Advancing the concept of rehabilitation towards cultural sensitivity: a concept analysis

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Davis, Sally M. (2013) *Advancing the concept of rehabilitation towards cultural sensitivity: a concept analysis*

PhD, Oxford Brookes University

Advancing the Concept of Rehabilitation towards Cultural Sensitivity: A Concept Analysis

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Degree Awarded by Oxford Brookes University

Submitted in partial fulfillment of the requirements of the award
of Doctor of Philosophy.

July 2013

Abstract

Background

This study was instigated in response to the researcher's own realisation, as a rehabilitation practitioner and educator, that the concept of rehabilitation as identified in the literature may not be culturally sensitive. This view was prompted by the researcher's interactions with international students undertaking an MSc in Rehabilitation at Oxford Brookes University in the UK. The literature defining and describing rehabilitation generally appears to be from Europe (including the UK), Australia and the USA with an emphasis on concepts and values such as independence, autonomy and individualism, which appears to represent the values the of the Western countries from which the literature originates. This view is supported by Saadah (2002) who identifies autonomy as such a concept, which is identified as the aim of rehabilitation in the literature (Cardol 2002a) and calls for a structural framework for rehabilitation based on understanding of different cultures and culturally sensitive care.

Aim and Objectives

The main aim of this study was to examine the concept of rehabilitation in the literature in relation to cultural sensitivity in order to gain new interpretations and understandings for rehabilitation practice and education. The objectives being to discover if there is an essence or core of rehabilitation that transcends culture; whether the International Classification of Functioning, Disability and Health (ICF) (WHO 2001) is suitable for use as a cultural framework and to identify implications for practice and education.

Methodology and Methods

Concept analysis (Morse 1995) was the research approach used as it fits in with the conceptual assumptions of the study and enabled the researcher to analyse the literature in depth in order to explore the concept of rehabilitation in relation to cultural sensitivity. Morse's approach was followed with the fundamental difference being the addition of qualitative data which were analysed along with the literature. The data were collected from a university and hospital in Manipal, South West India. A literature review was conducted accessing PubMed, CINHAL, AMED, PsycINFO, NARIC and IndMED data bases using inclusion and exclusion criteria. Following management of the literature using the ICF (WHO 2001) categories and critical appraisal a sample of 120 articles was identified. Thirteen patients with neurological or orthopaedic conditions undergoing rehabilitation were interviewed using qualitative interviews, seven focus groups were conducted involving physiotherapy, occupational therapy and nursing students, health care professionals and lecturers and participant observation was conducted.

Main Findings

The literature and qualitative data were analysed following Morse's concept analysis approach to establish the level of maturity. This enabled the concept of rehabilitation to be deconstructed in terms of its components (attributes, definitions, attributes, pre-conditions, outcomes and boundaries). As a result the concept of rehabilitation in relation to cultural sensitivity was identified as being mature in relation to pre-requisites, boundaries and outcomes but only partially mature in respect of definitions and attributes. A key finding of this stage is that rehabilitation needs to be meaningful to the person and their family. This then led to the next step of concept analysis: concept clarification, where critical questions were asked of the data in order to advance the concept in relation to cultural sensitivity. As a result, culturally safe rehabilitation, external factors, family centred decision-making and meaningful rehabilitation were all identified as being integral to the concept of rehabilitation being meaningful to the person and their family.

Conclusion

A key contribution of this study to the body of knowledge on rehabilitation is that, in order for rehabilitation to be culturally sensitive, it needs to be meaningful to the person-in-their-family-in-their-cultural context. This can be seen as the essence of rehabilitation that transcends culture. In order for this to happen, rehabilitation needs to be emergent: responding to the needs of the person in their cultural context with professionals allowing for variation in individual experiences and perspectives. These elements have been combined into a framework with the person-in-their-family-in-their cultural context at the centre. However, the findings and recommendations need to be treated with caution as they are based on a small sample of data representing one area of India with a limited number of participants and literature that is only representative of the country and discipline in which it is written. There are also other limitations in terms of data collection, data analysis and interpretation of results. Future research is required to explore the idea of 'meaningful rehabilitation' for patients and their families and to evaluate the framework in practice and in education.

Acknowledgements

I wish to thank all the patients, students, lectures and healthcare professionals in India for sharing their experiences and ideas with me and for making me feel welcome. Particularly to Neya and Jyothi for acting as my guides and translators. Having the opportunity to collect data in India was an honour made possible by a scholarship from the Nightingale Trust and approval from Manipal University.

Thanks to my supervisors: Professor Waltraud Ernst, Dr. Ann Ewens and Dr. Katy Newell-Jones for their perseverance with me, and their tremendous support. It has been a difficult journey at times but they have been supportive all the way. I feel very lucky in having three supervisors whose skills and expertise complemented each other. I also need to thank Paul Yerrell who started me of on this journey as my original supervisor.

Thanks to Lindsey and Fran for helping me with transcribing the data and organising the literature, to Bridget for the opportunity to eat nice food and share PhD experiences and to other colleagues for their support and encouragement.

Lastly my thanks go to all my friends and family for their support particularly to Gary for his patience and understanding and for encouraging me to keep going.

Dedication

I wish to dedicate this PhD to my mum and dad who were both there at the beginning of the journey but unfortunately not at the end. They always supported and encouraged me and remembering them has kept me going.

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Chapter 1: Introduction

> "We become not a melting pot, but a beautiful mosaic; Different people, different beliefs, different yearnings, different hopes, different dreams"
> (Jimmy Carter, 39th President of the United States, 1976: Pittsburgh Speech).

> Intercultural communication involves the "ability to put oneself in another's shoes… the ability to treat someone as they would wish to be treated"
> (Olson and Kroeger 2001:118).

The above two views set the scene for this thesis. The first talks about cultural diversity, which reflects the multi-cultural society of today and the uniqueness of people. The second identifies what is needed to operate in a culturally inclusive way in order to respond to this diversity. This study is set in the context of cultural sensitivity in rehabilitation practice and education. More specifically, the focus of this study is on the cultural sensitivity of the concept of rehabilitation and the implications for rehabilitation practice and education. This is in response to the recognition through the delivery of an MSc Rehabilitation Programme at Oxford Brookes University in England that rehabilitation as described and defined in the literature may not be culturally sensitive.

This study is concerned with rehabilitation for people with disabilities, required as a result of, for example, a musculoskeletal, neurological, spinal, cardiac, respiratory condition or incident. This type of rehabilitation is referred to as physical rehabilitation (Gutenbruner et al. 2007). However, this can be seen as a misleading term as it implies that physical rehabilitation is separate from non-physical aspects such as psychological and social factors (Wade 2006). Therefore, for the purpose of this study, the term 'rehabilitation' will be used rather than 'physical rehabilitation'; the former is defined in the Oxford English Dictionary (Soanes and Hawker 2008:865) as "to restore something to its future condition". Rehabilitation is not defined any further at this stage, as it will be examined as part of the study. This chapter sets the context for the study: defining culture, discussing cultural aspects related to disability and rehabilitation and cultural competence and cultural sensitivity in relation to rehabilitation practice and education.

1.0 Context

Leininger (1978:491) describes culture as “the learned and transmitted knowledge about a particular culture with its values, beliefs, rules of behavior and lifestyle practices that guides a designated group in their thinking and actions in patterned ways”. This view of culture being a set of guidelines influencing how individuals live in their own social group or within society is a common view within the literature (Helman 1994, O’Hagan 2001, Stone 2005). A group can be perceived in various ways, for example, in terms of profession, social activities and ethnicity[1]. This study is focused on culture for different ethnic groups rather than professional or social groups.

Understanding that people’s values, beliefs, expectations, experiences and actions are all shaped by their culture is necessary for the provision of effective rehabilitation services for the patient (Crabtree et al. 2006). This points to the need for rehabilitation professionals to develop cultural competence, which is defined as “a set of behaviours, attitudes, and policies that come together in a continuum to enable a health care system, agency, or individual practitioner to function effectively in transcultural interactions” (Leavitt 2002:37). Culturally competent care is recognised as being essential for all healthcare professionals in order to respond to the multicultural society of today: acknowledging and understanding differences, values and beliefs of others, and being aware of one’s own culture (Eunyoung 2004, Crabtree et al. 2006). Adebajo and Alegbeleye (2007), in a review examining the relationship between culture and the rehabilitation of rheumatic diseases, identify the need for rehabilitation professionals to understand the cultural and ethnic influences on rehabilitation in order to deliver high quality and appropriate rehabilitation services.

1.0.1 Cultural aspects of disability and rehabilitation

Disability has been an area where cultural anthropologists have focused on using ethnographic approaches in order to understand disability as a socio-cultural experience. Ruth Benedict a pioneer in anthropology conducted one of the first anthropological studies of disability on cross-cultural conceptions of epilepsy in the 1930s (Benedict 1932). However, it was Margaret Mead in 1953 who put forward the idea that persons with disabilities needed to be included in anthropological inquiry.

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[1] Ethnicity: “groups of people who are united socially, politically, and geographically and possess a common pattern of values, beliefs, and behaviours as well as language” (Sotnik and Jezeweski 2005:22)

The focus on understanding the lived experience of disability was brought to the forefront with the introduction of the disability movement and the independent living model in the 1960s and 1970s. There was a shift in thinking in the 1970s away from considering disability as the problem of the unfortunate individual and their family to considering disability in the context of the socio-cultural environment (Reid-Cunningham 2009). The World Health Organisation's revisions of their classification systems for illness and disease reflect this. The International Classification of Impairments, Disabilities and Handicaps (ICIDH), (WHO 1980) with its emphasis on impairment and disability was revised to the International Classification of Functioning, Disability and Health (ICF), (WHO 2001). The ICF (examined in more detail in chapter two) views disability from a biological, individual and social perspective taking into account not just the physical and psychological factors but the participation of the individual in life situations and society and the effect of environmental factors.

Since the 1960s a number of studies have been conducted looking at cultural aspects of disability. Seminal work has included Goffman's (1963) work on stigma; Joan Albon's studies (1988, 1999) exploring issues for individuals with genetic conditions; work by Norah Groce (1985) on the experience of deafness. These studies have focused on disability constructed from specific impairments, which has been a main focus of anthropological work in this area (Kasnitz and Switzer 2001).

Herhenson (2000) in a review of the literature examined the extent to which cultural anthropology has been applied to the understanding of disability and rehabilitation. Anthropology has been key in exploring disability but more limited in terms of rehabilitation. However, studies that have particularly explored cultural beliefs in relation to disability as a result of different conditions can help rehabilitation practitioners understand the cultural aspects that need to be considered in relation to an individual's rehabilitation. For example Ponchilla (1993) explored the cultural beliefs of Native Americans toward diabetes-related visual impairment. However, it is important that these beliefs are not generalised to all native Americans, taking into account that individualised view. There are though important points that need to be considered in the planning of rehabilitation services. Miles (1996) supports this view identifying that Western approaches to disability services planning are not applicable in South Asian cultures for example. Asian cultural values and local conceptions of disability need to taken into account.

Although cultural aspects of disability have been a focus in anthropological studies resulting in a rich understanding of the experience of disability, exploring cultural aspects related to rehabilitation has not received the same attention. With rehabilitation professionals and researchers focusing on the ICF there is scope for exploring the level of participation and contextual factors in relation to cultural aspects.

1.0.2 Culturally sensitive rehabilitation practice

In order for rehabilitation professionals to be culturally competent in the provision of rehabilitation services to the individual, they first need to demonstrate cultural sensitivity (Camphina-Bacote 1991). Cultural sensitivity is an essential component of cultural competence, which is described as the ”awareness by one person of the differences in values, beliefs, and behaviours of another, and the understanding that these values, beliefs, and behaviours are the basis for the way people interact with each other” (Sotnik and Jezewski 2005:34). This highlights the need for professionals to be sensitive to how a patient’s values and perceptions about health care differ from their own (Goicoechea-Balbona 1997). If rehabilitation is not culturally sensitive the consequence could be that the patient’s rehabilitation programme will not fit in with their values and beliefs or the values and beliefs of their family. This may then result in the patient becoming de-motivated and not engaging with their programme or the programme may create dissonance between the family, the patient and the health professionals. Cultural sensitivity applies not only to practice but to the resources that guide and direct practice such as the literature. Therefore, if rehabilitation is not defined in the literature in a culturally sensitive way, rehabilitation professionals and rehabilitation educators may not develop culturally sensitive practice.

One of the barriers to cultural sensitivity is ethnocentrism: the belief that one’s own cultural worldview is central to all reality (Bennett 1993). This results in choices and actions based on that view (Olson and Kroeger 2013). Consequently, ethnocentric behaviour is not culturally sensitive, as it does not see individuals from their cultural worldview. Bennett’s (1993) model of cultural sensitivity acknowledges this by identifying three ethnocentric stages (denial, defense and minimisation) and three ethnorelative stages (acceptance, adaptation and integration). Ethnorelativism, in contrast to ethnocentricity, identifies that cultures can only be understood within a cultural context. Olson and Kroeger (2001), in discussing intercultural sensitivity in relation to internationalisation of the curriculum, identify that as educators become more culturally sensitive they move through ethnocentricity to ethnorelativism. This transition could equally apply to healthcare professionals.

1.0.3 Culturally sensitive education

The call for education to be culturally sensitive is a key agenda in higher education with the focus on internationalising the curriculum. This has resulted in universities identifying graduate attributes that prepare students to be global citizens. Graduate attributes are identified as the “skills, personal attributes and values, which should be acquired by all graduates regardless of their discipline or field of study” (HEC, 1992:20). Including global citizenship as a graduate attribute demonstrates commitment to internationalisation: an ongoing, educational process, challenging “current course content and pedagogy, offering a transformative educational experience to students” (Clifford and Montgomery 2011:13). The aim of an internationalised curriculum is to enable students (home and international) to perform professionally, socially and emotionally in an international and multicultural context (Nilsson 2003).

Clifford and Haigh (2011), in an analysis of different universities’ views of graduate attributes, suggest that although the majority of universities addresses the idea of global citizenship, it may not be sustainable without recognition of students’ own personal development and personal responsibility. At Oxford Brookes University, (Strategy for Enhancing the Student Experience 2010-2015) global citizenship is included as one of the five graduate attributes for under-graduate and post-graduate students and is defined as “knowledge and skills, showing cross-cultural awareness, and valuing human diversity. The ability to work effectively and responsibly in a global context.” This includes having awareness of one’s own culture, developing the confidence to question one’s own values and those of others, and actively engaging in issues of equity and social justice. In considering this attribute in relation to the MSc Rehabilitation Programme, the content taught in the rehabilitation module I lead, which focuses on definitions and descriptions of rehabilitation in the literature, could be seen as being culturally insensitive. The definitions are mainly from Europe and the USA and can be seen as being ethnocentric by assuming that these definitions then apply to all cultures, which does not demonstrate cross-cultural awareness or valuing human diversity. It is this supposition that this study aims to explore.

In a study exploring the understanding of different disciplines of the concept of internationalising the curriculum, Clifford (2009:136) makes the point that lecturers in subjects such as science-based professions, where medicine and other health care disciplines, for example physiotherapy, would fit, believed that “the theories, principles and concepts of their discipline were the same the world over” and that their discipline was already international. This view could apply to rehabilitation in that rehabilitation educators and practitioners may believe that the concept of rehabilitation is the same in whatever cultural context it occurs. This could also relate to rehabilitation authors and researchers not considering the relevance of concepts under discussion or research findings for different cultural contexts. This view links in with Bennett’s (1993) model (discussed earlier) of ethnocentricity, where one cultural worldview is seen as superior over another.

1.0.4 Rehabilitation literature

The literature defining and describing rehabilitation generally appears to be from Europe (including the UK), Australia and the USA, with an emphasis on concepts and values such as independence, autonomy and individualism, which appears to represent the values of the countries the literature is from. Saadah (2002) identifies autonomy as such a concept, which is identified as the aim of rehabilitation in the literature (Cardol 2002a). Saadah (2002) concludes that accommodation and negotiation could be more appropriate values for rehabilitation where there are strong family relationships and different cultural backgrounds. This acknowledges the view that concepts cannot be universally applied across cultures as they may not be compatible with individuals’ cultural beliefs and values.

This view is supported by Iwama (2006a) who identified the need for alternative cultural worldviews resulting in the development of a model aligned to the culture of Japan. Iwama (2006a, 2006b) questions the cultural relevance of occupational therapy and rehabilitation frameworks and suggests that in order for occupational therapy and rehabilitation to be culturally sensitive they need to be understood from the position of the person receiving occupational therapy and rehabilitation. This supports the need for rehabilitation professionals to be culturally sensitive, as discussed earlier, focusing on the individual and his or her family. Rehabilitation therefore will mean different things to different people based on their cultural context. Recognising this diversity, Banja (1996) asks if there is an essence of rehabilitation, which remains unchanged regardless of cultural context. The crux of this thesis is to investigate if there is an essence or core of rehabilitation that is cross-cultural and if so what that is.

Saadah (2002) identifies the need for a structural framework for rehabilitation based on an understanding of different cultures and culturally sensitive care. The ICF (WHO 2001) is a framework, which guides rehabilitation practice and provides rehabilitation professionals with a common language. With its focus on the biopsychosocial model, the ICF could possibly be such a framework. This is a view with which Iwama (2006a) agrees with. However, he suggests that alternative culturally relevant theory and knowledge systems may be required to complement the ICF. As the ICF is a key rehabilitation framework, it will be explored in this thesis for its suitability in promoting cultural sensitivity in rehabilitation. The development of the ICF, its strengths and weaknesses are discussed in chapter two.

1.1 Personal Context

My interest in the cultural sensitivity of rehabilitation is due to my specialisation in neurological rehabilitation as a nurse, working for many years at a well-known neurological rehabilitation centre. As a principal lecturer at Oxford Brookes University, I lead a Masters Programme in Rehabilitation with the aim of providing an advanced learning opportunity in rehabilitation for health and social care professionals. This programme has been running for ten years and was last validated in 2012.

The MSc in Rehabilitation Programme currently focuses on concepts related to rehabilitation such as teamwork, goal planning, enablement, independence and autonomy. This programme mainly attracts registered healthcare professionals including nurses, occupational therapists and physiotherapists from the UK and other countries. Through experiences with international students on the MSc programme (mainly from India, but also from Pakistan, China, Saudi Arabia, Oman and Jordan), I became increasingly aware that the way rehabilitation is defined in the literature does not fit in with how it is perceived by health care professionals in these countries.

Different cultural perspectives are considered to a degree in the MSc programme by using literature from different countries, adopting a variety of case studies and discussing different cultures in terms of rehabilitation and disability. However, I began to question whether the main content, particularly in the core rehabilitation module, addressed definitions and concepts that can be viewed as giving a predominantly ethnocentric view. This reinforces the view previously discussed that the predominant view of rehabilitation is indicative of ethnocentricity, which may not enable international students to perform competently as rehabilitation professionals in their own cultural contexts or enable students from the UK to competently meet the needs of patients from different ethnic cultures.

Before coming into contact with the international students, I made an assumption that rehabilitation did not really take place in countries like India, Pakistan and China. On reflection, this was possibly due to rehabilitation in these countries not generally being represented or discussed in the literature. However, as I began to communicate with the students, I realised that rehabilitation does exist in these countries and some of the students had previously worked in rehabilitation wards and centres, for example in India. Initially, as we started to discuss concepts like enablement, autonomy, independence and goal planning, students would say that these concepts were not evident in their practice and therefore they were not engaged in rehabilitation. This challenged me to consider whether the definitions of rehabilitation and related concepts currently identified in the literature describing rehabilitation are sensitive to different cultures. However, as I had not undertaken a methodological, rigorous search of the literature from a variety of sources, I could not be certain that the literature I had seen was representative. This then led me to the idea of conducting a study exploring and analysing the literature to establish the cultural sensitivity of the concept of rehabilitation.

1.2 Aims and Research Questions

The rationale for this study, as discussed above, comes from the realisation that the concept of rehabilitation, as identified in the literature, may not be culturally sensitive. Rehabilitation educators in using this literature would then promote the same focus. This thesis will argue that rehabilitation, as identified in the literature, is not culturally sensitive, which will affect rehabilitation practice by not raising professionals' awareness of the need to consider patients' needs in the context of culture. In arguing this point, this thesis will also seek to confirm whether there is an essence or core of rehabilitation that transcends culture.

There are no similar studies that have analysed the rehabilitation literature in terms of cultural sensitivity. As discussed above (1.0.4), there are views expressed in the literature that the way rehabilitation is described is not appropriate for all cultures and that there is a need for further research focusing on culture and rehabilitation including cultural frameworks (Saadah 2002, Iwama 2006b). These views support the following aim and objectives:

Aim

To examine the concept of rehabilitation in the literature in relation to cultural sensitivity in order to gain new interpretations and understandings, which may lead to a new framework for rehabilitation practice and education.

Objectives

- To discover if there is an essence or core of rehabilitation that transcends culture
- To consider whether the ICF is suitable for use as a cultural framework
- To identify implications for practice and education

In order to address the above aim and objectives, the following research questions will guide this study:

> "Is the concept of rehabilitation as identified in the literature culturally sensitive?"
>
> "What are the implications for rehabilitation practice and education?"

The value of this study is that it conducts a rigorous analysis of the literature in order to make a decision on whether the literature is culturally sensitive. During this exploration, it is envisaged that there will be new insights into the relationship of rehabilitation and culture and the implications of this for practice and education. Recommendations are made which are of value to rehabilitation practitioners in helping them become culturally sensitive in their practice, and to rehabilitation educators in considering how their teaching can be culturally sensitive. The findings and recommendations may also be of value to practitioners and educators in other areas of healthcare in considering the cultural sensitivity of concepts relevant to their practice.

1.3 Overview of the Thesis

This thesis tells the story of a journey beginning with the identification of the need for the study and ending with recommendations for practice and education and future research. The story begins in chapter one with the contextual background (1.0), which gives the rationale and sets the scene for the research journey. Rehabilitation is further contextualised in chapter two with discussion of its historical development (2.2) and the development of the ICF (WHO 2001). This chapter supports the rationale for the study identified in chapter one, revisiting the research questions resulting in the addition of a third question (2.7).

The story then develops in chapters three and four, which detail the research methodology and the research methods. The conceptual position for the study is identified (3.1), leading into the chosen research approach (3.3). Decisions about the research design then determine the data collection methods appropriate for the research approach (4.1- 4.7) and the ethical issues considered (4.8).

The findings are presented and analysed in relation to the research questions in chapters five, six and seven. The story evolves in chapter eight with further development of the findings in relation to additional literature and identification of the implications for practice and education.

The story comes to a close, detailing the end of the journey in chapter nine, where conclusions are drawn, limitations and personal reflections are discussed, recommendations are made and the contribution to knowledge of this study are demonstrated.

