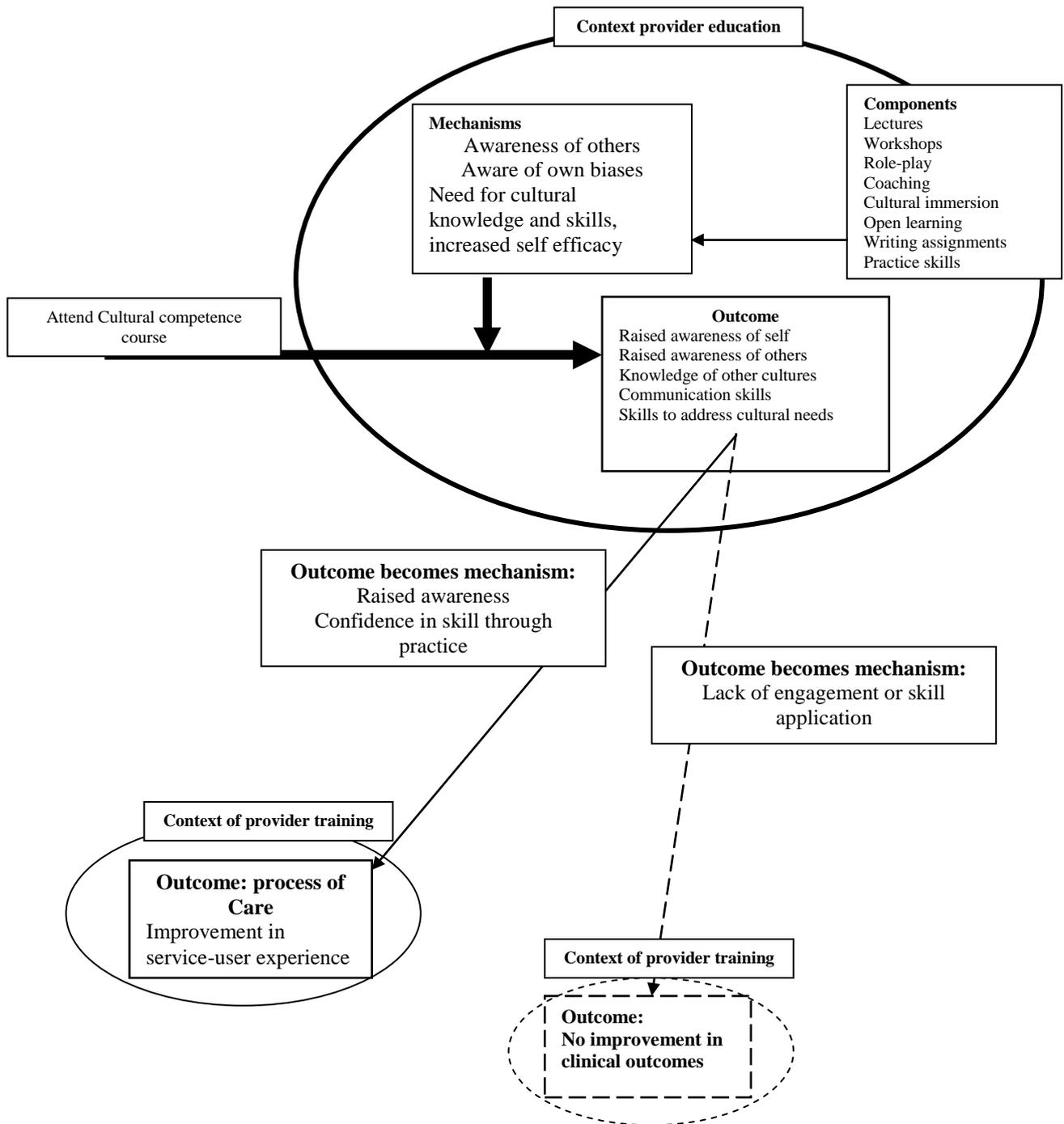


Figure 6.9 Concept chart connecting three types of outcome by C-M-O links

6.8.4 Conclusion

The findings of these sections of Chapter 6 were brought together into a concept chart that attempts to illustrate how these parts combine (Figure 6.9). Figure 6.9 suggests how the findings from the sections above can be combined to map the evidence found, to support the efficacy of cultural competence training and suggest mechanisms that brought about the outcome. In addition these findings will be used to support the components of the conceptual framework described earlier (Figure 6.8). This is necessary as none of the frameworks or models used in the earlier syntheses cited independent evidence for support. Though many of the trials reviewed in this section cited cultural competence models, only two explicitly used these models to design interventions, with mixed results (Berlin et al. 2010; Smith 2001).

At the top of the diagram there is a large oval which indicates the relative size of the body of evidence that indicates this CCMO configuration is successful. On the left hand side, the intervention component of skill practice has facilitated the mechanism of *confidence in skills*, which has had an effect of increasing satisfaction for service-users resulting in increased ratings of the service providers; this CCMO configuration was moderately successful. On the right hand side, a smaller body of evidence, but two large trials, failed to improve diabetes control. Here the intervention components were ineffective, or inertia by physicians caused a lack of engagement resulting in no improvement in service-users' clinical outcomes, rendering this CCMO configuration unsuccessful.

Where outcomes were based on service providers' self-reports, after an intervention of cultural competence training. they were perceived to be effective. This is based on

the aggregation of a range of interventions, with a range of disciplines on a range of outcome measures. When service providers were trained in cultural competence and the outcomes were based on service-users rating they were perceived to be moderately effective. The effective studies tailored the training intervention to suit the clinical interaction and a practice component. Where service providers were trained in cultural competence and outcomes were based on clinical assessments these were ineffective. Despite brief or intensive interventions with nurses, physicians or practice nurses, service-users' clinical outcomes did not improve.

It would be naive to think that a training module, with a chance to practice skills will automatically and consistently result in improved experiences and outcomes for service-users. What is known is that training people on cultural competence courses with a range of intervention components will increase their self-reported levels of cultural competence. There is some evidence that a practice component does seem to be effective in this small number of studies. To take this investigation further these findings were presented to a stakeholder group in a 'learner-teacher' exercise (Pawson 2001) to listen to their views on these findings, and discuss them in light of their experience.

6.9 Stakeholder group review

Background

Working with stakeholders is an integral part of realist work (Greenhalgh et al. 2009; Pawson 2001; Pawson & Tilly 1997). The rationale behind this is that every stakeholder involved in a programme of work has something to contribute.

Sometimes key points can be made unwittingly, and at other times listening to a stakeholder's perception of the problem, or the findings, can re-frame or re-focus the

investigator's own understanding. Pawson (1997), describes these sessions as 'learner-teacher' sessions, as the teacher (investigator) listens to the learner (stakeholders). It is the active listening element that elicits the most from these sessions (Walter et al. 2005). It is also the case that stakeholders may have the experience to comment on the structures and processes of care that can act as barriers and facilitators to implementing cultural competence in practice (Smith & Donze 2010).

Stakeholders

The stakeholders for this meeting were all associated with a university department of nursing. Including the author, six people attended, one male and five females aged from 22 to 61. Two stakeholders were of South Asian heritage and the remainder were white European. Four of the stakeholders had taught cultural competence modules either currently, or recently. Two stakeholders were leaders of programmes that include cultural components at home or abroad. The remainder were a recent graduate and a current student who is also a practicing research nurse, employed by the department.

Stakeholder session

All stakeholders were asked individually if they objected to having the session recorded. To protect confidentiality and anonymity, stakeholders were assured that the voice files would be destroyed after the recording had been analysed. The session was started by providing background information about the thesis, then asking some trigger questions about cultural competence to prompt discussions (see Appendix 15). The session lasted for two hours, and the findings of the realist review were presented for discussion (see Appendix 15).

Data processing

When the session had finished the voice file was analysed using Atlas-ti (Muhr 2010), a qualitative data management application. Sections of the voice file were marked with a numerical code; later the coded sections were reviewed a second time, and the code was renamed with a statement that summarised the content. These statements were exported to a text file, together with start and stop times for each statement. The text file was entered into Atlas-ti and the statements categorised using standard text coding procedure; many of the codes were *in vivo*, meaning the code was the same as the statement in the audio file. Actual quotations were also transcribed verbatim and added to each category for illustrative purposes. This is an effective and efficient way of extracting qualitative data while still accessing the audio discourse interactions (Halcomb & Davidson 2006).

Findings

After coding the text file in Atlas-ti, it was analysed using a thematic analysis and the results are shown below:

Organisational: *We cannot go back to how we were, in terms of who we look after and who looks after us* (Stakeholder).

- Cultural competence needs to be seen as important and not a passing phase
- Cultural competence needs to be an integral part of caring not an option for when time or resources are available
- Cultural competence needs to be separated from political correctness (cause for concern)

Education: *Cultural competence needs to be part of a wider approach* (Stakeholder).

- Cultural competence should be embedded teaching: teaching cultural competence cannot be a single or optional session, it needs to be a part of every sessions and module if possible just as ethics and safety are
- Cultural competence curriculum needs staff consensus
- Cultural competence should be an element on the practice assessment document
- Cultural competence needs to be seen as part of the objective of internationalism in nursing education
- Multicultural student groups can help to explore this issue

Leadership: *Cultural competence needs trickledown management (Stakeholder).*

- Clinical leadership needs to perceive cultural competence as important
- Role models and mentors need to demonstrate cultural competence
- Pre-registration nurse training and monitoring needs to assess cultural competence
- Strategies are needed to address inappropriate values-systems of individuals
- Clinicians need to understand service-users' priorities and values
- Leaders must be aware of cultural competence, and assist team members with stages of competence (From unconscious incompetence to unconscious super-competence)

Awareness: *When I saw my own prejudices...written on the flip chart... I was shocked...*

- Cultural immersion brings awareness to the forefront
- Raised awareness of self and own biases are essential for cultural competence
- Empathy is important and developed through examining own experiences in other cultures
- An uncomfortable frame of mind regarding biases raises awareness
- Brown eyes-Blue eyes study demonstrates discrimination (Elliott 2011)
- Minority group service-user engagement in teaching sessions to explore biases
- Cultural competence is not limited to visible minorities' care
- Embed cultural competence in all clinical sessions
- Explore individualism and values
- Many people are unaware of biases

Knowledge: ...*The knowledge bit is easy...it's what they do after...*(Stakeholder)

- Cultural competence results from basic good care
- Knowledge can be taught but practical experience is essential
- Awareness must precede knowledge

Skills *When you are busy, [on a ward] there is no time for the niceties ... [cultural competence] Stakeholder.*

- Develop basic admittance skills
- Confidence in cultural competence skills is important
- Causing offence is a concern
- Remedial strategies for inadvertent offensiveness
- Intercultural interactions need sincerity and transparency.

6.9.1 Evaluation

Cultural competence training

There was not full agreement about the importance of cultural competence in education and practice environments. For example, some stakeholders recognised that cultural competence can be seen in nursing practice as an option, to be put into practice when the ward is less busy, and that cultural competence training is seen as important but not essential.

Some of the stakeholders realised that the teaching of cultural competence needs to change. Cultural competence is currently taught as sessions in course modules and some of these are optional. There were recommendations that cultural competence would be better taught as a theme in clinical sessions, just as dimensions of safety and ethics are currently.

It was also recognised that knowledge and skills can be taught, but to make these effective, the new skills need to be practiced, monitored, mentored, and assessed in the workplace. The stakeholders indicated that awareness of biases and diversity issues, especially raising awareness of one's own biases, was the key to encouraging students to engage with the concept and develop cultural skills. Finally, cultural competence needs to be seen as important, and valued in the workplace.

Reviewing the output from the stakeholder session in light of the findings in earlier sections, some mechanisms can be suggested that could help service providers to develop cultural competence:

- Raised awareness of own biases
- Feeling well regarded as skilled in cultural competence
- Confidence in skill application
- Assuage feelings of discomfort with bias
- Assuage feelings of discomfort with awkwardness in interactions
- Vicarious reinforcement (role models).

Conclusion

This review and synthesis using realist principles described interventions that found it challenging to train service providers in cultural competence and moreover to expect this to have a positive impact on service-user clinical outcomes and experiences. The stakeholder group review of the findings brought reality to the rhetoric, and demonstrated why these studies found improving service-user outcomes a challenge. The stakeholders have described training and workplace environments that see cultural competence as important, but essentially an optional extra. They also

describe feelings of a lack of confidence and support when dealing with members of minority groups. In addition, they considered workplace support for those with new cultural competence skills, in the form of leadership and mentoring, as essential to ongoing development. They indicated that currently the provision and effectiveness of support varies from poor to excellent, depending on location. It is proposed that these structural changes will be required to facilitate the mechanisms described above, to assist the transition from novice to accomplished practitioner.

6.10 Extension of the evidence base

It would seem that in the stakeholder event, educators and practitioners have described the possible mechanisms that could trigger the outcome of true cultural competence. It is evident that structural changes are required to put these mechanisms in place, and bring about improvements for service-users from minority groups. The evidence has shown that training service providers in cultural competence results in limited improvement in service-user outcomes. Realist synthesis involves collecting evidence, comparing the evidence in light of the propositions of the investigation, and seeking alternative sources of confirmatory or contradictory evidence (Pawson et al. 2005). What is now required is to seek evidence from other contexts to add another perspective to the programme theories that were generated by the realist synthesis, and the stakeholder review (Pawson et al. 2005).

To explore the possibilities of evidence from other contexts a search of Medline, CINAHL, and Embase was conducted using the following search strategy (adapted to each search engine): Ethnic* OR Minorit* AND trial OR intervention OR control* AND culture* AND specific AND competent. The articles that resulted from this search were screened to see if they could contribute to confirming or contradicting the

findings of this Chapter so far. The search resulted in 418 articles from Medline, 136 articles from CINHALL and 98 articles from Embase. After removing duplicates there were 438 articles in total.

After screening the articles by titles, 24 problem-focussed, culturally competent interventions were retrieved. The screening criteria were; controlled trial; identifiable minority group, or high percentage in sample; problem-focussed intervention; and targeting a specific health condition. The title screening was also carried out in parallel by an independent associate, but not the abstract screening. A good level of agreement was reached and a consensus was arrived at for 24 articles. A further screening of the abstracts removed 12 studies for not matching the above criteria, leaving 12 controlled trials that investigated problem-focussed interventions with minority groups.

The data from these 12 articles were extracted using the same database and forms used in the systematic search in Chapter 5, and the data was entered into the same database as described in Chapter 6. This was not a full systematic literature review but a scoping review approach was used to assess the quality and breadth of literature available (Hagell & Bourke Dowling 2012). Because of this no additional search practices were undertaken, such as hand searching reference lists, or targeting salient journals for further material.

6.11 Scoping review

The studies were evaluated using the criteria in Table 4.2 to assess if they were fatally flawed; all were deemed acceptable. No study in this group explicitly described a cultural competence framework as underpinning the approach. The majority of the

studies (9) were carried out on the USA, two in the UK and one in Israel. Four of the studies considered primary prevention, four considered treatment management, and two each on health screening initiatives and psychological problems.

Primary prevention

The four studies in primary prevention contexts looked at increasing activity levels (Newton, Jr. & Perri 2004) smoking cessation (Wetter et al. 2007) sexual health (O'Donnell et al. 1995) and obesity (Kalter-Leibovici et al. 2010).

Three of the primary prevention studies were carried out in the USA with African-American or Hispanic minority groups (Newton, Jr. & Perri 2004; O'Donnell et al. 1995; Wetter et al. 2007). The three studies used random allocation to the study groups, and the sample sizes ranged from 32 to 1653 service-users. The fourth primary prevention study was conducted in Israel (Kalter-Leibovici et al. 2010); this was also a randomised design, with a sample size of 201 obese Arab females.

The intervention components (see Table 6.5) in these studies were each specifically designed to suit interventions and the target groups. Three of the studies used some form of group activity as an intervention component; these were also specifically designed to meet the needs of the target groups. However, the smoking cessation study used telephone counselling, and therefore did not use group activities (Wetter et al. 2007). Group activities were usually used in conjunction with other components, but the power of meeting with other people who are in similar circumstances cannot be underestimated (Frasure-Smith et al. 2000).

A unique enrolment approach was used in the smoking cessation study to encourage participants to telephone the counsellors. Targeted, paid-for television advertisements in Spanish were commissioned, which raised the response rate from 0.4 per month to 18 per month. This approach was deemed successful, as 90% of the calls were from groups previously described as hard to reach (Wetter et al. 2007).

All four studies had positive service-user outcomes, these include: increased exercise activity and cardio-respiratory fitness for African-American adults (Newton, Jr. & Perri 2004); increased number of Mexican-Americans wanting to cease smoking, with a low attrition rate (Wetter et al. 2007); weight reduction and improvement in triglyceride levels for Arab women (Kalter-Leibovici et al. 2010); and increased condom use and STD risk awareness, in African-American and Hispanic groups (O'Donnell et al. 1995).

Context	Component	Mechanism(s)	Outcome
USA and Israel Primary care prevention initiatives specifically designed for the target group.	Culturally specific counselling strategies, Support group activity. Guided exercises.	Feeling supported Feeling valued Confidence in programme	Weight reduction and improved triglycerides Increased fitness levels
Smoking cessation	Targeted TV adverts Telephone counselling	Intrinsic and extrinsic positive reinforcement	Smoking cessation: Increased number of callers for counselling
Condom use and sex risks	Specifically designed video and print material.		Increased condom use and awareness of risks

Table 6.5 CCMO Primary prevention culturally competent strategies

The components and mechanisms that may have facilitated these outcomes in these contexts have been suggested in Table 6.5. These will be discussed at the end of this section.

Condition management

Three trials investigated diabetes management (Bellary et al. 2008; Rosal et al. 2005; Sixta & Ostwald 2008) and one end-of-life care (Song et al. 2010). Three of the studies took place in the USA, and one in the UK (Bellary et al. 2010). All four studies randomised service-users to study groups, and the sample sizes ranged from, 19 to just under 1500 participants. The intervention components for these studies were designed specifically for the target groups and their health care problems. In the diabetes management interventions, one study used a problem-focussed team with a complementary skill-set. These included diabetes specialist nurses, coordinators and link workers. These teams understood the needs of South Asian service-users, and tailored their approach accordingly (Bellary et al. 2010). Another study used a series of specifically designed group sessions to work on motivation and practical diabetes management strategies with Spanish speaking Americans (Rosal et al. 2005). The final intervention used 'promotores', or community based support workers, as a conduit for information and training from a clinical team to manage diabetes in a group of Mexican-Americans (Sixta & Ostwald 2008).

The end of life care intervention worked with African-American service-users with kidney disease. The intervention component was the provision of a service-user-centred advanced care planner who worked with a service-user on a one-to-one basis (Song et al. 2010).

Two trials improved service-user outcomes by improving diabetes management and increasing levels of exercise (Bellary et al. 2010; Rosal et al. 2005). With service-users on end of life care, 90% of service-users, in the intervention group expressed a

wish to continue all life-sustaining treatments, which was seen as an improvement compared to the control group (Song et al. 2010). The one unsuccessful diabetes management trial improved diabetes knowledge, but not diabetes control (Sixta & Ostwald 2008).

In these problem focussed studies described in this section, the intervention components that facilitate mechanisms (see Table 6.6) are operating to bring about an improvement in diabetes control and end of life care. One suggestion is that the service-users develop a sense of being valued and regarded because of the close involvement of the components, such as: problem-focussed teams, or telephone counsellors, and because of the extra effort involved to understand their cultural needs.

The two studies of diabetes management (Bellary et al. 2010; Rosal et al. 2005) are in contrast to the diabetes management programmes described previously (Sequist et al. 2010; Thom et al. 2006). Where these successful/unsuccessful programmes differed is the interface with the service-user. The trials that were unsuccessful trained primary care physicians and expected them, even with feedback, to have an impact on clinical outcomes. The successful trials used a multi-disciplinary approach, with a complementary set of skills that had an impact on the service-user and their clinical outcomes. For the teams in the successful trials, intervening was the focus of their work. The individual physicians in the unsuccessful trials had other calls on their time.

Context	Component	Mechanism(s)	Outcome
Diabetes management in the UK and USA with South Asian and Hispanic groups.	Dedicated teams that understand the cultural and clinical needs of the target minority groups	Feeling supported. Feeling valued.	Diabetes control improvements, increased exercise.
End of life care in the USA with African-American kidney service-users.	Patient-centred Advance care planners with awareness of cultural needs	Confidence in programme. Intrinsic and extrinsic positive reinforcement.	Willing to continue with life sustaining measures. Improved diabetes knowledge but not improved control
Hispanic communities: diabetes management via promotores.	Promotores providing information from clinical team		

Table 6.6 CCMO for Condition management culturally competent strategies

Considering the mechanisms that may be bringing about the outcomes can provide some insight into why one study showed an improvement in diabetes knowledge but not diabetes management (Sixta & Ostwald 2008). What may be responsible for the lack of success was the use of promotores; these community members had been trained to act as agents between the community and the clinical team. In this case, the promotores involvement should have helped to improve HbA1c levels for service-users in the intervention group, but they did no better than controls on a waiting list. The promotores may have prevented the mechanisms from having an effect. This lack of a close and appreciated involvement of health professionals may not provide the intrinsic and extrinsic motivation required for compliance with a regimen when it is facilitated by a third party.

Screening

Health screening was the focus of two culturally competent intervention trials. One study looked at prostate cancer screening for 238 African-American males in the USA (Taylor et al. 2006). A second was a blood screening initiative for genetic disorders

in the UK. The genetic screening initiative was carried out in an area where 43% of births are to ethnic minority parents at high risk of haemoglobin disorders (Modell et al. 1998).

The intervention component in the prostate cancer study was a set of specifically developed information materials, in the form of video and booklets. This material was designed to address the cultural needs of the African-American sample. In the genetic screening study, the main intervention component was a nurse facilitator who provided a full time link to resolve communication problems between the primary care teams, haematology laboratories, and the service-users (Table 6.7).

Prostate cancer screening significantly improved for the intervention groups, but there was no differential effect for the booklet or video (Taylor et al. 2006). Genetic disorder screening in the intervention group increased 90%, compared to screenings the year before, whereas, control group screening requests decreased by 23% (Modell et al. 1998).

Context	Component	Mechanism(s)	Outcome
Genetic disorder screening in UK, high risk minority group locations	Dedicated nurse facilitator to improve recruitment and communication difficulties between agencies	Raised awareness of specific problem Increased ease of access to screening	Increased screening attendances
Prostate cancer screening in USA with African-American males	Culturally appropriate information video and booklet		

Table 6.7 CCMO for culturally competent screening programmes

The greatest barrier to not attending screening is a low level of awareness (Austin et al. 2009; Robb et al. 2008). In the prostate screening study the intervention component was the awareness raising strategy and the culturally specific materials (Taylor et al. 2006), and in the genetic screening, the strategy was the pro-active approach of the nurse facilitator (Modell et al. 1998), and both interventions were specifically targeted at high risk minority groups. The results were greater levels of screening attendances in areas that previously had low levels (Table 6.7).