Chapter 2: The Development of Rehabilitation

2.0 Introduction

This chapter sets the context of the study. It will achieve this through examination of the historical development of the concept of rehabilitation, the classification systems for illness and disease including the ICF (WHO 2001), and different views of rehabilitation and rehabilitation research. The implications of these viewpoints and research developments will be discussed in relation to the focus of this study and the research questions.

2.1 The Historical Development of Rehabilitation

The term rehabilitation originated in the late 15th century from medieval Latin roots, meaning ‘to restore to former privileges’ (OED 2013). Rehabilitation related to disability has a long history in human society. For example, there is evidence of people living with disability from 3000BC with Egyptian mummies showing signs of arthritis (Acevass-Avia et al. 2001); artificial limbs (one of the first rehabilitation aids) have been found from 100 BC and can now be found in the London Science Museum (www.sciencemuseum.org.uk) and the principles of rehabilitation medicine are evident in the Bible and in Hippocrates’ writings (Eldar and Jelic 2003).

However, rehabilitation was brought to the fore much more recently in relation to war injuries, beginning with the First World War from 1914-1918. Between the First and Second World Wars, the emphasis was on treating the poliomyelitis epidemic as well as a focus on survivors of spinal injury. In the United States, as the army prepared to enter the Second World War, plans were made for the ‘reconditioning’ of wounded soldiers that created an entirely new concept of rehabilitation. It treated the whole man and included ‘physical reconditioning and retraining, psychological adjustment and vocation guidance’ (Surgeon General’s Office 1970:82). After the Second World War, rehabilitation was recognised as a specialty. In 1951, a United Nations Rehabilitation Unit was established to facilitate the transfer of this specialty to developing countries with the aim of developing large urban-based rehabilitation centres using a professional team approach. These services were typically developed under colonial regimes making them accessible to the wealthy minority rather than the vast numbers of disabled children and adults living in the slums and villages (World Bank no date).

Following the Second World War, the International Federation of Physical Medicine and Rehabilitation was formed with the first international rehabilitation meeting in 1952. At this meeting, discussions were focused on physical education, resettlement and rehabilitation (Ring 2004). There was a consensus from the participants that

> rehabilitation aims to restore physically handicapped persons to normal life; that physicians should avoid an attitude of hopelessness or passive acceptance in the face of chronic illness or disability; that a dynamic approach to chronic illness can result in a fair measure of self-sufficiency, self-respect and happiness and that physicians should be interested not only in adding years to life but also in adding life to years (Ring 2004:667).

In the early developments of thinking about rehabilitation, quality of life in ‘adding life to years’ was seen as being an important aim, and it is still identified as an aim of contemporary rehabilitation (Davis and Madden 2006).

Shortly after the Second World War, non-governmental organisations formed the organisation now known as ‘Rehabilitation International ’ to take action on behalf of disabled people. Rehabilitation International is the only global disability non-governmental organisation that is both cross-disciplinary and cross-disability, championing ideas in the field of rehabilitation such as community rehabilitation (Groce 2002).

2.1.1 Expert Committees on Rehabilitation

The World Health Organisation (WHO), in recognising the need to provide medical rehabilitation for people with disabilities, facilitated Expert Committees on rehabilitation in 1958, 1969 and 1981 (table 2.1, page 13) to discuss the development of rehabilitation and rehabilitation services. These committees consisted of experts from different countries. Key issues and definitions were identified in the committees, which shaped the future process and delivery of rehabilitation.

Table 2.1: Expert Committees on Rehabilitation

Report	Key Points	Definition
WHO Expert Committee on Medical Rehabilitation. First Report: 1958	The general principles of rehabilitation discussed and agreed. The need for teamwork identified	"The rehabilitation process is a complex one, involving several disciplines and different techniques working together as a team to achieve the best end-results for the handicapped person" (WHO 1958:5)
WHO Expert Committee on Medical Rehabilitation. Second Report: 1969	The role of teamwork agreed. Role of education in rehabilitation identified. The need identified for rehabilitation units	"As applied to disability, this is the combined and coordinated use of medical, social, educational, and vocational measures for training or re-training the individual to the highest possible level of functional ability" (WHO 1969:6)
WHO Expert Committee on Disability Prevention and Rehabilitation: 1981	Disability prevention in developed countries. Rehabilitation services in developing countries	"Rehabilitation includes all measures aimed at reducing the impact of disabling and handicapping conditions, and at enabling the disabled and handicapped to achieve social integration" (WHO 1981:9)

The WHO Expert Committee meeting in 1958 (table 2.1, page 13) identified the rehabilitation principles of restoring the disabled person to their previous condition, developing physical and mental functions to the maximum, focusing on social as well as physical aspects, treating the individual as a whole and beginning treatment early (WHO 1958). The importance of a collaborative, team approach consisting of doctors, nurses, physiotherapists, occupational therapists, prosthetists, social workers and other paramedical personnel, was highlighted in the meeting and the roles agreed upon in the second WHO Expert Committee Meeting in 1969. This view of a collaborative approach was supported by Howard Rusk, a pioneer of rehabilitation medicine in the United States, in his first edition of *Rehabilitation Medicine* in 1958, who made the point that rehabilitation is everyone's business, guided by a team approach using the skills of the physician, physical therapist, occupational therapist, social worker, nurses, speech and language therapist, psychologist and prosthetic specialist. "Medical care is not complete until the patient has been trained to live and to work with what he has left" (Rusk1958:23). Throughout history, teamwork has been seen as being integral and vital to rehabilitation and it remains so in rehabilitation today.

Rehabilitation provision was discussed in the WHO Expert Committee meeting in 1969 with the proposal that medical rehabilitation units should be created, rehabilitation procedures should be initiated in developing countries and that governmental and voluntary bodies need to make a coordinated approach to rehabilitation. The importance of rehabilitation education for professionals was highlighted. The recommendations made at this meeting have continued to be a focus in the development of rehabilitation provision. For example specialised rehabilitation units or centres exist in a number of countries, rehabilitation programmes and courses are available for health care professionals and policies and procedures around rehabilitation and disability have been developed in different countries. Ideas around rehabilitation provision were further developed at the WHO Expert Committee meeting in 1981, which focused on disability prevention and rehabilitation, particularly in relation to developed countries. Social integration was identified as being necessary in order to provide adequate rehabilitation for people who are disabled and the importance of involving families and communities in the planning and implementation of rehabilitation services was emphasised.

Thinking around the concept of rehabilitation has changed as a result of the Expert Committee Meetings with rehabilitation moving from being a process (1958) with professionals working to achieve the best results for the individual, to it being a process (1981) involving the individual at the level of social integration as well as the level of functioning.

2.1.2 Rehabilitation and Disability

Rehabilitation through history has focused on the reduction of the impact of disability, which is reflected in the aims of rehabilitation identified by the Expert Committees on Rehabilitation (table 2.1, page 13). Historically, the medical model with its focus on disease and cure has been the main approach to understanding disability. The International Classification of Impairments, Disabilities and Handicaps (ICIDH) (WHO 1980) reinforced this view by focusing on impairment and disability and not taking into account other factors such as the environment. (The ICIDH is discussed in more detail in section 2.2). However, as discussed above, the Expert Committee on Rehabilitation (1981) began to shift their focus onto disability prevention, recognising a need for a more social perspective on rehabilitation and disability.

Around the same time, the disability movement in the UK identified the role social and physical barriers play in disability and the social model emerged (Oliver 1990; Oliver 2004). The social model represents a shift from the medical model where people are viewed as being disabled by their own bodies, to disability being seen as a socially created problem that needs full integration of disabled people into society (WHO 2001).

The World Report on Disability[2] (WHO 2011) identifies disability as being a complex multidimensional concept and identifies the need for a balanced approach between the medical and the social model. The International Classification of Functioning, Disability and Health (ICF), (WHO 2001), discussed in this chapter (2.3), with its biopsychosocial approach is a way of helping achieve this balance and help reduce the tensions between rehabilitation and the social model.

These tensions have arisen because traditionally rehabilitation has been provided in rehabilitation wards or centres and has been viewed predominantly as a medical problem, with a focus on impairment and disability, rather than also as a social problem. This can result in individuals being discharged home with, for example, increased function, but then not able to function in society because of environmental or societal problems. The disability movement (Marks 1997) identified the need for a shift in power in the relationship between rehabilitation professionals and people with disabilities with professionals respecting them as the experts in relation to their disability and working more collaboratively with them.

2.1.3 Community-Based Rehabilitation

The call by the 1969 WHO Expert Committee (table 2.1, page 13) for the development of rehabilitation units and rehabilitation services was identified as not being viable in developing countries due to the high cost of rehabilitation services, large urban areas and action not being taken by governments as advised by the World Health Organisation (1969). This was supported by an inventory of rehabilitation services undertaken by the WHO in developing countries, which led to the development of community-based rehabilitation (CBR). CBR was developed as a strategy with the aim of improving access to rehabilitation services for people with disabilities in developing countries. The development of CBR was also in response to the Declaration of Alma-Ata (WHO 1978) that called for action by all governments to protect and promote the health of all people.

A report in 2003 by the WHO was developed in consultation with United Nations' organisations, governments and disabled people's organisations. This report highlighted the need for CBR programmes to focus on the reduction of poverty, the promotion of community involvement, the development of multi-sectoral collaboration,

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[2] The World Report on Disability (WHO 2011) was developed to provide guidance globally for the implementation of the United Nations Convention on the Rights of persons with Disabilities.

the involvement of disabled people's organisations and the promotion of evidence-based practice (WHO 2003). CBR guidelines were developed in 2010 (WHO 2010) with CBR stakeholders to give guidance to project managers' suggestions on how to strengthen CBR programmes, particularly by increasing the participation of people with disabilities, family members and communities in the decision-making processes. CBR projects and programmes are referred to in the literature and are being implemented around the world. In their guidance, WHO (2010) use the term programmes to encompass short term projects often implemented by a local community group or a group of related projects which are managed in a coordinated way.

A key ingredient for the success of CBR programmes is ensuring that they are culturally appropriate: what may be appropriate for one group of people may not be for another group. One way of ensuring this is the close involvement of people with disabilities and their families in all stages of the CBR programme. This can be achieved through community involvement in planning, decision making and utilising available resources; transferring knowledge about disabilities and skills in rehabilitation to people with disabilities, families and communities; using a coordinated, multi-sectoral approach (Sharma 2007).

2.1.3.1 The challenges of CBR

The logic in introducing CBR in countries where there is a large rural population seems to be sound and a way of ensuring that rehabilitation reaches a large number of the population rather than a few and involves the community including persons with disabilities. However, there are a number of challenges to CBR which need to be overcome in order for it to meet its aim of implementing community-led, culturally appropriate rehabilitation programmes.

The CBR guidelines (WHO 2010) state that in order for CBR to be sustainable it needs to involve many people including rehabilitation services, non-governmental organisations (NGOs), government organisations as well as people with disabilities, their families and communities. However, involving this number of people and at varying levels requires a substantial amount of management and coordination and relies on all members involved respecting each other and working together towards an agreed goal. Although CBR needs to be managed by the community, in reality, professionals and managers often manage projects, without consideration towards community concerns. For example, three CBR projects in Botswana (Nordholm and

Lundgren-Lindquist 1999) set up to identify disabled people in a village in Botswana, to follow up disabled people and to assess the perceptions of rehabilitation workers, identified areas where not all the appropriate people were engaged. There was inadequate support from the government in providing sufficient support structures in terms of physiotherapists and occupational therapists to advise and train rehabilitation workers. Other projects have had similar experiences with the government not being engaged with the project or taking control of the project and therefore limiting community participation (Thomas and Thomas 1999, Cheausuwantavee 2007). In a CBR programme in Mongolia (Sharma and Deepak 2000) challenges included the difficulty of implementing a CBR approach in Mongolia's rural area and the lack of basic infra structure causing difficulties in terms of supervision and referral support from the health care team. This highlights that CBR programmes need to be responsive to their cultural context.

The issues identified above in relation to the coordination of CBR will have an effect on community participation, which has been emphasised as being key to CBR programmes. The challenge for CBR programmes is to identify how community participation can be realised within the constraints in terms of programme management and coordination, service delivery and community involvement.

2.1.4 Summary

Exploring the history of rehabilitation highlights the influence of the first and second world wars, resulting in the identification of the need for a team approach in rehabilitation and a focus on the whole person. The WHO Expert Committees on Rehabilitation have guided the process and delivery of rehabilitation throughout the years, identifying key principles for rehabilitation, the need for teamwork and the role of disability prevention in developing countries. The definitions identified in these committees are all similar in that they identify rehabilitation as a complex process involving different disciplines and focusing on the person with a disability.

The WHO Expert Committee's (1981) definition brings in a new aim of achieving social integration. Integrating people with disabilities back into their own community and society could be seen as a step forward in recognising people's cultural context. The development of CBR, which promotes community and social integration in the community, was in response to the recognition that the development of specialist rehabilitation units was not a culturally sensitive proposition. The aim of promoting CBR programmes that are culturally sensitive (WHO 2010) is aligned to the aim of this thesis in examining the cultural sensitivity of the concept of rehabilitation.

In examining the evidence discussed above, it can be concluded that the concept of rehabilitation has not shifted to a great extent. It has always been and continues to be about helping people with disabilities live with their disability. The discovery of artificial limbs in 100 BC demonstrates that rehabilitation was concerned with helping people adapt and live with their disability. This view has continued throughout history with the emphasis during the wars being on retraining and psychological adjustment, and the WHO Expert Committees on Rehabilitation (1958, 1969, 1981) emphasising a team approach and the goal of achieving social integration. The focus on social integration perhaps reflects the social changes in countries and the need to ensure that all individuals have access to rehabilitation, which has been the impetus for the development of CBR. The focus has shifted from handicap and disability to the relationship of the factors that can affect a person living with a disability which is the focus of the International Classification of Functioning, Disability and Health (ICF), (WHO 2001).

2.2 International Classification Systems

The World Health Organisation has played a key role in developing classification systems for illness and disease that have influenced the delivery of rehabilitation. The first of these systems was the International Classification of Impairments, Disabilities and Handicaps (ICIDH), published in 1980 (WHO 1980). The aim of the ICIDH was to create a classification system for the consequences of disease in order to help health care professionals deal with the complex issues related to chronic illness. As such, the ICIDH was considered to be a useful tool for rehabilitation, and complemented the International Classification of Disease (ICD) (WHO 1967), which was already a well-established system for classifying acute illness.

The ICIDH was considered to have a number of limitations, the main one being its focus on the medical model with an emphasis on impairment and disability, with little recognition being given to the effect of environment and other factors on the level of disability (Davis and Madden 2006). In addition, the ICIDH used terms such as ‘handicap’, which has been criticised by disability groups as being negative towards disabled people (Hurst 2003). Furthermore, the whole classification system was developed without any input from disability groups. Revisions of the ICIDH were made during 1996-1999. However, the revised version continued to attract criticism due to the continued use of medical terms to define disability. This led to a more complete revision resulting in the International Classification of Functioning, Disability and Health (ICF), which emerged in 2001 (WHO 2001), complementing the ICD-10[3] (WHO 1994).

The ICF was developed by a task force that included people from different parts of the world from WHO Collaborating Centres for the ICF, task forces, networks and non-governmental organisations, all representing different countries. The task force included disabled people and there was agreement from the WHO that disability was a rights issue (Hurst 2003). An Environmental Task Group, consisting of disabled people, was set up in the USA to produce the factors for the environmental context.

2.3 The International Classification of Functioning, Disability and Health

The focus of the ICF is on the constituents of health. It has become a ‘components of health’ classification rather than a classification of the ‘consequences of disease’ as the ICIDH was. This changes it from a classification that focuses on disease and the promotion of a predominantly medical view, to a framework that emphasises the relationship between the many factors that affect the rehabilitation experience for an individual. One of the aims of the ICF (WHO 2001) is to describe the situation of an individual within different health-related domains. It does this through the use of categories that classify health and health-related states within health and health-related domains. The ICF is available in different languages and is divided into two parts (table 2.2, page 20), functioning and disability, and contextual factors. Codes are allocated to the different aspects of each component, which enables comparison of data across health care services, disciplines and time, and provides a systematic coding scheme for health information systems.

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[3] ICD-10: The 10th revision of the International Classification of Disease, which provides a diagnosis of diseases, disorders or other health conditions.

Table 2.2: ICF Classification (WHO 2001:11)

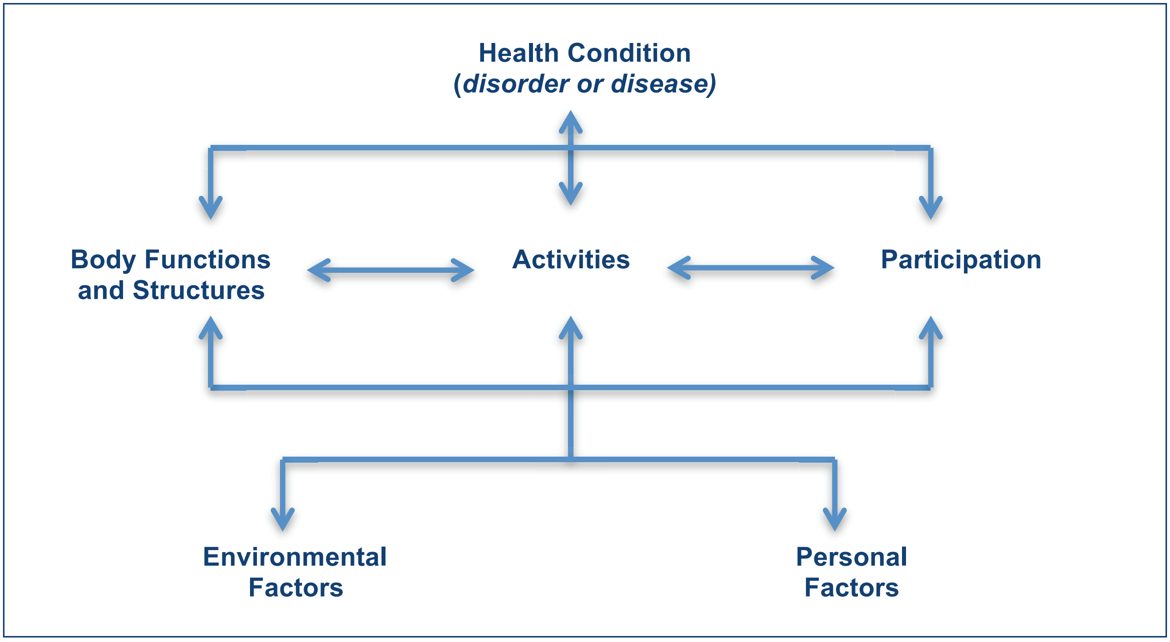
	Part 1: Functioning and Disability		**Part 2: Contextual Factors**	
Components	Body functions and structures	Activities and participation	Environmental Factors	Personal Factors
Domains	Body functions and structures	Life areas (tasks, actions)	External influences on functioning and disability	Internal influences on functioning and disability
Constructs	Change in body functions (physiological) Change in body Structures (anatomical)	Capacity Executing tasks in a standard environment Performance Executing tasks in the current environment	Facilitating or hindering impact of features of the physical, social, and attitudinal world	Impact of attributes of the person
Positive aspect	Functional and structural integrity	Activities Participation	Facilitators	Not applicable
	Functioning			
Negative aspect	Impairment	Activity limitation Participation restriction	Barriers/hindrance	Not applicable
	Disability			

Part one deals with body functions, encompassing the physiological and psychological functions of body systems, and body structures (i.e. the anatomical parts of the body). It also includes activities, which are the executions of an action or task by an individual (for example, getting dressed) and participation. The latter is defined as the involvement of an individual in a life situation (for example, socialising, going shopping). A distinction is made between a person's capacity or ability to carry out a task and their actual performance in the environment. For example, individuals who have had a stroke may have the capacity to dress themselves independently in the hospital environment, but in their home environment they may not be able to perform at this level.

Part two focuses on contextual factors. It is this element that was not addressed explicitly in the ICIDH. The first component in part two includes environmental factors that make up the environment in which people live their lives. This includes physical, social and attitudinal factors such as physical access, attitudes to disability and socialising opportunities. The second component in part two relates to personal factors: features of the person which are not part of a health condition or health state and which have an impact on the way people experience disability (such as gender, race, age, coping styles, behaviour patterns, values and beliefs, lifestyle and social background). All of the components in the ICF are further classified into specific codes except for the component of personal factors.

The components of the ICF interact with each other in a dynamic way (figure 2.1, page 21). For example, an individual's health condition, such as back pain, may have an effect on their mobility. Conversely, having mobility problems may have a negative effect on their back pain.

Figure 2.1: Interactions between the components of the ICF (WHO 2001:18)



Body functions and structures, activities and participation may be affected by environmental and personal factors and they may also have an effect on environmental and personal factors. For example, the coping strategies a person uses may affect the way they manage their back pain and conversely, back pain may disrupt their usual coping strategies.

The ICF is seen as a fundamental framework in rehabilitation, having been adopted by key documents such as The White Book on Physical Rehabilitation Medicine in Europe (Gutenbrunner et al 2007) and the World Report on Disability (WHO 2011). The latter aims to provide a common understanding of disability and guidance for the development of rehabilitation and support services, policies, standards and legislation. The White Book on Physical Rehabilitation Medicine in Europe aims to set out the areas of work and parameters of Physical and Rehabilitation Medicine in Europe, including competence, education and training of specialists (Gutenbrunner et al. 2007), taking into account the changing needs and demands in patients' medical care. The ICF is identified as the basis for Physical Rehabilitation Medicine, having been described by Ebenbichler and Resch (2009) as a major step towards establishing the practice as a medical specialty with unique features that needs to be recognised internationally. Although international rehabilitation societies have already adopted the name Physical Rehabilitation Medicine, there are only a few countries where the specialty is officially named.

2.3.1 Theoretical Background to the ICF

The ICF uses a biopsychosocial approach to view health from a biological, individual and social perspective. This model was developed from a seminal paper written by physician and psychiatrist George L. Engel in 1977. Engel criticised the biomedical model as being inadequate for fully explaining the impact of illness or disease on individuals.

> To provide a basis for understanding the determinants of disease and arriving at rational treatments and patterns of health care, a medical model must also take into account the patient, the social context in which he lives, and the complementary system devised by society to deal with the disruptive effects of illness (Engel 1997:196).

As a result, Engel advocated combining biomedical and psychosocial approaches into a biopsychosocial model.