Psychological

Two community based randomised controlled trials in the USA looked at depression (Miranda et al. 2003), and panic attacks (Roy-Byrne et al. 2005) (Table 6.8). In the depression trial just fewer than 1200 participants were recruited from 46 primary care practices, two thirds were white and the remainder African-American or Hispanic. The intervention component consisted of a problem-focussed, team-based approach that had developed material specifically for the minority groups. At six and twelve months the minority groups were significantly less likely to report probable depression, and more likely than at baseline to be on appropriate care (Miranda et al. 2003).

A team-based approach was also used in the panic attack trial. An ethnically diverse sample of 232 adults was allocated to intervention or control groups. The intervention component was to provide up to six sessions of cognitive behavioural therapy over 12 weeks and follow-up calls for nine months. The component team consisted of therapists and primary care physicians, working with a psychiatrist and pharmacist to administer a pharmacotherapy algorithm. At three months and twelve months follow-

up, the intervention group positively responded to the treatment compared to no change in the control group (Roy-Byrne et al. 2005).

Context	Component	Mechanism(s)	Outcome
Primary care team-based approaches in the USA Range of ethnic groups	Specialist teams that understand the cultural and clinical needs of the target minority groups	Feeling supported Feeling valued	Reduction in panic attacks
Panic Attacks		Confidence in programme	More likely to be receiving appropriate depression treatment
Depression	Culturally specific material provided	Intrinsic and extrinsic positive reinforcement	Less likely to be depressed

Table 6.8 CCMO for psychological disorders

6.12 Section conclusion

This scoping review retrieved 12 trials that did not formally train service providers in cultural competence, but used problem-focused culturally competent interventions and achieved success in all but one trial. The studies discussed in this scoping review (section 6.11) show that problem-focussed intervention components using appropriate resources can facilitate the initiation of mechanisms that brought about an improvement in experiences and outcomes for service-users (see Tables 6.5 -6.8). Though all but one of the studies improved outcomes for service-users, the mechanisms that triggered the successes can only be proposed at this early stage, however a body of evidence such as this can be sufficient to develop the initial programme theory (for example, problem focussed interventions can improve minority group service-users' outcomes) to a mid-range theory for further development.

The mechanisms set out in the CCMO table (Tables 6.5 -6.8) are what are considered to be facilitated by intervention components to bring these outcomes about. Feeling valued, regarded and extrinsically motivated may develop from the effort and resources that have been invested by the intervention teams. Intrinsic motivation and reinforcement may develop when a service-user recognises an improvement in their health condition; this may feed-forward to drive the service-user to further improvements, or to maintaining a stable condition.

The effect of the mechanisms of feeling valued, positive reinforcement and intrinsic and extrinsic motivation may be supported by a deviant case (Sixta & Ostwald 2008). In this study the component of a promotores was acting as a third party between the clinical team and the service-users with diabetes. The promotores may not have been valued as much as contact with a problem-focussed team with appropriate skills; this may have reduced the possibility of a valued extrinsic reinforcement. This lack of contact may have led to poor compliance with the prescribed regimen and thus no improvement in diabetes management and no intrinsic motivation.

This section has demonstrated how important the recognition of intervention components is. They may be an element of the overall context, but one of the arguments of this thesis is that intervention components should be recognised for the essential part they play in facilitating mechanisms to improve service-user outcomes.

The trials in this scoping review were of moderate quality, some with small samples and some with a risk of intervention contamination for the control groups. However,

these were generally pragmatic, real world initiatives and apart from a single trial they did improve clinical and non-clinical outcomes for service-users. A contributing factor to the success could be the level of structural engagement that facilitated a defined and specific set of processes. It requires a structural approach to instigate the interventions described in this section. For example the genetic screening programme (Modell et al. 1998) intervention was a community nurse who had a full time job acting as a coordinator between primary care, the blood screening laboratories, and supporting families. This required a structural approach to employ the nurse and enable coordination paths between the different providers.

By establishing structural interventions with culturally appropriate processes, these trials improved service-user outcomes without training service providers on cultural competence courses. However, the extra resources involved in providing these specialist intervention components may not be sustainable in supporting standard or regular service provision. It has been established that minority group service-user outcomes can be improved by making structure and process of care changes. Now a way needs to be found to make such improvements possible by training service providers in cultural competence.

6.13 Chapter conclusion

This thesis began by questioning what the barriers were to equitable stroke care for people of South Asian heritage. It was found that one of the major issues was that service-users had a perception that they were not being treated as well as they could have been. It was decided that service providers may lack cultural competence, that is they did not have the levels of cultural knowledge, skills and awareness to work appropriately with people from backgrounds different from their own.

In an effort to investigate how to address this issue, conceptual frameworks of cultural competence were explored. It was found that two syntheses of existing frameworks had been carried out but neither of these encompassed all the available components of a cultural competence framework. By reviewing the original sources of the two syntheses and using concept mapping a new meta synthesis was undertaken and a revised framework for cultural competence was proposed.

Independent evidence in support of the framework components was not cited by either the original framework developers, or the authors of the two recent syntheses. This Chapter has reviewed the available independent evidence and at the same time explored the efficacy of cultural competence training; the evidence was mixed and was mostly concerned with the processes of culturally competent care. When stakeholders reviewed the findings they suggested that structural solutions were required. Alternative evidence was sought and this confirmed that structural influence is generally required for a successful outcome. Eleven out of 12 of these trials were successful in improving service-user clinical outcomes by using problem focussed culturally competent interventions. However, it would be unrealistic to establish specialist problem focussed interventions as part of routine care. The next chapter brings the parts of the thesis together and makes suggestions to move forward by training all service providers in true cultural competence to improve minority group service-users experience of the process and outcome of care.

This chapter has gone part way to achieving the aims and objectives of Part 2 of this thesis. Part 2 aimed to explore what can be done to address the barriers for people of

South Asian heritage accessing equitable stroke care. The literature on conceptual frameworks and models has been reviewed (i), and a new Meta synthesis of a conceptual framework has been undertaken (iii). The evidence to support this new model has been evaluated (ii), and the next chapter will see these themes drawn together and culminate in the proposal for developing true cultural competence with service providers.

Part 2

Chapter 7

Findings and discussion

7.1 Introduction

The aim of this thesis is to explore the needs of people of South Asian heritage in accessing equitable stroke care and suggest ways in which these needs could be addressed. Members of South Asian minority groups collaborated in focus groups and individual interviews to explore these needs (Part1). Strategies to address the identified needs were developed from a review and evaluation of the literature using realist principles, and were confirmed with a stakeholder review of the findings (Part 2).

The empirical work in Part 1 addressed Research Question 1: ‘What are the issues for people of South Asian heritage in accessing health (stroke) services?’ The context of stroke and minority groups in the UK was discussed then focus groups were used to inform an interview schedule which was used in individual interviews. The findings indicated that participants who had not used stroke services held positive expectations about those services. Participants who had used stroke services had negative perceptions about their experiences. It was suggested by some Stroke survivors that to remedy this situation staff might need training to be competent to work with service-users from different cultures. A subsequent review of the literature on barriers to equitable access to health care validated and supplemented the findings. Part 1 concluded that service-users from minority groups may not be receiving an equitable level of care compared to the general population. To remedy this service providers needed to be culturally competent to provide appropriate care for minority groups

Part 2 addressed Research question 2: ‘What would be the (stroke) service requirements to meet these needs and overcome the issues described in Part 1?’

To address the objectives a number of tasks were undertaken. Firstly to review and meta-synthesize the constituent frameworks and models used in two independent syntheses of cultural competence conceptual frameworks (Balcazar et al. 2009; Jirwe et al. 2006). This work validated the core components of existing syntheses, but found that there was limited evidence to support the propositions. Secondly, to undertake a systematic search for independent evidence to support the component parts of the resulting new conceptual framework, and review the evidence using realist principles. The new conceptual frameworks and indications of evidential support are presented in Figure 6.8. The conceptual framework for cultural competence are generally based on cultural awareness, knowledge and skills components. These are the components typically used in cultural competence training interventions. The strength of evidence for the efficacy of these interventions varied by the outcomes assessed. Where intervention outcomes were based on service providers’ self-reports they were perceived to be effective; where outcomes were based on service-user ratings they were perceived to be moderately effective, and where outcomes were based on clinical assessments they were perceived to be ineffective. A stakeholder meeting was convened to consider the findings of the review and to suggest mechanisms and intervention components that were considered essential to providing practical culturally competent care.

The review and stakeholder suggestions prompted an extension of the investigation. This found that individuals or teams with effective levels of cultural skills providing

subject-specific health interventions improved service-user ratings of their perceptions of services, and had an effect on clinical outcomes. In realist terms this approach worked for a range of conditions, with a range of service-users, by a range of service providers. This indicates that improvement in service-users' experiences and clinical outcomes are possible when structures and processes of care have been reconfigured to a specific purpose. Therefore culturally competent processes are necessary (via training or approach) to improve experiences and outcomes for minority groups, but not sufficient without structural changes (Campbell et al. 2000b).

The next section will reflect on the findings in more detail and examine them in light of the literature, before moving to propose a further development of the new (meta-synthesis) conceptual framework for cultural competence. This framework, based on the best available evidence, will suggest how true cultural competence can be achieved in practice, and shows emphatically the contribution to knowledge of this thesis. This further development completed the final objectives for Part 2.

7.2 Part 1: Group and individual interviews

Part 1 consisted of Chapters 2 - 4 and the aims were to address Research Question 1 by establishing the context of South Asian minority groups in the UK, the political and clinical observations of these groups and how stroke affects this group. With the context established explore the experiences and perceptions of South Asian groups in one area of the UK. From these findings develop a tentative hypothesis that proposes the issues for these groups accessing equitable stroke care. Finally review the literature reporting barriers to accessing equitable care in the UK.

Chapter 2 established that for minority groups in the UK there have been calls for services to be made appropriate to the health needs of these groups (CHAI 2006; DH 2001; ICWPS 2000; IWPS 2004a; IWPS 2008), to be culturally appropriate (NICE 2008), to raise stroke awareness (NAO 2005) and to monitor service use by minority groups more effectively (APHO 2005).

Chapter 3 described how such services could be improved for minority groups, by using focus groups and individual interviews. Focus groups, with members of local South Asian communities, described their views on stroke care. These views were used as a reference framework for subsequent individual interviews. The service-users interviewed reported different issues depending on whether they had experienced, or not experienced, a stroke. The outcome was that stroke awareness was low, and that there was a perception the service providers were not culturally competent.

7.2.1 Participants who had not used stroke services

The non-stroke service-users were asked to respond to vignettes, and then answer questions about them. The vignettes were typical stroke or TIA situations, and explored issues of recognition of, and reaction to, the stroke event itself, as well as their experiences of an in-hospital stroke care pathway, through to transfer home. Most people could identify one or two stroke symptoms or risk factors but, reviewing the audio files, there was a notable hesitancy or lack of certainty in their responses. No participants knew what a TIA was, and nearly half would not call an ambulance even if they suspected a stroke. Before initiating emergency actions most would call a GP, or friends and family for support or information. These findings were supported by previous reports that minority groups, and the poorly educated, were consistently shown to have low levels of stroke awareness (Dr Foster Intelligence 2010; Jones et

al. 2010). Awareness of the effects of stroke is important, as health education has been shown to improve primary prevention of the major causes of adult deaths (Connell et al. 2008).

The participants were not reticent in accessing health care and claimed they would make a concerted effort to get urgent help if they suspected stroke symptoms. Few were aware that the group they belonged to (i.e. South Asian heritage) were more likely to suffer stroke than the general population (Gholap et al. 2010). Finally, when asked about how stroke services could be made more culturally sensitive, the general response indicated an expectation that these services were already culturally sensitive, but no clear explanation for this perception was provided.

The people from this group had limited awareness of stroke and TIA, signs and symptoms, or the associated risk factors. A lack of awareness could prevent people from these groups assessing emergency care if a stroke occurred, or from reporting TIA symptoms to their GP. A failure to report TIA symptoms to a GP could prevent management of the condition by the GP, or referral to rapid access clinics, both of which could help to prevent further TIAs, or full stroke in the future (Coull et al. 2004; Rothwell & Warlow 2005). This concern is supported with evidence, as risk factors for stroke and diabetes are more likely to be undetected and untreated in minority groups compared to the general population (Bennett et al. 2010; Patel et al. 2007).

7.2.2 Participants who had used stroke services

The participants who had experience of stroke also had limited awareness of stroke issues, and were unaware that the minority groups they belong to are more likely, than the general population, to suffer from stroke, and its risk factors: diabetes; and/or

hypertension (Gholap et al. 2010). This is especially important for those who have experienced a stroke, as management of the condition can help to prevent further strokes (Raine et al. 2009).

The Stroke survivors reported negative experiences of their care, which related to inter-personal care. Inter-personal care includes most of the non-clinical aspects of care; aspects rated negatively by the participants included: lack of courtesy, lack of respect, being ignored, poor communication, feelings of isolation, information giving, and lack of consideration of families. Despite this, none of the participants would let any of these experiences prevent them from accessing hospital stroke care again.

These participants did not raise any criticism of the quality of their clinical care. However, it may be difficult for the participants to make judgments about their clinical care, as there is a general lack of knowledge within South Asian minority groups of what is available (Madhok et al. 1992; Madhok et al. 1998).

The issue of poor inter-personal care has independent support in the literature in studies with service-users from visible minority groups. For example, poor communication (Johnson et al. 2004), less active engagement in provider - service-user interactions (Cooper et al. 2006), lower ratings of satisfaction (Taira et al. 2001) and perceptions of not being treated with respect (Collins et al. 2002). Service-users in these studies were asked how to improve such negative experiences; the response was that the staff needed to be trained in dealing with people from other cultures. This validates a proposition of this thesis that, from a structural perspective, systems need

to be put in place to facilitate culturally competent processes of care (Campbell et al. 2000b).

The phenomena of negative experience and positive perceptions of care was reported with a sample of Pakistani older adults (Cortis 1998). Service-users expected nurses to be caring, respectful, cheerful, and considerate, and to have an understanding of ethnic needs. What they experienced was ethnocentric attitudes and behaviours, which led to a poor understanding of minority group needs. This supports the findings for the experiences/perception dichotomy described above; also the findings that the focus of negative experiences were inter-personal care issues.

The findings of negative experiences of care described by service-users in this thesis and Cortis (1998) have support from an observational study where nurses had poor levels of cultural competence and engaged in victim blaming and ethnocentric practices (Vydelingum 2006). Service-user satisfaction with service provision is an important quality of care outcome measure, but caution must be used as it is seen to be related directly to the quality of the processes of care, but these are moderated by the unseen structures of care provision (Campbell et al. 2000b). In addition satisfaction is associated with level of illness and related to prior satisfaction with health service provision (Crow et al. 2002). Further, the characteristics of participants are not associated with dissatisfaction ratings, but are associated with the level and quality of care they receive (Pound et al. 1999).

The problem of negative experiences of care are not restricted to inter-personal care issues, as when some South Asian minority groups do access care, they are managed

differently from the general population. For example, Bangladeshis are less likely than white Europeans to have their cholesterol levels measured, or to receive statin therapy (Bourke et al. 2006; Hsu et al. 1999); South Asian diabetics on management programmes have different outcomes from white Europeans (Bellary et al. 2008), which leads to a higher risk of CVD (Bellary et al. 2010).

7.3 Part 1: Barriers to accessing equitable health care

Ethnic minority groups tend to be among the most deprived people in the UK (Oakley et al. 2009), and the likelihood of death from stroke and heart attack is strongly associated with deprivation in early life, which can transcend social improvement in later life (Ryan 2010). Low level of health education, social deprivation and poor access to non-acute services are associated with a lack of equity in service delivery (Dixon-Woods et al. 2006; Goddard & Smith 1998; Szczepura 2005). Thus, social deprivation and ethnicity are linked to inequitable health service provision. Although deprivation is a factor of inequitable health care, this does not explain why visible minorities who are not all deprived despite trans-generational transmission (Champagne 2010), are still receiving inequitable care (Bellary et al. 2010).

A problem investigating the issue of equitable service is that it seems to vary by the type of service. For example, Goddard and Smith (1998) reported that the socially deprived used GP and acute services more than other groups. An explanation for this could be the concept of service permeability, or the ease of gaining access to a service (Dixon-Woods et al. 2006). Accident and emergency and GP services are seen as more permeable than other services, such as psychology, rehabilitation and secondary prevention clinics (Shah & Cook 2008).

The concept of permeability does support some of the issues reported by the participants in Part 1, as no difficulty was reported gaining access to acute stroke treatment or GPs. The findings in Part 1 have further support from a recent review of a London hospital stroke register (Addo et al. 2011). It was found that the ethnic minority stroke sufferers were more likely than white stroke sufferers to gain access to acute stroke care. However, the findings also indicated that the rate of stroke admittances for the white population was decreasing and the rates for minority groups were increasing. This could explain the increased numbers from ethnic minority groups in acute stroke care, but it also raises a question of why minority groups' strokes are on the increase. An explanation for this could be that primary prevention and health information services are less permeable and so require a higher level of 'navigation' skills (Dixon-Woods et al. 2006).

For the participants in Part 1, accessing follow-up services, such as rehabilitation and clinics, was more problematic. In over half of the cases, the participants who suffered a stroke indicated that follow-up was not discussed or provided; the remainder had discussed post-stroke follow-up but, apart from instances of GP monitoring, rarely engaged with the services. Goddard and Smith (1998) also found that apart from the more permeable services like GP and A&E, other services were less permeable or more difficult to gain access to. These services included health screening, and care for long-term conditions.

Dixon-Woods (2006), in a review of similar literature, proposed that ethnic minority groups had problems accessing less permeable services because of problems with candidacy. Candidacy is the awareness of 'rights' to the services in question. People

from disadvantaged groups may not have a clear understanding of their candidacy. A review of access for minority groups claimed that two other concepts need to be considered that may inhibit access to such services, for example ‘newness’ and ‘linguistic factors’ (Szczepura 2005). Newness relates to a low frequency of interactions with health care systems, resulting in potential service-users unaware of what is available, or the confidence of the right to use it. Linguistic factors relate to the difficulty in fully understanding what is being described to service-users, for example how or when to take medication.

Newness and linguistic aspects relate to another of the concepts devised by Dixon-Woods (2006), that of ‘navigation’. Navigation is how a potential user of a service can negotiate barriers to obtaining that service. Service-users with limited English and lack of confidence or self-efficacy in dealing with complex access paths to services may fail to initiate or discontinue attempts to access health care (Szczepura 2005). Dixon-Woods (2006) provides evidence that the less permeable services, such as prevention clinics, rehabilitation, or elective surgery may require more sophisticated negotiations to gain access. Even NHS Direct may be difficult to ‘navigate’ by the disadvantaged as this requires a reasonable level of confidence and articulation (Shah & Cook 2008).

Candidacy, permeability and navigation can help to explain the negative experiences reported by the Stroke survivors. Despite gaining access to acute stroke care, the Stroke survivors experienced feelings of isolation, not being respected or considered, and had problems getting information on care issues that related to their cultural needs. Newness, linguistic factors and ethnicity related needs, over and above what

could be considered normal needs, may have been difficult for service providers to deal with (Szczepura et al. 2003). This difficulty may manifest itself in service provision being less permeable by being difficult to navigate and requiring candidacy from a group of service-users who lack the awareness and linguistic skills to claim that candidacy. This was evident in a study with Bangladeshi diabetes service-users who could gain access to services, but the attitude of the service providers prevented them from making full use of that service (Rhodes et al. 2003). It would seem that issues such as these may have played a part in the dissatisfaction with care by the stroke survivors' reports in this thesis.

A recent report by Goddard and Smith (2009) reviewed government policy as well as interventions addressing equity of access and their evaluations. Goddard and Smith (2009) proposed that although some improvements have been made, some of the policies have not worked and some may even have exacerbated the problem. The report also indicated that the main problem that contributes to these policy failures is that the main barrier to access in each case had not been identified prior to implementation.

The ability to explore further the issues of access is severely restricted by the lack of a comprehensive and valid ethnicity monitoring system in health care (Aspinall & Jacobson 2005). Ethnicity data recording is not currently mandatory for primary care and its use is not standardised, which makes comparisons and estimations about service use or need by minority groups difficult (Aspinall & Jacobson 2005; APHO 2005; Banerjee et al. 2010).

7.3.1 Part 1: Conclusion

The empirical work in Part 1 indicated that the participants had a low level of stroke awareness, despite some having had a stroke. In addition, there was a dichotomy of non-stroke participants holding positive perceptions of future stroke care and Stroke survivors reporting negative experiences of care. The development of cultural competence in service providers was seen to be a logical approach to addressing the negative aspects and fulfilling the positive expectations of minority group stroke service-users by preventing future negative experiences. Part 1 also indicated where barriers to equitable care could exist. These points have been set out in a suggested barriers flow chart in Figure 7.1.

Drawing together the issues about barriers to access in Part 1 has resulted in a proposition that barriers to accessing equitable health care exist for minority groups. The flow diagram in Figure 7.1 is interpreted thus, if a member of a minority group has a health need and they decide not to address it, the barrier lies within themselves, an individual barrier. The next barriers are related to their level of candidacy: they have to know about the service (newness/linguistic factors) through appropriate communications about the service, be able to communicate (linguistic factors), and expect a service sensitive to their ethnic needs (ethnicity) (Dixon-Woods et al. 2006; Szczepura 2005) .

If the service-user has candidacy, the next issue is service permeability; services such as GPs and A&E are seen as high permeability, some other services are less so (Knowles et al. 2006; Shah & Cook 2008). Once a service-user has gained access the service needs to be successfully navigated to get optimal care.

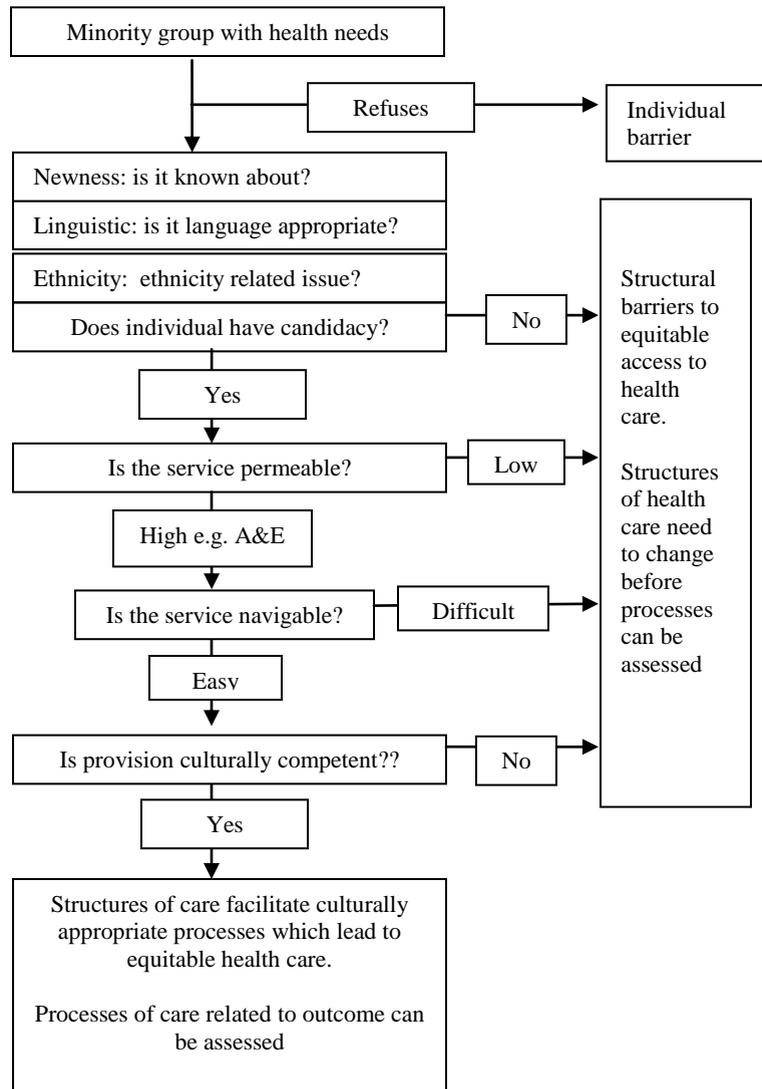


Figure 7.1 Suggested barriers to access points for minority groups

A navigable service could be seen as comprising culturally competent systems and providers. At each stage of the flow chart a barrier can be encountered and it is proposed that while health care processes are in operation at each stage and these can be implicated in the barriers, the structures of care facilitate or moderate these processes and are ultimately responsible for inequitable access.

In the empirical work in Part 1, all service-users had low levels of awareness of stroke. Half of the Stroke survivors called someone other than emergency services for advice when they suffered their stroke. This indicates a barrier of newness or linguistic factors because of the low levels of awareness (Szczepura 2005). The service-users who suffered a stroke demonstrated candidacy by accessing care for their stroke indicating that stroke services are permeable (Dixon-Woods et al. 2006). The stroke service-users reported negative experiences in the non-clinical aspects of their care. Service-users may not have felt qualified to evaluate, and then report on, the level or quality of clinical care they received, and reported no events that caused them concern. The negative experiences led to the proposition that cultural competence in care was lacking which can be seen as a lack of quality in the process of care, but it could also be seen as a service navigation problem (Dixon-Woods et al. 2006). Not all the Stroke survivors were treated in stroke units, and there were mixed experiences accessing rehabilitation and follow-up clinics, providing further evidence of service navigation problems.

As can be seen from the above, when the Stroke survivors accessed stroke care the process of care was not always culturally competent. Though this could be seen as processes of care that failed to bring an optimum outcome in service-users' experiences, it has also been shown that processes are moderated by the structures of health care as processes cannot exist in isolation (Campbell et al. 2000b). Ensuring equity of access to health care is still an issue that needs to be addressed, but it is also clear that this will not be a straightforward matter. It would seem that service providers in the UK in general are not fully competent in interacting effectively with

people from cultural groups different from themselves; this will require structural changes to be properly addressed.

Up to this point the context of stroke care and South Asian minority groups in the UK have been discussed. The stroke care experiences and perceptions of South Asian groups in one area of the UK have been explored and from these findings a tentative hypothesis was developed that proposes the issues for these groups accessing equitable stroke care. Finally a review of the literature reporting barriers to accessing equitable health care in the UK validated and supplemented the findings.

7.4 Part 2: Cultural competence: theoretical and conceptual frameworks

Part 2 comprised Chapters 5, 6 and this Chapter. The aim of Part 2 was to review the literature on the models and frameworks of cultural competence and cultural competence training interventions. Using these reviews, a new theoretical framework of cultural competence was proposed which encompassed all original frameworks. This led to the next stage which was to consider the evidence to support the proposed new framework, and recommend how cultural competence can be developed in practice.

A literature search for Chapter 6 retrieved a number of theoretical and conceptual frameworks of cultural competence. Included in these were two syntheses of some of these frameworks. The syntheses were carried out independently in Europe (Jirwe et al. 2006), and the USA (Balcazar et al. 2009). Neither of these syntheses incorporated all available published frameworks, but together they did. For this thesis and as a contribution to knowledge, a meta-synthesis was undertaken to include all the

available frameworks. To establish validity of the proposed new framework, the original source material was retrieved and synthesised. The use of concept mapping enabled a proposed conceptual framework from the meta-synthesis (see Figure 6.2 – 6.7) and the evaluation of the two original frameworks of Jirwe et al. (2006) and Balcazar (2009) (Hoffman et al. 2002).

The preliminary meta-synthesis of the frameworks of Jirwe (2006) and Balcazar (2009) are in Appendix 11; the data extraction tables for this process are in Appendix 13 and the concept maps are Figures 6.2 – 6.7. The conclusions of this process was that the inclusion of the core concepts of cultural competence, cultural knowledge, awareness and skills by Jirwe (2006), Balcazar (2009) were valid. The differences between the two syntheses were in the pre-requisite stage of cultural competence (Stage 1 Figure 6.8) and the later on-going development stage (Stage 3 Figure 6.8). The initial framework developed for this thesis (Figure 6.8) included both the pre-requisite concepts and the on-going development and organisational support phase, and this claim was supported by the concept maps (Figures 6.5 – 6.7).

However, neither Jirwe (2006), Balcazar (2009) nor the majority of the original framework authors provide any independent evidence for the component concepts of the frameworks. One of the purposes of this part of the chapter is to propose a comprehensive cultural competence conceptual model, explore the evidence for the component concepts, and ultimately the final proposed framework. Finally, how this new model relates to the concept of care quality using the structure, process, outcome framework is explored.

7.5 Part 2: The impact of cultural competence training

The purpose of Part 2 of this thesis was to use realist methods to evaluate the independent evidence that cultural competence training for service providers would result in more appropriate and equitable health care for ethnic minority groups. Interventions in health care with service-users and providers are complex interventions (Bond et al. 2010; Campbell et al. 2000a), because of this, realist methods were considered the most appropriate (Pawson et al. 2004) to try to make sense of the evidence where traditional reviews had been less than successful (Anderson et al. 2003; Beach et al. 2005; Lie et al. 2010).

Chapter 6 described, and evaluated the evidence that was retrieved to support and inform the development of a new synthesis of a cultural competence conceptual framework (Figure 6.8). The evidence is grouped into three types: cultural competence training interventions for service providers; outcomes from a stakeholder review of the findings; and problem-focussed culturally competent interventions assessed by service-user clinical outcomes.

The first body of evidence is from studies that used interventions to train service providers to be culturally competent. These studies were grouped by the type of outcomes they assessed, which were: service provider self-report; service-user experiences; and service-user clinical outcomes.

7.5.1 Cultural competence training: Service provider self-reports

Of the 21 trials retrieved, 11 trained and assessed service providers on cultural awareness, knowledge, and skills (see Appendix 14.2). A further six trials taught and assessed individual or combinations of these components (see Appendix 14.2). The majority of these studies reported an increase in the self-perceived levels of cultural awareness, knowledge and skills. Sampling, or design issues confounded interventions that failed to show an improvement in assessment scores.

There were a range of intervention components, the majority of which used activity based teaching approaches, e.g. role-play, used in combinations. Only one self-assessment instrument was used more than once (see D'Andrea et al. 1990), otherwise instruments were devised by the framework developer, or adapted from one that was previously published. The service providers in the trials were mainly nurses but some included counsellors or social workers.

A further four trials used versions of cultural self-efficacy scales (CSES) as an assessment measure with nurses and counsellors (Bernal & Froman 1993) (see Appendix 14.1). Cultural self-efficacy is the judgment of a person's ability to accomplish a task, working with members of other cultural groups to a certain level of competence (Bernal & Froman 1987). One of the trials taught cultural awareness, knowledge, and skills (Smith 2001). The remainder used cultural immersion, which is living or working with minority groups at home or abroad. Intervention groups from three of the studies improved their scores on the CSES. The study that failed to show improved scores was hampered by confounding issues such as the control group attending their usual cultural diversity training, and multiple significance testing

(Alpers & Zoucha 1996). The items in the CSES are grouped into three sections, knowledge of cultural concepts, confidence in knowledge of cultural patterns within groups and confidence in performing transcultural skills (Smith 2001). These groupings are similar to the awareness, knowledge, and skills scales used in the trials in the previous group. The CSES assesses cultural awareness, knowledge, and skills but the focus is on how confident the participant is in the use of these components.

Cultural immersion at home or aboard did seem to consistently have a positive impact on cultural competence training in seven cases. The duration seemed to make no difference to this positive impact as interventions ranged from half a day (Shellman 2007) to 12 months (Godkin & Savageau 2001). This has been found in other training situations, for example teacher training with two weeks of home based cultural immersion (FERENCE & BELL 2004). The immersion experience provides the opportunity to raise awareness of cultural issues, increase knowledge and practice skills, reinforcing the training sessions (Ekelman et al. 2003; FERENCE & BELL 2004; York Frasier et al. 2005).

The trials that used service provider self-reports as an outcome assessment generally reported successful completion of that assessment. A minority of these interventions were explicitly based on a cultural competence conceptual framework. The remainder referred to previous studies that had been based on a conceptual framework, or referred to a previously used approach and did not mention a framework. Despite this lack of theoretical underpinning, the findings of this section do fit in with the frameworks of Jirwe (2006), Balcazar (2009) and the proposed framework in Figure 6.8. The core components of cultural awareness, knowledge, and skills appeared to be

successfully taught, with positive outcomes for people who completed the interventions. This finding merely indicates that the people were trained on course components and could pass an end of course assessment, not that they were culturally competent in practice or had an impact on clinical outcomes. What was also not evaluated in these studies is how people from minority backgrounds regard the service they receive from the people who have been trained.

7.5.2 Cultural competence training: Service-user outcomes

This next group of trials did consider the effect of service provider cultural competence training on service-users. In all there were eight trials that assessed service-users' cultural competence training by using service-user outcomes. Some trials assessed a range of outcomes, for example service-user satisfaction and clinical outcomes (Thom et al. 2006). A lot less emphasis was placed on cultural competence frameworks to inform the interventions. Only two studies discussed frameworks (Thom et al. 2006; Wade & Bernstein 1991) but all training interventions except one (Ho et al. 2008) focused on cultural awareness, knowledge and skills. The intervention components lasted a short time compared to the studies in the group above, 0.5 to 2.5 days, and as in other interventions, tended to focus on activity-based sessions related to a service issue.

Communication skills

Four of the trials considered cultural sensitivity training and communication skills for service providers (Harmsen et al. 2005; Ho et al. 2008; Ho et al. 2010; Schouten et al. 2005) (Appendix 14.3). These trials found that the groups who were trained in cultural sensitivity and communication skills were rated higher on a range of

measures. Mutual understanding and duration of consultations increased in two related studies (Harmsen et al. 2005; Schouten et al. 2005), and eliciting service-users' perspectives increased in others (Ho et al. 2008; Ho et al. 2010). The common factor with these intervention components was a contextual element that could be practiced, for example, opportunities to practice assessments and diagnoses (see Harmsen et al. 2005).

Findings: communication skills

For training interventions that improved service-users experiences, the best evidence available indicates that: in the context of service provision for minority groups by counsellors, physicians and nurses, cultural competence training intervention of approximately two days, focusing on intervention components that include intercultural interactions through activity-based sessions improves service-users' ratings of service providers' communication skills.

Satisfaction ratings

Four trials used service-user satisfaction ratings to assess service providers who had received cultural competence training (Harmsen et al. 2005; Majumdar et al. 2004; Thom et al. 2006; Wade & Bernstein 1991) (see appendix 14.3 & 14.4). Only one trial succeeded in receiving increased ratings for the intervention group (Wade & Bernstein 1991). Two of these studies had design issues, as described in Chapter 6. However, satisfaction ratings and surveys with minority groups are consistently reported to be difficult in terms of reliability and validity, which could explain the outcomes (Boniface & Burchell 2000; Pasick et al. 2001).

Findings: service-user satisfaction

For training interventions that improved service-users experiences, the best evidence available indicates that: in the context of service provision for minority groups by counsellors, physicians and nurses, cultural competence training interventions of approximately two days, focusing on intervention components that include intercultural interactions through activity-based sessions improves service-users' ratings of service satisfaction with counsellors but not with other disciplines.

Clinical outcomes

The third groups of trials considered improving service-user clinical outcomes by training service providers on a cultural competence course. Three trials assessed service-user clinical outcomes (Majumdar et al. 2004; Sequist et al. 2010; Thom et al. 2006)(see Appendix 14.4). Two of these trials aimed to improve diabetes management but produced no significant improvement, such as lowered blood pressure, or controlled blood sugar (Sequist et al. 2010; Thom et al. 2006). The third trial found an increase on two items of a social functioning scale at 12 months was the only improvement for long-term care service-users, on a battery of health and functional measures (Majumdar et al. 2004). Only one trial was based on a conceptual framework (Thom et al. 2006); the interventions used a range of focused activity based training approaches that lasted from 2.5 days to a number of weeks, and physicians in the diabetes studies received regular feedback on performance from the research team.

The reasons for the failures have been discussed in Chapter 6. However, the association between training on a cultural competence course and service-users clinical outcomes are complex (Craig et al. 2008) .

Finding:

For studies that train service providers in cultural competence and assess this by measuring service-user outcomes: in the context of service provision for minority groups by physicians and nurses, cultural competence intervention components of approximately two days focusing on intercultural interactions through activity-based components with performance feedback are insufficient to improve clinical outcomes of long-term conditions.

Where intervention outcomes were based on service providers' self-reports they were perceived to be effective. Assessing an individual on new knowledge and skill indicates the level of retention by the learner. What it does not do is assess the application or impact of the new knowledge and skill on service-users. However, service providers do need to be trained in cultural competence, so it is important to know the efficacy of interventions in knowledge transfer. One finding from these trials that needs further research is the positive impact of cultural immersion as this seemed to consistently have a beneficial effect on training interventions.

The difficulty of translating knowledge and skill into service-user outcomes was demonstrated when service-users rated service providers, as when outcomes were based on service-user ratings they were perceived to be moderately effective. There were a limited number of trials considering communication skills training, and service-user satisfaction ratings. Communication skills ratings were more positive than satisfaction ratings but ratings and surveys with minority groups are difficult and reported to have issues with regard to reliability and validity (Bird et al. 2011; Boniface & Burchell 2000). These issues include low levels of agreement between

open-interview and survey item responses (Boniface & Burchell 2000), differential response rates across South Asian sub-groups (CHI 2004), and responders differing significantly from non-responders on confounding factors such as level of deprivation and education (Boersma et al. 1997). Where outcomes were based on clinical assessments they were perceived to be ineffective. Three trials trained service providers on cultural competence and then assessed them using clinical outcomes. Despite two small improvements in one trial, overall the outcomes indicated no difference in the intervention compared to the control groups.

An important consideration in realist work is stakeholder review (Figure 5.3) (Pawson et al. 2005). One of the guiding principles of realist evaluation is to engage in a learner-teacher interaction with stakeholders who work in the programmes under evaluation on a regular basis (Pawson & Tilly 1997). In the learner-teacher approach, programme evaluators (teacher) listen to programme workers (learner) to find out what they think the generative mechanisms are that bring about outcomes and in what context.

7.5.3 Stakeholders review

The findings from Chapter 6 were presented to a group of programme stakeholders involved in cultural competence education. This group consisted of university teachers, nurses, students, and programme directors. The stakeholders indicated that raised awareness of cultural issues was a key mechanism that is needed to prime service providers to engage in learning cultural knowledge and skills. The stakeholders also indicated that providing skill and knowledge to service providers can be done using existing methods for teaching clinical skills. They also highlighted that after the course ends the service providers still require on-going skill development

with support in terms of leadership and shaping when applying new skills in the workplace. In addition, after completing cultural competence training, service providers were reporting concerns that mistakes made in cultural interactions would upset service-users, or be seen as politically incorrect or racist. Stakeholders proposed that 'confidence in ability' was a potential mechanism that would facilitate an outcome of true cultural competence. The stakeholders indicated that these are important issues as lacking in confidence and concern about offence can inhibit the use of new skills and exacerbate negative transcultural interactions. This requires a structural solution to encourage the use of culturally competent processes with confidence.

Confidence in ability is related to two mechanisms, identified by stakeholders that could act as barriers to developing new skills in the workplace. 'Fear of causing offence', and 'needing support' are powerful mechanisms, that could inhibit skill use. What may be required is practice development for cultural competence, operating in the same way as it does for clinical processes of care (McCormack et al. 2006). Personal development through facilitation has been shown to improve confidence in clinical skills, and at the same time organised practice development can reveal the deeply embedded characteristics of structural cultures that often inhibit effective skill use (McCormack et al. 2006).

In realist work, the aim is to look for what works, for whom, and in what circumstances. One way of doing this is to explore what mechanisms work, and do not work, to bring about a desired outcome (Pawson & Tilly 1997). Training interventions were not seen to be effective when assessed by service-user clinical

assessments (section 7.5.2). The next action was to explore the feasibility of cultural competence approaches in other contexts that have brought about improvements in service-user clinical outcomes. Improving service-user clinical outcomes is also important for service-user satisfaction as it is associated with level of illness (Crow et al. 2002) and the level and quality of care they receive (Pound et al. 1999).

7.5.4 Supporting evidence: problem focussed interventions

The trials above were not successful in bringing about improvements in clinical outcomes for minority groups as a result of cultural competence training. To find trials bringing about such an improvement a scoping review of the literature was undertaken (see section 6.11). The result was 12 controlled trials that aimed to improve service-user outcomes by using individuals or teams with effective levels of cultural skills implementing subject-specific health interventions.

These trials differed from cultural competence training trials in context and component. Rather than using training mechanisms and expecting providers to implement their new skills in an effective way without structural support, these interventions were carried out by individuals or teams with effective levels of cultural and clinical skills that were matched to service-users' needs. Of the 12 trials retrieved, 11 were successful in improving service user outcomes.

In the training interventions review in Chapter 6 two trials were unsuccessful in improving diabetes management for minority groups. In these trials the intervention was the training of service providers in cultural competence. The subsequent scoping review found two trials that used culturally competent problem-focussed interventions and were successful in improving diabetes management for ethnic minority service-

users. One study achieved this through culturally competent education programmes for service-user self-management (Brown et al. 2002) and one through a culturally competent out-patient programme (Bellary et al. 2008).

These interventions used a problem-focussed approach with a team representing distributed expertise. Distributed expertise is when a team consists of people with complementary specialisations rather than a single 'expert' (Hohu & Saksena 2011). The teams for these problem-focussed interventions included specialisations in cultural issues, clinical issues and organisational or support issues.

One trial failed to improve diabetes self-management compared to controls (Sixta & Ostwald 2008). This trial used 'promotores' to lead the project and act as a bridge between the clinical staff and service-users. Promotores are members of remote or hard to engage communities, trained to work with the community in health related matters. This could have been the reason for the failure of the project, as the effects of a distributed expertise approach were attenuated by working through third parties. This trial could be seen as a deviant case, where an individual without full expertise is used as a conduit for care.

The remainder of the trials were successful when using specifically designed problem focussed approaches, and included increasing condom use (O'Donnell et al. 1995), screening (Modell et al. 1998; Taylor et al. 2006), depression management (Miranda et al. 2003), reduced obesity, (Kalter-Leibovici et al. 2010), end of life care (Song et al. 2010), smoking cessation (Wetter et al. 2007), and increasing activity (Newton, Jr. & Perri 2004) (see section 6.11).

Findings:

The best available evidence is: in the context of problem-focussed subject specific intervention components such as teams, with the appropriate skill-set that includes cultural expertise, service-user clinical outcomes and experiences can be improved.

The salient issue here is that culturally competent interventions have demonstrated that with the appropriate expertise and a problem-focussed approach service-user experiences and outcomes can be improved. While problem-focussed approaches may be appropriate for specific issues, such as diabetes management programmes, they may not a viable approach for standard or regular service provision because of resource implications. However, the studies above have indicated that by introducing structural changes and influences, the processes of care can be adapted to improve clinical and experiential outcomes for service-users.

Part of realist work is to explore and suggest the mechanisms facilitated by intervention components that can help service providers to work effectively with people from other cultures, and explore how to incorporate these into practice.

7.6 Part 2: Suggested mechanisms of action

Searching for mechanisms of action in these interventions is difficult, not only is there insufficient detail about how outcomes were linked to intervention components, but mechanisms can become a context, resulting in a chain effect towards the ultimate outcome (see Figure 7.1).

The findings from the cultural competence training interventions above indicate that training people on cultural competence courses increases their own perception of their

cultural awareness, knowledge, and skills. The majority of trials that used service-users' experiences and clinical outcome as an assessment used these three components as well. These are also key components in the new framework in Figure 6.8. The stakeholder group claimed that raising awareness was the first and important component from which the rest of cultural competence training followed. If this information is taken together, then tentative generative mechanisms can be proposed.

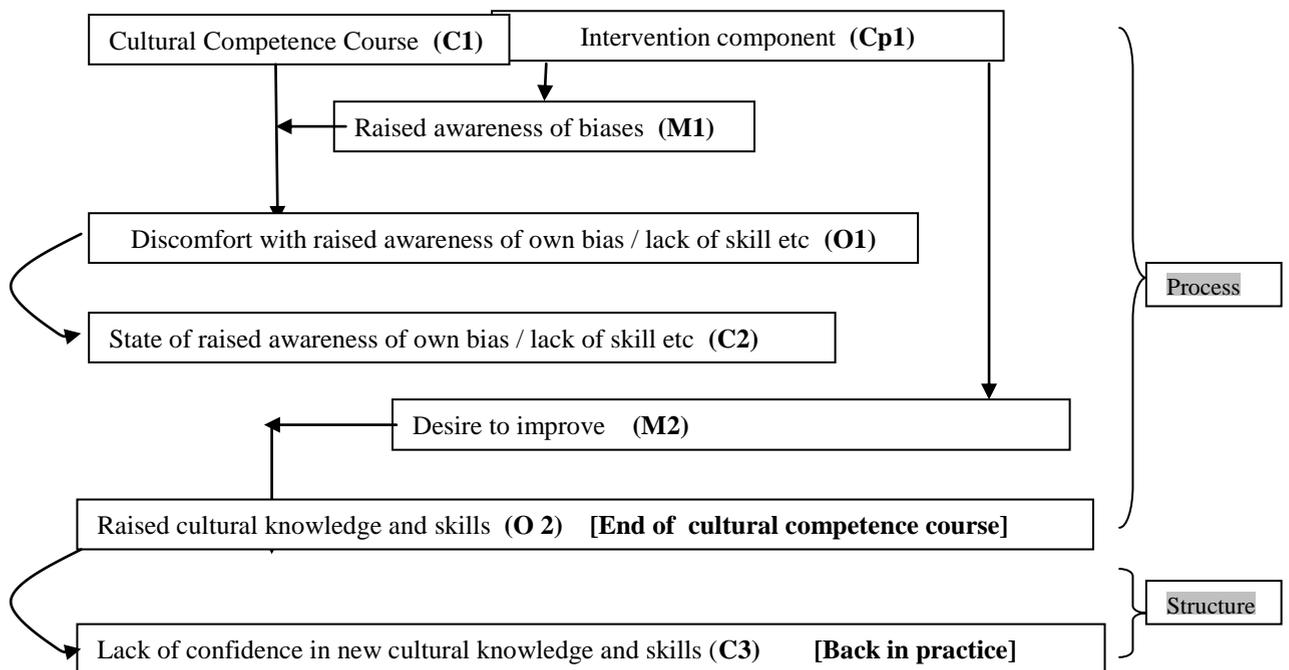


Figure 7.2 Suggested C-C-M-O chain for cultural competence course

Referring to Figure 7.2, the context is attending a cultural competence course (C1), but the intervention component (Cp1) actually triggers a mechanism (M1) of raised awareness; this has an outcome of discomfort (O1). This new state of raised awareness is in turn a context (C2) that triggers a further mechanism of desire to improve (M2), and results in the outcome of increased cultural competence (O2). This is the level of service provider development at the end of a cultural competence course, and is a process of care issue. However, the implementation is a structure of care consideration. This is the final part of Figure 7.2 as despite completing a cultural

competence course, a new context has developed as providers move back into practice and lack confidence in application of skills and knowledge (C3).