Allan et al (2006) found in their review that the biopsychosocial model is not widely implemented in medical practice and that in the allied health literature the term is used interchangeably with holistic health care and the social model of health care. Barnitt and Pomeroy (1995) identify a holistic approach as being key to rehabilitation, where the focus is on the person and the interlinking factors such as the environment and participation. This links in to Popper's (1957) definition of holism in that the whole is greater than the sum of the parts and was a concept recognised during the Second World War as discussed earlier (2.1) with the new concept of rehabilitation being recognised as 'treating the whole man'. With its focus on the different components of function, structure, activities, participation and environment, the ICF has the potential of enabling rehabilitation professionals to achieve the goal of holistic rehabilitation. In order to address this complexity, the ICF, with its focus on a biopsychosocial model, has been adopted as the conceptual framework for the World Report on Disability (WHO 2011). This confirms the position of the ICF as a key framework for steering disability policy and strategy globally.

2.3.2 Strengths and Weaknesses of the ICF

One of the strengths of the ICF is that it provides a common language for health care professionals, researchers and policy makers to describe health and health-related states. It enables data to be compared across countries and health care disciplines and provides a systematic coding system. However, it is lengthy and has been criticised for being impractical for everyday use (Stucki et al. 2002).

Core sets

In order to increase the usability of the ICF, short lists (referred to as core sets) of relevant ICF concepts have been developed by researchers for specific health conditions and health care situations for example, the core set for stroke has been developed by experts from 39 countries (Geyh et al. 2004). Other developed core sets include cardio-pulmonary conditions (Boldt et al. 2005), breast cancer (Brach et al 2004), musculoskeletal conditions (Stoll et al. 2005) and neurological conditions (Stucki 2005). These core sets briefly describe a client with a specific health condition, guiding multidisciplinary teams in the assessment and delivery of rehabilitation and facilitating the mapping of existing outcome measures (McIntyre and Tempest 2007). However, McIntyre and Tempest (2007) caution that using core sets to classify individuals according to their disability, could be seen as focusing on the medical model with the emphasis being on disability rather than the person in their environment. This then does not fit into the ethos of the ICF in promoting a biopsychosocial model approach reflecting the holistic nature of the person.

Different contexts

The ICF introduces a number of different contexts that are important aspects of the experience of an ill person, which enables rehabilitation professionals to take into account contexts such as the environment and the social context the patient comes from (Davis and Madden 2006). Adebajo and Algbeleye (2007) identify a number of factors that influence rehabilitation such as race, culture, socio-economic status and education. This corresponds well with the description of environmental factors in the

ICF, which describes social norms as “customs, practices, rules and abstract systems of values and normative beliefs … that arise within social contexts and that affect or create societal and individual practices and behaviours” (WHO 2001:191).

Wade and Halligan (2003) identify the main strength of the ICF as being a useful framework by which to understand the situation of patients and how the rehabilitation team might help them. However, they criticise the ICF for being based on the here and now and not acknowledging that an individual has a past and future. This is a valid point, particularly given that the ICF will be used predominantly for people with long-term chronic conditions where their past and future will have a significant effect on their rehabilitation journey. Davis and Madden (2006) demonstrate through case studies how the ICF can help rehabilitation professionals create a more complete picture of a person, taking into account their past and future.

The different components in the ICF including participation and contextual factors enable health care professionals to focus on a number of different elements that can help individuals achieve the quality of life that is important to them. Although there are elements in the ICF that relate to an individual’s quality of life, such as communication, support and relationships, natural environment, technology or employment, quality of life is not explicitly described, which could be due to it being a difficult phenomenon to define or measure. However, quality of life is a widely used phrase, identified by some authors as being the aim (Davis and Madden 2006) or outcome of rehabilitation (Taylor et al. 2008, Fuhrer 2000) and, therefore, should either be included or reasons given for excluding it (Wade and Halligan 2003). Wade and Halligan (2003) suggest an expanded ICF model which includes a description of quality of life, as well as other factors such as happiness and role satisfaction that affect quality of life.

Personal factors

While personal factors are identified in the ICF, acknowledging that they need to be recognised, they are not classified in the same way as other components: “assessment of personal factors is left to the user, if needed” (ICF, WHO 2001:19). Although this lack of attention to the classification of personal factors may be due to the highly diverse nature of cultural and social differences (although this is not explicitly stated), it can be considered as a limitation of the ICF. There is a danger that professionals will not consider personal factors alongside other components, due to them not being explicit. The danger, therefore, is that the ICF will not be a holistic framework incorporating all biopsychosocial factors as was intended.

This lack of classification of personal factors has also been identified by researchers who have developed core sets for different diseases, such as multiple sclerosis (Khan and Pallant 2007) and rheumatoid arthritis (Kirchberger et al. 2008) that are inherently personal characteristics. These include attitudes and beliefs of the patient, fatigue level, mood and effect, dependence on others, self efficacy, coping ability; depression, helplessness, worries about the future, optimistic/positive attitude, endurance, acceptance, illness knowledge, social competence, life values, life goals and role identity. A number of these factors relate to the person's cultural context such as values and beliefs. The person's cultural context may also influence their coping styles, their knowledge about illness, life values and goals and worries about the future.

This view of a person's culture influencing different aspects of their life relates to the view of culture being a set of guidelines that influence how individuals live their lives (discussed in chapter one:1.0). This demonstrates the importance of understanding the person's cultural context, including the identification and influence of internal cultural factors (factors personal to the individual) such as age, gender and experience and external cultural factors such as tradition, religion and economic factors. Including aspects of culture as personal factors does not go far enough in ensuring that a person's cultural context is addressed. This view is supported by Wade (2000) who argues that personal context should be the focus of rehabilitation as a patient's beliefs and expectations can influence the extent and nature of their disability.

2.3.3 The ICF as a Theoretical Framework

A number of researchers are exploring the development of the ICF as a theoretical framework, recognising its potential in providing a holistic, multidisciplinary framework or conceptual model for directing rehabilitation practice and research. The ICF is regarded as a new paradigm for rehabilitation and disability research in that it attempts to reconcile the medical and the social models of disability and could be the first step towards a theory of functioning and rehabilitation (Reinhardt 2011).

In order to advance this proposition, Reinhardt and Stucki (2009) have begun working on an ICF-based theoretical model for rehabilitation practice and research. This model can be "considered to be a 'macro' theory explaining a wide range of phenomena, and a ‘micro’ theory providing a mechanistic explanation of specific events, such as the multifactorial causes of disability” (Graham and Cameron 2011:77). However, work is needed to assemble the pieces of theory in the ICF and the many studies on rehabilitation to formalise them into a set of hypotheses for testing. For example, research is continuing to be undertaken to develop further the components of activities and participation (Beckung and Hagberg 2002, Nordenfelt 2003, Rochette et al. 2006) and contextual factors (Schneidert et al. 2003, Duggan et al. 2008, Kuipers et al. 2009).

The ICF has also given researchers a starting point from which to develop a conceptual description of rehabilitation as a health strategy (Meyer et al. 2011), which has been adopted by European organisations in physical and rehabilitation medicine. The aim of developing a conceptual description of rehabilitation is to foster common understanding amongst rehabilitation professionals and to serve as a frame of reference. However, developing a common understanding of rehabilitation or a single conceptual description in a culturally diverse world could be ambitious and challenging for rehabilitation providers (Meyer et al. 2011). This is a valid viewpoint and has implications for this study in terms of the conclusions that are reached, for example it may not be appropriate to advocate that one definition of rehabilitation is appropriate for all cultural contexts.

2.3.4 Summary

The revision of the ICIDH to the ICF recognises the importance of viewing disease and illness using both medical and social model perspectives. Professionals, patients, disabled people and carers welcome the identification of contextual factors in the ICF, which emphasises the influence of environmental and personal factors on rehabilitation. The ICF enables a holistic view to be taken of the person and their rehabilitation journey. However, one limitation of this is the lack of classification of personal factors. If personal factors are to be seen as of equal importance as other components, then there is a need for them to be made explicit in the ICF.

Personal factors are integrally related to a person’s cultural context, which is also not explicit in the ICF. The ICF already provides a framework for considering internal and external cultural factors with its focus on the different components. These factors need to be taken into account to ensure that rehabilitation is culturally sensitive and they therefore need to be identified as part of this study.

2.4 Views of Rehabilitation

Rehabilitation can be viewed as a process, strategy or philosophy. This section will present these different views, which will be discussed in more depth as part of this study. The Expert Committee on Medical Rehabilitation (WHO 1969) describes rehabilitation as a multi-disciplinary process: a view shared in the literature by recent authors (Sinclair and Dickinson 1998, Gutenbruner et al. 2007, Wade 2009). Stucki et al. (2002) describe this multi-disciplinary process as consisting of a 'rehabilitation-cycle' that involves identifying the patient's problems, defining treatment, planning, implementation and coordination of treatment, and assessment and evaluation of effects. The process commences from the beginning of the illness and continues when the patient has been discharged into the community. The rehabilitation cycle is adapted in the World Report on Disability (WHO 2011) by relating problems to modifiable and limiting factors. Wade (2009) includes goal setting in the cycle.

As well as viewing rehabilitation as a process, the World Report on Disability (WHO 2011) describes rehabilitation as an essential strategy for enabling people with disabilities to participate in life, which is achieved by addressing education, work, social life and providing a range of measures targeting the components of the ICF. The report also identifies that in middle to high-income countries with established rehabilitation services the priorities will be different to those in lower-income countries where the focus will be on gradually expanding cost-effective rehabilitation services, mainly through CBR.

Rehabilitation can also be thought of as a philosophy of care that considers how professionals fundamentally think about individuals and rehabilitation (Davis and Madden 2006). Key beliefs around this philosophy include valuing the patient as an individual by identifying their strengths and weaknesses, past experiences and hopes for the future; adopting enabling and facilitating strategies that assist the individual in achieving their full potential; thinking about the future for the patient and their family at the beginning of the rehabilitation process and focusing on the individual's quality of life as they see it (Davis and Madden 2006). Embracing this philosophy makes rehabilitation integral to health care practice rather than an addition. However, the views around this philosophy may need expanding to make them more culturally sensitive, for example, family and cultural beliefs are not addressed by Davis and Madden (2006). By exploring the cultural sensitivity of the concept of rehabilitation, this study will help in identifying how these limitations can be addressed.

2.5 Rehabilitation Research

Rehabilitation research in the past has tended to focus on different patient groups, looking at assessment, function and interventions. However, it is now time for research in rehabilitation to focus on the activities and processes that define the unique nature of rehabilitation and the inter-relationship between disease and contextual factors (WHO 2001). The ICF (2001) provides a framework for exploring the inter-relationships between these and ICF components such as activities and participation and the environment and personal factors. Using the ICF as a framework for research can help ensure that research encompasses both medical and social model perspectives, enabling researchers to focus on the patient's experience.

There are studies that have already been conducted or are underway that assess the utilisation of the ICF in rehabilitation settings, or conduct research using the ICF as a theoretical framework. For example, Ohman (2005) reports on the value of a qualitative methodology in rehabilitation research in enabling a focus on individuals' lived experiences, and understanding perceptions of rehabilitation and disability by patients and carers to improve the rehabilitation journey.

Wade (2001:229) identifies a number of priorities for rehabilitation research such as focusing on "multi-disciplinary teamwork and goal-setting; working within a systematic framework that recognises the interactions of many different factors upon an individual's illness; and changing behaviour". The focus of this study aims to address some of these research priorities by investigating cultural sensitivity in relation to how the concept of rehabilitation is implemented in practice. It thereby addresses the interaction of different factors in rehabilitation, and the multi-disciplinary team. If cultural context is not considered in relation to the way professionals are defining and considering rehabilitation, approaches to patients are likely to be affected. This supports the rationale for the research questions.

2.6 Chapter Conclusion and Implications for Study

Just before the Second World War, rehabilitation was referred to as a concept, which treats the 'whole person'. This expectation of rehabilitation treating the whole person, considering physical, psychological and vocational factors, has remained true today and has been emphasised more with the development of the ICF (2001) that enables professionals to consider a number of factors that affect the person living with their disability. These include social participation and social context, both of which are closely linked with cultural context. However, it could be debated whether the ICF enables a holistic view with the limitations discussed in this chapter (2.3.2), one of these being the lack of classification and clarity of personal factors and no acknowledgment of the importance of cultural factors and context to a person's rehabilitation journey.

The development of CBR, which arose as a result of western ideas of rehabilitation units not being appropriate on their own for developing countries, points towards the recognition of the need for culturally sensitive rehabilitation. Early definitions and ideas about rehabilitation do not appear to be insensitive to different cultures, however, it is not explicit that they are culturally sensitive either. A more rigorous exploration of the concept of rehabilitation as it is defined in the literature is needed before making a decision about its cultural sensitivity, which, as discussed in chapter one, is the awareness and recognition by rehabilitation professionals of cultural differences and the effects these have on the way people engage in rehabilitation.

The key argument of this study is that there is a gap in that only Saadah (2002) and Iwama (2006a) appear to talk explicitly about cultural sensitivity in relation to rehabilitation practice. Cultural sensitivity may be implicit in the definitions of rehabilitation and developments discussed in this chapter, however this is not sufficient. In order for rehabilitation to be culturally sensitive, it needs to be explicitly discussed in relation to rehabilitation practice and education.

This study will put the cultural sensitivity of the concept of rehabilitation at centre stage by conducting a more rigorous exploration of definitions and descriptions of rehabilitation in the literature. This will include the identification of internal and external cultural factors, which need to be considered to ensure cultural sensitivity. This study will also meet the research priorities (identified in section 2.5), in addressing the interaction of different factors in rehabilitation and in considering patients' behaviour in relation to their rehabilitation and how this relates to cultural context. This supports the views identified in chapter one (1.0.4) that there is a need for alternative cultural world views (Iwama 2006b) and culturally sensitive values for rehabilitation (Saddah 2002).

As a result of exploring the development of rehabilitation in this chapter, which has highlighted a number of points related to this study, a third research question has been added:

> “What cultural factors need to be considered to ensure that the concept of rehabilitation is culturally sensitive?”

Having set the context of this study in this chapter and revisited the research questions, chapter three will consider the research methodology best suited to answer the research questions.

Chapter 3: Methodology

3.0 Introduction

This chapter discusses the rationale behind the methodology and research design that best addresses the three research questions posed in chapters one and two.

> "Is the concept of rehabilitation as identified in the literature culturally sensitive?"
> "What are the implications for rehabilitation practice and education?"
> "What cultural factors need to be considered to ensure that the concept of rehabilitation is culturally sensitive?"

On examining these questions, it is clear that they are exploratory in nature and will require a research methodology and design that allows an in-depth understanding of the cultural sensitivity of rehabilitation to emerge. Qualitative research is the obvious choice as it is more appropriate for exploratory research questions (Morse and Field 1998) and enables the researcher to gain a detailed understanding of the phenomena being studied (Denzin and Lincoln 2011). To achieve the best fit with the research questions, a number of methodological issues need to be explored. This chapter details the conceptual positioning of the thesis, followed by consideration of the methodological approaches of this study, and then finally the research design is outlined.

3.1 Conceptual Position

Decisions made relating to any research methodology and design are influenced by the researcher's own values and beliefs in respect of the research topic being studied (Creswell 2007). It is therefore important that the researcher makes explicit the values and beliefs on which the research is based. For this reason, this section sets out the conceptual assumptions on which this study is framed.

3.1.2 Conceptual Assumptions

There are two key considerations that need to be posed: the position around reality (ontological position) and the relationship between the researcher and the participant (epistemological position) (Guba and Lincoln 1994). These are considered in relation to the key conceptual assumptions on which this research is based, namely:

Rehabilitation is ultimately about what is important to the patient within their family context.

Rehabilitation involves a number of healthcare professionals working collaboratively with each other.

Rehabilitation is not just about professional responses to a medical diagnosis or impairment. It involves social, personal and cultural factors.

3.1.2.1 Rehabilitation is ultimately about what is important to the patient within their family context

The patient's view of the world must have a place in the research design because to address questions about the cultural sensitivity of rehabilitation in a meaningful way, requires the views of the patient, their family or significant others to be included.

The relationship between the researcher and participants (i.e. patients) envisaged in this study is one that allows patients to share their experiences and identify what is important to them. The role of the researcher is to facilitate, encourage, represent and enable patients' stories to emerge. This is in opposition to the idea of the objective researcher within a positivist paradigm in which the researcher and the researched are independent entities (Guba and Lincoln 1994) and the researcher has no place within the emerging discourse.

3.1.2.2 Rehabilitation involves a number of healthcare professionals working collaboratively with each other

Healthcare professionals may hold different perspectives, which will be influenced by cultural factors. Therefore, in this study it is important to examine the perspectives assumed by healthcare professionals from different cultures in order to explore the cultural sensitivity of the concept of rehabilitation.

As the nature of rehabilitation is complex and a team endeavour, it is important that the researcher captures a multidisciplinary team perspective on the concept of rehabilitation. The role of the researcher in this context is based on a 'professional' understanding due to their experience as a rehabilitation practitioner. This experience will enable easier access to the multidisciplinary team perspective, however bias and preconceived notions are a risk. Reflexive strategies used to manage this risk are discussed in chapter four (4.7).

3.1.2.3 Rehabilitation is not just about professional responses to a medical diagnosis or impairment. It involves contextual factors

For the purpose of this study, it is important to capture the reality or authenticity of the patients' experience in regards to their rehabilitation. To ignore contextual factors (for example social, environmental and personal factors) involved in the process of rehabilitation would be to limit the view of rehabilitation to a purely physical or medical occurrence. Therefore rehabilitation is conceptualised as a cultural and social endeavour.

Certain types of research questions require the researcher to adopt a highly focused approach to data collection and the range of what is included is limited. For example, in experimental research, the researcher is normally focused on a single variable and a single dependent variable while maintaining control over other variables (Robson 2002). In this study, in order to address the questions posed relating to social and cultural factors, the researcher must adopt a wide lens on what to include as data.

3.1.3 Summary of Conceptual Position

Following the above discussion, it is possible to identify that, in order to answer the research questions posed a qualitative, exploratory study would be appropriate. The study will need to incorporate the perspectives of the patient, family and the multi-disciplinary healthcare team about the cultural sensitivity of the concept of rehabilitation and the researcher will be an integral part of the research process as opposed to being detached. This position sits within the constructivist research paradigm and the next section will justify this choice.

3.2 Constructivist Paradigm

Guba (1990:17) describes paradigms as being "a basic set of beliefs that guide action", while Weaver and Olson (2006:460) expand on this definition by identifying paradigms as being:

> Patterns of beliefs and practices that regulate inquiry within a discipline by providing lenses, frames and processes through which investigation is accomplished. They are patterns defined as a worldview, based on a set of assumptions and values.

The constructivist paradigm arose from the debate around the appropriateness of the traditional paradigms of positivism and post-positivism in analysing complex situations (Guba and Lincoln 1989). This perspective was originally termed “naturalistic enquiry” (Lincoln and Guba 1985) and seeks to understand how individuals view and experience their world, a view confirmed by Schwandt (1998:221), who states:

> Proponents of these persuasions share the goal of understanding the complex world of lived experience from the point of view of those who live it. This goal is variously spoken of as an abiding concern for the life world, for the emic point of view, for understanding meaning, for grasping the actor’s definitions of a situation, for *Verstehen*[4]

Constructivists believe in understanding and constructing the meanings that both the researcher and the researched hold. In considering the implications of this position, Guba and Lincoln (1994) identify a number of practical issues to be considered: the aim of the inquiry, the nature of knowledge, the researcher relationship, and the role of values.

3.2.1 The Aim of the Inquiry

The aim of this study (identified in chapter one (1.2), is to examine the concept of rehabilitation in relation to cultural sensitivity and gain new interpretations and understanding. This is in keeping with the constructivist paradigm where research aims to gain an understanding of the world from the perspectives of individuals within a given context. Guba and Lincoln (1994) go further to say that research holds the possibility of capturing these perspectives and developing new meanings. Developing new meanings of the concept of rehabilitation in relation to cultural sensitivity may be an outcome of this study resulting in recommendations for practice and education.

3.2.2 The Nature of Knowledge

Knowledge around the concept of rehabilitation may vary depending on how knowledge is formulated and on the meaning people place on rehabilitation. This may result in the concept of rehabilitation not being culturally sensitive. Within the constructivist paradigm, the nature of knowledge arises from the meanings people place on their experiences, which may be shared within a given social or cultural context. Even if a consensus exists in this paradigm, it is not considered certifiable as

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[4] Verstehen “German term for understanding used to refer both the aim of human sciences as well as their method” (Schwandt 2007: 314).

true, as it is ever changing (Guba 1990). Understanding how meaning and knowledge are constructed in the world of rehabilitation will help gain an understanding of these multiple perspectives and meanings and offer opportunities for better understanding of the cultural dimensions of rehabilitation. This opens up the possibility of new meanings and understandings of rehabilitation emerging as different perspectives are gained through the research process.

3.2.3 The Researcher Relationship

The relationship between the researcher and the researched is closely linked due to the researcher being a rehabilitation practitioner and educator. In light of this, as the researcher, I will need to reconsider my own construction of the concept of rehabilitation in relation to cultural sensitivity and consider other participants' views. This has implications for the role I adopt in the relationship. In the constructivist paradigm, this role is identified as being one of facilitation with the researcher being "actively engaged in facilitating the reconstruction of his or her own construction as well as those of all other participants" (Guba and Lincoln 1994:115). The closeness of this relationship raises a number of challenges for me in being aware of the influence of my own assumptions and values around rehabilitation and my own position on the collection and analysis of the data.

3.2.4 The Role of Values

The values on which this study is based are reflected in the conceptual position outlined earlier in the chapter. Constructivists adhere to the view that research inquiry cannot be value free and if reality can be seen through a theory window (as in other research paradigms), then it can equally be seen through a value window (Guba 1990). It is inevitable that the outcomes of any study will reflect the values on which it is based (Guba and Lincoln 1994) and will, therefore, in this study include the perspectives of the researcher, the patients, the multidisciplinary team and a social/cultural perspective as opposed to a medical one.

3.2.5 Summary of Constructivist Paradigm

Constructivism is an appropriate paradigm for this study because the principles on which it is based are about gaining understandings and perspectives of individuals and meanings that may be shared within a given social or cultural context. This provides the opportunity for the researcher to construct and reconstruct a concept such as rehabilitation informed by the concept analysis. These principles match the conceptual assumptions discussed earlier in 3.1.2.

Having established the conceptual position and the research paradigm of this study, it is now necessary to consider a research approach that is coherent with constructivism and able to answer the research questions.

3.3 Choosing a Research Approach

In choosing a research approach for this study, my decision was guided by the research questions posed and the identified conceptual position in that it needs to accommodate the examination of different perspectives on the cultural sensitivity of the concept of rehabilitation. The chosen approach also needs to take into account the close relationship between the researcher and the researched. As identified in chapter one, the topic of rehabilitation is extensively documented in the literature. However, it is apparent that the major contributors to this literature are mainly located in Europe, America and Australia. This prompts the need to explore the conceptualisation of rehabilitation in the literature in relation to its cultural sensitivity. Taking this into account, concept analysis is identified as an appropriate research approach because it enables an in-depth analysis of the concept of rehabilitation in relation to a particular issue, using the literature as a main source of data. However, in order to give a more informed view of the cultural sensitivity of the concept of rehabilitation, I made the decision to collect qualitative data alongside the literature, from one setting in India, which is a country which is not well represented in the literature in terms of rehabilitation.