Different mechanisms apply to problem-focussed intervention components because of the distributed expertise of the intervention teams (see for example Bellary et al. 2008). However, expertise does not necessarily bring about an improvement in service-user outcomes. Information from the stakeholder review about lack of confidence in new skills in practice suggested that the reverse of this, ‘confidence in ability’, could be a mechanism in successful interventions. Figure 7.3 illustrates the context-mechanism-outcome chains for problem focussed interventions, and proposes that the context is the problem focussed intervention (C4), expertise is the component part of the context (Cp4), and the mechanism is the confident approach of the team to intervene (M4), which triggers the outcome (O4) of feeling valued and reassured. Via CMO chains, when a service-user feels valued and confident (C5) that the care is appropriate, they comply with the new regimen (M5), and the eventual outcome is improved management of the condition (O5).

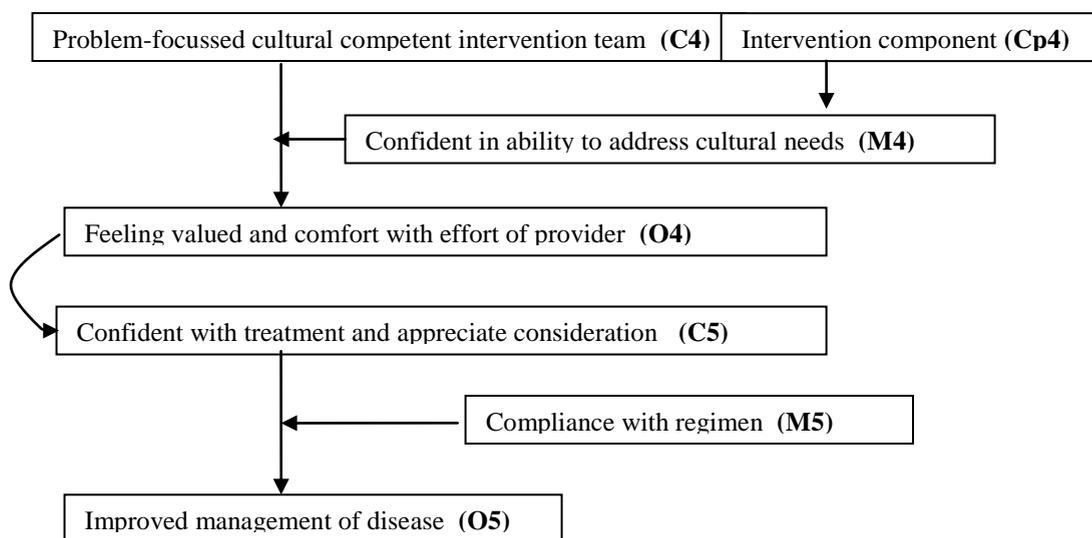


Figure 7.3 C-C-M-O chain for problem-focussed cultural intervention

To develop cultural competence in practice for service providers, the next step is to find the mechanisms that can bring this confidence about in day-to-day interactions with minority group members. The first consideration should be to elicit the intervention components that trigger the appropriate mechanisms. In training situations, cultural immersion has demonstrated potential benefits (FERENCE & BELL 2004).

In problem-focussed interventions, the common factor across all the trials discussed in Chapter 6 has been the purposely designed intervention that requires structural involvement. The trials that were successful in improving service-user outcomes seem to have developed confidence in the service providers triggered by specific skill development. These providers were already skilled in their professions but required specific training to help them work with minority groups. In two cases it was communication skills training (HARMSSEN ET AL. 2005; HO ET AL. 2008), and in the other it was developing levels of knowledge about the client group and specific skills in client/provider interactions (WADE & BERNSTEIN 1991). Though these are processes of care, structural insight would have been required: participants attended cultural competence training but the interventions with service-users were similar to problem focussed interventions.

7.7 Confidence in Cultural competence application

Part 1 of this thesis proposed that low levels of cultural competence in service providers was a major issue that was a barrier to South Asian service-users receiving equitable stroke care. Due to the paucity of relevant literature, the barriers to equitable care for minority groups has been explored in general, as a proxy for South Asians and stroke. Part 2 of this thesis explored models and frameworks of cultural competence

and the evidence to underpin them. Objective (iv) of this Part was to propose how service providers can be developed so they can practice cultural competence in an effective way. Training service providers in cultural competence is merely the first step towards proficiency the difficulty is translating this training into effective cultural competence in practice. This training and practice conundrum is not just a phenomenon for cultural competence, as it has been estimated that interventions, successful in research situations fail to convert into meaningful real-world service-user outcomes in many areas (Damschroder et al. 2009). Estimates of effectiveness have claimed that only a third of organisational efforts to implement change, even based on a theoretical model, have been successful (Burns 2004).

The barriers to successful implementation can occur at many levels including service-user, clinician, organisation, and team or group (Ferlie & Shortell 2001). With such barriers, it would be a challenge for an individual with newly acquired cultural competence skills to work effectively when faced with cultural interactions.

Conceptual frameworks, in this case Figure 6.8, indicate that skills in cultural competence need to be developed until both the organisation and the individuals are confident in the ability to address cultural need. The challenge is how to achieve this.

Cognitive psychology has demonstrated that when we encounter new knowledge it must be processed in certain ways, so it is not only retained but also integrated with other knowledge in ways that are meaningful for the individual (Craik & Lockhart 1972). Likewise, when a new skill is acquired it is generally at a stage when conscious thought is required which incurs a cognitive demand. Skills must be processed via practice to develop them into a less demanding process where they are operated with minimal (if any) conscious thought (Treisman et al. 1977).

Teaching cultural competence for health care practice is a complex matter and a course alone, irrespective of components or duration, is insufficient for the concepts to be fully embedded and employed at a level of proficiency (Reece & Walker 1997). Two interrelated theoretical models are useful to help understand the stages of embedding cultural knowledge and skills.

Communication theory was designed to identify competency levels when learning a language and describes the process from novice to expert (Howell 1982). When a student starts a course, they have unconscious incompetence, where they do not know what they should know. During the course, they develop conscious incompetence, where they appreciate what they do not know. At the end of the course they are consciously competent, they know what they should know, but do not know how to use it effectively. The final stages are unconscious competence where they apply the concepts in all situations, but still have to think when using the skills, until super-competence occurs, when use becomes second nature (Howell 1982).

A developmental model of cultural sensitivity (Bennett 1986) is phenomenological in approach as it is related to the worldview of students, and the experiences that shaped their view. The model describes the transition from ethnocentrism to ethno-relativism. The ethnocentric stage starts with 'denial' that there is a culture problem. The next stage is 'defence' of a position by negative stereotyping or denigration of difference. This is followed by 'minimisation' of any differences between cultures to rationalise the growing awareness of cultural differences. The start of ethnocentrism is when

‘adaptation’ to working with diversity begins. Finally, ‘integration’ is achieved when working with diversity becomes part of the student’s new worldview.

Communication theory (Howell 1982), although limited in supporting evidence, provides a basis for understanding why cultural competence training interventions do not readily translate into effective cultural competence behaviours in health care situations. The developmental theory (Bennett 1986) gives detailed descriptions for each stage, although it has been questioned if ‘defence’ and ‘minimisation’ are two separate components (Culhane-Pera et al. 1997). Bennett (1986) claims the theory is based on evidence but no evidence is referenced.

Both the models are useful as tools to aid the development of educational programmes for cultural competence. However, the developmental model provides more detail about how to recognise a stage the service-user has reached, and how to assist them to move forward (Bennett 1986). Communication theory provides a useful plain-language descriptor for the stages (Howell 1982).

Used together these models can assist in indicating what stage service providers are at on their progress through the cultural competence framework. This is useful as it highlights what needs to be done to move service providers from one stage to the next (see Figure 7.5).

7.8 Proposals for the development of cultural competence

The developmental model (Bennett 1986) can indicate what is required to move a service provider from one stage of their development to the next. In the case of cultural competence training this entails moving from attending training and completing training to applying the cultural skills and knowledge effectively and unconsciously. Implementing theory into practice is problematic (Ferlie & Shortell 2001) and there have been a number of conceptual frameworks that propose solutions to these problems (for a review of this see Greenhalgh et al. 2004). These frameworks of implementation have considerable overlap and not all the important constructs are in all of the frameworks. A recent paper proposed a consolidation or synthesis of the constructs from the frameworks in the form of the Consolidated Framework for Implementation Research (CFIR) (Damschroder et al. 2009). The CFIR lists five main components that need to be considered for successful implementation: intervention characteristics (mechanisms); inner settings; outer setting; characteristics of the individual (context); and implementation processes (outcome). The strengths of the CFIR are that it recognises the influence of contextual elements, such as organisational impact, and wider constructs like external influences (see Figure 7.4). However, it was recently formulated and has yet to be supported by evidence.

A model that informed the development of the CFIR, is the ‘Promoting Action on Research Implementation in Health Services’ (PARiHS) model (Rycroft-Malone et al. 2002a; Rycroft-Malone et al. 2002b). There is also evidence from intervention studies that supports PARiHS (Perry et al. 2011; Stetler et al. 2011).

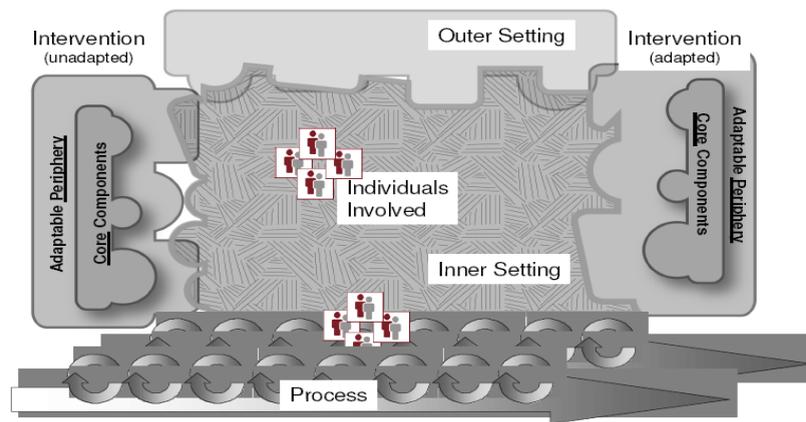


Figure 7.4 The Combined Framework for Implementation Research (Damschroder 2009)

The PARiHS model proposes that without appropriate facilitation mechanisms, implementation is unlikely to be successful. Facilitation mechanisms are most effective when there is a holistic purpose and individuals who can provide an enabling role in leadership and skill development (Rycroft-Malone et al. 2002b). Although the CFIR is potentially useful with its wide ranging or macro approach, the PARiHS uses a more micro approach and provides a checklist to evaluate new skills up to a competent level and benchmarking information.

7.9 Part 2: Final conceptual framework.

In Part 1 of this thesis it was discussed that low levels of cultural competence in service providers was a barrier to South Asian service-users accessing equitable stroke care. It was also discussed that equitable care was closely associated with good quality care and that quality of care should be assessed in terms of structures,

processes and outcomes (Donabedian 2005). A case was made for the meta synthesis of conceptual frameworks into a single entity that contained the essential components. Supporting evidence for the concepts within this framework was also explored (see Figure 6.8). The difficulty of implementing newly acquired skills was discussed, as were models of implementation, communication and stages of personal development. Figure 7.5 indicates how these different frameworks and models could fit together to bring about true cultural competence for service providers. This is a proposed comprehensive conceptual framework for effective training and implementation to enable individuals to become culturally competent. The aim of this framework is to provide a model that can be used to develop training programmes in cultural competence for service providers, and in research.

Previous models did not conflate skill development and organisational or structural concepts as a major component, which is the phase that turns conscious competence into unconscious competence where using the skills eventually becomes second nature (Bennett 1986). Balcazar (2009) removed a practice/application element from his synthesis and Jirwe (2006) indicated that cultural competence was an on-going process, but did not explore this further.

When considering the best available evidence reviewed in this thesis, it became apparent that the 'core' components of previous cultural competence frameworks could be taught if all that was required was to describe component concepts or train service providers to succeed on a self-reported outcome measure. However, these frameworks did not seem to go far enough to suggest how to bring about an improvement in service-user experiences or clinical outcomes. The proposed meta-

synthesis of concepts that could bring about cultural competence in service providers is shown in Figure 6.8, and Figure 7.5 illustrates a further development of this. The pathway through to true cultural competence is seen to begin at Stage 1, with a 'willingness to engage' a pre-requisite to learning. This includes openness to diversity, willingness to learn, and sensitivity. This would seem to be correct but no evidence has been found for the validity of this component. At this point service providers are at an ethnocentric stage and in a state of unconscious incompetence, they do not appreciate their ignorance on the topic (Howell 1982).

Stage 2 includes the core components typically taught on cultural competence courses. The concept 'critical awareness' includes the sub-components of raising awareness of self and others. The stakeholder group saw this as the key component that would prime service-users to engage with learning the subsequent taught components. Secondly, at stage 2, 'culturally able' contains the two 'ability' core components, cultural knowledge and skills, which are essential components of all competencies (Kane 1992). The result of course assessment will indicate the effectiveness of the intervention programme this also indicates how service providers perform on assessment items, not that they can demonstrate cultural competence in practice. The culmination of Stage 2 would be the state of knowledge and skills in cultural competence at the end of a cultural competence course. There is strong evidence for the efficacy of programmes that have used these components in interventions, and this has been described in Chapter 6 with details in Appendices 14.1 and 14.2.

Service providers at Stage 2 will have moved from being unconsciously incompetent to a stage of consciously competent (Howell 1982). At this point, service-providers

should be at a transitional stage from ethnocentric, believing their own perspective is the only correct one, to ethno-relativism, understanding that there are other perspectives that may be as valid (Howell 1982). Stages 1 and 2 are related to the processes of care, these are the attitudes and skills that need to be used in practice to be perceived as culturally competent (Papadopoulos et al. 1998). Stage 3 is related to the structures of care and require organisational involvement to bring these about and ensure the training from Stages 1 and 2 are used effectively in practice (Rycroft-Malone et al. 2002a).

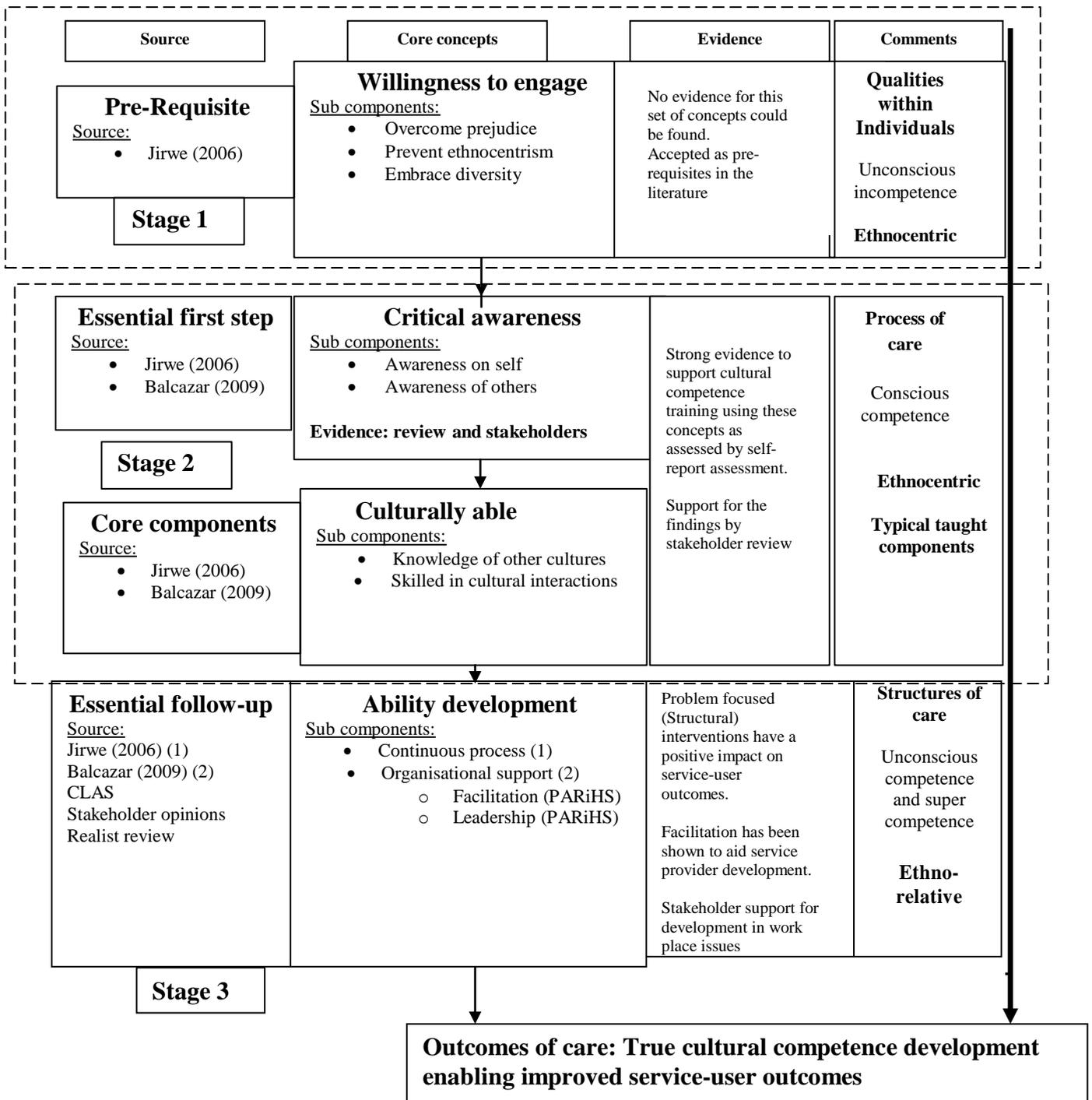


Figure 7.5 Final synthesised conceptual model of cultural competence

What has been proposed is that the end of a cultural competence training course is the starting point on a service provider's path to true cultural competence. This is the beginning of Stage 3 where, according to stakeholders, service providers who have undergone cultural competence training have low confidence in performing their new skills. The stakeholders also described having to take the new skills back to a range of cultures in the workplace that are themselves shaped by other cultures, external and internal structural forces. The concept of 'facilitation' in the PARiHS model is useful in this situation; the learner can be guided through facilitation that includes leadership, mentoring and shaping to become unconsciously competent (Rycroft-Malone et al. 2002a). This is when providers work with minority groups in appropriate ways without conscious deliberation (Howell 1982).

The evidence for achieving unconscious competence is limited, but in the spirit of realist work, information collated from a number of sources can inform a proposition (Pawson & Tilly 1997). Stakeholders with experience of this area of practice and training indicated that the support of the host organisations is essential to develop culturally competent practitioners. Problem-focussed interventions described in Chapter 6 have demonstrated that a clearly focussed, structurally supported approach, with appropriate health care processes can result in effective culturally appropriate outcomes for minority groups. Implementation science has indicated that putting theoretical approaches into practice is possible but success is dependent on a number of issues, mainly the nature of the supporting evidence, an appropriate implementation context and effective management of the process (Rycroft-Malone et al. 2002a).

This new cultural competence conceptual framework (Figure 7.5) has three stages of development to move a service provider from unconscious ignorance to unconscious competence. This was developed using realist principles that considered the impact the context of an intervention had on the mechanisms that resulted in an outcome. This thesis has also discussed how the quality of health care improvements can be assessed in terms of structure, process and outcomes of care. These three frameworks have been central to this thesis; therefore the possible relationship between the frameworks needs to be explored.

In the early days of quality assessment of health care, it was thought that quality evaluation could use a selective approach to structure, process, and outcome assessments (Donabedian 2005). More modern thinking is that the complexity of health care systems needs to be reflected in the complexity of assessments. As such quality needs to be assessed in a holistic way using all the components of the S P O framework (Campbell et al. 2000b). This new approach to S P O was discussed in Chapter 2 (see Figure 2.4) and describes the moderating effect of structural elements on the processes and subsequently the outcomes of care. As the realist concepts of C-M-O are targeting outcomes as well as the new cultural competence framework it seems logical to explore any symbiotic relationships between the three frameworks (see Figure 7.6). Symbiosis is the close relationship between two or more unlike entities, generally for mutual benefit, and has previously been used to describe framework merging (Andersen et al. 1994).

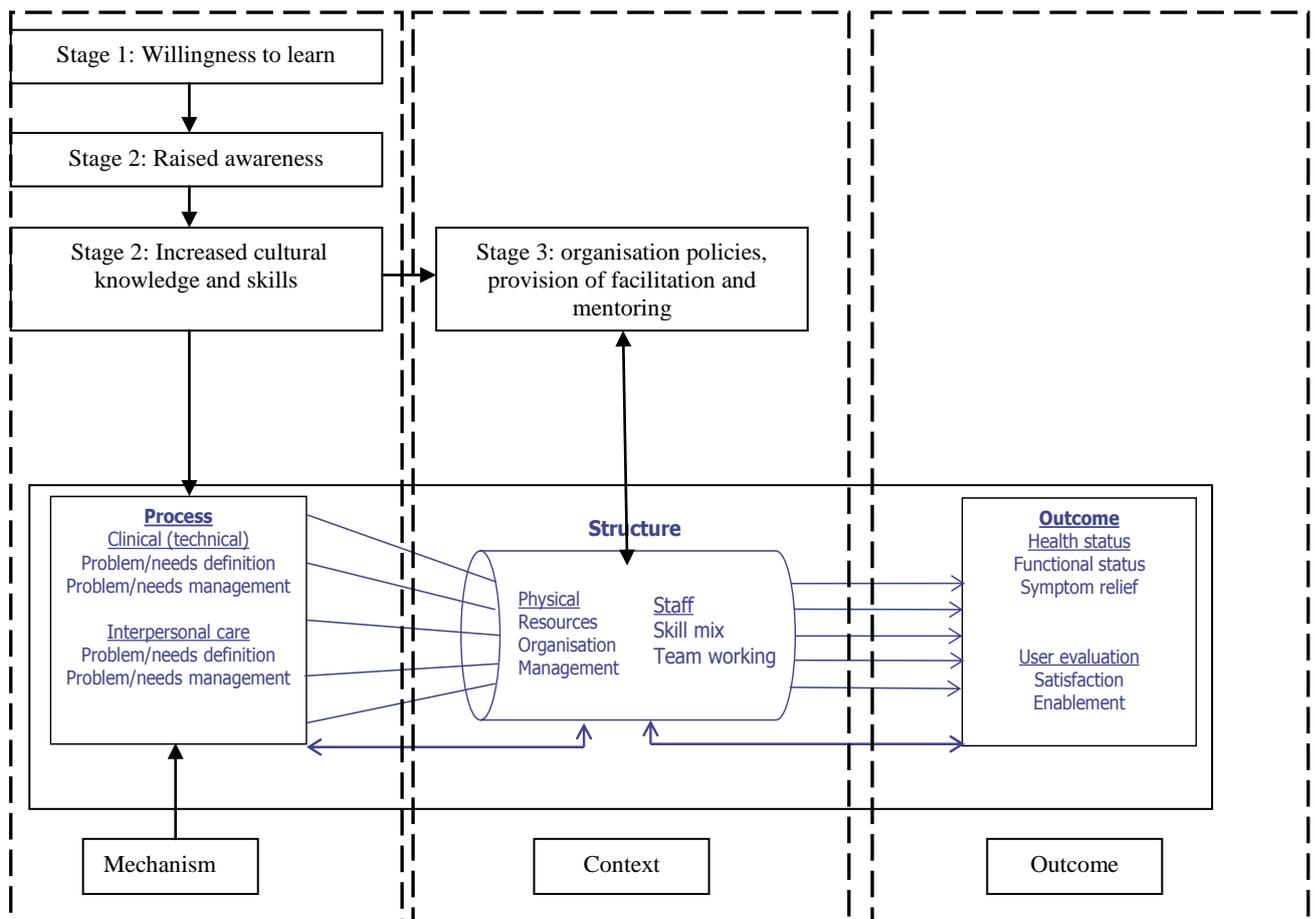


Figure 7.6 Symbiosis of three conceptual frameworks of this thesis

Figure 7.6 shows the combination of the three conceptual frameworks that have been used in this thesis. This figure shows the relationship between them. At the top of the diagram are Stages 1 and 2 of the new cultural competence framework (see Figure 7.5). These are essential component concepts for a service provider to learn how to be culturally competent. This training informs the processes of care and at this stage a range of mechanisms can potentially operate (Left hand side box). For example, at this point a mechanism ‘Desire to do a good job/not repeat past errors’ may be operating when a service provider wants to include their new skills and knowledge in a process of care. The outcome will be moderated by the context (Pawson & Tilly

1997). Stage 3 of the new framework of cultural competence, the organisational elements, and the structure of the SPO framework are both the context (Middle box). The context has a moderating effect on the processes that in turn impact on outcomes, where the three frameworks conclude. Therefore a service provider in a practice situation who is at a stage of conscious competence will need facilitation provided by the structural elements to develop unconscious competence.

Conclusion

This thesis set out to explore the needs of service-users of South Asian background when accessing stroke services, and what should be done to address the issues that arise. Across the sample of collaborating participants, there was a low level of stroke awareness. Despite the low levels of awareness of stroke issues, the service-users displayed candidacy by seeking acute stroke care. Although acute stroke care had access permeability, after admission South Asian service-users' needs were not being met, indicating poor navigability of acute stroke care for these participants. They reported negative experiences of their care and access problems with rehabilitation and on-going support. It was a proposition of this thesis that this outcome was related to service providers not being effective in intercultural interactions.

Cultural competence training for service provides was seen as the most appropriate remedy. A review of cultural competence conceptual frameworks found that they did not encompass all the possible components that may make such training effective in terms of improved service-user outcomes or experiences. A meta-synthesis of all obtainable cultural competence frameworks was carried out and independent evidence to support the component concepts was sought.

The best available evidence indicates that cultural competence intervention components are effective in developing service providers up to a level of conscious competence. Further practice development is required with an intervention component such as facilitation. Through facilitation, a possible mechanism of *supported development* can enable service providers to develop their new cultural skills in safety until they can develop true cultural competence. When this is achieved, if they are unfortunate to require it, there will be an increased possibility that South Asian stroke service-users will see their positive perception of their care translated into positive experiences of the processes of care.

This chapter describes how the aims and objectives of this thesis have been addressed. Within the constraints of a thesis addressing these aims and objectives is the response to the two research questions: What are the issues for people of South Asian heritage in accessing health (stroke) services?

What would be the (stroke) service requirements to meet these needs and overcome these issues?

7.10 Contribution to knowledge

Part 1 of this thesis used a method of effective research collaboration with groups who are generally seen as difficult to meaningfully engage. This method is transferable to working with other groups presenting similar difficulties. The product of Part 1 was a framework that can be used to inform subsequent work when interviewing South Asian service-users about their care.

In Part 2, a realist evaluation was used to consider the evidence for components of cultural competence conceptual frameworks. The realist approach sees the context of a situation as a key element that has an impact on the mechanisms that bring about outcomes. This thesis contends, as a contribution to knowledge, that in a teaching context there are many elements to consider, though all of these elements have a bearing on the mechanisms that trigger outcomes. The intervention components of the teaching context must be singled out for extra consideration, as it must have a more direct effect on the mechanism than other contextual components. It is suggested that the Context-Mechanism-Outcome configuration, typically used in realist work, needs to be adapted to Context-Component-Mechanism-Outcome configuration for education applications.

Until Jirwe (2006) and Balcazar (2009) synthesised frameworks for cultural competence, there had been no attempt to rationalise them into a single entity. Moreover, until this thesis, these two frameworks have existed independently with no attempt to make a single framework that encompasses all the possible and logical elements, or explore the evidence base for these components. The two synthesized conceptual frameworks were based on different sets of previous frameworks but had three in common. Neither synthesised frameworks were supported with independent evidence for the effectiveness of the frameworks in practice. This thesis has sought the best available evidence for cultural competence frameworks when applied in a training situation. This also provides independent evidence for the core component of the new conceptual framework (Figure 7.5). At the same time this thesis has explored the mechanisms of action, using realist principles, which may help service providers to develop true cultural competence.

7.11 Implications for practice

It is important when people are ill that they receive the clinical care they need. It is of equal importance in a society that values the individual that they are treated well in other aspects. It has been reported that service providers are under pressure to deliver their clinical roles and inter-personal care is seen as an additional courtesy that is fully implemented when there are less demands on time (Stakeholder response).

Training service providers in cultural competence is essential if service-users are to have positive health care experiences and outcomes. What is also needed is that organisations instigate practice development and a form of facilitation based on implementation theories which will translate skills developed in formal training into true effective cultural competence. Cultural competence philosophies can improve experiences and outcomes for all service-users, not just minority groups as they are premised on respect for the individual.

7.12 Limitations of the thesis

In Part 1 the empirical phase described work carried out by Community Researchers with members of their own communities. Though this is not ethnographic work this type of inquiry can suffer from the same potential biases. Possible biases are, the capacity of the investigator to accurately represent cultures different from themselves (Woolgar 1988a), the descriptions are unreliable and the findings are social artefacts generated by the interaction (Wolcott 1990). This implies that when using these methods investigators get 'too close' to the data and fail to contextualise it or operate reflexively and accept that other realities may exist (Atkinson 1990).

These criticisms were addressed by collaborating with members of the communities under study. Every effort was made to ensure the accuracy of the reports, not just with the translations, but also in understanding the text in the context of a different culture. This was done by having regular meetings with the community researchers to discuss the interpretations drawn from the data.

The problem of getting too close to the data is inherent in all qualitative work, as the gap between a valid and supported interpretation and a partial and skewed construction is narrow. By acting as a coordinator of the community researchers, who collected, translated, and in some cases transcribed the data, each element could be regarded as part of the overall whole and seen in that context. In addition the regular meetings with community researchers to verify the data provided an opportunity to examine interpretations of the data.

Regarding the data being a social artefact, apart from the steps already described, verification from other sources was sought as much as possible. However, despite achieving data saturation with the interviews there is still a danger that the small sample are unrepresentative of reality and have resulted in the production of partial interpretations of the data. The data could also have a geographical bias. Despite working with two differently composed communities, these could be unrepresentative of South Asian groups throughout the UK. However, as the samples were dissimilar, and the findings were supported by the literature describing many minority groups, this bias is improbable.

Realist evaluations are not without weaknesses or criticisms and issues have been raised about the approach (Pawson 2001). The methods can be seen as over intricate, involving delving into the minutiae of descriptions to try and elicit mechanisms, and for whom they do and do not work, with a constant reference to context. This may be so but in the area described in this thesis available evidence is sparse and of poor to moderate quality. Traditional reviews and evaluations would find working with such material a challenge, where a realist approach can provide a workable alternative resulting in a usable output (Anderson et al. 2003; Chipps et al. 2008).

A further weakness of the realist method could be that the findings and the approach in general are based on judgment. What is essential is that the claims made for the judgments are supported and transparent, but most of all premised on a desire to produce a set of conclusions and recommendations from a collection of disparate research findings.

The major critique of the realist approach is that the findings are inconclusive and feeble. What this alludes to is that the end-point of a realist evaluation is usually a set of recommendations for what works, for whom, and when, rather than firm conclusions. Traditional systematic reviews to date, generally call for larger and more robust trials that should result in a firm conclusion. However, this is still a challenge, for example, a randomised controlled cluster trial with 8000 cases collecting objective data did not reach a firm conclusion (see Sequist 2009). Realist evaluation makes a set of considered recommendations from scrutinising and synthesising the best available evidence.

One of the main issues with health research from a realist point of view is the lack of details reported for the intervention programmes. It would have been revealing if sufficient detail were supplied so the effectiveness of each intervention component on each framework component could have been estimated, as reported previously (Wong et al. 2010).

7.13 Areas of further research

One of the main reliability issues for research with ethnic minority groups is the poor quality of data monitoring. Many of the reports published in the last two decades have been hampered by this issue and have called for a remedy (APHO 2005).

Without such monitoring the estimates of incidence and prevalence of conditions, estimates of service use and service need are unreliable. A standardised and consistently applied monitoring system would be one of the biggest steps taken in the study of the health of minority groups (APHO 2005).

Clinical audits are a common occurrence in service provision. In recent years, the remit of audits has been increased so that organisational audits are also undertaken (Intercollegiate Working Party for Stroke 2007). It would be interesting to widen the organisational remit to include a barrier to care audit (or an ABC, Audit of Barriers to Care). This could be based on the concepts developed by Dixon-Woods (2006) of permeability, candidacy and navigation, as well as those of Szczepura (2005), newness, linguistic skills, and ethnicity. The development could also be influenced by the design of the PARIHS with checklists and benchmarking criteria. Such an audit could highlight barriers to equitable service provision, and provide recommendations to address them.

Four further areas of cultural competence would provide fruitful areas of research. Firstly, there is no standardised scale for assessing cultural competence. Gozu (2007) reported that there were over 20 unique cultural competence assessment tools, less than half had reported any reliability or validity data, and less than ten per cent had been evaluated independently of the developer. The current position makes using such instruments for education and research questionable.

Secondly, physicians performed poorly when involved with cultural competence studies. They either failed to achieve effective service-user outcomes or were not fully accepting of the principles of cultural competence. There were studies when this was not the case but they were in the minority.

The last two issues are related to cultural competence training interventions; cultural immersion seemed to be the only intervention component that could be identified as related to an outcome. This has been shown to be the case in other training areas (FERENCE & BELL 2004) and more work needs to be carried out to find out what duration and variety of cultural immersion are the most effective.

Finally, the components 'willing to engage' and 'willingness / openness to learn' are suggestive of concepts used in motivational interviewing; importance and confidence. Motivational interviewing is a talk-based, directive, cognitive therapy that has been used successfully in behaviour change with addictions treatments (Moyers et al. 2005), and dealing with depression in acute stroke service-users (Watkins et al. 2007; Watkins et al. 2011). Near the beginning of the therapy, the interviewees are asked to indicate on a scale of 1 to 10 how important change is to them, and how confident

they feel about making that change. A form of assessment based on these concepts could be administered before service providers undertake a course, and at the end of the course. Exploring the possibilities of motivational interviewing concepts could be an area of further research to assess ‘willingness to learn’, and exploring how unwilling individuals can change their attitudes.

7.14 Thesis conclusion

For at least ten years stroke services providers have been challenged to address the needs of people from ethnic minorities. This thesis explored those needs with South Asian minority groups, and how stroke services can address them. The participants who had used stroke services were negative about their overall experience. The attitudes and behaviour of service providers were seen as poor, with a notable lack of understanding of culturally specific issues. In addition, participants expressed a need to be treated as an individual, to feel cared for, and respected. It was concluded that the barriers to accessing equitable health care were organisational (structure) rather than individual (process). To remedy this it was suggested that health care staff receive training in cultural competence and develop this in practice by facilitation.

Further research explored the efficacy of training service providers to be culturally competent. The available evidence has shown how to provide cultural awareness, knowledge, and skills training, but not how to translate this into improvements in service-users’ experiences of the processes of care or clinical outcomes. Using realist principles, this thesis explored further evidence to indicate how to develop effective culturally competent service providers. Based on a systematic literature search and a review using realist principles, this thesis has synthesised a new model that proposes how true cultural competence can be achieved in practice.

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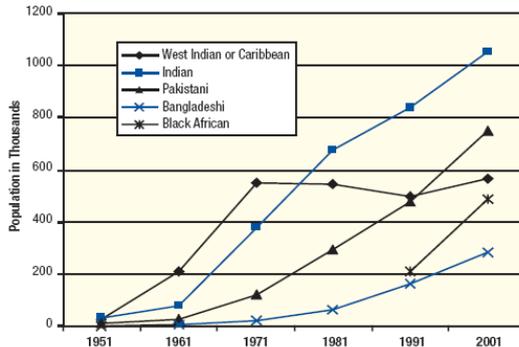
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Appendices

Appendix 1 Distribution of ethnic minority groups in the UK

FIGURE 1: Growth of Minority Ethnic Populations in Britain 1951-2001



Source: 1951-1991 data reproduced from Peach (1996).
2001 data from 2001 Census Key Statistics Table 6.

TABLE 1: Size of Ethnic Groups in Britain 2001 (with 1991 for comparison)

	1991 population (000s)	2001 population (000s)	% of total population 2001	% of minority ethnic population 2001
White	51873	52481	92	
All minority ethnic groups	3014	4623	8	100
Black Caribbean	500	566	1	12
Black African	212	485	1	10
Black Other	178	97	0	2
Indian	840	1052	2	23
Pakistani	477	747	1	16
Bangladeshi	163	283	0	6
Other Asian	197	247	0	5
Chinese	157	243	0	5
Other	290	229	0	5
Mixed race	0	674	1	15

Note: Columns do not sum to 100% due to rounding
Source: 2001 Census: Key Statistics Table 6.

THE GEOGRAPHICAL DISTRIBUTION OF MINORITY ETHNIC GROUPS

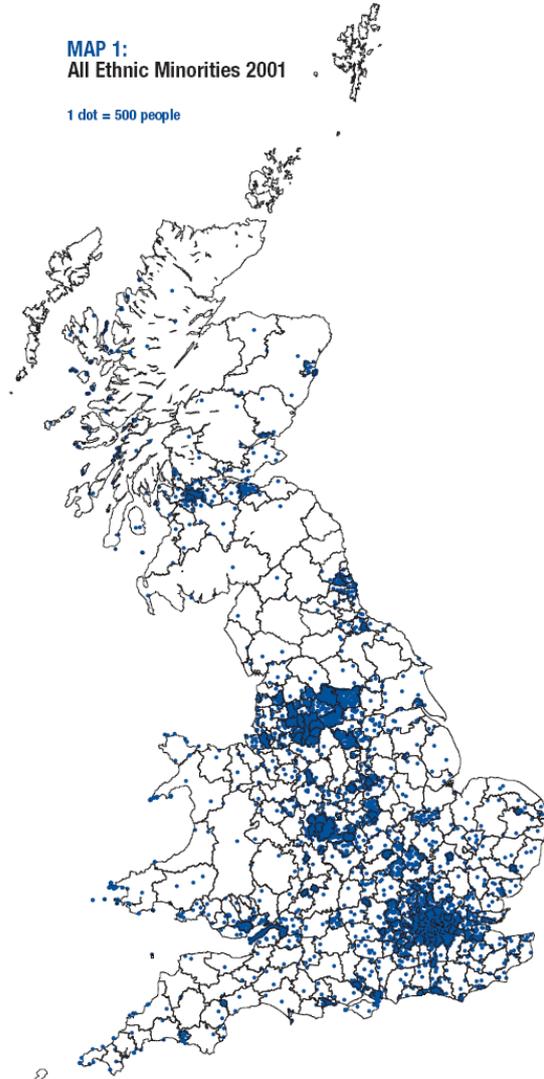
The original settlement patterns of immigrant groups in towns and cities where their labour was in demand and where older private housing was available have resulted in a very uneven distribution of minority ethnic groups, skewed heavily towards the inner areas of London and certain other cities and towns.

Map 1 shows the distribution of people from minority ethnic groups in 2001. It shows a strongly urban pattern, with high concentrations in London and the surrounding area, in Birmingham and the cities of the Midlands such as Coventry, Leicester, Nottingham and Derby, in Lancashire and West and South Yorkshire and in other cities such as Glasgow, Liverpool, Bristol and Cardiff.

Maps 2-7 show the distribution of the different groups in 2001. They show the same urban pattern. In the broadest terms, minority ethnic groups tended to be settled in the large cities and industrial towns where there were other minority ethnic groups. However the patterns were not exactly the same for the different groups:

MAP 1: All Ethnic Minorities 2001

1 dot = 500 people



- The Indian population was concentrated in London, and in the cities of the Midlands, and in Lancashire and West Yorkshire.
- The Pakistani population was strongly represented in Manchester, Lancashire and West Yorkshire and also in Birmingham and the Midlands cities, with a smaller proportion of the population in London than was the case for Indians.
- The Bangladeshi population was concentrated in London and to a lesser extent Birmingham.
- The Black Caribbean population had a similar pattern to the Bangladeshi population but with London even more dominant.
- Black Africans were very heavily concentrated in London.
- Chinese were more widely dispersed than other groups.

Appendix 2 Focus group material

Focus Groups Scenarios

- Imagine a member of your community awoke one morning and could not move their left leg and arm, one side of their mouth had drooped, and their speech was not clear. They could have had a stroke or transient ischemic attack.

What do you think they would do?

What do you think they should do?

What would you do?

(Probe: What stops them from calling an ambulance?)

- With your current knowledge of health services imagine this person has decided to call an ambulance. They are taken to Accident and Emergency, Tests \ Scans \ X-rays are carried out then they are moved to a bed on a ward.

How would they be treated in a way that considers your culture/ religion/ ethnicity?

What needs to be done to make sure they are treated in a way that considers your culture/religion/ethnicity?

- This person still has a problem with their arm and leg but is now speaking well and now is moved to a ward that specialises in trying to restore the use of their arm and leg.

How would they be treated in a way that considers your culture/ religion/ ethnicity?

What needs to be done to make sure they are treated in a way that considers your culture/religion/ethnicity?

- This person is now being discharged but is walking with a stick and still has problems with their arm and needs a lot of help with things they normally do at home.

What resources are available to them in the community?

What needs to be done to make sure they are treated in a way that considers your culture/religion/ethnicity?

Appendix 3 Individual interview material (Non Strokes)

Introduce self and purpose of interview (to explore knowledge of stroke in the community, and how stroke service should be delivered).

Ensure informed consent had been completed and participant has a copy.

Focus group theme	Main issue	Probe/ sub-issue
	1. Complete demographic proforma	
Knowledge of Stroke	2. Briefly ask what causes a stroke.	Ensure that interviewees are aware that stroke is a brain attack , and can be caused by either a bleed or blockage in the brain . (Try not to explore signs and symptoms at this stage).
	3. What they think the risk factors of stroke are.	When they cannot identify anymore, use prompt sheet 1 to explore what they think about any remaining risk factors.
	4. Ask them to identify whether they think they are at risk or not, and why.	
	5. Can they think of anyone in their family who may be at risk, and why.	Ensure confidentiality by asking them not to name family members.
	6. What do they think the signs and symptoms of a stroke are?	When they cannot identify anymore, use prompt sheet 2 to explore what they think about any remaining signs and symptoms
	7. Do they know the difference between a stroke and a mini-stroke or Transient Ischemic Attack (TIA)	Use the prompt sheet 3 to describe the difference between the two in later parts of the interview.
	8. Inform the interviewee that the next part of the interview is about what they would do in certain stroke-related situations.	
	10. Use the TIA scenario If a family member told them a similar story, what would they advise and why?	TIA Scenario: A friend of yours tells you they have had blurred vision, slurred speech, and a numb arm for about 3 hours. This has happened a couple more times and they feel concerned about it. They ask your advice –What would you say?
	11. If they experienced these symptoms themselves, what would they do and why.	
	Keen for health advice/care	12. Use the stroke scenario If a family member experienced these symptoms what would they do and why.
Keen for health advice/care		
Service issues	13. What do they think health services can do for people with stroke	Have they heard about rehabilitation? What do they think this is and how effective do they believe it is?
Service issues	14. Explain that the final part of the	Explain each stage of the journey using the prompt sheet 4 ,

	interview will focus on what usually happens to people after a stroke, if they are admitted to hospital or not, and what they feel about this.	and ask them
		At each stage ask how they would feel about this and what they would expect to happen
Food/Gender/Religion/Language		What anxieties they would have about this (Issues that may be discussed are; gender, food, family, language, religion)
		What would stop them accessing this service (if appropriate)
Service issues	15. Ask them if there is anything else that they think: -	
		<ul style="list-style-type: none"> • should be included in hospital stroke care • would encourage people to use hospital stroke care
Community		<ul style="list-style-type: none"> • would make things easier for people living with stroke in the community
	16. Thanks and closure	Anything else regarding stroke/health care that they would like to discuss

stroke Service issues		Why was that? What did the GP do or say? How did you feel about that?	
Language Communication Service issues Cross gender issues	Ambulance journey	If you went to hospital, how did you get there? How did that feel? In what ways did the staff try to understand your needs and wishes?	Could this be improved?
Language Communication Service issues Cross gender issues Family referencing	Accident and Emergency	Could you tell me what happened in A&E? How did that feel? What concerns did you have in A&E? In what ways did the staff try to understand your needs and wishes? Were your family/friends with you? How did you feel about this? What information did you get about what was going on? Who from? Was this helpful?	How could this be improved?
Service issues Communication Family referencing	Ward-based care	Could you tell me what happened when you moved onto a ward? How did that feel? What concerns did you have? In what ways did the staff try to understand your needs and wishes? Was anyone with you at this time? Did you have any visitors?	How could we make things better on the wards?