Before reaching this decision, I considered conducting an ethnographic study in India but I felt this did not then place the literature at centre stage and I did not have the time to fully immerse myself in the culture. Following discussion with my supervisory team, I made the decision to include this data as part of the concept analysis, applying an ethnographic perspective when collecting the data in India.

3.3.1 Concept Analysis

John Wilson first introduced concept analysis as a technique in the 1960s to give his high school students a method by which to examine concepts (Wilson 1963). This approach was then adapted for use in nursing by Chinn and Jacobs (1987) and Walker and Avant (1983) as a step in the development of nursing theory. These methods were further modified (Rodgers 1989, Schwartz-Barcott and Kim 1993) in an attempt to improve rigour in developing nursing theory. All of these methods use literature as a data source for analysing concepts. Hupcey et al. (1996) refer to the concept analysis methods used by these authors as Wilson-derived methods. In a review of Wilson-derived methods of concept analysis, Hupcey et al. (1996) found that they tend to produce non-cohesive outcomes, with steps in the process being isolated from each other. These methods do not enable in-depth analysis of the concept, and appear to be limited by focusing on one reality. This does not fit in with the conceptual stance on reality adopted in this study and can be seen as limiting the development of the concept.

An alternate approach to the Wilson-derived methods of concept analysis was developed by Janice Morse (1995) which is referred to as a

> process of enquiry that explores concepts for their level of development or maturity as revealed by their internal structure, use, representativeness, and/or relations to other concepts (Morse et al. 1996a:255).

As opposed to the completion of specific stages as in the Wilson-derived methods, Morse (1995, 1996a) suggests using various techniques of qualitative enquiry such as analysis of the literature, observation or interviews to appraise and develop a concept. Morse developed her approach in response to her critique of the traditional methods of concept analysis (Chinn and Jacobs 1987, Walker and Avant 1983, Rodgers 1989) discussed above. Morse's (1995) approach can be identified as being a more interpretive approach allowing for multiple realities of a concept to be explored and facilitating advancement of the concept. This mirrors the conceptual position identified for this study and the therefore fits into a qualitative research methodology and design.

3.4 Morse's Concept Analysis Approach

Morse (1995:33) identifies a concept as "abstract, cognitive representations of perceptible reality formed by direct or indirect experience. They range from directly observable, empirical observations to relatively abstract, indirectly observable, mental inferences". A challenging aspect of this study has been whether rehabilitation is a concept and therefore is open to examination through concept analysis. As a rehabilitation professional, I have always thought of rehabilitation as a concept. In an initial email communication with Janice Morse regarding rehabilitation as a concept she was of the opinion that it is a scientific concept rather than abstract and therefore not appropriate for concept analysis. I felt that her understanding and experience of rehabilitation was not the same as mine. In a subsequent conversation with Janice Morse at a conference three years later, her view was that scientific concepts could be examined using her concept analysis approach. Such an example is the concept of social support (Hupcey 2008) which has developed over the years from being a term referring to an interaction, person or relationship to becoming more abstract encompassing a variety of definitions and explanations, causing the concept to remain fuzzy.

In order to make a more informed decision whether rehabilitation is a concept or not, the meaning of the term ‘concept’ was explored in the literature, where it is described in a variety of ways. For example, Bolton (1977) describes concepts as stable organisations achieved through rules of relation[5] and Meleis (2012) as labels that explain phenomena. Chinn and Kramer (1991) identify concepts as mental formulations being on a continuum between empiric and abstract. Empiric concepts are those that are directly observable (e.g. height, weight), while abstract concepts are those that are inferred from direct and indirect observations, for example, self-esteem, for which there are no direct measures. There are concepts that lie somewhere on the continuum between these two definitions. Chinn and Kramer (1991) identify cardio-vascular fitness as an example that requires a definition as it is directly observable, but as an object does not exist. It is evident from the definition by Chinn and Kramer (1991) that Morse’s (1995) view of a concept is clearly aligned to it.

Rehabilitation can be seen as being half way on the continuum between empiric and abstract, as described by Chinn and Kramer (1991): while it is not always directly observable, aspects such as physical function can be measured. Considering the definitions of concept by Chinn and Kramer (1991) and Morse (1995), rehabilitation reflects the view that a concept is a mental formulation or a cognitive representation and, therefore, the definitions offered by Chinn and Kramer (1991) and Morse (1995) are accepted.

To identify the appropriate methods to develop a concept, the first step of Morse’s (1995) concept analysis is to establish the level of maturity of the concept in the literature using the following indicators (Morse et al. 1996a):

- In order for a concept to be mature, it must have a meaningful definition and attributes (characteristics) that define it.
- The boundaries of the concept need to be clearly defined.

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[5] Bolton’s rules of relation: “stable patterns of utilisation of factors, attributes, properties or characteristics that form the concept” (Morse et al. 1995:35).

- The preconditions (antecedents) and outcomes (consequences) for the concept should be demonstrated.

If these criteria are not met, this indicates an immature concept. Where the criteria are met to some extent, a partially mature concept is evident and where the criteria are clearly met, the concept can be identified as being mature.

At this point it is not clear at what level of maturity the concept of rehabilitation is, despite a large amount of literature being available, including clinical evidence and instruments, which measure aspects of rehabilitation. As identified in chapter one, doubt is cast upon the idea that rehabilitation is a mature concept in relation to cultural sensitivity and through this study, the concept of rehabilitation is examined to explore if it is a mature, partially mature or immature concept in terms of cultural sensitivity. This indicates the appropriate type of concept analysis required to advance it to a higher level of maturity.

In order to check the maturity of the concept of rehabilitation in relation to cultural sensitivity, the literature has been examined. However, as the literature is orientated mainly towards Europe, America and Australia, unlike previous concept analysis approaches (Walker and Avant 1983, Rodgers 1989, Morse 1995), this issue is addressed by including, as part of the concept maturity check, the collection of qualitative data from a different country not well represented in the literature as previously discussed (3.3). This is a departure from Morse, who advocates the use of qualitative data in the development of the concept but not in the maturity check.

3.4.1 Types of Concept Analysis

Once the maturity of the concept is established, the second step according to Morse et al (1996a) is to identify the appropriate type of concept analysis enquiry. Morse identifies a number of indicators, which determine the appropriate type of analysis and the tasks required for the inquiry (table 3.1, page 40).

Table 3.1: Types of concept analysis enquiry (Morse 1995, Morse et al. 1996a)

Indicators	Type	Task of the researcher
Immatute Concepts		
There is not a concept that accurately describes a phenomenon: borderline concepts	Concept identification	Identify essential features of a concept in the literature using rules of relation (Bolton 1997)
Definitions of a concept may not be adequate, missing characteristics, antecedents or consequences	Concept development	Identify and verify attributes and identify manifestations of the concept in the literature
Two concepts appear to be linked together as if they are part of the same experience	Concept delineation	Comparing the 2 concepts in the literature using the rules of relation
Partially Mature Concepts		
Numerous concepts exist to explain a phenomenon. The area of inquiry is underdeveloped	Concept comparison	Content analyse the literature according to underlying values for each concept
A concept seems to be mature due to a large body of literature however on examination it appears to be murky with competing implicit assumptions	Concept clarification	Compare and contrast the attributes in the literature and ask critical questions. Additional literature may be required
A concept is consistently defined and appears to be well developed there appears to be inappropriate application of the concept to practice	Concept correction	Ascertain assumptions and attributes of the concept in the literature. Conduct observations and interviews in the clinical setting
Mature Concepts		
A concept appears to be well developed with identified dimensions and boundaries, but the validity of the conceptualisation has not been determined across contexts	Concept refinement/ measurement	Use quantitative data collection methods

Of the various types of enquiry identified by Morse (1995, 1996a), concept identification and concept comparison are not appropriate for this study as they are focused on a phenomenon that is not described by a concept, or described by numerous concepts. Rehabilitation involves phenomenon that is not described by other concepts. Concept delineation, which is used when two concepts appear to be closely linked together as part of the same experience, is also not suitable for the purposes of this research as it does not apply to rehabilitation. Rehabilitation is not linked in that way to another concept.

This leaves four types of enquiry, which relate to rehabilitation:

> Concept development: Although rehabilitation is defined, it could be seen as being immature because the definitions and characteristics may not be adequate in relation to cultural sensitivity.

> Concept clarification: The concept of rehabilitation appears to be mature because there is a large body of empirical evidence focusing on rehabilitation. Rehabilitation is generally measured in terms of impairments, activities and participation (WHO 2001), but this appears to be restrictive, as these measures do not encompass the entirety of rehabilitation, as discussed in chapter two. There are a number of definitions of rehabilitation and a number of concepts that relate to rehabilitation. However, there is little evidence that these definitions and key concepts are appropriate for rehabilitation in different cultural contexts.
>
> Concept correction: Rehabilitation appears to be mature because it is consistently defined in the literature and appears to be well developed. However, these definitions do not seem to be culturally appropriate for rehabilitation practice in all contexts.
>
> Concept refinement: Rehabilitation appears to be well developed with identified dimensions and boundaries. However, the effectiveness of rehabilitation across different cultural contexts has not been determined.

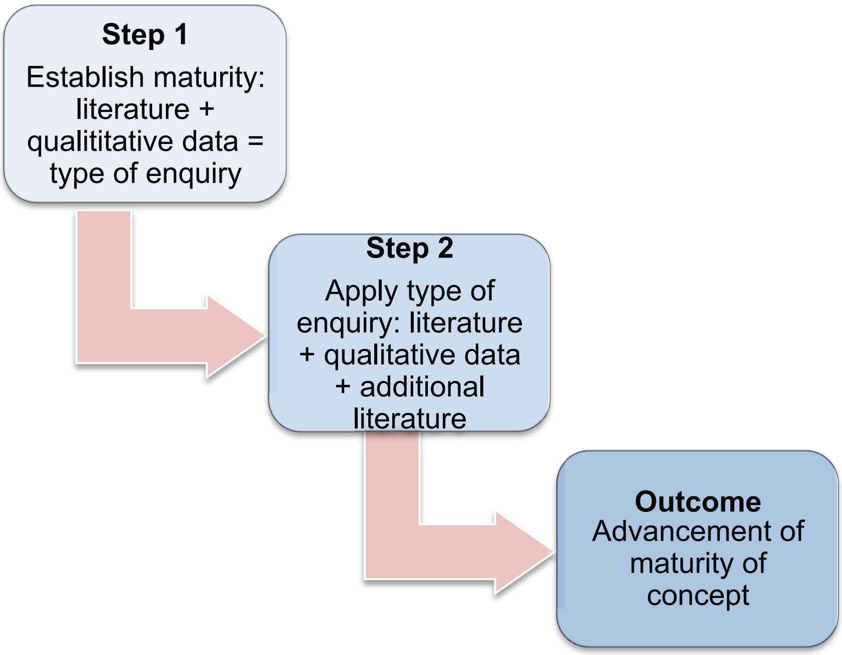
The type of concept analysis appropriate for this study depends on whether the concept of rehabilitation is identified as being immature, partially mature or mature. This will be confirmed through analysis of the literature and qualitative data, as previously discussed.

3.4.2 Concept Analysis Process for this Study

The concept analysis process for this study (figure 3.1, page 42) follows Morse's (1995) process with the fundamental difference being the use of additional qualitative data alongside the literature as discussed in 3.3 to check the maturity of the concept. In step two, additional literature identified may also be required to enhance the analysis (figure 3.1, page 42). Analysis of additional literature (identified as a result of the maturity check) at this stage is considered to be appropriate by Morse (1995).

After completing step one, which is to establish the level of maturity through examining the internal structure of the concept (definitions, attributes, pre-requisites, boundaries and outcomes), the next step involves the identification and utilisation of the appropriate type of concept analysis enquiry as discussed in table 3.1 (page 40) in order to advance or develop the concept. These steps will be detailed in chapters five and six.

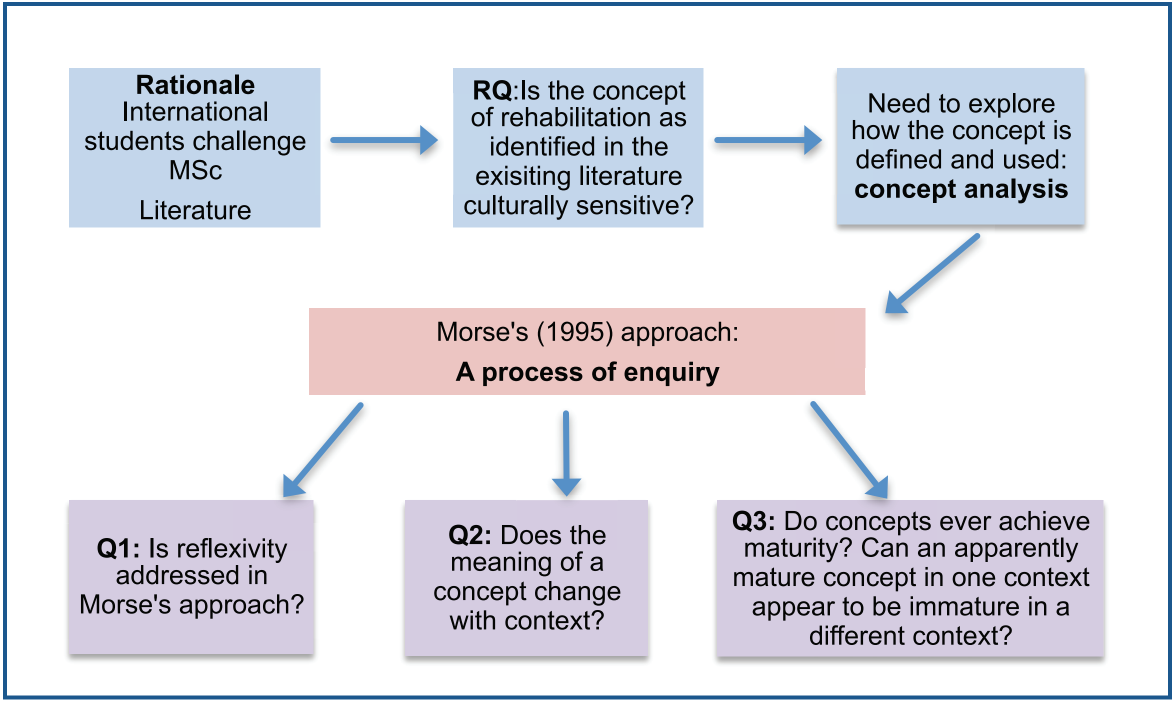
Figure 3.1: Process of Concept Analysis for this Study based on Morse (1995)



3.4.3 Questions Arising from Applying Morse's Approach

In examining Morse's approach to concept analysis three main questions have arisen concerning reflexivity, context and maturity (figure 3.2, page 43). These areas became important and key to this study as I read more about Morse, critically discussing the use of her approach in answering the research questions in supervision meetings and at research seminars.

Figure 3.2: Challenging Questions in Applying Morse's Approach



3.4.3.1 Is reflexivity addressed in Morse's approach?

Reflexivity is an approach that recognises the impact that the researcher's subjectivity and context has on all stages of the research project (Freshwater and Rolfe 2001, Finlay 2008). Rodgers (2000) highlights that extra measures such as reflexivity are needed in concept analysis to decrease personal bias as it is not uncommon for investigators to analyse concepts that are of interest to them and they therefore may have pre-existing views on the concept. This view is supported by Beckwith et al. (2008:1834) who identify that a number of concept analysis frameworks, (including Morse's framework), are based on hermeneutic methodologies where the investigator is in "a world of recognisable practice, which they aim to make more easily intelligible".

Hermeneutics emerges out of the work of philosophers such as Heidegger (1962) and Gadamer (2004) where understanding and interpretation (an evolving process) are interlinked. It is recognised that individuals perceive the same phenomenon in different ways in accordance with their historical background, previous understandings and lived experience (Heidegger 1962). Morse (2000:339) acknowledges this by stating that "research is not value free, and the author's bias, perspective, or theories used provide, albeit indirectly, a means to infer the researcher's perspective on the concepts". Therefore, the researcher needs to identify and record assumptions used in the literature. It is not clear whether this also applies to the researcher's own assumptions and perspectives on the concept under study.

The views by Heidegger (1962) also apply to the researcher's historical background, understandings and experience, as these have an effect on the decisions made in relation to the collection and analysis of the data. In order to understand the merging of the horizons between the participants and the object being studied, the researchers own experience needs to be evaluated (Gadamer 2004). This is important to this study as I am conducting the concept analysis while being embedded in the social world as a rehabilitation practitioner and educator. The challenge is maintaining my objectivity and being aware of the effect my own views and prejudices may have on the research process. There are a number of reflexive strategies that can help with this, which will be discussed in chapter four.

In response to the question, "is reflexivity addressed in Morse's approach?" The answer is yes. Morse (2000) identifies the need for reflexivity. However, this aspect is not prominent in studies using Morse's approach. For example, in the concept analysis of patient acuity (Brennan and Daly 2008) and of ethical sensitivity in professional practice (Weaver et al. 2008), the authors do not reflect on their own bias and values in interpreting the literature, nor do they consider these in relation to the authors of the literature. This could be due to the researchers not having a close relationship with the concept under scrutiny unlike this study where there is a close relationship between the concept and the researcher.

Following the principles of hermeneutics, this study, will therefore proactively foreground reflexivity in order to explore the cultural sensitivity of the concept of rehabilitation. This approach connects well to the conceptual assumptions (identified in 3.1.2) in that a number of different perspectives will be gained from patients and healthcare professionals from the literature and the qualitative data. It is recognised that their background, previous understandings and experiences will have an influence on how they see rehabilitation. These are taken into account in the analysis of the concept.

3.4.3.2 Does the meaning of a concept change with context?

In concept analysis, 'context' is referred to in terms of "theory" (Morse 1995, Paley 1996, Risjord 2008) as well as different backgrounds and environments, for example, cultural context, ethnic context, social context and disciplinary context (Morse 2000, Rodgers 2000,).

Paley (1996:577) identifies theories as the contexts that determine the meaning of a concept. He suggests “the only way to clarify a concept is to adopt a theory that determines what its niche will be”. However, Paley (1996) cautions against trying to define a concept in relation to a number of different theories. There could be a danger that the meaning of the concept may then change depending on the theory. Examples of this in relation to the concept of rehabilitation are the World Health Organisation classifications: the ICIDH (International Classification of Impairments, Disease and Handicap) and the ICF (International Classification of Functioning, Disability and Health), discussed in chapter two. Within the ICIDH, the concept of rehabilitation is set within a predominantly medical perspective whereas in regards to the ICF, the relationship between the many factors that affect the rehabilitation experience for an individual is prominent.

Penrod and Hupcey (2005:404) use the analogy of a tapestry to capture the links between concepts and theory, which exemplifies how a concept relates to context:

> The power of concept analysis is to identify the existing theoretical strands that define a concept of interest and ultimately to tie and re-tie the conceptual knots to form a stronger, more coherent tapestry of theory. Theory (i.e. the tapestry) is strengthened as the individual strands (i.e. concepts) are clarified and developed.

The strands (key characteristics) of a concept need to be flexible enough to transcend contexts or there may be different strands for different contexts. Perhaps a concept should be seen as emergent in that it allows for variation in the experience and perspectives of individuals within their social and cultural context. Morse et al (1996b:388) state that “characteristics must be abstract enough to define the concept regardless of the context in which the concept appears”. However, Beckwith et al (2008) argue that there is inconsistency in Morse’s views in that she also suggests that “concepts are not manifest in different contexts in the same pattern” (Morse et al. 1996b:389).

Here it will be argued that, in relation to the cultural sensitivity of rehabilitation, the 'conceptual knots' may need to be retied or left untied to ensure that the concept transcends different contexts. Some fluidity in the concept may need to be maintained in order to ensure that the concept of rehabilitation is appropriate to the cultural and social context in which it occurs. The process of concept clarification might provide insight into which conceptual knots need to remain adaptable.

Does the meaning of a concept change with context? The answer to this question is 'no' according to Morse et al (1996b). However, for this study the answer is 'yes'. A concept could mean one thing in one context and then another in a different context (for example, in a different social or cultural context). The way rehabilitation is defined in the current literature may not be culturally sensitive and the characteristics may not be flexible enough to transcend contexts. In this study, the contexts in which the concept is defined and implemented are taken into consideration. This will include historical, social and cultural contexts and the disciplinary context (for example, medicine, sociology, psychology).

3.4.3.3 Do concepts ever achieve maturity? Can an apparently mature concept in one context appear to be immature in a different or additional context?

The maturity of a concept is a fundamental aspect of Morse's (1995) approach, which is referred to as "a process of enquiry that explores concepts for their level of development or maturity" (Morse et al. 1996a). As previously discussed (3.4), in order for a concept to be mature it needs to have a meaningful definition and attributes, clear pre-requisites, boundaries and outcomes (Morse et al. 1996a). Morse et al. (1996b:387) stipulate that "a concept must be mature before it can be operationalized and definable in measurable units". Maturity in Morse's approach is identified as a pre-requisite and an absolute. However, this raises the question as to whether maturity of a concept can be achieved and whether this is desirable.

The maturity of a concept could be dependent on the context in which it occurs. For example, the social context may have an effect on the way rehabilitation has been defined and this may then mean that, in a different social context, the definition and characteristics of rehabilitation are not clearly defined. The social context may also change over time so how the concept is situated historically needs to be considered. Concepts may dip in and out of maturity: being mature in one context or at one point in time and then immature in another context or at another time. It therefore could be that a concept will never achieve maturity and if it is assumed that it is fully developed, factors such as cultural factors may not have been taken into account. This indicates perhaps that the development of a concept is continuous or maturity could be related to the flexibility of the concept to adapt to cultural or social contexts.

The concept of rehabilitation can be seen to be mature in relation to the abundance of literature and the current research evidence, which is an indicator for maturity (Morse et al. 1996a). However, when relating it to a specific arena such as cultural sensitivity, it can appear to be immature. Therefore, identifying rehabilitation as a mature concept in a broader arena could be seen as misplaced maturity. If it is established that the concept is immature in relation to cultural sensitivity, then it will not be appropriate for all individuals undergoing rehabilitation, which then does not meet Morse's indicator of being applicable to practice (Morse et al. 1996a).

In terms of the theoretical context (Morse 1995, Paley 1996), the maturity of a concept could change if the theory changes. As discussed earlier (3.4.3.2), there are two theoretical frameworks connected to the concept of rehabilitation: the ICIDH (WHO 1980) and the ICF (WHO 2001). The meaning of rehabilitation within the ICIDH framework does not fit with the ICF framework. Therefore the concept could be seen as mature within the ICIDH (WHO 1980), but needing development to fit in with the ICF (WHO 2001).