Food/Religion		<p>How did you feel about visitors?</p> <p>What information did you get about what was going on?</p> <p>Who from?</p> <p>Was this helpful?</p> <p>What were the facilities like? For example, was it easy to practise your religion (e.g. pray) if you wanted to?</p> <p>Did you feel comfortable as an (e.g. as a person from an Asian background) whilst you were in hospital?</p> <p>Why was this?</p>	
<p>Communication</p> <p>Cross gender issues</p> <p>Service issues</p>	Therapy / Rehabilitation	<p>Where you moved to a rehabilitation unit/area?</p> <p>How did that feel?</p> <p>What part did this play in your recovery?</p> <p>Did you have any concerns or worries on this department?</p> <p>What information did you get about what was going on?</p> <p>Who from?</p> <p>Was this helpful?</p> <p>Were your family with you?</p> <p>How did you feel about this?</p>	<p>What could be done to make rehabilitation / therapy better for you?</p>
<p>Communication</p> <p>Family referencing</p> <p>Community</p>	Going home	<p>When you were told you could go home were you or your family involved in the decision?</p> <p>How did you feel when you were told you could go home? Did you have any fears or worries about this?</p> <p>How did you find it when you first went home?</p>	<p>What could be done to make going home better for you?</p>

<p>Service issues</p> <p>Communication</p> <p>Family referencing</p> <p>Community</p>	<p>Outpatients and follow-up</p>	<p>Could you tell me about any stroke related visits to the hospital since discharge?</p> <p>What happened?</p> <p>Who went with you?</p> <p>How did you feel during these visits?</p> <p>Did you have any tests? What has the hospital told you?</p> <p>Have you had any other type of care (day-hospital, GP, Family)? Has that been helpful?</p> <p>Could you tell me what other support you have had since you came out of hospital (e.g. From the community)?</p> <p>What further support did you feel you need(ed)? Where should this come from? How should it be delivered?</p>	<p>In what ways could discharge be improved?</p> <p>In what ways could post hospital care be improved?</p>
	<p>Personal Identity</p>	<p>How you think about yourself after the stroke:</p> <p>Did you feel differently about your body?</p> <p>Did you always expect life to carry on as it had?</p> <p>Have you changed you thoughts about the future?</p>	<p>How could these be helped</p>
	<p>Social Identity</p>	<p>Discuss groups:</p> <p>Can you tell me how you feel towards the groups you belong to (e.g. Family, work, social)</p> <p>Can you tell me if members of those groups see you differently after your stroke?</p> <p>Can you explain this?</p>	<p>How could this be helped</p>
	<p>Close</p>	<p>Thank the participant for spending their time with you</p>	

		<p>This information will be really helpful in making =services better for all people who have strokes but especially people from our community</p> <p>Do they have any questions</p> <p>We will be sending some information out about the research later on in the project</p>	
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Appendix 5 Interview material: Prompt sheet 1

Prompt Sheet 1

Symptoms for TIA and Stroke	
Muscle weakness or paralysis	
Loss of sensation (loss of feeling or numbness)	
Difficulty with speech	
Visual symptoms	
Dizziness	
Headache	
Vomiting	
Drowsiness or unconsciousness	
Definite Risk factors	
Increasing age	
Male gender	
Increasing blood pressure	
Cigarette smoking	
Diabetes mellitus	
Atrial fibrillation	
Ischaemic heart disease	
Transient ischaemic attack or previous stroke	
Possible Risk Factors	
Physical inactivity	
Obesity	
Snoring and sleep apnoea	
Recent infection	
Family history of stroke	
Diet (salt, fat)	
Alcohol (none, or heavy drinking)	
Race	
Social deprivation	
Stress	

Appendix 6 Interview material: Prompt sheets 2 - 4

Symptoms of Stroke	
Loss of consciousness	
Weakness on one side of the body that may affect the whole side or just the face, arm or leg	
Problems with balance or co-ordination	
Difficulty speaking	
Difficulty understanding speech	
Difficulty writing	
Problems with memory, thinking or attention	
Difficulty swallowing	
Problems with bladder control	

Prompt Sheet 2

Difference between a TIA and stroke – Prompt sheet 3

A transient ischemic attack is a temporary minor stroke. The symptoms of a TIA soon disappear, usually within 24 hours. A stroke is the brain equivalent of a heart attack.

A haemorrhagic stroke occurs when there is bleeding from an artery in the brain. An ischemic stroke occurs when there is a blockage in an artery in the brain.

Stroke Pathway – Prompt sheet 4

Event	When the stroke happened
Inward journey	How the person got into hospital
GP	The patient journey may stop here
A&E	What happened in A&E
Acute stroke unit or other ward	What happened on the acute stroke unit or another ward
Rehabilitation ward	What happened on the rehabilitation ward
Transfer back home or into a nursing home	Leaving hospital or the first few weeks at home
Long term	What happens after hospital

Appendix 7 Data capture form

Stroke Service Redesign with Cultural and Religious sensitivity	
Date of Interview:	Location:
Time:	Interviewer:
2 nd Interviewer	Validator:
Participant Code:	Interview No:
Gender:	Date of Birth:
Place of Birth:	
Languages spoken:	Languages read:
Any family members had stroke/tia.	Self identified cultural/religious group
Notes/Reflections/Background Information	

Appendix 8 Extra information extracted from interviews

See over

Themes	Non-stroke participants	Stroke survivors
<u>Stroke Awareness</u>	Levels of awareness were consistently poor. Many could name one symptom unprompted but some none. Stroke as an emergency was judged by the severity of symptoms.	Most of the participants had a reasonable but not comprehensive knowledge of risk factors and secondary prevention.
	<i>Interviewer: Do you know what happens (when a stroke occurs) Respondent: No I do not know much about all that at all. (10:2)</i>	<i>Interviewer: At that time did you think it was stroke or.... Respondent: No, no, no, [I thought] no such thing, honestly. (8:2)</i>
<u>Validation</u>	Either they would telephone friends or family or a GP. The remainder would telephone for an ambulance. In all cases hospital care was the ultimate aim.	Typically participants called GPs, friends who were doctors or family members. When made aware of the seriousness, all called emergency services. Second strokes generally called emergency services immediately.
	<i>I would ring my GP and get it checked as soon as possible (7:12)</i>	<i>I rang a friend of mine who is a consultant and he said put the phone down I'm ringing an ambulance... one was there within a few minutes (1:14)</i>
<u>Willingness to access health services</u>	No participant avoided health care services. There was no evidence of reticence in accessing hospital services.	Even though some participants sought validation very few indicated any reticence in accessing hospital stroke services.
	<i>Interviewer: Would anything stop you accessing the service? Respondent: Not really .. think if someone has a problem like medical problem they should go in hospital....(9:12)</i>	<i>When they took me to hospital they checked my blood, they were ok. Ambulance staff were fine; only doctors didn't check what it is or isn't. (7:9)</i>
<u>Generational issues</u>	The difference is between people born here (or very in tune with the mores of the general population) and those who have migrated to the UK and have not been fully immersed in the wider society.	Participants with very good English understood the nuances of the language and recognised negative attitudes, respondents with poor English had to rely on other cues.
	<i>Respondent: People might think that a lot of older Asian men and women are quite rude but if you know the way they're speaking... obviously you've got to understand they've got a language [communication] barrier (6:23)</i>	<i>Well the first impression is...you work out is they think that all elderly [Asian] service-users do not speak English (3:1)</i>
<u>Gender</u>	Most participants were pragmatic in accepting that treatment by the opposite sex was a possibility that had to be endured to get better.	Apart from commenting on mixed sex wards, most participants took a pragmatic approach and if necessary would accept cross-gender care from staff
	<i>Respondent: No I do not think so as long as I think I want someone who can help me. Interviewer: You do not mind them being male? Respondent: No.(2:33)</i>	<i>Interviewer: With the service, in regards to men and women, did you have any problems in relation to gender and culture? Respondent: No...No...(10:7)</i>

<u>Themes</u>	Non-stroke participants	Stroke Participants
<u>Family</u>	Families are referenced in a number of contexts and did not need to be probed. Illness that affects a person is seen as affecting the family, and is seen as such by the participants.	Families were discussed by all participants without prompting. However there were distinctions between the family and extended family that were not explained.
	<i>From seeing my neighbour it [disability] affects the family a lot. When they go home that's when it really starts, (3:46)</i>	<i>This is one thing that the doctors and nurses do not do..they do not tell us what is going to happen next.. they do not tell us [Family] until the day after they have done it (17:11)</i>
<u>Religion</u>	Religion does not play a major role in the perceptions of service, it is never made a salient issue.	Religion did not seem to be an issue. Typical responses were that they had no problems; a few complained that their religion was not considered.
	<i>to do the blood pressure either on my clothes or to draw the curtains round to maintain some sort of privacy because of my religious background 4:6</i>	<i>R: I couldn't wash...how could I pray...I used to pray orally but I could not bend 7:15</i>
<u>Language</u>	Language was not seen as a major barrier. It was more a case of lack of clear communication; the language problem could be coped with.	Non-English speakers were not provided with interpreters, families translated. Service-users felt that staff would not put the extra time required to get a point across. Staff assume older Asians do not speak English .
	<i>You do get from nurses, you get that kind of hmm, they do not, they do not feel as if they're being rude but obviously you've got to understand they've got a language barrier, so the please and the thank yours are not there, (6:16)</i>	<i>One thing that would go along way is if the staff learned how to pronounce peoples name properly and if they could say basic please and thank-you's (3:11)</i>
<u>Food</u>	Food did not play a major part in the discussions about issues that need resolving, in most cases the participants were prompted about food. The food issue was seen to be resolved, vegetarian or halal food was commonly available.	A minority of service-users thought the food was adequate in hospital, but complained it was rather restricted in choice. Quite a number of families brought food in for the service-users, which met with a variety of staff responses.
	<i>Nowadays most of hospitals have Halal food. (1:26)</i>	<i>Well its always the same in hospitals. you ask for halal food there and they give you just rice and a meat. (10:17)</i>

Themes	Non-stroke participants	Stroke Participants
<u>Discrimination/Racism/Xenophobia</u>		<p>There were some instances of low-level discrimination. Translators indicated that unless an Asian service-user had a high level of language many remarks would go unnoticed. This is supported by the two service-users who spoke English very well who did pick up on discriminatory remarks.</p> <p><i>We thought well if she's being racist [a nurse they had problems with] then she probably won't look after Mum properly but there were other nurses on the ward as well which were nice, so they were all right, but some of the nurses were just so miserable. would not say hello etc. 17:25</i></p>
<u>Informed about the progress</u>		<p>Information from staff to service-user about their condition/progress was poor.</p> <p><i>I: Did they give you any information [about condition] at that time? R: No I: In the hospital? R: At that time they gave me nothing [Information] (7:14)</i></p>
<u>Fear of hospitals</u>	<p>This was typically a generational issue. Younger participants did not see hospitals as frightening as older participants. Some participants see it as an older people issue and some as a familial response.</p> <p><i>Ah, yeah, cos I know that I mum and grandad and grandma, they hate the hospitals, anything to do with a hospital, forget it, not going, erm, whereas the GP, (5:42)</i></p>	
<u>Staff attitude</u>		<p>Participants were mixed about staff attitudes. Some were complimentary; others saw the staff as negative. .</p> <p><i>She [SLT] came once or twice...they put something like a brick on him and they left him ...then they said he's [the service-user] is not interested and I never saw them again (10:22)</i></p>
<u>Being heard (Getting the message across)</u>		<p>Communication is tied in with language. Communication between staff and service-users of the general population has been reported as poor. Therefore inter-race communication with the lack of understanding on both sides is especially difficult.</p> <p><i>[Over] seven days I stayed in that ward without any medicine, without any care (8:6)</i></p>

Appendix 9 Search criteria cultural competence trials

#	Searches	
1	cultural competency/ or cultural diversity/	
2	exp *Population Groups/	
3	Minority Groups/	
4	cultural.tw.	
5	exp clinical trial/	
6	Comparative Study/	
7	exp Program Evaluation/	in some cases exp a bottom hierarchy term returns more refs than un exp, in this case 6000+
8	exp feasibility studies/ or exp pilot projects/	
9	control\$ trial\$.tw.	
10	exp "review"/	in this case 1200+
11	Ethnology/	no more in this case
12	meta analysis.pt.	
13	exp empirical research/	
14	qualitative.tw.	
15	review.pt.	
16	exp *Education/	
17	health education/ or consumer health information/	
18	Sensitivity Training Groups/	
19	"Attitude of Health Personnel"/	
20	Transcultural Nursing/	
21	exp "Delivery of Healthcare"/	
22	1 or 2 or 3 or 4	All "Culture" catagories
23	6 or 11 or 7 or 9 or 12 or 8 or 10 or 15 or 5 or 13 or 14	All "Design" catagories
24	20 or 21 or 18 or 19 or 17 or 16	All "Intervention" catagories
25	24 and 22 and 5	All terms with Clinical trials(Mesh)
26	24 and 6 and 22	All terms with Comparison studies (Mesh)
27	26 not 25	All Comparison studies not Clinical trials
28	7 and 22 and 24	All Prog evaluation studies (Mesh)
29	28 not (24 and 22 and (5 or 6))	Prog Eval not Clin trials or Comp studies
30	8 and 22 and 24	All feasibility studies or pilot programs
31	30 not (24 and 22 and (5 or 6 or 7))	Feasibility not Clin trial, Comparison studies or Program evals
32	9 and 22 and 24	All Clin\$ Trial\$ studies
33	32 not (22 and 24 and (5 or 6 or 7 or 8))	Clin\$ Trial\$ studies not Clin trial, Comparison studies, Program evals or Feasibility

Appendix 10 Screening criteria for retrieved papers

Cultural Competence Papers: Screening Criteria		
	Inclusion Criteria	Guidance
Section A	English Language papers	Can be from any country but the paper must be in English
	Participants	Health care staff (see below) any nationality, will be adult, but they must be interacting in a health care context, with people of a minority group, of any age. The interaction can be for any health condition, or primary or secondary prevention.
	Cultural competence Staff Training\Education	Training may be described as culturally sensitive, cultural awareness, culturally congruent, cultural diversity, etc. terminology is not used consistently. Any health care staff, (includes admin, volunteers, contractors, therapists, medics, nursing, radiography, GPs, pharmacists, etc.) that interact with the client group.
	Intervention; any style of intervention, affective, behavioral, cognitive	Can be one or a combination of: affective: interventions that change, feeling, or emotions towards people of a different culture.
		Behavioral: interventions that address how staff act towards (including speech) people from other cultures.
		Cognitive: interventions that change what people think or how they perceive people from other cultures, plus change a participants knowledge of other cultures.
	Evaluation (see Research designs below)	The paper must include an approach to establish the efficacy of an intervention
Mixed interventions are acceptable as long as the cultural competence element is distinct and able to be evaluated on its own.		
Theory and models of cultural competence education/training. Lack of a theory or model should not prelude the selection of an article. Similarly, lack of an intervention should not prelude theory/model articles.	These may also be described as culturally sensitive, cultural awareness, culturally congruent, cultural diversity. Articles may be descriptive or opinion papers or the theory and /or model may be described as underpinning an intervention. Theory articles with no interventions kept for information.	
Section B	Research Designs	
	RCT, Quasi RCT	Randomised controlled trials (including cluster or individual), controlled before and after studies, and interrupted time series. Mixed interventions are acceptable as long as the cultural competence training element is distinct.
Section C	Systematic reviews of cultural competence training/education interventions	Examine the review for secondary references that can be assessed as primary research. Keep reviews for information
	Observational studies	Can be observations of client group and/or health care staff as long as it is evaluating a cultural competence intervention with health care providers
	Qualitative studies	Qualitative studies that explore the views and perceptions of providers or client group about a cultural competence training/education intervention.
	Exclude: Information articles	Information articles that include no theory or model or and evaluation. Typical articles will explain how to implement a cultural competence programme.
	Exclude: case studies	Organisational case studies may be suitable if they can be treated as a design specified above.

Appendix 11 Preliminary mapping of existing conceptual frameworks

See over

Cultural competence frameworks					
From left to right, where colours abut one another, these components are common through the three theories. Shaded boxes are non common components. No one source cites either of the others.					
Office of Minority Health; Culturally and Linguisticly Appropriate Services Standard 3 (CLAS 3) (2001)	Balcazar (2009) F/W #1		Balcazar (2009) F/W #2	Jirwe (2008)	
CLAS Components	Assumptions	Components	Components	Sub Components	Components
Awareness of the effects of differing cultures will bring to a clinical encounter		Critical awareness	Critical Awareness Cultural Knowledge	Awareness of oneself	Awareness OF Human diversity
Awareness of impact culture on health care				Awareness of the other	
Effect of cultural differences among providers and users on all aspects of healthcare	Knowledge of impact of difference (socio-economic, racial etc) on need, use and outcomes	Cultural Knowledge		Knowledge of other cultures	The ability to care for individuals
Requirements for differential clinical management of all aspects of health care		Skill acquisition	Skill acquisition	Skilled in performing cultural assessments	
				Ability to meet specific cultural needs	
		Desire to engage		Willingness to learn	Non Judgemental openness for all individuals
				Interest in others	
				Overcome prejudices	
				Avoid ethnocentrism	
				Encourage equality to diversity	
		Iterative process	Practice/Application	Sensitivity to diversity	Enhancing Cultural competence is a long term process
				A step by step process	
				an ongoing process	
develop effective communication channels			Organisational support		
Ensure all parties are aware of legal requirements and sanctions					
develop individual and organisational conflict resolution procedures					

Appendix 12 Data extraction form

Nature of control group, if any	
Study date and duration	
Methods of data collection and who collected by (e.g. researcher/practitioner)	
Any research tools used	
Stakeholder views reported	
Analysis used	
Nature of intervention (where applicable)	
Intervention?	
Name of intervention	
Aims of intervention	
Location/setting	
Target population (any info re: age, ethnicity, gender)	
Who provided the intervention (e.g. social worker, volunteer)?	
How was the intervention/service delivered (e.g. group work, home visits, teaching module)?	

How and why was intervention developed (e.g. reasons for development, any 'needs assessment' or involvement of target population)

Implementation issues identified

Any theoretical framework drawn on to develop the intervention

Outcomes and results

Outcomes measures used

Details of outcomes/findings

Cost data reported

Any details of strengths/limitations of the study (including diversity of sample)

Author's conclusions

Appendix 13 Integration table: Balcazar (2009) and Jirwe (2006)

Synthesis	Country	Ref ID	Author/date	Discipline	Rationale	Context	Journal(JA)/Book(Book)	Components	Explanation	Measure	Comment	Evidence	
Balcazar 2009	USA	1	Doorenbos and Schim (2004)	Nurs	To develop Culturally competent (CC) practitioners by increasing awareness of cultural diversity (CD) , enabling practitioners to become more sensitive to cultural	No	JA	Cultural diversity	Recognition that cultural diversity exists--base for other components	Yes	Limited information on model and it was not referenced.	Tool developed and tested, but pre-existing levels of CC tested only.	
							Cultural awareness	Knowledge of elements of variability of groups					
							Cultural sensitivity	Recognition of CD attitudes and beliefs, communication skills					
		UK	2	Glockshuber (2005)	Coun	To test a US instrument in the UK, that explore counsellors perceptions of their multicultural competencies. Model based on competencies subscales.	No	JA	Cultural beliefs	Self awareness of own biases and level of comfort working with the CD	Yes	Regression analyses indicated that cultural beliefs were the greater predictor of perceived CC.	instrument tested but only on pre-existing cultural competence.
								Cultural Knowledge	Developed through theory and experience knowledge of cultural issues relating to the client				
								Cultural skills	The application of culturally appropriate interventions--good levels of suitable empathetic understanding				
		USA	3	Harris-Davis and Haughton (2000)	Diet	To enable nutritional counsellors to use the model to develop multi cultural counselling competencies.	No	JA	Multicultural counselling Awareness	14 competencies: Awareness of self biases and awareness of diversity issues	Yes	Adapted existing models, Sue 1993 and Campina-Bacote (C-B) (1999) to nutritional counselling. Developed a survey and this resulted in three factors, not C-Bs 5, though the competencies included statements on all 5.	Scale and factor analysis but testing pre-existing CC, not training.
								Multicultural counselling Skills	8 competencies: Application of cultural knowledge into culturally appropriate interventions				
								Multicultural counselling knowledge	Knowledge of food related issues in target cultures				
		USA	4	Hart, Hall and Henwood (2003)	Nurs	Develop a model that can raise awareness of cultural inequality. Emphasis on working towards equality for all cultures by developing a inequality imagination.	No	JA	(Equalities) desire	Key component- willingness to develop competence	No	Essentially changed the components of C-B model to suit their thinking on equality.	No evidence cited.
								(Equalities) awareness	Exploring ones own biases and attempting to look at wider issues				
								(Cultural) knowledge	Seeking to establish a sound knowledge base about target minority groups				
								(Equalities) skill	Ability to make assessments and deliver appropriate interventions				
							(Cultural) encounters	continued exposure to a divers range of clients					
							(Equalities) analysis	A critical approach to how disadvantage and inequality are constructed					
							(Equalities) actions	Actions that challenge inequalities					

Table Appendix 13.1

Synthesis	Country	Ref ID	Author/date	Discipline	Rationale	Context	Journal(JA)/Book(BK)	Components	Explanation	Measure	Comment	Evidence
Balcazar 2009	USA	5	Jzewski and Sotnic (2005)	VR coun	Focus is on cultural brokering: finding a way of mediating between client and clinician of different backgrounds to reduce discord or resolution of conflict.	No	BK	Stage 1: Identification of cultural problems or need	Critical awareness of potential employer and employee cultural issues that may be mismatched	No	Cultural brokering is different from cultural competence. If the potential employer was culturally competent they would not be needed. A form of brokering is the use of link workers.	This is a model of mediation, no evidence cited.
								Stage 2 Propose interventions or strategies	Extensive knowledge of cultural issues on both sides to propose a strategy			
								Stage 3: Examine the outcome if unresolved move back to stage 1	High level of skill to assess outcomes and further recommendations			
	USA	6	Kim-Godwin, Clarke and Barton (2001)	Nurs	Development of the Culturally Competent Community Care (CCCC) model and the Cultural Competence Scale (CCS). To develop CC community nurses.	Yes	JA	Cultural competence	Cultural sensitivity: Affective aspect of care, respect for other cultures	Yes	Kim-Godwin devised the CCS from the concept of CC. This was developed from existing models. The CCS was piloted on 192 nursing students and reports internal consistency and factor analysis data. Only two factors resulted Sensitivity and Skills-Knowledge was presumed to be spread across these two concepts. One of the few to cover Structure Process and Outcome.	Supported by own study, no independent evidence cited.
									Cultural knowledge: The understanding of other cultures that is needed for CC care			
								Health care system	Community nurses knowledge of the healthcare system and their cultural knowledge helps them to resolve issues that arise because of dissonance between them			
								Health outcomes	The result of the care provided to culturally divers groups			
	USA	7	McPhatter (1997)	SocWk	Significantly more children (in USA) from minority cultures require social worker interventions that the mainstream. Social workers need competencies that enable them to work with other cultures.	Yes	JA	Enlightened consciousness	Self awareness of own views, reorientation of workers world view.	No	Provides three sections that deal with the three components. The knowledge section provides a minimum knowledge base that would be needed but not where or how to get the information , the other components are describe in more detail but not how to develop them. Theoretical basis is not discussed and it has not been empirically tested by the writer.	No evidence cited , not tested.
								Grounded knowledge base	History of oppression, racism, sexism, etc. Family structure, religious beliefs			
							Cumulative skill proficiency	Development of skills in working with families from other cultures in a sincere manner and equality based approach				