Following the above discussion, it can be concluded that the concept of rehabilitation may never achieve maturity due to changing contexts or changing theory and that achieving maturity might not necessarily be a good thing. It may be possible for a concept to appear to be mature, but when examined within a more specific focus such as cultural sensitivity, it may be immature. This may or may not apply to other concepts.

3.4.4 Summary of Concept Analysis

Concept analysis as identified by Janice Morse (1995) has been chosen as the research approach for this study. It enables the researcher to explore the multiple realities of a concept such as rehabilitation. Morse's approach permits the concept of rehabilitation to be analysed with the aim of developing it in relation to cultural sensitivity. This includes establishing the level of maturity. Following Morse's criteria for maturity, it appears that the concept of rehabilitation is a mature concept on account of the volume of literature and research associated with it. However, in relation to cultural sensitivity, it might be seen as immature.

In considering Morse's approach in relation to this study limitations have been identified in terms of reflexivity not being prominent, context being seen as static and unchangeable and maturity of a concept being fundamental. Therefore the concept analysis approach for this study follows Morse's (1995) process to a large extent, but with some vital adaptations. These include the addition of qualitative data to enable a more appropriate maturity check and to enhance the subsequent analysis; the proactive use of reflexivity in collecting, interpreting and analysing the data and awareness of whether the concept changes in different contexts.

3.5 Data Collection Methods

The data collection methods for this study need to be in keeping with the conceptual assumptions identified (3.1) and the research questions. Therefore, they are required to capture the experiences of individuals and their families and significant others undergoing rehabilitation, the perspectives of healthcare professionals, and the influence of contextual factors on those experiences in order to explore the concept of rehabilitation in relation to cultural sensitivity. It has already been established (3.4) that concept analysis as identified by Morse (1995) fits the conceptual position for this study and is appropriate for an in-depth inquiry of the literature, which addresses the research questions. Although there is a large amount of literature on different aspects of rehabilitation, in relation to the cultural sensitivity of rehabilitation, as previously discussed (3.4), the literature is mainly from Europe, America and Australia.

The decision has therefore been made as discussed (3.0) to complement the literature review by collecting qualitative data from India, a country which is not well represented in the literature, to give a more informed view. Therefore, the data to be collected is a review of the literature and qualitative data via qualitative interviews, focus groups and participant observation.

3.5.1 Review of the Literature

As discussed above (3.3), there is an extensive amount of literature documenting rehabilitation, which Morse et al. (1996a) identify as being a requirement for studying a concept by means of concept analysis. Rather than letting a concept emerge through the data, a thorough, detailed, theoretical and conceptual analysis of the literature is suggested (Morse et al. 1996a, Morse 2000). Therefore, the first step in establishing the maturity of the concept and the subsequent concept analysis approach is a comprehensive review of the existing literature. Morse (1995) recommends that all pertinent databases are searched and relevant literature, including books and articles, retrieved. However, in this study, books are not included as they generally focus on rehabilitation of different conditions at the levels of impairment and disability rather than the patient's experience and include definitions of rehabilitation that are already published in journal articles by other authors. Journal articles have been retrieved from databases from the different academic disciplines of medicine, sociology and psychology to ensure a balanced view as advocated by Morse (1995) and reviewed in relation to definitions, attributes, pre-requisites, boundaries and outcomes. This process is discussed in more detail in chapter six (6.1)

3.5.2 Qualitative Data

Although this study is not an ethnographic study, it is appropriate that the data collected follows an ethnographic approach as the study focuses on the understanding of rehabilitation from the perspective of healthcare professionals and patients in India. This fits in with the characteristics of ethnography (Atkinson and Hammersley 2007) where the researcher focuses on understanding phenomena from the perspective of people in their own natural setting. This study will therefore employ commonly used data collection methods in ethnography, namely qualitative interviews and participant observation.

3.5.2.1 Qualitative interviews

Qualitative interviews (Britten 2006) are used in this study as they fit in with one of the conceptual assumptions (3.1.2.1), which is to find out about the participants' experience of rehabilitation. Knowledge about rehabilitation will be constructed from direct interactions between the researcher and the participants, with the researcher actively guiding the participant in a more in-depth exploration of their views in order to gain understanding of their experiences (Kvale 1983) in relation to rehabilitation. This has been achieved through semi-structured interviews that mainly use open questions and focus on specific situations such as the participants' experiences of rehabilitation rather than general opinions (King 2004, Kvale 1983).

The main strength of using qualitative interviews for this study is that they are flexible, enabling the researcher to respond to specific answers and to non-verbal behaviour. They are therefore suited to examining topics such as rehabilitation, in which different levels of meaning need to be explored (Coombes et al 2009, Kvale 1996, Morse 1991).

They also produce detailed contextual information, which helps in understanding the full meaning of the responses (Coombes et al. 2009). This is particularly relevant in this study as the data has been collected from a different country and so additional contextual information enables responses to be related to the interviewees' specific contexts.

3.5.2.2 Focus group interviews

Another type of interview that is in keeping with the conceptual assumptions of this study (3.1.2.2) is the focus group interview. This is an appropriate method for collecting perspectives from a multi-disciplinary healthcare team on their perspectives of rehabilitation. Focus groups are a way of understanding how people view their own reality (Krueger 1994), for example, rehabilitation, and are appropriate when interaction among interviewees will likely yield the best information and when interviewees are similar and cooperative with each other (Krueger 2009, Morgan 1996, Kitzinger 1995).

Using focus groups in this study increases the potential for group interaction (Morgan 1996, Krueger 2009) between different members of the multi-disciplinary team, enabling participants to contrast their views and experiences of rehabilitation, resulting in a consensus of opinion as well as highlighting the diversity of perspectives. Participants can be encouraged to raise queries with each other and to elaborate on their views. This is particularly productive when participants are in their own environment (Krueger 2009). Focus groups will enable participants to feel more secure in sharing their experiences of rehabilitation in an interactive way rather than in a one-to-one interview. As the researcher is from a different country and culture, this is important in enabling participants to feel comfortable in sharing their experiences. The researcher will also have the opportunity to ask participants for comparisons between their experiences and views rather than aggregating individual data (Morgan 1996). This sharing and discussing of views will provide a more in-depth knowledge of rehabilitation in a country not well represented in the current literature.

3.5.2.3 Participant observation

Observation fits with the conceptual assumptions of this study in that it can enable the researcher to observe rehabilitation practice and can assist in interpreting the patients' rehabilitation experiences and healthcare professionals' perspectives. A key challenge for the researcher is to identify the appropriate observer role to adopt.

Observation is generally referred to as ‘participant observation’ where the observer becomes involved in the activities of the group being observed (Pretzlick 1994) and ‘non-participant observation’ where the observer is not involved in the group at all (Couchman and Dawson 1995). However, dividing the role of the observer between these two categories does not always fit and the observer may combine elements of both the participant and non-participant role (Sarantakos 2005). The level of involvement of the observer can vary from complete participant (full involvement) to complete observer (no involvement), with levels in between of participant-as-observer, where most of the researcher’s time is spent participating and observer-participant, where only a small amount of the researcher’s time is spent participating in normal group activity (Gold 1958). This is supported by Spradley (1980) who refers to these levels of participation as complete, active, moderate and passive.

In this study, the researcher adopts the role of observer-participant. This is appropriate because the group will know the researcher as a researcher and rehabilitation professional. Therefore, adopting the role of a complete observer would be difficult. The role of observer-participant fits with the aims of the observation in that it enables the researcher to observe behaviour (Mays and Pope 1995) of rehabilitation professionals, gaining an insight into processes and procedures. Adopting an observer-participant role enables the recognition of any inconsistencies in what participants say in the interviews and focus groups in contrast to what they actually do. It will also assist in identifying the biases present in the interviews due to factors such as differences in recall, influences from the roles they occupy and wanting to be seen in a good light (Mays and Pope 1995). It can also assist in exposing ‘the beliefs and social meanings held by individuals and groups’ (Miller and Brewer 2003:223). Using participant observation will also allow the researcher to respond to changing circumstances and to pursue particular themes or issues as they arise (Taylor 2009).

3.5.3 Summary of Data Collection Methods

The data collection methods discussed have been chosen as they are suitable for answering the research questions and they fit with the conceptual assumptions of this study. It has been argued that establishing the level of maturity of the concept of rehabilitation in relation to cultural sensitivity and then further developing the concept by using the existing literature as data and incorporating patients’ and healthcare professionals’ perspectives is appropriate. Using Morse’s (1995) approach enables a rigorous, structured analysis of the concept of rehabilitation in relation to cultural sensitivity using the existing literature and additional data. Interviews, focus groups and observation have been chosen to collect this data as they enable the researcher to identify the participants' experiences in relation to rehabilitation. The interviews and focus groups engage with patients and health care professionals from a culture that is under represented in the current literature. Participant observation will enable the researcher to gain an understanding of the environment and context the patients and healthcare professionals are referring to and will also enable her to gain an understanding of practices, procedures and other factors affecting rehabilitation in that context.

The challenges of adopting the above data collection methods and the strategies identified to address these will be discussed in chapter four, where implementation of the chosen data collection methods will be addressed.

3.6 Data Analysis

Data analysis is an essential part of the research process and should be consistent with the conceptual assumptions of a study. Therefore, in this study, the analysis needs to capture the multiple realities represented in the data collection and also take into account the relationship between the data and the researcher. The aim of the analysis is to make sense of these different perspectives in order to answer the research questions. This is in keeping with Schwandts' (2007) view of qualitative analysis as being the activity of organising, interpreting and making sense of the data with close involvement of the researcher working back and forth between data and ideas (Pope and Mays 2006).

Data analysis needs to be custom built and "choreographed" (Miles and Huberman 1994) with all the steps in the process being interrelated. Dey (1993) and Cresswell (2007) describe this process as an iterative or repetitive spiral, consisting of collecting and managing and reading the data, describing, classifying them into categories or themes, interpreting and making connections. The final stage of the process is presenting the data. Dey (1993:33) considers contexts as an important part of this process as they are a "means of situating action, and of grasping its wider social and historical import". This is particularly relevant to this study as the way rehabilitation is described in the data may change depending on historical, social and cultural contexts. The techniques identified by Morse et al. (1996a) as discussed in 3.4 are used to analyse the existing literature and the additional qualitative data. (The process of data analysis is discussed in chapter six, 6.1).

One of the issues for the researcher to consider is whether to read the data literally, interpretively or reflexively (Mason 2002). This will depend on what the researcher is interested in. For example, if reading the data literally, they will be interested in the content, structure, style and layout, looking at the words and language used and the sequence of interaction. Looking at the data interpretively involves the researcher looking for meaning and focusing on what they infer from the data. This involves "reading through or beyond the data" (Mason 2002:149). Reading the data reflexively means that the researcher is part of the data and needs to explore their role and perspectives in the data analysis process. In this study, the data will be read on all of these levels: looking literally at the literature for common definitions, attributes, the words and language used; interpreting the data for meaning and understanding; looking reflexively at the role of the researcher in the collection and interpretation of the data.

A challenge for the researcher in analysing qualitative data is managing the complexity and volume of it. The data in this study has been prepared for analysis through appraisal and categorisation of the literature, transcription of interviews, coding of the observation and reflexive journal excerpts (Miles and Huberman 1994). Computer assisted qualitative data analysis software such as NVivo can support this process by organising and keeping track of the data, managing ideas and organising theoretical knowledge, asking questions of the data, developing models of concepts and ideas and developing a report from the data (Bazeley 2007). NVivo is used in this study to record the literature and the qualitative data and categorise it under the characteristics identified by Morse (1995): definitions, attributes, pre-requisites, boundaries and outcomes. Using NVivo enables relationships to be made between the multiple realities obtained from the data, which, in this study, is the existing literature and the qualitative data.

In summary, data analysis in this study is concerned with making sense of the data using strategies that are consistent with the study's conceptual assumptions. Analysis begins with collection and ends with the presentation of the data. Analysis of the literature and the data from the interviews, focus groups and observation has been conducted using the techniques identified by Morse et al. (1996a) to establish maturity, which will then point to the appropriate process of enquiry. The challenge lies in handling both sets of data (the existing literature and the elicited qualitative data) with integrity. Reading the data literally, interpretively and reflexively enables the interpretation of all types of data with consistency. The qualitative data may require a more interpretative analysis.

3.7 Reliability and Validity

A key issue in any research is ensuring that it is of a high quality. In quantitative research, reliability and validity are identified as important criteria in establishing the quality and credibility of quantitative data (Bryman 2012). However, there is a debate about the use of these terms when applied to qualitative research. Lincoln and Guba (1985) prefer the use of credibility, transferability and dependability, whereas Morse (1999) maintains that the terms of reliability and validity are equally valid in qualitative research. When considering different definitions, ‘reliability’ tends to be defined in relation to dependability, transferability and credibility, whereas ‘validity’ is related to legitimacy and rationality, namely the extent to which “the research findings represent reality” (Morse and Field 1996:139).

Following Morse (1999), the terms ‘reliability’ and ‘validity’ will be adopted in this study, as they are no less important in qualitative research than in quantitative research. The use of different terms for quantitative and qualitative research seems to imply that one approach is less rigorous than the other. This need not be the case, although care must be taken to ensure that the strategies utilised to promote validity and reliability fit qualitative research.

3.7.1 Verification Strategies

Morse et al (2002) identify a number of verification strategies suited to qualitative research, which can be used to ensure reliability and validity and achieve rigour: methodological congruence, appropriate sample, collecting and analysing data concurrently, thinking theoretically and theory development. These strategies will be discussed in relation to this study.

Methodological congruence: Methodological congruence, as identified by Richards and Morse (2007), is the fit between elements of the research process: the research problem and the question, the question and the method, and the method, data, data collection and data analysis. The decision making process that has occurred in identifying the research approach is in itself a way of ensuring reliability and validity.

“Methodological congruence refers to the fact that projects entail congruent ways of thinking” (Richards and Morse 2012:35). This congruence is evident in this study starting from the development of the research questions, which came about in response to a dilemma from practice, which then led to the conceptual position of this study. Following this, concept analysis was identified as the main research approach. This logical process provides rigour in moving from the research question to the research approach and demonstrates congruent thinking.

Appropriate sample: Determining an appropriate sample size for qualitative data is not as straightforward as for quantitative studies, as the depth as well as the quantity of data must be considered. However, the selection of an appropriate sample is just as critical, with the quality of the research being dependent on the adequacy and appropriateness of the sample (Morse 1991). A common type of sampling in qualitative research is purposive sampling (Morse 1991, Miles and Huberman 1994,), where the researcher selects participants on the basis of their knowledge of the research topic. There are no clearly established rules for sample size; it needs to be based on the informational needs of the study and normally carries on until sample saturation is reached, which is the point where no new information is obtained (Polit et al 2006).

In this study, a clear search strategy has been used to identify the sample of literature, which includes inclusion and exclusion criteria and justification of databases. For the interviews and focus groups, participants were selected according to identified criteria for inclusion in the study. As ideas developed during the course of the interviews, further participants were selected, if required, with different knowledge or experiences. Any sample size is partially dependent on the availability of the participants who fit the inclusion criteria. However, saturation of data has been aimed for.

Collecting and analysing data concurrently: Morse advocates that the interaction between data and analysis is important in attaining reliability and validity. It establishes a link between what is known and what one needs to know (Morse et al. 2002). The literature is analysed in this study to establish the level of concept maturity (3.4) and to identify the appropriate type of enquiry. As the literature is analysed, the need for further data may arise. The data from the interviews and focus groups have been analysed as they have been collected to enable interaction with the data, and identification of what is known, what still needs to be known and whether further data collection is needed.

Thinking theoretically and theory development: Morse et al. (2002:13) identify theory development as moving “between a micro perspective of the data and a macro conceptual/theoretical understanding”. As the focus of this study concerns cultural sensitivity, there is a need to explore the internal and external cultural factors through the literature, which relates to the level of a macro understanding. This is then examined in relation to the International Classification of Functioning, Disability and Health (ICF, WHO 2001), which is the theoretical context for this study previously discussed (3.4.3.2).

As well as the above strategies, the evaluation criteria for concept analysis described in table 3.2 (page 56) is used to help achieve rigour. As suggested by Morse et al. (1996b), an extensive literature search and in-depth analysis of the data has been conducted to help achieve an acceptable standard. Additional qualitative data have been added to add depth to the analysis, as discussed in 3.4. The relationship between context and the concept of rehabilitation has already been discussed (3.4.3.2) with due emphasis on the contention that the concept of rehabilitation may have different meanings in different contexts.

Table 3.2: Criteria for Evaluating Rigour of Concept Analysis Research (Morse et al 1996b:271)

Criteria	**Standard**	
	Unacceptable	**Acceptable**
Extensiveness of the data base	Thin and scant: brief reports, confabulated examples	Rich and complete: lots of literature, full description, widely sampled examples
Depth of analysis	Absent, trivial, insignificant, lacks depth	Intellectual rigor, logical, creative and original
Development of argument	Confusing, hidden meaning, lacks reasoning	Logical, has clarity
Validity	Lacks specificity to concept	Delineates inclusion/exclusion criteria
Level of abstractness	Context/situational bound	Encompasses all forms and situations of the concept
Contribution to knowledge	Findings are obvious. Research does not contribute to the literature	Findings make intuitive sense. Provides new insights and new perspectives into the phenomenon. Empirical questions identifiable. Facilitates inquiry

Using reflexivity as a key approach in this study will enable assumptions to be challenged and any bias to be identified. An audit trail of the study process will be kept through documents such as a reflexive diary, field notes, and collection of raw data.

3.7.2 Summary of Reliability and Validity

Reliability and validity in qualitative research refers to the transferability and credibility of findings and the extent to which reality is represented. Morse et al. (2000) identify verification strategies that can be used to ensure reliability and validity: methodological congruence, appropriate sample size, collecting and analysing data concurrently and thinking theoretically. These strategies are employed in this study along with the evaluation criteria for concept analysis identified by Morse et al. (1996a) and reflexivity strategies to challenge the researcher's assumptions.

3.8 Ethics

Considering ethics is important at all stages of the research design and needs to be a high priority for the researcher. Therefore, achieving ethical clearance is one of the first stages in the research process. The ethical guidelines identified by Oxford Brookes University were used in this study and these reflect the Nuremberg Code published in 1947,[6] which first signaled the need for research ethics to become a major concern. This was followed by three other key documents: the Declaration of Helsinki[7] (1964,1975), the Belmont Report[8] (1979) and the International Ethical Guidelines for Biomedical Research Involving Human Subjects[9] (1993, 2002). All of these guidelines are concerned with the application of the ethical principles of autonomy, beneficence, non-maleficence and justice.

3.8.1 Ethical Principles

Autonomy: The principle of autonomy is concerned with respect of others, their goals and interests, and treating people as autonomous individuals. This includes protecting those with diminished autonomy from harm (Boulton 2009). Treating people as autonomous is also about respecting their right to participate in research voluntarily, which highlights the need for informed consent. The Belmont Report (1979) identifies that the consent process needs to address the issues of information, comprehension and voluntariness.

Informed consent was obtained in this study for the interviews, focus groups and observation. Giving the participants information and obtaining consent are discussed in

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[6] Nuremberg Code: http://ohsr.od.nih.gove/guidelines/nuremberg.html

[7] Declaration of Helsinki: http://ohsr.od.hih.gov.guidelines/helsinki.html

[8] The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research: http://ohsr.od.nig.gov.guidelines/belmont.html.

[9] International Ethical Guidelines for Biomedical Research Involving Human Subjects: http://www.cioms.ch/frame_guidelines_nov_2002.htm.

more detail in chapter four along with the strategies that were used to ensure confidentiality of the participants and data. The principle of autonomy is also applied to the analysis of the literature through the researcher ensuring that authors' work is not misrepresented.

Beneficence: The principle of beneficence includes an obligation to provide and balance benefits for the participants against risks (Beuchamp and Childress 2001). Non-maleficence is concerned with doing no harm and minimising risk. Research therefore needs be of social or scientific value and be conducted in a rigorous and trustworthy manner, resulting in trustworthy findings. Researchers need to be competent in conducting the research and in protecting the welfare of the participants (International Ethical Guidelines for Biomedical Research Involving Human Subjects 2002).

Researchers need to identify support measures for participants to use if the data collection methods cause any anxiety or distress. This study will add value to the body of knowledge addressing rehabilitation, and may have a positive effect on rehabilitation practice and education. Support measures are identified for the participants in the study in chapter four.

Justice: The principle of justice in relation to involving human subjects in research is about ensuring that participants are treated in a fair and equitable way and that special provision is made to protect the rights and welfare of vulnerable persons (International Ethical Guidelines for Biomedical Research Involving Human Subjects 2002). In relation to this study, the involvement of participants in the interviews, focus groups and observation was conducted in a fair and equitable way. The researcher ensured that the literature and the direct engagement data (from the interviews and focus groups) were also treated in a fair and balanced way.

In summary, in order to ensure that research is conducted in a fair, respectful way without causing harm to participants, ethics needs to be a key consideration of any research study. A number of key ethical codes and guidelines highlight the ethical principles of autonomy, beneficence, non-maleficence and justice, which will be addressed in this study in terms of consent, confidentiality, protecting the welfare of participants, treating them in an equitable way and ensuring that the study adds to the body of knowledge.

3.9 Chapter Summary

The research design discussed in this chapter has been guided by identified conceptual assumptions, which have made explicit the values and beliefs on which this study is based: addressing individuals' experiences and healthcare professionals' perspectives, and identifying cultural factors. The principles of the constructivist paradigm correspond with these and it is therefore the chosen research paradigm to guide the study. Concept analysis, as identified by Morse (1995), has been chosen as the research approach as it dovetails with the conceptual position and research paradigm. This approach begins by establishing the level of maturity of a concept and then identifies the appropriate type of enquiry (Morse et al. 1996a) to advance or develop the concept. In exploring Morse's approach, a number of questions have arisen concerning reflexivity, context and maturity. These have been discussed and will continue to be considered throughout the process of collection, analysis and discussion of the data.

The data collection methods for this study will be an analysis of the concept of rehabilitation in the existing literature following Morse's (1995) approach, plus focus groups and ethnographic data collection methods: qualitative interviews and participant observation to gain different experiences and perspectives from patients and healthcare professionals in one setting in India. While using these methods, the researcher will be aware of her own weaknesses and take appropriate measures to deal with these. The data will be analysed using the strategies identified by Morse (1995). Verification strategies and criteria for evaluating concept analysis research (Morse et al. 1996a, 2002) will address issues of reliability, validity and rigour. Ethical principles of autonomy, beneficence, and non-maleficence are discussed in relation to the research and, more specifically, to issues in this study including confidentiality, consent and participants' rights.