Table Appendix 13.2

Synthesis	Country	Ref ID	Author/date	Discipline	Rationale	Context	Journal (JA)/ Book (BK)	Components	Explanation	Measure	Comment	Evidence
Balcazar 2009	Can	8	Moffit and Wuest (2002)	Nurs	In sub arctic Canada the majority of the population are indigenous non European, whereas the majority of healthcare workers are white. This article proposes a way of developing culturally appropriate care.	Yes	JA	Cultural integration	[Cultural awareness and self awareness.]This is pursued by being inquisitive, receptive, iterative and reflective.	No	Based on qualitative research and existing models (C-B, Sue) was decided that these models did not propose how to integrate cultural knowledge into practice for their specific cultural group. However, the validity of the framework is not explored but assumed and little is provided in the logistics of following this approach when time is limited.	Not tested , no evidence.
								Knowledge acquisition model				
	USA	9	Poole (1998)	SocW	To help social workers to appreciate the differences and similarity between the dominant group culture and that of diverse clients. This includes the historical, political etc.	Yes	JA	Knowledge of contextual factors	Develop [in cultural knowledge] outside of the work context	No	This is more like an opinion paper and has resulted in a proposition that the components described will result in a culturally competent workforce. However, it would seem that it is based on observation as years as a practitioner and educator. No theoretical basis, no measure and no objective evidence.	No evidence, not tested.
								Ability to adjust working practice to cultural situations	Flexibility in practice to accommodate and assimilate cultural factors			
								Diversity in staffing policy, incorporating more people from target groups	positive inclusion in staffing			
								Developing openness to others	Raise awareness of self and of others			
	USA	10	Salimbene (1999)	Nurs	To help nursed develop cultural competence and skills working with interpreters. Cites the need for an integrated nursing system.	Yes	JA	Ethnocentricity	Awareness of self and others	No	Proposes a structural approach and a process approach as well as an outcome discussion, but no evidence, theoretical discussion, constructed tool. Currently seem at a basic propositional level.	No--not even references, no antecedents.
								Awareness and sensitivity				
								Avoidance of stereotyping				
								Knowledge acquisition	Cultural knowledge			
								Development of skill	Cultural skills			
	USA	11	Steenbarger (1993)	Coun	Maps brief therapy assumptions, skills and principles onto multicultural counselling. Problems are located in the individual and the system.	Yes	JA	Engage in clients life context		No	Premised on school and collage communities. Therefore is on a parochial scale. Does not describe how to bring these changes about or another detail. No evidence no measure, based on brief counselling approaches. Empowerment model that helped the CD develop a 'voice'.	None cited.
							Facilitate (in the client) new ways of experiencing and acting	Cultural skill				
							Help counsellors to develop skills to interact effectively and sensitively with diverse clients	Cultural skills				
							Explore issues at a person-environment level	Cultural knowledge				
							Aim to modify communities to change and accept diversity an influence decision makers	Cultural skills and knowledge				

Table Appendix 13.3

Synthesis	Country	Ref ID	Author/date	Discipline	Rationale	Context	Journal(JA)/ Book(BK)	Components	Explanation	Measure	Comment	Evidence
Balcazar 2009	USA	12	Sue (19981)	Coun	Uses the Association for Multicultural Counselling and Development (AMCD) guidance to map counselling skills onto cultural competence. Aim to help counsellor engage with people from diverse communities.	No	JA	Development of counsellors assumptions, biases and attitudes: (AKS) Understand clients worldview (AKS) Develop appropriate interventions: (AKS)	Used in a 3*3 matrix, each component is described in terms of attitude, knowledge and skills (AKS) required to address the component	No	Does give sets of competencies for each component, these can be used to construct a scale or organised training.	None cited.
	USA	13	Suh (2004)	Nurs	To develop a theoretical guide for developing strategies to achieve culturally competent care in research and practice.	Yes	JA	Antecedents: Needed before CC can be developed: Cognitive (Knowledge), Affective (attitude, awareness), Behavioural (skills) and environmental(arranging cultural encounters) Attributes: the antecedents prepare the individual to be culturally competent in terms of cultural ability, openness and flexibility Consequences: the impact on the provider and user as well as outcomes for the user		No	Bases on a systematic review and a content analysis.	Some references to support the concepts but these are opinion papers or poor studies.
	USA	14	Wells (2000)	Nurs	This Cultural Development Model sets out to provide a framework to assess growth of individuals and organisations that goes beyond cultural competence.	Yes	JA	Pre-cursor: awareness of own biases and world view Cognitive phase: cultural awareness and cultural knowledge Affective phase: the integration of the cognitive phase into individual and organisational behaviour	Cultural incompetence [Wells]. Cultural awareness of self Cultural incompetence [Wells]. Cultural awareness and knowledge of others Culturally competent to proficient [Wells]. Cultural skills	No	One of the few models that considers CC as developmental and requiring organisational change.	No evidence, developed from earlier works by others
	USA	15	Willis (1999)	Nurs	Uses existing nursing theoretical models and adapts them for cultural competence. This framework is intended to help individuals achieve cultural competence.	No	JA	Knowledge of ones own culture and biases Knowledge of others Non threatening interactions Tolerance Inclusion / Acceptance	Self awareness Cultural knowledge Cultural skills Cultural skills Cultural skills	No	One of the first models that recognises that leadership in the workplace is important, but does not include it in the model.	Informal pilot study mentioned but not references or described.

Table Appendix 13.4

Synthesis	Country	Ref ID	Author/date	Discipline	Rationale	Context	Journal (JA)/ Book (BK)	Components	Explanation	Measure	Comment	Evidence
Balcazar 2009 & Jirwe 2008	USA	16	Campina-Bacote (1999; 2003)	Nurs	Framework to facilitate the training and development of individuals and organisations to work effectively with the culturally diverse (CD).	Yes	JA & BK	1 Cultural awareness 2 Cultural knowledge 3 Cultural skills 4 Cultural encounters 5 Cultural desire	exploration of ones own cultural background obtaining a sound knowledge base of the CD ability to assess and treat the CD face to face contact with the CD A 'want to' engage attitude to the CD	Yes	Widely cited and used.	Non cited but widely used, some evidence in intervention studies.
	USA	17	Leininger (1993; 2002)	Nurs	The development of a holistic approach to transcultural care. Described as a comprehensive view of healthcare when working with different cultures. It describes how transcultural nursing is different from monocultural.	Yes	JA & BK	Level 1 Understanding of local and global structures and the world view of clients Level 2 Identifying the value systems of other cultures and their healthcare approach Level 3 Understanding the healthcare system Level 4 Recognising the roles of healthcare providers	Critical awareness of differences in experiences Knowledge of expectations and experiences of healthcare Awareness of how other health systems work	No	Leininger work has resulted in a mid range theory and this has been the basis for many of the models described here. It is similar in many ways to Purnell's model and wonder who came up with it first. A complexity based model. Similar in constructs and approach to Spector and Parnell, which was the original is unclear.	Most widely cited and acknowledges transcultural nursing approach. Been used many times and with many adaptations..
	UK	18	Papadoploulos and Lees (1998; 2002)	Nurs	Based on Campina-Bacote model who is not cited but Leininger is, but presents the framework in two layers. Culture generic and culture specific. The intention is to help to develop culturally competent healthcare workers.	No	BK	Cultural awareness: Generic , applicable across groups and specific, applicable to a single group. Cultural Knowledge: generic and specific Cultural sensitivity: generic and specific	Awareness of self and others examine own beliefs and biases. Become more reflective--this awareness leads to the acquisition of knowledge In addition to facts collection, this is gained through contact with people of other cultures This includes skills such developing trust and empathy, communication skills and respect.	No	Papadoploulos sees cultural competence developing firstly through raised awareness and knowledge which will lead to sensitivity. Book provides teaching resources and guides. Though stating that it has been used in many research projects non are identified and no assessment tool is discussed.	Not tested or no tool, through extensive research it emerged that two CC need to be developed.

Table Appendix 13.5

Synthesis	Country	Ref ID	Author/date	Discipline	Rationale	Context	Journal(JA)/ Book(BK)	Components	Explanation	Measure	Comment	Evidence
Jirwe 2008	USA	19	Andrews (2002)	Nurs	Nursing text book to describing transcultural concepts of nursing that can help them become culturally competent practitioners.	Yes	BK	Cultural self assessment: the provider needs to self assess their own levels of cultural competence.	Using the scale developed by the authors, providers need to self assess to find their level of cultural competence	No	Draws heavily Leininger's model.	No evidence cited.
							Assessment: In include the skills and knowledge to assess Family and client variables; organisational cultural variables; professional and societal variables	The book provides a guide to assessing people from different backgrounds: Using the assessment tool in the book providers will be able to make a comprehensive assessment of any individual				
							Planning: skills and knowledge to plan interventions appropriate for the client					
							Intervention: involving Cultural accommodation, Cultural preservation, Cultural re-patterning	This is the key part of the model. This is taken directly from Leininger and is about accepting the clients world view, experience and wishes and working with them and the provision system to deliver appropriate care.				
							Evaluation: ability to negotiate appropriate outcome with client					
	USA	20	Giger and Davidhizar (2004)	Nurs	To provide a comprehensive approach to assessment of culturally diverse patients, this can then be used to tailor interventions and assess outcomes.	No	BK	Awareness of culturally unique individuals	Cultural awareness	No	No discrete formal model or framework. Based on Leininger and Spector's models. This is a detailed 'generic' assessment tool that can inform practice. It takes no account of individual or organisational attitudes, policies or protocols for working with the CD.	Used comprehensively but non cited.
							Detailed cultural assessment in 6 areas provides knowledge of unique individuals	Cultural knowledge				
							Application of assessed information informs intervention	Cultural skill				
	USA	21	Lipson and Steiger (1996)	Nurs	To help nurses to work with people from different backgrounds when instructing patients in self-care.	Yes	BK	Affective domain: attitudes, beliefs, feelings	Cultural awareness	No	No discrete formal model or framework. Encourages practitioners to consider the cultural perspective, that is, an objective view of the patient, a subjective view of self and set this in the socio-economic and political contexts.	Non cited.
						Cognitive domain; knowledge and understanding	Cultural knowledge					
						Behavioural domain: communication and assessment skills	Cultural skill					

Table Appendix 13.6

Synthesis	Country	Ref ID	Author/date	Discipline	Rationale	Context	Journal(JA) Book(BK)	Components	Explanation	Measure	Comment	Evidence	
Jirwe 2008	USA	22	Purnell (2003)	Nurs	Similar in many respects to Leininger. Aims to provide a framework for all healthcare providers. The cultural aspects of a person should inform their care, to ensure it is sensitive and appropriate for their needs. Sees this as a developmental model.	Yes	BK	Understanding of local and global structures and their influence	Cultural awareness	No	Similar in many ways to that of Leininger so it is also a complexity model. Complexity models acknowledge that there are interrelated ever changing systems that never reach equilibrium. Developmental.	Widely used and cited in papers, Purnell cites no evidence.	
							Identifying the value systems and healthcare approaches of patients	Cultural knowledge					
							Understanding the healthcare system and its interactions with the culturally diverse	Organisational issues					
							Competence is a developmental process	On-going process					
							Ability to assess and communicate with CD patients	Cultural skill					
		USA	23	Spector (2004)	Nurs	To increase knowledge of the dimensions and complexities involved in caring for people from diverse cultural backgrounds. In addition to help readers explore the interaction between care within the North American health care system and the diverse consumers of health care.	Yes	BK	Health providers heritage	Awareness of self	No	Considers the wider context and explores health care systems(traditional and modern) and the interaction with people from diverse backgrounds.	Non cited
							Heritage of others , and related issues	Awareness of others					
							Health and health beliefs and practices - competing or aligned	Cultural knowledge					
							Modern health care culture and system - all the issues and problems related to modern health care delivery.	Cultural skill					
							Traditional health care systems - the situation for the majority of the world population	Cultural knowledge					
							On-going process of growth	On-going					
		NZ	24	Wepa (2003)	Nurs	The central tenet of this approach is cultural safety in relation to health. The notion is that the health beliefs of indigenous peoples should be preserved from extinction and used in harmony with modern approaches.	Yes	BK	CC is a process that helps toward the goal of cultural safety		No	Cultural competence is the skill and ability of the practitioner and how they feel about cultural diversity, this may be inadequate and the only measure that is essential is how the patient feels about their care (cultural safety).	Non cited.
							Cultural awareness of others	Cultural awareness					
							Cultural awareness of self	Cultural awareness					
							Cultural knowledge	Cultural knowledge					
						Skill to implement and interact	Cultural skill						
						On-going step by step process	Developmental process						
						Cultural safety	CC training is insufficient cultural safety is the primary goal						

Table Appendix 13.7

Appendix 14 Data extracted from trial of cultural competence interventions

Appendix 14.1 Self-efficiency studies

Trial 1	Alpers RR; Zoucha R	Year: 1996	Country: USA
Methods	Design: Target pop: Allocation Process: Intervention duration: Study date and duration: Sample size:	Quasi Senior community nursing students Quasi 1 semester 1996, 12 months Intervention (32), control (31)	
Participants	Intervention: Comparison group: Participant characteristics:	32 fall cohort, Cultural sensitivity class and 10 weeks home visits 31 spring cohort, no intervention Mostly white, female and average 27 years	
Intervention	Implementation: Intervention element:	Home visits with Hispanic families Lecture; cultural immersion	
Outcome	Mostly, control did as well as or better than intervention, and expressed more confidence with Asian families despite no contact		
Bias	Blinding process: Contamination:	Not possible Possible	
Authors' conclusions:	Students who received some cultural content feel less confident than those who did not		
Comment:			

Trial 2	Shellman J	Year: 2007	Country: USA
Methods	Design: Target pop: Allocation Process: Intervention duration: Study date and duration: Sample size:	Quasi-non-equivalent groups Student nurses, elder care None 2 hours 2 2005, 13 weeks	
Participants	Intervention: Comparison group: Participant characteristics:	43 (30) Reminiscence sessions with elders 21 (15) Cohort from the following year, no intervention 85% white, 97% female, mean age 25 years	
Intervention	Implementation: Intervention element:	Intervention reminiscence sessions Cultural immersion; support material	
Outcome	Increase in elder cultural self-efficacy in intervention group		
Bias	Blinding process: Contamination:	None Possible but unlikely	
Author's conclusions:	Reminiscences interventions increase nurse confidence via self-efficacy, this may decrease patient outcomes		
Comment:			

Trial 3	Smith LS	Year: 2001	Country: USA
Methods	Design: Target pop: Allocation Process: Intervention duration: Study date and duration: Sample size:	RCT (stated as quasi) Registered nurses 94 from fliers sent to all nurses in Alabama. Randomly allocated to intervention and control stratified by race 8.5 hours (1 day training) 2001, 3 weeks 94	
Participants	Intervention: Comparison group: Participant characteristics:	48 trained on transcultural assessment course 46 undertook health informatics course 90+% females, all nurses, 70% white, no significant differences in characteristics between groups	
Intervention	Implementation: Intervention element:	Giger and Davidhizar training model and cultural knowledge Lectures; role play; small group work	
Outcome	Significant increase of cultural knowledge and self-efficacy scores for intervention group		
Bias	Blinding process: Contamination:	Not possible Possible - classes held at same time	
Author's conclusions:	G and D approach increases cultural knowledge and self-efficacy, a one day course seems sufficient		
Comment:			

Trial 4	St Clair A; McKenry L	Year: 1999	Country: USA
Methods	Design: Target pop: Allocation Process: Intervention duration: Study date and duration: Sample size:	Quasi experimental with controls Student nurses (grad and undergrad) Intervention students volunteered 2-3 weeks 1997-took up to 12 months to collect data 200	
Participants	Intervention: Comparison group: Participant characteristics:	89 Cultural Immersion abroad 111 usual studies, but worked with minority groups in USA Both groups demographically similar - factors not stated	
Intervention	Implementation: Intervention element:	Intervention group lived and worked in UK, Jamaica, Ghana Cultural immersion; personal learning journal	
Outcome	Positive increase in Cultural Self Efficacy scores for immersion students		
Bias	Blinding process: Contamination:	Not possible Possible with interaction on return	
Authors' conclusions:	Immersion students were more prepared to work with minority groups than students who had an experience with minorities in the USA		
Comment:			

Appendix 14.2 Provider training: Knowledge skills and Awareness

Trial 5	Berlin A; Nilsson G; Tornkvist L	Year: 2010	Country: Sweden
Methods	Design: Target pop: Allocation Process: Intervention duration: Study date and duration: Sample size:	RCT-Cluster Primary care child health nurses Not described 2 days + 4 weeks clinical work + 1 day 2010, 3 days 27 areas (51 Nurses)	
Participants	Intervention: Comparison group: Participant characteristics:	24 (15 areas) 25 (2 dropped out) (12 Areas) 90%+ Swedish, most spoke 2 languages, majority (>70%) had some previous cultural training	
Intervention	Implementation: Intervention element:	Cultural competence education programme based on Campina-Bacote Lectures; small group work; difficult case studies; 4 weeks clinical work	
Outcome	Skill and anxiety significantly improved in intervention group, awareness / knowledge did not		
Bias	Blinding process: Contamination:	Nurses know which group they were in Unlikely	
Authors' conclusions:	4 weeks clinical work may be insufficient to embed learning. Sample too small		
Comment:			

Trial 6	Caffrey RA; Neander W; Markle D; Stewart B	Year: 2005	Country: USA
Methods	Design: Target pop: Allocation Process: Intervention duration: Study date and duration: Sample size:	Quasi experimental pre and post-test with controls Student nurses; any discipline none 5 weeks 1993 < 1 year 44 (32 took post-test)	
Participants	Intervention: Comparison group: Participant characteristics:	7 Integrated Cultural Curriculum (ICC) plus cultural immersion 25 ICC only All female, mostly white average age 25 years	
Intervention	Implementation: Intervention element:	Cultural immersion students with local clinicians then alone Lectures; cultural immersion	
Outcome	Higher scores on CCCHS*, greatest effects sizes for: Perceived ability to provide culturally competent care, and perceived comfort supervising diverse staff. Controls scored well on knowledge		
Bias	Blinding process: Contamination:	Not possible Possible. Cultural immersion students emailed fellow students and reported experiences	
Authors' conclusions:	Cultural immersion can have dramatic impact on cultural competence; otherwise the cognitive level (Knowledge) is as far as a student can go		
Comment:	*CCCHS = Caffrey Cultural Competence Health care Scale		

Trial 7	D'Andrea M; Daniels J; Heck R	Year: 1991	Country: USA
Methods	Design: Target pop: Allocation Process: Intervention duration: Study date and duration: Sample size:	Quasi-experimental with controls Graduates undertaking a multicultural counselling course None-Quasi 1 semester (36 - 45 hours) 1990, one semester 96 (90)	
Participants	Intervention: Comparison group: Participant characteristics:	Study 1: 19; Study 2: 19; Study 3: 24 Study 1: 15; Study 2: 18 Stated as non-equivalent groups, no characteristics described except mostly East Asian – class members	
Intervention	Implementation: Intervention element:	3 intervention groups that vary by intensity of training Lecture; workshop; small group work	
Outcome		Significant increase in MAKSS* within and between groups pre to post for all intervention groups (average = twice as much). Minimal differences between delivery intensity	
Bias	Blinding process: Contamination:	Students not blind Possible as they are at the same institution	
Authors' conclusions:		The theoretical format makes the delivery work whatever style used. Skills is the most difficult to teach (Labour intensive). Educators should use this approach because of the dramatic (sic) gains observed	
Comment:		*MAKSS = Multicultural Awareness Knowledge and Skill Scale	

Trial 8	Godkin MA; Savageau JA	Year: 2001	Country: USA
Methods	Design: Target pop: Allocation Process: Intervention duration: Study date and duration: Sample size:	Quasi experimental with controls Pre clinical medical students Class cohorts 2 years 1997-1998, 2 years pre-clinical 26 (plus control cohort)	
Participants	Intervention: Comparison group: Participant characteristics:	26 Multicultural Track student volunteers 104 Non Track cohorts Selection process not described. All medical students in pre-clinical years, 88% white, 66% female, keen to work with underserved groups	
Intervention	Implementation: Intervention element:	Cultural immersion (Home and abroad) Cultural immersion; Bi-monthly seminars	
Outcome		Intervention group had increased knowledge of aspects of local minority groups, greater tolerance of people who do not speak English and more at ease with people of different cultures. Significant increases between groups on cultural knowledge and attitude at pre and post measures	
Bias	Blinding process: Contamination:	Not possible	
Authors' conclusions:		'Track' is an effective way of increasing students cultural knowledge, but costs of such a programme need to be factored in to any proposed	
Comment:			

Trial 9	Kutob RM; Senf JH; Harris JM	Year: 2009	Country: USA
Methods	Design: Target pop: Allocation Process: Intervention duration: Study date and duration: Sample size:	RCT (see allocation) Practicing family residents (GPs) Applying students alternately allocated to two conditions 5 weeks max 2005 122	
Participants	Intervention: Comparison group: Participant characteristics:	58 take on line cultural competence course 64 only complete pre and post-test questionnaire No significant differences were evident for characteristics	
Intervention	Implementation: Intervention element:	Intervention applicants took 1 hour online course Online course	
Outcome		Overall the intervention group scored higher than the controls significant 0.004. Sub set analyses indicated that two domains of the CCAT* were responsible for the differences, cultural knowledge and non-verbal behaviour (Computer mediated). Perceived skills and awareness was assessed	
Bias	Blinding process: Contamination:	Applicants and data collectors knew what each group was No	
Authors' conclusions:		A brief programme that does not require tutor time was able to improve self-report cultural competence skills. Combination of skills based approach and accessibility makes it a potentially useful tool to reduce disparity. Applicants and data collectors knew what each group was	
Comment:		Online courses are feasible - need to develop the elements more - some seem redundant This is really a KSA study *CCAT =	
Trial 10	Lasch KE; Wilkes G; Lee J; Blanchard R	Year: 2000	Country: USA
Methods	Design: Target pop: Allocation Process: Intervention duration: Study date and duration: Sample size:	RCT? Oncology nurses who work with diverse populations Claimed but not described Approx. 4 days 1992 - 1995 575	
Participants	Intervention: Comparison group: Participant characteristics:	371 workshops, 116 Workshop & Enriched 86 oncology nurses with no cultural training	
Intervention	Implementation: Intervention element:	>90% female, age 30 - 50, >80% white, >90% RN, Stated as similarity between groups, but no statistics Didactic cultural awareness. Precepted bedside visit with specialist, focus groups	
Outcome		Significant increase in knowledge, awareness and skill, (Workshop and Enriched groups), compared to control group. No significant difference between intervention groups	
Bias	Blinding process: Contamination:	Not possible Possible. Nurses from each group worked at the same institutions	
Authors' conclusions:		One day programme is an effective method of imparting the information. More resource costly approaches may not be necessary (enriched). This inexpensive approach could help to relieve the cancer pain for a large number of patients from minority groups	
Comment:			

Trial 11	Majumdar B; Keystone; Cuttress LA	Year: 1999	Country: Canada
Methods	Design: Target pop: Allocation Process: Intervention duration: Study date and duration: Sample size:	Quasi experimental with controls Foreign born medical graduates Separate cohorts of intake 15-16 days 1999, 2 weeks 48	
Participants	Intervention: Comparison group: Participant characteristics:	24 (20) 24 (18) All landed immigrants (permanent resident but non-citizen). Control and intervention approx. similar (equal gender split, 80+% landed immigrant, 75% married, resident Canada average 4 years)	
Intervention	Implementation: Intervention element:	Two cohorts of immigrant medics, one culturally trained the other not Workshops; role-play; support materials	
Outcome	Intervention participants more accepting of own limitations, more willing to take risks, more able to deal with stress of interactions, increased ability to read a patient from different backgrounds, more receptive to verbal and non-verbal behaviour, stated as cultural knowledge, skills and awareness		
Bias	Blinding process: Contamination:	Not possible Possible	
Authors' conclusions:	Canada needs doctors that are sensitive to the both the Canadian and the culture of the minorities it contains. This programme may prove to be effective to achieve this		
Comment:	A reverse of the usual, immigrant doctors trained to deal with Canadian cultural mix		

Trial 12	Paul CR; Devries J; Fliegel J; Van CJ; Kish J	Year: 2008	Country: USA
Methods	Design: Target pop: Allocation Process: Intervention duration: Study date and duration: Sample size:	Quasi with controls Paediatric medical students Students assigned to groups, no description 9 months 2002, 9 months 91	
Participants	Intervention: Comparison group: Participant characteristics:	22 working in high density migrant community 69 working in typical hospital Not described; no significant differences in baseline scores	
Intervention	Implementation: Intervention element: role-play	Both groups culturally trained, then work in different locations Working in high density migrant environment; coaching, workshops;	
Outcome	Significant increase in perceived: skill, awareness, written knowledge, modelling behaviours and OSCE* compared to controls, no significant increase in perceived knowledge		
Bias	Blinding process: Contamination:	Not possible Possible - work at different location but may have contact	
Authors' conclusions: approach	Good way of introducing medical student to cultural competence, using relevant and multimodal		
Comment:	*OSCE = Observed Standardised Clinical Examination		

Trial 13	Robinson B; Bradley LJ	Year: 1997	Country: USA
Methods	Design: Target pop: Allocation Process: Intervention duration: Study date and duration: Sample size:	Quasi with controls Undergrad students: 75% social science students None; two independent cohorts 45 hours over 3 weeks 1997, 3 weeks 57	
Participants	Intervention: Comparison group: Participant characteristics:	29 (23 final); Multicultural issues summer school course 28(21); unrelated course All between 18 – 25 years old, no gender information	
Intervention	Implementation: Intervention element:	Attending a cultural awareness course or not Workshops; small group work; open learning; written assignments	
Outcome		Significant increase in MAKSS overall, significant increase in knowledge and awareness subscales, not skills. No significant difference between groups at baseline	
Bias	Blinding process: Contamination:	Not possible Possible	
Authors' conclusions:		The course as used increased cultural knowledge and self-awareness	
Comment:			

Trial 14	Wang VO	Year: 1998	Country: USA
Methods	Design: Target pop: Allocation Process: Intervention duration: Study date and duration: Sample size:	Quasi-experimental non-equivalent groups Students of Genetic Counselling course No randomisation (2 independent cohorts) 10 hours 1998, approx. 1 year 62 (70; 8 dropped out)	
Participants	Intervention: Comparison group: Participant characteristics:	32 1 st year cohort 30 2 nd year cohort Average 25 years, 90% female, middle class, white graduates from 80%+ white neighbourhoods	
Intervention	Implementation: Intervention element:	Intervention has 5* 2 hours sessions on multicultural content Lectures; group exercises; role play	
Outcome		MAKSS scores significant increase over controls post intervention and at 6 months follow-up MAKSS scores no significant difference between groups after controls receive same intervention	
Bias	Blinding process: Contamination:	Two separate years used, advised not to talk about course and course taken at different times Unlikely - time tabled months apart and the participants were separate	
Author's conclusions:		Intervention effective for increasing multicultural counselling competence. When the curriculum was taught it had little impact on outcome	
Comment:		Good compromise design to demonstrate validity and reliability. Looks at presentation at different times along the course pathway, looks at retention of learning at 6 months	

Trial 15	Williams CC	Year: 2005	Country: Canada
Methods	Design: Target pop: Allocation Process: Intervention duration: Study date and duration: Sample size:	Quasi - experimental, non-equivalent groups Social workers, counselling (mental health) Volunteers who could/could not attend the sessions 12 hours 2005, 2.5 months 47	
Participants	Intervention: Comparison group: Participant characteristics:	29 Multi-cultural skills training (could attend) 18 'Standard' diversity training on a waiting list Mostly female, aged between 20 and 54, mostly white Canadian, majority with Master's degree, average 10 years' experience, 90% had some previous diversity education	
Intervention	Implementation: Intervention element:	Intervention: 4* 3 hours multicultural training sessions Lectures; large and small group discussions; case studies; role play	
Outcome	No significant differences between groups for MCI* and MCC**, but intervention group significantly increased awareness. Qualitative data indicated a perceived benefit at 6 months by intervention group		
Bias	Blinding process: Contamination:	No Possible, could work together	
Author's conclusions:	Students need to be grounded in cultural awareness so they can build on this with counselling skills later on		
Comment:	*Multicultural Counselling Inventory; **Multicultural Case Conceptualisation		

Service Provider training: Not full knowledge skills and awareness

Trial 16	Bhawuk DPS	Year: 1998	Country: USA
Methods	Design: Target pop: Allocation Process: Intervention duration: Study date and duration: Sample size:	Quasi-expt. - post-test only with controls Junior year students about to embark on an exchange visit (any department) Randomised (not described) to one of 4 conditions Overnight and one day 1998, less than 1 week 102	
Participants	Intervention: Comparison group: Participant characteristics:	77 (in three groups*) 25 Average age 21 years, junior year students - no other information	
Intervention	Implementation: Intervention element:	Intervention work on cultural assimilators**; controls read a text on diversity Workshops; working on assimilators; role-play; interview a foreigner	
Outcome	Three groups always performed better than control on ISI***, ICA [#] group recalled more knowledge Some variation between intervention groups but not significant. No significant differences between any groups on face to face with a foreigner		
Bias	Blinding process: Contamination:	Students may guess which group they are in, researchers knew which group each student was in Limited as students completed overnight but could have collaborated	
Author's conclusions:	Theory based intervention using assimilators improves cultural sensitivity. Theory of collectivist and individualist societies is useful in teaching cross cultural issues		
Comment:	*Three different types of culture assimilator, **Assimilator = critical incident vignettes, ***Intercultural Skills Inventory, [#] Individualist / Collectivist Assimilator		

Trial 17	Brooks GS; Kahn SE	Year: 1990	Country: Canada
Methods	Design: Target pop: Allocation Process: Intervention duration: Study date and duration: Sample size:	Quasi expt. With controls, pre and post test Graduate counselling psychology students Opportunity sample 13* 2.5 hours weekly sessions 1987-1988, 16 months 57	
Participants	Intervention: Comparison group: Participant characteristics:	34 ethnicity awareness course 23 normal counselling courses 84% female, mean age 35 (21-49), 80% white euro American, no sig diffs between groups reported.	
Intervention	Implementation: Intervention element:	34 ethnicity awareness course 23 normal counselling courses	
Outcome	Awareness: No significant differences between the intervention and control. In addition, the mean scores for both groups did not exceed the level of moderate ethnic awareness. Six month follow-up phone interview indicated (qualitative) that interventions were more had more ethnic awareness		
Bias	Blinding process: Contamination:		
Authors' conclusions:	Follow-up period was too short; sample too small and unrepresentative; teaching could have been the factor that inhibited cultural awareness or instruments flaw		
Comment:	*Thirteen weeks sessions was adequate - either curriculum or assessment flawed		

Trial 18	Genao I; Bussey-Jones J; St George DM; Corbie-Smith G	Year: 2009	Country: USA
Methods	Design: Target pop: Allocation Process: Intervention duration: Study date and duration: Sample size:	RCT Third year medical students Students randomised to intervention and control 6 hours 2001 - 2004 109	
Participants	Intervention: Comparison group: Participant characteristics:	62 attended Cultural competence course 47 attended another module No significant differences between groups on age, gender, ethnicity or previous cultural competence training. 66% group white	
Intervention	Implementation: Intervention element:	Attend / not attend course, tested Pre and post intervention module Workshop; discussion groups; vignettes	
Outcome	Intervention overall knowledge scores increased by 20% compared to 4% (significant)		
Bias	Blinding process: Contamination:	Data analyst blind --others not possible Possible, though controls undertook another class they still part of the cohort	
Authors' conclusions:	Previous training in cultural competence or race and ethnicity had no impact on outcome. This trial indicates that this curriculum as assessed by their "validated" measure can improve the cultural competence knowledge of medical students		
Comment:	Outcome measure was devised for the assessment and was multiple choice		

Trial 19	Napholz L	Year: 1999	Country: USA
Methods	Design: Target pop: Allocation Process: Intervention duration: Study date and duration: Sample size:	Quasi- experimental, with controls (Non-equivalent groups) Nursing students, second year Allocation to two groups not described Not recorded 65	
Participants	Intervention: Comparison group: Participant characteristics:	16 usual cultural teaching plus time with cultural advisor 49 usual cultural teaching Junior level 2 nd year nursing students, rest not described. Sample came from 2 different campi.	
Intervention	Implementation: Intervention element:	During clinical experience consultant gave advisory sessions 3* 2 hours sessions with a consultant in addition to traditional' cultural teaching v traditional only	
Outcome	Intervention group performed better on a perception of cultural skills test (significant on all items) but also significant differences between groups at pre-test, but there was a significant improvement		
Bias	Blinding process: Contamination:	Non possible Not discussed, it is unknown if the groups mixed professionally or socially	
Author's conclusions:	Nurse Educators need to examine the differences in learning experiences related to cultural diversity that may account for differences in student attitudes		
Comment:			

Trial 20	Parker WM; Moore MA; Neimeyer GJ	Year: 2001	Country: USA
Methods	Design: Target pop: Allocation Process: Intervention duration: Study date and duration: Sample size:	Quasi experimental, with controls. Pre and post test White counselling students Two cohorts used 15 weeks 2000, 15 weeks 96 (54)	
Participants	Intervention: Comparison group: Participant characteristics:	48 (32) Multicultural counselling course (required module) 48 (22) Counselling skills course (required module) White and 40% male - no other characteristics described	
Intervention	Implementation: Intervention element:	Both cohorts took pre and post-module WRDCS* and the ICI** Lectures; workshops; group work with role-play and mentoring	
Outcome	Intervention significantly increased 3 dimensions of White racial consciousness (contact, pseudo-independence and autonomy), and significantly enhanced interracial comfort - but not disintegration and reintegration		
Bias	Blinding process: Contamination:	Not possible Possible - separate classes but same year/body of students	
Authors' conclusions:	Multicultural training develops a greater sense of comfort in attitudes of White trainee counsellors towards non-whites. A significant increase in the development of positive or less negative attitudes towards non-whites		
Comment:	*WRDCS=White Racial Consciousness Development Scale, **Interracial Comfort Inventor		

Trial 21	Scisney-Matlock M	Year: 2000	Country: USA
Methods	Design: Target pop: Allocation Process: Intervention duration: Study date and duration: Sample size:	Quasi experimental with controls Senior student nurses Separate year groups 1 semester 1995-1997, 2 years 127	
Participants	Intervention: Comparison group: Participant characteristics:	57 new teaching approach, tested on MLSS* 65 Standard teaching approaches tested on MLSS Average age 24, mostly female (90%), mostly white (80%)	
Intervention	Implementation: Intervention element:	2 independent groups tested at semester end one year apart Targeted classroom lectures, written and verbal presentations; population related data task; work within mixed ethnic groups	
Outcome	Intervention group had more knowledge of cultural diversity, read more about it and were more comfortable with it as well as engaging in more diverse interactions		
Bias	Blinding process: Contamination:	Not described but the two cohorts were min 18 months apart Limited	
Author's conclusions:	"Drastic and remarkable" differences detected. Conceptual frameworks for teaching can add value and impact to future teaching		
Comment:	*MLSS= Michigan Longitudinal Study Scales		

Appendix 14.3 Communication Training Studies

Trial 22	Harmsen H; Bernsen R; Meeuwesen L; Thomas	Year: 2005	Country: Holland
Methods	Design: Target pop: Allocation Process: Intervention duration: Study date and duration: Sample size:	RCT Cluster GPs / Non-western minority groups Practices randomised, but analysis at service-user level 2.5 days February 2000 – November 2000 GPs 38, 986 consultations	
Participants	Intervention: Comparison group: Participant characteristics:	19 GP practices: 176/172/151 dyads 19 GP practices 175/161/151 dyads Control/intervention comparison by regression analysis (Some differences but only gender significant)	
Intervention	Implementation: Intervention element: video	Service-users categorised as culturally Modern or Part modern/Part traditional or Traditional. Intervention GPs attended communication skills training GPs: workshops; mentored reflective meeting. Service-users: instruction video	
Outcome		Overall non-western service-users intervention group: at 6 months significant increase for mutual understanding and quality of care, satisfaction increased but not significant. GPs increased positive perception of cultural skills	
Bias	Blinding process: Contamination:	Not possible for GPs but service-users blind to allocation of practice and data collectors blind to allocation. Limited	
Authors' conclusions:		Working on consultation communication problems decreases the gap in quality of care between western and non-western service-users	

Trial 23	Ho MJ; Yao G; Lee KL; Beach MC; Green AR	Year: 2008	Country: Taiwan
Methods	Design: Target pop: Allocation Process: Intervention duration: Study date and duration: Sample size:	RCT Medical Students (80% Taiwanese) Random number generation 4 hours Basic 6 hours Extended First 6 months of 2006 57	
Participants	Intervention: Comparison group: Participant characteristics:	15 Basic (4 hours training); 15 Extensive (6 hours training) 27 Standard communication training 5 th year students mean age of 25 years, 20% female. No significant differences for age, gender, nationality, and prior communication skills training between groups	
Intervention	Implementation: Intervention element:	Cultural communication sessions for intervention group Workshops; Role-play (Extensive only)	
Outcome		Standardised Patients (SP) rated Extensive tuition and basic tuition groups better than controls on clinical skills - except in basic communication	
Bias	Blinding process: Contamination:	Students blind to assessment; SPs blind to student groups Possible - student group small and worked together	
Author's conclusions:		Cultural competence training can be effective in a 'none western' setting; just two workshops can make a major difference when working with minorities	
Comment:		SPs were Taiwanese as well and used scripts. Study 24 is a 12 mth follow-u	

Trial 24	Ho MJ; Yao G; Lee KL; Hwang TJ; Beach MC	Year: 2010	Country: Taiwan
Methods	Design: Target pop: Allocation Process: Intervention duration: Trial date and duration: Sample size:	RCT Medical Students (80% Taiwanese) Random number generator See Study 22 2006 for 12 months 57, 2 lost to follow-up (55)	
Participants	Intervention: Comparison group: Participant characteristics:	29 Cultural communication training (collapsed groups) 26 Standard communication training 5 th year students mean age of 25 years, 20% female. No significant differences for age, gender, nationality, and prior communication skills training between groups	
Intervention	Implementation: Intervention element:	Used same participants and assessment as Study 22 See Study 22	
Outcome	Regarding SPs reporting their illness related social factors (SF) and perspectives (PP): At original OSCE there were significant differences between intervention and control groups. At 12 months these had both significantly reduced and there was no difference between intervention and control for SF and a reduced difference for PP		
Bias	Blinding process: Contamination:	See study 22 12 months and mixing of students on clerkships. Some control scored increased, these students had been imitating behaviours of intervention students	
Authors' conclusions:			
Comment:			

Trial 25	Schouten BC; Meeuwesen L; Harmsen HA	Year: 2005	Country: Holland
Methods	Design: Target pop: Allocation Process: Intervention duration: Study date and duration: Sample size:	Cluster RCT GPs / Non-western minority groups Not described 2.5 days 2000, 12 months GPs 38, Patients 124	
Participants	Intervention: Comparison group: Participant characteristics:	GPs Communication training / Service-users; primed with training video N/A	
Intervention	Implementation: Intervention element:	Intervention GPs attended communication skills training GPs: workshops; mentored reflective meeting. Service-users: instruction video	
Outcome	Significant increase for intervention group on: consultation time, amount doctors spoke and mutual understanding. For service-users no difference between groups except for the more acculturated who had increased therapeutic information giving		
Bias	Blinding process: Contamination:	Not for GPs, service-users yes Limited	
Authors' conclusions:	Used a sub group from Study 22		
Comment:			

Appendix 14.4 Service-user outcomes studies

Trial 26	Majumdar B; Browne G; Roberts J; Carpio B	Year: 2004	Country: Canada
Methods	Design: Target pop: Allocation Process: Intervention duration: Study date and duration: Sample size:	RCT Agency care providers and nurses Not stated, described as randomly allocated Not described Not stated, 12 month till end of follow-up 114 (in RCT) 133 patients in verification groups	
Participants	Intervention: Comparison group: Participant characteristics:	54 reduced to 40 60 No differences between groups on age, gender, experience and years in Canada. However, intervention group nurses sought information on cultural issues, health care literature and considered culture more important than the control group nurses	
Intervention	Implementation: Intervention element:	Specially devised cultural competence training Experiential workshops	
Outcome	Intervention groups significantly improved in cultural awareness, knowledge and skill compared to controls. At 12 month, increase in social functional capacity and use of social resources for service-users in intervention groups. No between group diffs for: client satisfaction, health and ADL		
Bias	Blinding process: Contamination:	None Not apparent, but probably	
Author's conclusions:	Culturally sensitive training results in improved knowledge and attitude for health providers and improved social and economic functionality for patients		
Comment:	"Minority groups" were UK and European migrants		
Trial 27	Sequist TD; Fitzmaurice GM; Marshall R; Shaykevich	Year: 2010	Country: USA
Methods	Design: Target pop: Allocation Process: Intervention duration: Study date and duration: Sample size:	Cluster RCT Primary care clinician teams, physicians and nurse practitioners (NP) (+ diabetic service-users) Randomisation of clusters stated but not described 2* 1 day training plus approx. 12 months including feedback and recommendations 2007-2008, 1 year 124 clinicians (7557 service-users)	
Participants	Intervention: Comparison group: Participant characteristics:	16 teams, 46 physicians, 16 NPs, 3773 service-users 15 teams, 45 physicians, 17 NPs, 3784 service-users Clinicians: Average 19 years' experience, 60% physicians, 90% nurse = female, 82% white. Service-users no significance between group differences	
Intervention	Implementation: Intervention element:	Train GP and NP on cultural competence / assess service-users Workshops, small group work, mentoring (feedback on performance)	
Outcome	No significant difference in black service-users clinical outcomes. Intervention clinicians more likely to perceive racial disparity after the intervention, increased awareness of racial disparity but decrease in perception that cultural competence would reduce this disparity and not altered statin prescribing rates		
Bias	Blinding process: Contamination:	Clusters would know which group they were in, service-users would not Possible, they belong to the same healthcare group	
Author's conclusions:	Increased awareness of clinical disparity between racial groups was not accompanied by a reduction in outcome disparity		
Comment:			

Trial 28	Thom DH; Tirado MD; Woon TL; McBride MR		Year: 2006	Country: USA
Methods	Design: Target pop: Allocation Process: Intervention duration: Study date and duration: Sample size:	Cluster RCT Primary care physicians / minority group service-users Cluster randomised by practice site - not described 4 hours average 2006 53 physicians; 429 service-users		
Participants	Intervention: Comparison group: Participant characteristics:	23 Training and feedback 30 Feedback only Physician: average age 40, 45 % female, 30% resident 72% white, and more Latinos in intervention group (27% v 7%) Service-users: Compared to controls, intervention group were, younger, more males, spoke less English, were heavier, less diabetics and more hypertensive		
Intervention	Implementation: Intervention element:	Training and feedback on performance; assess service-user outcomes Lecture; role-play; small group work; videos; feedback on performance		
Outcome		PRCCS* improved for both groups. Weight loss improved for intervention group, satisfaction, trust, Blood Pressure and Blood Glucose improved for controls, but none significant		
Bias	Blinding process: Contamination:	Patients did not know if physician was trained in cultural competence Low possibility		
Authors' conclusions:		Training intervention inadequate or PRPSS not sensitive enough		
Comment:		*Patient Reported Physician Cultural Competence Scale. Feedback to both groups may have confounded the outcome. Better instrument sensitivity may detect small changes not clinically significant. Non-equivalent groups		

Trial 29	Wade P; Bernstein BL	Year: 1991	Country: USA	
Methods	Design: Target pop: Allocation Process: Intervention duration: Study date and duration: Sample size:	RCT College counsellors, black females, lower middle class (sic) Random numbers with blocking to assign counsellors; clients. Were allocated by appointments available 4 hours 1991 8 counsellors; (4 black 4 white); 80 clients		
Participants	Intervention: Comparison group: Participant characteristics:	4 (2 black 2 white) counsellors, 40 clients Ditto Black, female, average age 37.5; household income <\$15000; 2.74 people per household; 70% graduated high school, 10% had further education; 20% married, 35% separated, 27.5% divorced, 17.5% single; 76% had personal problems and 24% work related issues. There were no significant differences between the groups		
Intervention	Implementation: Intervention element:	Intervention group counsellors received cultural competence training Lectures; small group discussion; workshops		
Outcome		Significant increase for intervention group over control in: positive relationship; satisfaction; credibility and attractiveness. Race of counsellor not a factor but same race dyads had less attrition		
Bias	Blinding process: Contamination:	Neither group knew the existence of the other group or the nature of the study Very low possibility		
Authors' conclusions:		Sensitivity training can raise perceptions of counsellors and was more important than racial pairings it also reduced attrition rates considerably, factors that facilitate maintaining appointments need to be		

Appendix 15 Material for stakeholder event

- What would be the most valid outcome measure for cultural competence training
- What mechanisms do you suggest trigger the students etc to adopt a culturally competent approach
Why?
- Describe experiences that make them think this
- What would or did help them to adopt a culturally competent approach
- Is there one or is a combination of mechanisms required
- If you have taught CC how did students react to it?-- what did you engage with most/least