This chapter has focused broadly on the methodology and research design for this study. The next chapter discusses more specifically the methods and strategies used to identify, collect and analyse the data and to address specific ethical issues.

Chapter 4: Methods

4.0 Introduction

This chapter discusses the research methods used to obtain the data to answer the research questions:

> "Is the concept of rehabilitation as identified in the literature culturally sensitive?"
> "What are the implications for rehabilitation practice and education?"
> "What cultural factors need to be considered to ensure that the concept of rehabilitation is culturally sensitive?"

As discussed and justified in chapter three (3.4), the research design best suited to the research questions and the conceptual assumptions (3.1.2) on which it is based is a concept analysis following the approach identified by Janice Morse (1995), which consists of:

- A review of the literature in order to establish the level of maturity of the concept, which is the first step in selecting the appropriate concept analysis approach as discussed in chapter three (3.4). This literature is also used with additional literature as data in the selected concept analysis approach.

- The collection of additional data from health care professionals, students and lecturers in a university and hospital in the Karnataka region of India, via qualitative interviews, participant observation and focus groups. As discussed in chapter three, the aim of collecting this data is to complement the literature, which adds to the maturity check and the appropriate concept analysis enquiry (3.4.1) by providing a perspective from a country that is not well represented in the literature in relation to the focus of this study.

India was selected because most of the international students undertaking the MSc Rehabilitation programme are physiotherapists from India and there is no literature on the meaning of rehabilitation in India. Following visits to other hospitals recommended by the Indian students and colleagues, the decision to use the university and hospital in the Karnataka region was based on the easy access it offered to different healthcare professionals and to patients undergoing rehabilitation.

As well as the research methods used in this study, this chapter will discuss reflexivity and identified ethical issues.

4.1 Identifying the Literature

In order to conduct a comprehensive literature review, Morse (1995) recommends that all the literature around the concept be examined. However, a decision was made to exclude books from this study, as discussed in chapter three (3.5.1), as they generally focus on a specific condition, for example brain injury, at the level of impairment and disability. Therefore, the focus has been on journals covering a range of disciplines (Morse 1995). The steps in reviewing the literature for this study has involved identifying the parameters of the search with inclusion and exclusion criteria, searching appropriate data bases and identifying strategies for the management of the data.

4.1.1 Search Strategy

The broad nature of the first research question meant that it was necessary to identify inclusion criteria to narrow the literature search, while still ensuring the question was fully addressed. This resulted in a focus on the following three areas:

Type of Rehabilitation: Physical rehabilitation i.e. rehabilitation associated with physical disability.
It was important to specify the type of rehabilitation to exclude material on drug, alcohol or purely psychological rehabilitation. Physical rehabilitation includes the psychological aspects related to disability as discussed in chapter one.

Population: People aged18 years and over.
Rehabilitation of children was excluded as were studies conducted on animals. The focus of this study is on the rehabilitation of adults, and, in India, adulthood is seen as starting from the age of 18.

Years: From January 1999 to May 2009.
In order to make the literature analysis manageable, the search was restricted to a ten year period. The ICF (International Classification of Functioning, Disability and Health) was implemented in 2001 so ten years seemed an appropriate period of time to capture this.

Language: No restriction.

The search was not restricted to English Language publications; however, the few articles found that were not in English focused on the level of impairment so were not included in the sample. Using ‘rehabilitation’ as a search term on its own produced an unwieldy amount of references, therefore combinations of the following relevant terms were used to make the search more meaningful and manageable: 'autonomy’ and 'quality of life’ as they are frequently used in modern literature in association with rehabilitation; ‘rehabilitation services’ and ‘rehabilitation systems’ captured literature relating to different ways of delivering rehabilitation and ‘international rehabilitation’ identified literature that focused on the delivery of rehabilitation in different countries.

Key Terms: The following key terms were added to ‘humans’ and ‘adults’:

Physical Rehabilitation (Phys.Rehab)
Autonomy and Rehabilitation (Aut/Rehab)
Rehabilitation Services (Reh.Ser.)
Quality of Life and Rehabilitation (QOL/Reh.)
Rehabilitation Systems (Reh.Sys)
International Rehabilitation (Int.Reh.)

Databases:

Taking into account the view of Morse (1995) that data needs to be from different disciplines, databases were accessed that covered a range of literature from different disciplines, for example, nursing, medicine, physiotherapy, occupational therapy and sociological and psychological perspectives. This was also appropriate as rehabilitation is a multidisciplinary endeavor therefore views from different disciplines need to be taken into account. The data bases used were PubMed (US National Library of Medicine), CINAHL (Cumulative Index to Nursing and Allied Health Literature), AMED (Allied and Complimentary Medicine Data Base), PsycINFO (Psychological Information Data Base), NARIC (National Rehabilitation Information Center) and IndMED (National databases of Indian Medical Journals). I accessed this latter database while in India. Two more databases were accessed but were not included due to the low number of relevant hits, and their focus on the level of impairment: the Centre for International Rehabilitation Research Information (CIRRIE) and the Cochrane Data Base.

The chosen databases yielded a large number of references (table 4.1, page 63).

Table 4.1: Databases. Period covered: January 1998 – May 2009

Database	**Key Terms**					
	Phys.Reh	**Aut/Reh**	**Reh Serv.**	**QOL/Reh.**	**Reh.Sys**	**Int.Reh.**
PubMed	24,932	595	9,705	10,196	2,058	1,556
Psyc INFO	1,247	180	977	2,288	192	859
AMED	152	145	561	1,874	17	13
CINAHL	2,022	117	414	1,658	25	13
NARIC	1000	57	779	727	920	527
IndMED	191	0	0	0	0	0

4.1.2 Management of the Data

Following the initial search, it was necessary to manage the data and to focus on articles that specifically talked about the meaning of rehabilitation and people's experiences of rehabilitation. As the ICF (WHO 2001) is a fundamental biopsychosocial framework used in rehabilitation (as discussed in chapter two), it seemed appropriate to use it to manage the data. I therefore accessed the titles and, if appropriate, the abstracts as well, categorising the articles under the ICF components (table 4.2, page 64). I discussed this process in supervision meetings, sharing examples of categorised articles and the reasons for not including articles. This helped in confirming some reliability in the process adopted.

Table 4.2: Components of the ICF (WHO 2001)

Body functions, structure and impairment (Category one)
1a: body functions - physical and physiological functions
1b: body structures – organs, limbs and components
1c impairments
Activities and participation (Category two)
2a: learning and applying knowledge
2b: general tasks and demands
2c: communication
2d: mobility
2e: self-care
2f: domestic life
2g: interpersonal interactions and relationships
2h: major life areas – work, leisure etc.
2i: community, social and civic life
Contextual factors (Category three)
3a: products and technology
3b: natural environment and human-made changes to environmental access
3c: support and relationships
3d: attitudes: external to the individual. Observed as a result of customs, values, religious beliefs etc.
3e: services, systems and policies
Personal factors (Category four)
4a: experience of rehabilitation or disability
4b: coping styles/strategies
4c: life satisfaction

Articles in categories three and four (contextual and personal factors) are included in the study (table 4.3, page 65) as they tended to discuss issues related to the patient's experience and the meaning of rehabilitation. The majority of articles in the databases related to impairment and disability, (categories one and two), and therefore were not included.

Table 4.3: Number of Articles in Categories three and four

Database	**Key Terms**						**Total**
	Phys. Reh.	**Aut/Reh**	**Reh.Serv.**	**QOL/Reh.**	**Reh.Sys**	**Int.Reh.**	
Pub Med	2	2	2	16	1	0	**23**
PsycINFO	3	15	9	7	2	0	**36**
AMED	1	14	27	7	2	0	**51**
CINAHL	12	0	17	3	1	21	**54**
NARIC	1	0	7	8	1	2	**19**
IndMED	9	0	0	0	0	0	**9**

The total number of articles in categories three and four are 192 (with duplicates removed).

The identified articles came from websites, conference papers and journals from different countries covering a wide variety of conditions and aimed at different professionals (appendix 1). There are only one or two articles attributed to each journal publication; however, the countries and conditions referred to are wide ranging. The type of journals identified, include nursing, medicine, counselling, occupational therapy, physiotherapy and social work. The journals also cover a range of conditions and client groups, for example, head trauma, spinal injury, elderly people, cardiac, respiratory, stroke, rheumatology, musculo-skeletal and people with chronic conditions. The countries referred to include Australia, China, India, Japan, New Guinea, Norway, Sweden, Thailand, United Kingdom, United States of America and Zimbabwe.

The full articles in categories three and four were obtained and the content of each article appraised and summarised. This appraisal followed the assessment tool developed by Aveyard et al. (2011:15) which asks six strategic questions.

- Where…does this information come from?
- How…did they come to their conclusions?
- When…was this said/written?
- What… are the key messages or research findings?
- Who…has written/or said this?
- Why…has this been written/said?

This tool was used because it is suitable for assessing the quality of any material. Summary sheets were attached to each article summarising the article or study in terms of the above questions. The articles were also assessed for addressing whether the articles contained the indicators identified by Morse (1995) of definitions, attributes, preconditions, outcomes and boundaries and the extent of the articles' links between rehabilitation and culture. Articles were discarded that did not discuss the meaning of rehabilitation and/or the patient's experience and therefore did not address any of Morse's indicators. This then resulted in a sample of 120 articles.

4.2 Interviews

The main impetus for collecting data in India was to have the opportunity to talk to patients, students and staff about their experiences of rehabilitation. Qualitative interviews were chosen to gain an understanding of patients' experiences (as discussed in chapter three, 3.5.2.1) as they are in keeping with the conceptual position of this study, in that they enabled a closer relationship with participants and acknowledged multiple realities as seen by the participants. Interviewing also enabled reflection on my own values and beliefs in interviewing people from a different culture in their own country. Semi-structured interviews were used consisting of core questions as these enabled a focus to be maintained on the patient's experience of rehabilitation.

4.2.1 Identifying Participants

The university and the hospital gave permission for posters to be displayed on wards and in student areas, which raised awareness of my presence in the department. The posters were only displayed in English so would not have been accessible for patients who could not read English however, it communicated the study to students and staff. In organising the study, my main contact was the Head of the Physiotherapy Faculty at the university. On my arrival, he allocated two lecturers to be my main contacts and organisers for the interviews. They in turn allocated me two postgraduate female students, who agreed to interpret and assist in organising the interviews.

For inclusion in the study, participants had to be over the age of 18 and going through the rehabilitation process on a neurological or orthopaedic ward. I wanted to interview patients who had experienced neurological and musculoskeletal rehabilitation in order to give a view of different types of rehabilitation. These were the areas in which the two allocated students worked. In addition, these are the study pathways in the MSc in Rehabilitation at Oxford Brookes University, for which I am course lead. Children, cognitively impaired adults and adults with communication impairments were excluded from the study.

The two allocated postgraduate students identified patients that met the inclusion criteria and then discussed them with me. They initially spoke to the sister on the ward or the physiotherapist in the orthopaedic gym to ensure that it was convenient for me to speak to the patients, and then asked the patients if they would be happy to meet me to discuss the interviews. We then agreed a suitable time that did not interfere with the patient's treatment. The two allocated students introduced me to the patient and their carers (if they were present) and then interpreted if required or left me if not. For the two patients interviewed in the Ayurveda hospital, a nurse introduced me to two patients who met my criteria and who were happy to be interviewed. They both spoke English. I visited the patient at home with the CBR (Community Based Rehabilitation) team, and he agreed to be interviewed.

Organising the patient interviews depended on appropriate patients being available for interview and an appropriate interpreter being available. Although I was allocated a postgraduate student as an interpreter, they did not speak all the Indian dialects. For two patients, a nurse interpreted. The limitations of using an interpreter are discussed later in this chapter (4.4). Thirteen interviews were conducted with six patients on the neurological ward, four in the orthopaedic gym, one patient at home and two patients in the Ayurveda hospital. The sample consisted of five females and eight males ranging in age from 20–74 years (table 4.4, page 68).

Table 4.4: Patient Sample

Code	**Personal Details**	**Diagnosis**	**Location**
Pt. F1	Female: 35	Spinal Cord Injury	Neurological ward
Pt. M1	Male: 42	Stroke	Neurological ward
Pt. M2 (translated)	Male: 20	Spinal	Neurological ward
Pt. M3 (translated)	Male: 74	Fractured leg	Orthopaedic gym
Pt. M4 (translated)	Male: 38	Fractured leg	Orthopaedic gym
Pt. M5 (translated)	Male: 66	Fractured leg	Orthopaedic gym
Pt. F2 (translated)	Female: 26	Back pain	Orthopaedic gym
Pt. F3 (translated)	Female: 34	Blood clot	Neurological ward
Pt. F4 (translated)	Female: 28	Blood clot	Neurological ward
Pt. M6 (translated)	Male: 45	Tumour	Neurological ward
Pt. M7 (translated)	Male: 25	Spinal Cord Injury	At home
Pt. M8	Male: 53	Brain tumour	Ayurveda Hospital
Pt. F5	Female: 72	Stroke	Ayurveda Hospital

4.2.2 Conducting the Interviews

It was difficult to find a quiet, private area on the ward in which to conduct the interviews. A tutorial room was sometimes available, but, although this was a private room, it was very noisy due to a ceiling fan that needed to be on for the room temperature to remain comfortable. Some of the interviews took place in the ward with a screen around the bed. In the outpatient physiotherapy clinic, it was quieter and interviews were conducted in a bay or in a treatment room. I bought a sophisticated microphone in the UK to record the interviews, but this was too sensitive and picked up all background noise making transcription of the first two interviews impossible. Luckily, I was able to purchase a more basic microphone from a local shop, which was less sensitive.

The interviews began with me introducing myself and the study, through an interpreter if required. The information given about the study followed the information on the patient information sheet (appendix 9) and was given to the patients who spoke

English, but I explained the study verbally as well. I talked through the consent form (appendix 2), emphasising that the interviews would be taped and that participants could withdraw from the study at any time. They then signed the form.

An interview schedule (appendix 3) was used to maintain focus in the interviews and to ensure some consistency in interviews across participants. The aim of the interviews was to explore the patient's rehabilitation journey and to identify what aims they felt were important to them in their rehabilitation.

The initial guiding questions for the interview were:

> "Tell me a little about your family"
> "Why are you in hospital/why were you in hospital?"
> "Tell me about your time in hospital?"
> "What is important to you regarding your rehabilitation?"

After the first three patient interviews (which included the two discarded interviews) I felt I did not follow up adequately on questions answered, and was therefore unable to fully identify the patient's experience of rehabilitation. I also encountered a difficulty with the final question, as none of the patients understood the term 'rehabilitation'. After critical reading of the third interview by a colleague, the final question was changed to 'tell me about a typical day for you in hospital?' Although this did not specifically ask about rehabilitation, I was then able to use follow up questions about therapy, types of activities they did and what expectations they had, in order to gain the same information. Immediately following all interviews I made my own notes. Details of the patients interviewed are presented in table 4.5 (pages 69-72).

Table 4.5: Thumbnail Sketches of Patients Interviewed

Pt.F1 *Interviewed on her bed in neurology ward: 12.5 minutes.*

Female, 35 years old. Spinal cord injury as result of coconut falling on her three years ago while visiting her parents. Has been in hospital ever since. Paralysed with some movement in hands, needs help with all care. Was a product engineer working in Mumbai. Family (mother, brother and sister in law) all live together twenty minutes away. Family visits everyday, bringing food and helping with care. Receives daily therapy from the occupational therapists and physiotherapists. Her aim is to continue to be able to read and have physiotherapy every day. Has seen improvement in that she can now sit in chair without a neck collar.

Pt.M1 *Interviewed in a quite room in neurology ward: 8.41 minutes.*

Male, 42. Second stroke, been in hospital a month. First stroke four years ago, made fairly good recovery and returned home. This time has lost movement in right arm and leg. Having occupational therapy and physiotherapy. Married with a seven year old boy, lives in a village an hour away. A material contractor before his stroke in 2004, but hadn't been able to work since then. Wife works as a school headmistress, which maintains the family financially. His aim is to ride his bicycle to enable him to return to work and to improve his writing.

Pt.M2 *Interviewed on his bed in neurology ward: 5.10 minutes. Uncle present.*

Male, 20. Lost strength in right leg and hand, diagnosed with cord compression. Admitted to hospital for surgery, in hospital for two months then discharged home. Lost strength in right leg and hand. Now in hospital for radiotherapy treatment, physiotherapy and occupational therapy. Studying for an Electronics Diploma at college. Lives two hours away with mother, father, uncle and brother. His aim is to improve and return to college.

Pt.M3 *Interviewed on bed in orthopaedic gym: 20.57 minutes. Daughter present.*

Male, 74. Agricultural worker, pulling plant at work, lost balance and fractured leg. Has been in hospital for two weeks, being discharged. Lives three hours away with wife who has back problems, has three daughters and three sons. Having weight bearing exercises daily and heat treatment for osteoarthritis in his knees to mobilise his knees to help his walking. His aim is to walk and return home with his wife. Going home with a home exercise programme.

Pt.M4 *Interviewed in wheelchair in orthopaedic gym:16.15 minutes*

Male, 38, teacher. Was walking when he was hit by a motor cycle and sustained a leg fracture. In hospital for ten days. Lives four hours away, married with two daughters: six months and six years old. Father-in-law is staying with him and bringing in food. Having exercises daily to strengthen muscles is helping him walk with crutches. His aim is to walk without crutches and return to work.

Pt.M5 *Interviewed on bed in orthopaedic gym: 14.25 minutes.*

Male, 66. He was on his way from his house to a market cycling, when he had a sudden blackout and fell, fracturing left leg. Has a history of hypertension. In hospital for 13 days, being discharged. Lives two hours away. He was an agriculturist but now not working due to lack of jobs. Married with daughter (18) and son (20) who live with him. Has been walking with a walker and having physiotherapy exercises. His aim is to get home although his level of activity is less than before the accident.

Pt.F2 *Interviewed on bed in orthopaedic gym: 10.20 minutes.*

Female, 26, beautician with her own shop. Has had back pain for six years after washing heavy blankets. It was aggravated following the birth of her second child. Has been in hospital for five days, ready for discharge. Married with five year old daughter and one year old son. Lives two hours away. Here with her husband, mother looking after the children. Has been having electrical stimulation therapy and traction. Her aim is to return to work and have less pain. Is being discharged home with a home exercise programme and a belt to wear.

Pt.F3 *Interviewed on her bed in neurology ward: 9.10 minutes. Sister present.*

Female, 34. Suddenly started to have headaches and vomiting, sent to hospital. Had surgery for removal of blood clot in brain. In hospital for two weeks. Ready for discharge. Married, two children: ten and six years. Lives six hours away with husband, children, mother-in-law and father-in-law. Her two sisters are looking after her while she is in hospital, bringing in food. Having physiotherapy exercises helping her to walk with a walker. Her aim to is get home to her children. Her sisters will look after her at home.

Pt.F4 *Interviewed on her bed in neurology ward: 9.32 minutes. Mother present.*

Female 28. Went to local hospital after headaches and vomiting. Advised to go to Manipal hospital for treatment. Had surgery for removal of blood clot in the brain. In hospital for 15 days. Married with two sons: seven and four years old. Lives four hours away. Mother staying with her in hospital. Having physiotherapy and occupational therapy to improve walking. Wants to get home. Family worried about expense of her staying in hospital.

Pt.M6 *Interviewed on his bed in neurology ward: 5.35 minutes.*

Male 45. Admitted to hospital following increased leg pain and fever, unable to walk. Diagnosed with benign spinal tumour. In hospital for 14 days. Runs and owns farm. Lives with wife and two children (eleven and nine). Brother staying with him in hospital. Having suspension therapy and physiotherapy to help him walk and stand. Taking pain medicine as very painful. Doesn't know when he is being discharged. Aim to return to work.

Pt.M7 *Interviewed on bed in his house: 9.22 minutes. Mother present.*

Male 25. Electrician. Had accident six years ago. Was going to work on his motor bike, braked and went under a vehicle. Sustained spinal cord injury. Was initially in hospital for two months and has returned to hospital many times for infection. Lives with mother, father and brother. Unable to stand or walk and no movement in legs and limited movement in arms. Mother looks after him and gives him Ayurvedic massage with oils and exercises. Has regular visits from the doctor.

Pt.M8 *Interviewed in his room in the Ayurveda hospital: 27.00 minutes. Wife present.*

Male 53. Food technologist. Lives in Mumbai with his wife and twenty two year old daughter. Had brain tumour removed two years ago, which left him paralysed on his left side. Despite physiotherapy he was unable to straighten his hand and had limited movement in his arm. He was walking with a splint and stick. An uncle recommended the Ayurveda hospital. He came three months ago for treatment and is here for follow-up treatment consisting of a de-tox programme and exercises. Wife is with him. He can straighten his hand and has movement in the elbow and shoulder and can walk without the splint. He is now a chocaleteire with his own business, making chocolates at home.

Pt.F5 *Interviewed in her room in the Ayurveda hospital: 6 minutes. Sister-in-law present.*

Female 72. Lives near Mumbai with her husband. Seven years ago had a stroke and was admitted to hospital. This then left her with loss of strength and pain in her right foot and hand. Eventually with some physiotherapy exercises she improved and was able to walk with walker. Admitted to the Ayurveda hospital to try and get some improvement in her legs as they are painful at night. She will stay about fifteen days and have detox treatment, massage and exercises. Sister-in-law staying with her.

Ten patients came from rural areas in Karnataka and three patients were from an urban area: Mumbai. Ten of the participants were married with children and seven had a member of their family with them who either visited daily or stayed in or near the hospital. Nine interviews were conducted through an interpreter and four participants spoke English.

The interviews lasted between five and twenty seven minutes (refer to appendix 4 for transcript of patient interview). This was less time than I expected and they did not all give the in-depth data one would expect from a qualitative interview. There could be a number of reasons for this. The fact that I was a person the patient did not know and a person from a different country speaking a different language may have affected my relationship with them. It was difficult to recruit suitable patients. Although they all met the inclusion criteria, having more patients with long-term conditions may have given more depth to the interviews. The nature of my questions and my follow up questions may not have been totally effective.

4.3 Focus Groups

The main reason for choosing focus groups as a data collection method was that I considered this method to be in keeping with the conceptual position (3.1.2.2) of the study of rehabilitation involving a number of healthcare professionals working collaboratively with each other. Focus groups enabled different professionals working with patients going through the rehabilitation process to share their experiences and perspectives of rehabilitation.

4.3.1 Identifying Participants

The study was advertised on the wards and in the university using posters and the focus groups were organised by the head of the physiotherapy faculty and the physiotherapy lecturers allocated to me (as discussed in 4.2.1). The inclusion criteria for the focus groups were:

- Health care professionals working with neurological or musculoskeletal patients going through the rehabilitation process

- Academic staff teaching occupational therapy, physiotherapy or nursing in the university
- Students studying occupational therapy, physiotherapy or nursing in the university.

Students were informed by a tutor that the study was taking place: although these students could choose whether or not to participate, although it is not clear whether they felt able to opt out due to the request from their tutor to take part. Before the focus group I set up the room with chairs in a circle and positioned the microphone. At the start of each focus group, I introduced myself and asked the participants to introduce themselves. I then gave out the information sheets, answered any questions and gave participants the opportunity to 'opt out' before they signed the consent form (appendix 5). No one opted out.

4.3.2 Conducting the Focus Groups

Seven focus groups were conducted in the university either in the College of Allied Health or the College of Nursing. Five of them were with students and two with staff (table 4.6, page73). All participants spoke English.

Table 4.6: Focus Group Participants

Focus group interview 1 (FG1)	12 students. 3 PT: female; 2 PT: male; 3 OT: female; 4 nurses: female
Focus group interview 2 (FG2)	8 PT students: female
Focus group interview 3 (FG3)	7 PG nursing students: 6 female, 1male
Focus group interview 4 (FG4)	7 PG PT students: female
Focus group interview 5 (FG5)	4 PG OT students: 3 female, 1 male
Focus group interview 6 (FG6L)	7 allied health professionals/lecturers 3 OT: female; 1 OT: male; 3 PT: female
Focus group interview 7 (FG7L)	6 nursing lecturers: 5 female; 1 male
Key: PT: physiotherapy; OT: occupational therapy; PG: postgraduate	

The number of focus groups needed to ensure that data saturation is reached depends on the research question, but three - five groups is recommended for each participant category (Morgan 1996, Krueger and Casey 2000). In this study, five of the groups contained trained health care professionals (FG3, FG4, FG5, FG6L, FG7L) and two of the groups contained interns working in practice (FG1, FG2). Therefore, all of the groups could be said to contain similar participants in that they all had experience of rehabilitation practice and could therefore provide insight into the research topic (Krueger and Casey 2000). The range of participants in each group was between four and twelve. This is in keeping with the suggested size for a focus group, which is identified by Kreuger (2009) and Morgan (1996) as being as few as four and as many as twelve as long as it is small enough to allow people to share insights and large enough to provide a variety of perceptions (Krueger 2009, Morgan 1996).

The focus group interviews were semi-structured using an interview schedule (appendix 6) to guide them, containing ground rules, which were emphasised at the start of the interviews. These covered confidentiality in the group, not using patient or staff names, a request for participants to speak one at a time and to respect the views of others. The core questions used were:

> "What do you see as the main characteristics of rehabilitation in India?"
> "What factors are important to rehabilitation in India?"
> "How do these factors affect the rehabilitation of patients in India?"

After the first two focus groups I felt that, although I was obtaining relevant data, I was not conducting a focus group interview. Instead, participants were looking to me to ask questions, which they subsequently answered and interaction between participants was minimal or absent. Transcribing the focus groups immediately after their taking place helped me realise that I was using leading questions and introducing concepts such as 'goals' and 'team', rather than allowing the concepts to emerge out of the discussion.

I emailed a transcript of the first focus group to a fellow PhD student for feedback. This confirmed that I was using leading questions and that the focus group had become more of a group interview. I also emailed my three supervisors sharing my anxieties and they gave me the following advice:

- Explain the focus group more clearly, comparing it to a discussion in a market place where one person starts up a conversation and other people join the conversation.

- Record the changing nature of interviewer and interviewee as I try the new technique.
- Do not lose confidence.

As a result of this feedback, I asked participants to give an example where rehabilitation was successful and where it was not successful. This enabled participants to agree with each other and share experiences more interactively. This is significant as a key feature of focus groups is the interaction within the group and how the members can help and support each other in providing insights from their own experience (Morgan 1998). I was mindful that contributing in a focus group might have been difficult for some of the participants in that they may have been discussing issues in a group that were in opposition to their cultural norms (Willgerodt 2003). This included my being aware of people's body language and reactions to the questions asked and responding by asking the question in a different way.

In conducting the focus groups, I tried to keep track of the interactions within the group in case this had some bearing on the context of the comments. However I found this difficult to manage, which resulted in recordings in which I could not always distinguish between participants. Morgan (1996) identifies that this difficulty in discerning between the multiple voices on the recordings can cause chaotic data. In reality, this did not appear to affect the data to any great extent, as I was generally able to distinguish between views from the different professionals or students. I also took additional notes during the focus groups and afterwards, which helped put the interactions into context. Taking comments out of context or out of sequence could have changed the conclusions (Kreuger 2009). The focus groups are described in table 4.7 (pages 75-76).

Table 4.7: Focus Group Interviews

Key: PT; Physiotherapy; OT: Occupational Therapy; PG: Postgraduate; AH: College of Allied Health; N: College of Nursing
FG1: *12 students. 3 PT: female; 2 PT: male; 3 OT: female; 4 nurses: female. 46 minutes. AH.* The physiotherapy and occupational therapy students were interns and 4th year nursing students. The students sat together in the circle in their disciplines. There was good interaction in the group although only 4/5 PT's spoke, 2/3 OT's and 2/4 Nurses. The nurses in particular seemed quiet so I did ask them on a couple of occasions for their view and then two of them continued to contribute more. There was however indication of agreement with nodding of heads and murmurs from others when a student was talking. The students responded to my

questions and there were times when there was interaction between them.
FG2: *8 PT students. Female. 18 minutes. AH.* The room was noisy with the ceiling fans however it was partitioned into two with students using computers in one half. I turned the fan of in my half of the room but it was still noisy. There were originally nine students in this group but one left at the beginning as she was not able to stay for the length of the interview as she had another appointment. The students were not as talkative as group one however all the students spoke and responded to each other.
FG3: *7 PG nursing students. 6 female, 1 male. 40 minutes. N.* Two of the students were taking PG study in oncology and four in cardiology. The room had a quiet fan so noise wasn't an issue. There was good discussion in the group between the participants. The male student was as vocal as the female students.
FG4: *7 PG PT students. Female. 25 minutes. AH.* The room was noisy with the ceiling fans and building work that meant it was difficult at times to hear the students. The students engaged well with each other. My input was minimal. I felt my role particularly in this interview was more facilitative than directive.
FG5: *4 PG OT students. 3 female, 1 male. 25 minutes. AH.* Good discussion between the 3 female students particularly discussing the case of a young female patient. The male student did not say anything except to nod and contribute the odd word in agreement with the other students.
FG6: *7 allied health professionals/lecturers. 3 OT: female; 1 OT: male; 3 PT: female. 37 minutes. AH.* Meeting took place in a meeting room at lunchtime to enable participants to attend during their lunch break. There was confusion at the beginning as to how the long the interview would last as two of the participants had to leave after 30 minutes. I got the impression that they were told about the interview late that morning and maybe felt that they were expected to attend. There was some good interaction between them and good discussion about rehabilitation. The male OT was the head of the OT department, which may have prevented participation. Although he was quite vocal all of the other participants contributed to the discussion. I was aware of including them in the discussion.
FG7: *6 nursing lecturers. 5 female, 1 male. 30 minutes. N.* Interview was difficult to arrange as I had to write a formal letter to the Dean of Nursing following my contacts efforts to arrange it and previous discussion with the Dean. Subsequently I interviewed the lecturers the morning of the day I was returning to the UK. The lecturers taught in different areas: medical, surgical, community health, child health, maternity and psychiatric. It was difficult to engage them in conversation about rehabilitation as they were not able to easily relate to previous patients and give examples.

To limit hierarchy issues, the groups were designed to ensure that students from different years were not combined, and that students and lecturers/health care professionals were not in the same group interview. This is an important issue to consider when bringing a group together as the dynamics of a group can limit or facilitate the discussion. Some participants may dominate the conversation and others may be reluctant to speak which can be identified as being a weakness of focus groups (Kitzinger 1995, Morgan 1996, Kitzinger 2006). For example, in one of the focus group interviews (FG6L), there was a male head of the occupational therapy department, who may have affected the dynamics of the group in that he was quite vocal in his opinions. He was also the manager of some of the other participants in the focus group, which may have affected their participation. I tried, as the facilitator, to achieve a balance as advocated by Halcomb et al. (2007) between encouraging participants to talk and coercing or pressuring them into contributing.

The students were either interns (students who had completed their four years of training and were now in full practice for six months) or postgraduate students where they are trained in their profession and in the process of undertaking an MSc. Postgraduate students have more experience of practice than interns as they have worked in practice as qualified healthcare professionals. FG1 was the only mixed student group consisting of physiotherapy, occupational therapy and nursing intern students. This was because it was difficult to identify a time when occupational therapy, physiotherapy and nursing students could meet together due to their practice and educational commitments. There was generally good interaction in all the groups, although in FG1 the nurses were less vocal than the occupational therapy and physiotherapy students and needed encouragement to join in. (Refer to appendix 7 for transcript of focus group interview).

The two staff groups were a group of occupational therapy and physiotherapy lecturers (FG6L) and a group of nursing lecturers (FG7L). Occupational therapy and physiotherapy lecturers also work as health care professionals, whereas the nursing lecturers do not work in practice and generally go into academia as soon as they become qualified nurses. This could account for the reasons why they could not relate easily to practice examples.

4.4 Use of an Interpreter

Although English was the language spoken and written by the health care professionals, students and educators, the majority of the patients did not speak it, which meant I needed an interpreter. At the planning stages of the study, this was one of the issues that caused me concern. How would I know if the interpreter asked my questions as I asked them and also if the responses received were the true answers? I have personal experience as a rehabilitation professional working with patients' relatives in the UK, where relatives only translated parts of the conversation that they felt the patient ought to know, rather than the full content of the discussion. My anxieties are supported by the literature as being valid. Murray and Wynne (2001) identify a number of potential difficulties in the interpreted interview: three way production of data, selective translation, reliability of interpretation, impartiality of the interpreter and confidentiality.

I discussed with my contact the need to have someone who did not have a professional or family relationship with the study participants. As professional interpreters were not available, I was allocated two female postgraduate physiotherapy students. One of these worked with neurological patients and one with orthopaedic patients. Although these students were involved in therapy with some of these patients, they were not directly responsible for the patients' therapy. I therefore felt that using the students did not majorly compromise the professional relationship. Using postgraduate students also meant that they were trained physiotherapists and had a certain confidence and experience, which helped in my relationship with them. On reflection, I wonder if the fact that I was female was the reason for being allocated two female students. Interestingly, my main contacts and coordinators were male.

Murray and Wynne (2001) used a strategy of interviewing the interpreter to reveal their own opinions and reflections on the research topic and process. I felt this was a useful approach, and discussed the study aims with both of the students. They confirmed that they were happy to help, and that they did not feel it would affect their relationship with patients. Before the interviews, I discussed with them their views about rehabilitation and we also had regular discussion before and after the interviews. There were two instances where I had to use a nurse to translate, as the nurses were the only people able to speak the patient's language. (In India, there are many languages and dialects so it is not feasible to expect that an interpreter can speak them all). The implication of this was that I did not have the opportunity to build a relationship with these nurses, although I was able to explain to them the purpose of the study. During the interviews, I asked the patient questions, ensuring that I spoke to the patient, not the student, and the student translated the questions and responses. I felt that this was important in establishing a relationship with the patient and also showing respect for their views even though I could not speak their language.

4.5 Observation

Observation was used in this study to give a fuller understanding of the culture and practices around rehabilitation and the experiences of patients, carers, healthcare professionals and students and to set the context for the interviews and focus groups. Observation focused on the environment where the participants interviewed came from and the staff and students worked, namely the neurological ward and the orthopaedic gym, and the activities within it. This included attending a ward round, listening to therapists and nurses talking to patients and carers and having informal conversations with health care professionals. Other activities included attendance at a nursing conference, a visit to the Ayurveda hospital and going out with the CBR (community based rehabilitation) team.

My role as observer was at the level of observer-participant as discussed in chapter three (3.5.2.3). This decision is supported by Robson (2002) who argues that anyone who is known to be a researcher takes on that role within the group and therefore becomes part of the group. This fits in with Allan's (2006) realisation that she could not stop being immersed in the social world she was observing, because of her experiences as a nurse and researcher that meant she already had experiences and feelings associated with the group. I felt the same way because of my experiences as a rehabilitation professional, educator and researcher and found it difficult to be totally outside of the group.

Before going to India, I undertook a pilot observation in a rehabilitation centre in Oxford. As a result, I identified strategies for recording notes such as drawing a layout map, being clear what the uniforms meant and developing symbols to make recording easier, for example different symbols for 'patient in wheelchair' or 'patient with walking aid' etc. In the centre, I was able to sit in one place and observe the activities and interactions in one area. However, it was not possible to do this in India due to the layout of the ward, and the language barrier. I therefore observed interactions between health care professionals and patients by shadowing health care professionals, attending team meetings on the ward and the ward round. I made notes about the environment I was in, looked at policy documents and patients' notes. Informal interviews were used, where appropriate, to clarify points from the observation.

An information sheet was posted up on the wards and in the nursing, physiotherapy and occupational therapy schools. I made it clear on the information sheet that my role as investigator and observer was to try and prevent being drawn into the activity being observed. Becoming too involved or 'going native' (Hammersley and Atkinson 1983) can become a problem for the researcher and possibly more likely to occur if the researcher is observing in an area they work in or have expertise in, such as in this study.

Using the same strategy as Allan (2006), I kept two sets of field notes (observation notes and a reflexive diary), which enabled me to distinguish between what I observed and my own feelings and views. This can be recognised as observer bias: a weakness of participation observation where the researcher's personality and beliefs may influence the collection and interpretation of data (Roper and Shapira 2000).

I was also aware that the behaviour of the people I observed could have been affected by my presence. This is supported by Morse and Field (1996) who identify that there may be a change in behaviour of people being observed when the observer is present which can decrease as the observer is trusted and participants feel less threatened. At the beginning of the observation, people seemed to be wary and self-conscious. However, as they became used to me, they seemed to accept me more.

4.6 Reflexivity Strategies

Reflexivity has been identified in chapter three (3.4.3.1) as being key in guiding this study through all stages of the research process. An important element of reflexivity for the researcher is to place themselves emotionally and socially in relation to the research participants, particularly in the analysis of the data (Mauthner and Doucet 2003). This is significant in this study, due to my experience and stance as a rehabilitation professional and educator, which cannot be separated from the way I conducted the concept analysis and the research decisions made.

Reflexive journal and diary:

From the very beginning of this journey, when I registered for the PhD, I kept a reflective journal of supervision meetings, thoughts and ideas which have been invaluable in looking back to see how I have developed in my thinking and how my assumptions and beliefs have been challenged. While conducting fieldwork, I kept a detailed reflexive diary where I specifically thought about the feelings and experiences I was having whilst in India. This included being reflexive of my role as interviewer and the effect this had on the relationship with the interviewee, being aware that, although the qualitative interview can be seen as a caring, empowering relationship, it is also a hierarchical relationship with the interviewer ruling the interview (Kvale 2006). On my return to the UK, my reflective diary has been invaluable in remembering the experience in India in relation to context, feelings and challenges.

Critical friends:

My three supervisors have helped in this process by being ‘critical friends’, and challenging and questioning my views and assumptions, and also in helping me reflect on the data and key literature. Another ‘critical friend’ has been a fellow PhD student who gave me feedback on my first interviews. We have supported each other, giving each other critical feedback and advice on our projects, both of us drawing on our own experiences.

Writing book chapter:

I presented a reflective paper of my journey at an educational conference on globalisation and was then asked to write a chapter from it (Davis 2011). I was particularly encouraged by the editor to write it in a reflexive way and I found this invaluable in helping me take reflection to a deeper level.

Adopting role as insider:

In India, I wanted to adopt a role that was half way between outsider and insider to help me blend in. Although I wore linen trousers and a shirt, I felt I was very conspicuous. It was my student guide who suggested taking me to an Indian clothes store where I bought salwar suits (Indian top and trousers). It was surprising how different I felt wearing these clothes: although I was still a white woman and felt conspicuous in that environment, I did not feel as noticeable and I felt more confident. People seemed to smile at me more and acknowledge me. This also helped my confidence in the interviews. The way an interviewer dresses, their manner and etiquette can all help put the respondent at ease and Denzin (1989) particularly highlights the importance of self-presentation when the interviewer differs in ethnicity and gender. Making an effort to address this can help reduce the risk of respondents answering in the way they think will please the interviewer.

Presenting at seminars and conferences:
During this PhD journey, I have presented papers at various seminars and conferences on different aspects of the journey. I have used some of these to obtain the audiences' opinion and views on different aspects of the study, which has helped me in reflecting on the methodology, methods and results. I always reflected on these in my journal.

4.7 Ethical Issues

Ethical approval for the study was obtained from the University Research Ethics Committee (appendix 8). As a requirement of the ethics approval, permission for the study was gained from the Chancellor of the University in India. The permission from India included interviewing, observing patients and staff, attending meetings and ward rounds and examining patients' hospital records. The following ethical issues were considered:

Potential risks
For participants in India, there were no obvious risks from this study. However, there was a possibility that asking patients to talk about their rehabilitation journey may invoke distress and unpleasant memories. Patients were given the opportunity to talk to a counselor from the clinical psychology department if they so wished. This was organised with the Chancellor of the University and confirmed by email.

There was also a possibility that the interviews could raise issues that were not related to the study. I therefore identified an action plan, were this to happen. If patients complained about their care during the interviews, it was agreed with the ethics committee that I would direct them to the appropriate channels for making a complaint, in this case, the consultant. If students raised anxieties about care or they needed to talk through issues, I would direct them to speak to their mentor or head of department, which is the usual channel for students. Hospital and university staff would be directed to speak to their head of department or the dean of their faculty. Hospital and university staff also had regular staff meetings where they had the opportunity to discuss issues of concern.

Benefits to participants
There were no clear benefits to participants taking part in the study. However, it is possible that, as a result of the study, the health care professionals, students and lecturers interviewed will reflect on their responses to the interviews and that this may

have an effect on the way they think and behave. In the long term, the study will contribute to the body of knowledge on rehabilitation in different cultures and will inform practice and education. The results may affect the MSc in Rehabilitation for which I am Programme Lead, and therefore may have benefit for future students.

Consent

Participation in the study was voluntary. Even though the tutor asked students to attend, I did give them the choice to opt out. In order to obtain informed consent, posters about the study were displayed in the faculty and ward areas and information sheets were given to all participants prior to the interviews and the observation. Two information sheets were developed: one for patients and carers and one for students and staff (appendices 9,10). The interpreters translated the sheets to patients who could not speak English. The information sheets followed the format suggested by the ethics committee and explained the purpose of the study, what the participant had to do, the advantages of taking part and the principle of giving consent.

Participants signed the consent form (appendices 2, 5), before undertaking any interview, which again followed the format recommended by the ethics committee. Consent was required for participating in the interviews, consenting to observation and agreeing to the use of anonymised quotes in publications. I emphasised through the consent form and before the patient interviews that participants could withdraw at any time. For the focus group interviews, it was made clear on the consent form that participants could only withdraw any unprocessed focus group data.

Confidentiality and Management of Data

For the focus groups, the information sheet identified that participants would be expected to maintain confidentiality by refraining from discussing the issues raised after the focus group was completed. Confidentiality was also one of the ground rules discussed before each focus group. In transcribing the interviews, codes were used instead of names, and in presenting the data codes will continue to be used. In India, the data was kept in a locked filing cabinet in the faculty rather than in my hotel room; this was a condition of the ethics committee. In the university, data was kept in a locked filing cabinet.

Other Issues

The ethics committee highlighted a number of additional issues that were of particular concern. It was originally identified in the study that I would interview patients and carers together, but there were concerns as to whether women would feel free to discuss their views if their husband or carer were present. Reflecting on this and after talking to my students and contact in India, I took the view that this would depend on the individual woman and whether they wanted their husband or carer to be present. If they did, then I would respect this, but would reflect on how this may have affected their responses.

I decided to interview patients alone (with the interpreter), unless a carer was present and it was then appropriate to interview them as well. This meant that I was able to interview a larger sample of patients. In my original proposal, I planned to interview patients both in the hospital and the community. However, the ethics committee was concerned about my safety when conducting interviews in the community, and also the impact of any person accompanying me on the interview and the data generated. On reflection and in discussion with my contact in India, I conducted the study in the University and hospital only, with the exception of a single patient who I had the opportunity to interview in the community during a visit with the Community Rehabilitation Team and two patients I interviewed in the Ayurveda Hospital. The CBR team and the Ayurveda hospital are linked to Kasturba Hospital and Manipal University so were covered by the ethics approval.

The ethics committee suggested that it may be better for the interviews to be conducted in the native language and then translated back to English, as they felt that this would help increase the validity of the data. I considered this, but using an interpreter meant that I could then respond more spontaneously to the responses from the participant, which I felt was an important part of the data collection. I used the strategies discussed in chapter three (3.7.1) to address the concerns around validity.

4.8 Chapter Summary

The data collection methods discussed are in keeping with the conceptual position of this study in that they gain perspectives and experiences from patients and rehabilitation professionals on their experiences of rehabilitation. This all contributes to the aim of concept analysis in exploring whether the concept of rehabilitation is culturally sensitive as defined and described in the literature (which includes the data from India). A decision was made to limit the sample of literature in terms of years and journal articles. Although Morse (1995) advocates the need for all literature around the concept to be examined, her guiding principles can be deviated from as long as rigour of the concept analysis is maintained (Morse 2000).

Data was collected via interviews, focus groups and participant observation to obtain data from India to complement the literature. The key challenge in conducting the interviews was the way the questions were originally worded, which resulted in participants not understanding what was asked (in the individual interviews) and in my asking leading questions (in the focus group interviews). The rewording of the questions helped to address these difficulties. These challenges perhaps reflect my relative inexperience of conducting semi-structured interviews and focus groups and also not sufficiently considering the implications of interviewing in a different country and different culture.

Using different research methods such as questionnaires would not have enabled issues (such as the wording of the questions) to be picked up or changed so easily. It has to be remembered that, although different research methods have been used in this study, this is all part of Morse's (1995) concept analysis approach, which enables advancement of the concept of rehabilitation in relation to cultural sensitivity, resulting in new insights.

The observation is detailed in chapter five and the data analysis process and results of the maturity check presented in chapter six.

Chapter 5: Observation Context and Data

5.0 Introduction

The aim of this chapter is to describe and discuss the observation I conducted in a university and hospital in the town of Manipal in the State of Karnataka, South West India. This will help set the context for the discussion of the interviews and focus groups in chapter six. Ethnographic observation was used in this study to give a fuller understanding of the culture and practices around rehabilitation and the experiences of patients, carers, healthcare professionals and students in one setting in India.

My role as observer was at the level of observer-participant as discussed in chapters three (3.5.2.3) and four (4.5), which acknowledges the influences my own experiences as a rehabilitation professional and educator could have on the observation. For example, being careful not to react in a certain way both verbally and non-verbally to responses from people interviewed or people and events being observed. As I immersed myself in the observation I made a conscious effort to put aside or bracket my own assumptions and past experiences to prevent them influencing the observation. This chapter reflects this with an immersive description of the observation and then interpretation of and reflections on the experience.

5.1 National and Social Context

In order to understand the experiences of the participants in the study it is important to take into account the broader social context of India. This includes having an understanding of India as a nation and an understanding of the country's healthcare system. India is a vast, diverse country with a rich and complex history including becoming part of the British Empire in 1858 then becoming independent in 1947 when it was divided into India and Pakistan. India is the second most populated country in the world with eighteen official languages as well as additional minor languages and dialects. Hindi is the main language although it is less prominent in some parts of the country. English is generally studied by India's middle classes, from kindergarten through to college, and it is used in government, higher education, the judiciary, corporate activity and the media (Pinto and Sahu 2001). Religion is an integral part of the Indian way of life in all aspects of life from daily chores to education and politics. In the 2011 census, Hinduism was identified as the main religion of India with 80% of the population practicing it. Islam was the second more popular with 12% of the population.

Pintu and Sahu (2001), in their guide to Indian culture, identify the patriarchal and nuclear family structures as being key components of Indian society. In the patriarchal family structure, there is a male head of household who is responsible for his family, his married sons come next in the hierarchy and then all of the wives and children follow. There are variations of this for example where the head of the household lives with his extended family, married brothers and their extended families. The nuclear family is generally the male head of the household, his wife and any unmarried children. In India, the proportion of these two structures are fairly equally proportioned although the nuclear family is more prominent in Southern India.

Generally, individuals are expected to marry into the caste (community) into which they were born. Although this is no longer as influential as it used to be, Pintu and Sahu (2001:8) note that “it still functions as a social support system and is more than a subtle influence in the lives of the Indian people”. Historically the caste system has been an important influence on Indian society therefore it was important for me to be aware of it in case it had an influence on the practices and events observed.

5.1.1 Health Care System in India

The health care system in India is run by the constituent states and territories of the Indian Union and consists of public and private health service providers. Healthcare facilities run mainly by state governments provide low cost primary, secondary and tertiary health care facilities. In some facilities for patients who cannot afford health care it is subsidised by voluntary organisations. There are a number of healthcare issues detailed in India’s five-year plans, which aim to centralise and integrate the national economy.

One of the objectives of the Eleventh (2007-2012) Five Year Plan (Planning Commission, Government of India, 2008) was to achieve good health for poor and underprivileged people in India. This was continued in the Twelfth (2012-2017) Five Year Plan (Planning Commission, Government of India, 2013), which aims to establish a system of Universal Health Coverage in the country. The plan identifies this as addressing the following weaknesses of India’s health care system: the availability of healthcare services which varies from being adequate in urban areas to being limited or unavailable in rural areas and the quality of healthcare services which varies because not all healthcare practitioners are suitably qualified. Affordability of health care is another major issue being addressed in the Twelfth Five Year Plan particularly with tertiary care, which is limited in the public health sector. This means that individuals have to buy services from the private sector, for example out-patient clinics, mobility aids, communication aids. The definition of health adopted in the Twelfth Five Year Plan is the WHO (1948) definition of health where health is viewed as “not merely an absence of disease but as a state of complete physical, mental and social well being” (WHO 2006:1). There has not been an amended definition since 1948, which raises questions as to its appropriateness given the changes in populations and patterns of illness since then (Huber et al. 2011).

There appears to be a greater focus on issues related to disability in the Eleventh and Twelfth Five Year Plans. The Eleventh plan emphasises a “rights-based approach to empower persons with disabilities” (Planning Commission, Government of India 2008:9), which is continued in the Twelfth Five Year Plan with the adoption of a “two-pronged strategy incorporating service delivery and generation of public awareness about disability rights” (Planning Commission, Government of India 2013:263).

5.1.2 Disability and Rehabilitation in India

According to the 2001 census 2.13% of the population in India are people with varying disabilities including visual, hearing, speech and locomotor impairment and people with mental disabilities. These statistics may not be accurate due to the inadequate screening of mild and moderate disability in India in urban and rural areas (Ganesh Kumar 2009).

The Department of Preventive and Social Medicine (Ganesh Kumar et al. 2012:69) identifies disability as an important public health problem in India, which “will increase in future due to the trend of increased non-communicable diseases and increased life expectancy”. There has been a focus by the Government of India (2006:2) on improving conditions for people with disability, resulting in the following legislation:

- Mental Health Act, 1987.
- Rehabilitation Council of India Act, 1992.
- Persons with Disability (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995.
- National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disability Act, 1999
- National Policy for Persons with Disabilities, 2006

The Rehabilitation Council of India Act (Government of India 1992) was set up by the government of India to regulate and standardise training policies and programmes in the rehabilitation of people with disabilities. It continues to proactively promote training and research initiatives and regulate training standards for rehabilitation workers.

The aim of the Persons with Disabilities Act (Government of India 1995) was to ensure equal opportunities and the protection of rights for people with disabilities and full participation in all aspects of life. Even though the Act came into existence in 1996 it took about three years for the government to take steps to make it operational (Dalal 2002). Despite these steps the Government of India contend that “the Act is being poorly implemented”. Reasons for this included lack of commitment to the Act in some states and poor public awareness of the Act and benefits available.

In 2006 the National Policy for Persons with Disabilities was introduced with the aim of providing a comprehensive document on national policy for persons with disability and addressing the shortcomings in the Persons with Disabilities Act 1995. The Policy supports the need for medical and community based rehabilitation programmes. Community based rehabilitation (CBR) as discussed in chapter two (2.1.3) was developed to fulfill social rehabilitation needs in urban areas in countries such as India where resources for rehabilitation remain untapped in the community. It has been promoted by the World Health Organisation as the most viable and practical solution for addressing disability in India and other developing countries. However, as discussed in chapter 2 (2.1.3.1) if it is to be effective it requires coordinated efforts by Non Governmental Organisations (NGOs) and the local, district and provincial authorities.

5.1.3. How do the General National Trends in India Translate to Karnataka?

In terms of the percentage of people living with a disability in Karnataka the figure is slightly lower (1.8%) than the national figure of 2.13%. Approximately two thirds of the disabled population in Karnataka (940,643) live in villages with the one third living in urban areas (Office of the State Commissioner for Disabilities 2002, 2003, 2004). A year-long, community-based cross sectional study (Ganesh et al. 2008) of 1000 people with disabilities was carried out over a year in 2004 in four randomly selected villages in Karnataka. The prevalence of disability was higher among females than males and higher among people aged over above 60 years. It was found that people with disabilities were better educated in Karnataka compared to people with disabilities in other areas.

Karnataka was one of the first states to establish an independent Office of the State Commissioner under the Persons with Disabilities Act 1995 to focus on the rights of people with disabilities and to monitor disability funds (Kumar 2009). As a result, many examples of best practice came out of Karnataka which have been adopted by other states, for example, legal support for disabled people, a disability voluntary service, outreach programmes, commissioning of social audits. Karnataka has also produced a number of schemes to benefit people with disabilities in response to the Person with Disabilities Act 1995 in the areas of employment, education, housing and financial assistance. These include reasonable adjustments for students with disabilities, scholarship schemes, a scheme to provide a maintenance payment and to assist people with disabilities to purchase aids and appliances; the provision of an identity card which entitles people with disabilities to free or subsidised travel and tax exemption.

Community based rehabilitation programmes are being implemented in Karnataka in collaboration with NGOs: for example a programme covering nine sub-districts has been running since 1998 and directly involves 22,000 persons with disabilities (Deepak et al. 2013). CBR workers visit homes and provide information and support to newly identified persons with disabilities. Research evaluating the project provided evidence of the positive impact it has had on persons with a variety of disabilities including physical and intellectual disabilities, in the areas of health, education and social participation (Deepak et al. 2013).

5.2 The Setting

The setting for the observation, the interviews and focus groups was a university and hospital in Manipal, in the state of Karnataka, on the Malabar coast of South West India (figure 5.1, page 91). Karnataka was created in 1956 from the princely state of Mysore and is one of the wettest regions in India. It is mainly a rural area with the majority of people speaking the local language of Kanada.

Figure 5.1 : Map of India showing Karnataka (red area)

Manipal (figure 5.2, page 91) is a university town with a population of approximately 15,000, located in Karnataka and situated a few kilometres from the temple city of Udupi and 60km north of Mangalore. It lies between the hill ranges of the Western Ghats and the Arabian Sea and has a climate that varies from being humid and warm between November and May to being wet and cool between June and October.

Figure 5.2: The Centre of Manipal

Dr. TMA Pai, a renowned physician, banker, educator and philanthropist, developed Manipal from a barren hill into a university town in the 1950s. The Kasturba Medical College was the first college established in the town in 1953. Now there are twenty colleges covering medicine, dentistry, pharmaceuticals, nursing, allied health, technology, communication, hotel administration, management, information sciences, life sciences and jewellery management.

In an article in the *Chronicle of Higher Education* (Neelakantan 2010:1) Manipal University is described as making "a name for itself as one of the most successful private universities in a country where the private sector is more typically associated with shoestring operations". Manipal University is part of the Manipal group, which has different campuses in Nepal, Dubai and Malaysia. There are 40 other Universities in the state of Karnataka and 537 in India. As a university town, Manipal is only one of four in India the others being in Rajasthan, Tamil Nadu and West Bengal. Historically, Manipal has been known as a 'haven for wealthy students who could not get into top schools" This is a view from Mr. Palety, the founder of the Centre for Forecasting and Research, which ranks universities in India (Neelakantan 2010). However, this reputation has changed with Manipal featuring in the top 100 Indian universities in the various ranking scales.

Figure 5.3: Manipal University

The university (figure 5.3, page 92) has an enrolment of over 15,000 students, allocating 15% of its places to international students who have Non Resident Indian

(NRI) status, i.e. citizens of India (with an Indian passport) who have temporarily emigrated to another country. For this study, my contact was with the Colleges of Nursing and Allied Health. The College of Nursing was established in 1990 and runs an undergraduate and post-graduate programme. The duration of the Nursing BSc is four-years long, plus six months of compulsory work experience. This is reflected in the BSc Physiotherapy and Occupational Therapy programmes (commenced in 1995) which are also four-years long, plus six months rotating clinical internship. The postgraduate programmes in Nursing, Physiotherapy and Occupational Therapy are all two-years long. Students come from all areas of India. According to the University's prospectus there is an annual intake of 60 students a year on the Adult Nursing BSc and 25 on the MSc. Numbers are similar for the Physiotherapy BSc and MSc and smaller on the Occupational Therapy programmes. I was unable to establish the actual numbers.

Facilities for the students include air conditioned lecture theatres; a comprehensive modern library (figure 5.4, page 93); swimming pool and gym; various sports courts for example: tennis, basketball and cricket; access to different clubs such as music, debate, photography; access to language classes. Students stay in hostel accommodation and a food court is available providing a variety of food.

Figure 5.4: Manipal University Library

As discussed in chapter four (4.0) I chose this university and hospital for two main reasons:

- The Indian students taking the MSc Rehabilitation programme at Oxford which I lead recommended it to me pointing out that it combines a university and hospital and would give me the opportunity to talk to students and professionals from different healthcare professions and also to observe rehabilitation.
- I was then able to confirm on a pre-study visit to the University and Kasturba hospital that there were nursing, physiotherapy and occupational therapy students and healthcare professionals there as well as patients undergoing rehabilitation.

Permission for the observation, interviews and focus groups, (discussed in chapter four, 4.7), was given by the Chancellor of Manipal University. The study, which included the observation, was advertised on the wards and in the nursing, and allied health colleges. The two allocated lecturers and postgraduate students (chapter 4, 4.2.1) helped me to access areas for the observation.

Kasturba hospital (figure 5.5, page 95) was built in 1960 as a teaching hospital for the Medical College at Manipal University. It is the largest tertiary hospital in the region with around 1600 beds, and because of its location is the single largest hospital in the world with a rural background (‘Udipi Pages’, no date). Kasturba hospital is recognised as one of the top hospitals in India with specialist services including oncology, orthopaedics, neurology and rehabilitation. Facilities include a theatre complex with 18 operating theatres, intensive care units, an isolation ward, a dialysis unit and up to date investigative equipment including Magnetic Resonance Imaging (MRI) and a Computed Tomography (CT) scanner. Patients generally come from rural areas in the state of Karnataka and also surrounding states e.g. Kerala, Goa (‘Manipal University’, no date).

Figure 5.5 : Kasturba Hospital

The hospital provides special health care schemes and also subsidises the cost of treatment for patients who cannot afford it through the Manipal Foundation, which is a charitable trust recognised under the Indian Income Tax Act (1961). Patients have bills signed that go onto their account for each day. If patients cannot pay they may approach the Foundation. I was unable to establish what percentage of patients were subsidised and how accessible and affordable it is considered to be by patients from different sections of Indian society.

The period of observation lasted for three weeks, during which I stayed in the hotel at the university. The hotel is used for training students on the hotel management course and is next door to the Graduate School of Hotel Administration, across the road from the main campus and about five minutes from the hospital and the nursing and allied health colleges. Visitors to the university stay at the hotel and students and staff from the university used the restaurant and café to socialise. The hotel is also used for university conferences and meetings as well as private functions such as weddings.

5.3 Observation Activities

As well as conducting the interviews and focus groups I engaged in observation and was involved in a number of observation activities (table 5.1, page 96) over the three weeks. These all helped achieve the aims of the observation as discussed in section 5.0: to gain an understanding of the culture and practices around rehabilitation and the experiences of people involved in it.

Table 5.1: Observation Activities

First Week • Observation on neurological wards including ward round. • Visit to Occupational Therapy Department.
Second Week • Attended two-day nursing conference on action learning. • Observation in the orthopaedic gym. • Conducted a search in the library of the data-bases and examined the rehabilitation books.
Third Week • Home visit with the CBR (Community Based Rehabilitation) Team. • Spent time reflecting on the data to see if I had any gaps: as a result went back to the neurological ward to look at documentation and interviewed more patients. • Visited Ayurveda hospital

5.3.1 Observation on the Neurological/Neurosurgical Ward

There was one neurological/neurosurgical ward with 43 beds, situated in the neurological department with an intensive care unit and operating theatres. On the ward there were neurosurgical and neurological patients: for example, patients having surgery for brain tumours, blood clots or spinal injuries or patients who have a neurological condition such as Parkinson's Disease, Multiple Sclerosis or Stroke.

The ward was divided into a female and male area, each with separate ten-bedded bays. Although on the same ward, the female and male areas were separate from each other with their own toileting and bathing facilities. Each ten-bedded bay had five beds on either side. There was a nursing station in the female area and one in the male area. The ward seemed to be adequate for the number of beds and there was enough room between the beds for a locker. Although there were separate bays the wall separating them was only half a partition: waist high. Portable screens were used to give privacy for treatments, as there were no curtains around the beds. However: the screens were generally not used during conversations between the patient, relatives and healthcare professionals. There was a small gym on the ward where physiotherapists worked with the patients, sometimes together with occupational therapists.

I observed collaboration between the healthcare professionals: for example the physiotherapist and occupational therapist walking a male patient, and then instructing the patient's wife on how to assist him in walking. This working together happened at a prearranged time with the nurses to ensure it did not clash with any treatments. On another occasion, I observed on another occasion the physiotherapist and occupational therapist working in the physiotherapy area with a young man instructing his father on exercises he could do in the ward and at home. The physiotherapy area on the ward was also used as a teaching area where one or two physiotherapy lecturers observed students treating patients. Each morning and afternoon, I observed each morning and afternoon three to four physiotherapy students and two post-graduate physiotherapy students working in the physiotherapy area and on the ward. The occupational therapy students were not consistently on the ward. They attended ward rounds and came to work with a specific patient with an occupational therapist.

There were always four trained nurses on the ward: two in the male area (23 patients) and two in the female area (20 patients). The nurses worked different shifts, varying from working all day (7.30-16.30), in the morning (7.30-13.30) or evening (16.30-19.30), or all night (19.30-7.30 the next day). Family members were educated by the nurses to take care of the patient. I observed a number of instances where this happened: for example, where a nurse instructed the patient and their family on medication, instructing a wife on how to help her husband with feeding.

The majority of the patients on the ward had at least one or two family members with them at various times during the day, assisting them with activities such as walking, washing, dressing and feeding. Family members seemed to be as much a part of the ward as the patients. In some instances home nurses were used to care for patients who needed help with washing, dressing, feeding and who did not have relatives to help them. Home nurses are healthcare assistants who work on the ward. They are trained by the nurses to care for particular patients and are paid for by the patient. For example, a 63 year old male spinal injury patient had a home nurse to help him with his care as his family was not able to visit regularly. More commonly the family seemed to fill that role. Family members either stayed in hostel accommodation in Manipal or travelled daily and often provided food for their relatives from street food sellers on the university site or in Manipal. There was hospital food available but the patients and carers I spoke to identified the food as being poor quality.

5.3.2 Ward Round

I observed a ward round in my first week which was led by the neurological consultant and consisted of one speech and language therapist, a psychologist, two house doctors, one registrar, two occupational therapists and two physiotherapists as well as two post graduate physiotherapy students and two post graduate occupational therapy students. This resulted in 15 people including myself moving from bed to bed, discussing the patients under the care of the consultant in the male bay, which catered for eight patients. The consultant spent more time with some patients than others. This seemed to depend on whether they were new patients or there was a change in their treatment or condition. The nurse-in-charge of the ward was conducting a medication round but inputted into the ward round when the consultant asked her a question about a particular patient: for example he wanted feedback on how well a particular patient was managing with feeding himself. One of the house doctors asked the nurse to join the round for that patient. For another patient the consultant called the nurse over and asked her to teach the patient's wife how to administer naso-gastric feeds. After the ward round a nurse explained that there were only two nurses on the ward, so it was not possible for the nurse in charge to be on the round for every patient.

The consultant discussed the patient's progress with the team on the ward round in English and then gave feedback to the patient in Hindi or the local dialect. This was the usual procedure with English being the main language used for communication between health care professionals. There were no curtains around the bed to give privacy and patients and their relatives appeared to be listening to what the consultant was saying to other patients. One of the nurses pointed out that most of the patients and carers could not speak English and would not understand what was said. However, patients and their family members could hear the translation. The consultant appeared to focus on the patient as a person rather than on the symptoms, asking patients and relatives how they managed at home and what the issues were for them and then referring to the team for their views. For example in discussing a newly admitted male patient with Parkinson's disease the consultant made the following comments to the doctors on the ward round:

> "Whom should we treat, the human being or the symptoms? We need to see how the tremors are affecting his activities of daily living. With Parkinsons we don't treat the tremors unless they affect his life. If he has accepted it so well, why treat it?"

These comments came after the consultant had had a conversation with the patient, asking him what activities he could do at home. The consultant then spoke to the patient again, explaining that the purpose of his admission was for assessment and exploration of different therapies or treatments.

5.3.3 Occupational Therapy Department

Following the ward round I visited the occupational therapy department, which consisted of three beds divided with curtains and two treatment rooms. There was also a splinting room and a room for adapting equipment such as kitchen utensils and wheelchairs. On that day I observed a physiotherapist and occupational therapist working together to make a splint for a man who had sustained a stroke and needed a hand splint for sleeping. I also observed a lady being fitted with a hand support with the occupational therapist teaching a post-graduate student how to apply it. The therapist fitting the support was unable to speak the patient's language so another occupational therapist was translating the fitter's instructions to the patient and responses from the patient back to the fitter and the student. This did not seem a good use of a trained therapist's time. However, there was no one else in the department who could speak the patient's language.

The Head Occupational Therapist showed me around the department and talked about adapting occupational therapy methods and equipment to fit in with the culture and religion of the patient. He explained that his emphasis was on asking the patient what he or she wanted to do: for example developing a kitchen aid to help a 19 year old woman with weakness in her hands lift heavy pans off the stove and adapting a rolling pin for rolling chapatis. This was in response to the woman's, and her mother's, worries that she would not be eligible for marriage if she could not cook in the kitchen for her family.

5.3.4 Nursing Research Conference

While I was in India the Nursing College was hosting an Action Research Nursing conference over two days, held by the Nursing Research Society of India (NRSI). I felt privileged to be invited to attend the conference and felt that it would help me understand nursing and nursing issues in India. There were 400 delegates (figure 5.6, page 100) who were nurses from rural and urban areas all over India: for example, Delhi, Mumbai, Vellore, Bangalore, Madhya Pradesh, Trivandrum, Chennai and Ethirmedu. The delegates were from different fields of nursing namely surgery, medicine, neurology, orthopaedics, mental health and paediatrics. The opening of the conference was conducted by official dignitaries and began with a prayer about learning and nursing. It was obviously an important event for nurses in India and for the hosts at Manipal University.

Figure 5.6: Delegates at Nursing Conference

The focus of the conference was on how action research could be used to increase the number of nursing research projects in India. A common view from speakers at the conference was that nursing research is required in India to advance nursing practice. Action research was advocated as a good methodology for nurses as it can be used to research and evaluate nursing practice. Professor Reena Bose, the president of the National Research Society of India opened the conference:

> "Action research is one of the means by which nursing knowledge could be applied to new practices. Action research has led to evidence-based quality care, which is the aim of the nursing profession. The responsibility and obligation of each professional nurse is to strive for better knowledge and skill. Action research can help in the transformation of knowledge into skill through which quality care can be rendered to the patients. Research is not realised yet by nurses, it is seen as reading research rather than doing".

There was discussion about the lack of regulation for nursing colleges in India, which means that anyone can set up a nursing college. There are no quality standards that colleges have to meet in terms of the content of nurse training and the qualifications of the lecturers. This lack of regulation was identified as affecting the quality of nursing in India, resulting in trained nurses not being able to carry out clinical skills competently.

The conference highlighted that nurses in India can go into nursing lecturer roles without having any clinical experience other than their six months internship, which is in clinical practice. This is different for physiotherapy and occupational therapy lecturers who continue working in practice. Consequently nursing lecturers do not always have a large amount of clinical experience and their role does not enable them to continue to develop their expertise. Yet they are supposed to supervise and instruct nursing students in clinical skills. It was interesting understanding the differences in clinical experience between nursing and allied health lecturers as this helped explain the differences in the focus groups between the physiotherapy and occupational therapy lecturers (FG6L) in contrast to the focus group with the nursing lecturers (FG7L) where the participants were not able to reflect on experiences of patients undergoing rehabilitation.

Another issue raised at the conference was that nursing is not seen as a profession in India. Two nursing lecturers I spoke to from nursing colleges in Mangalore and Udipi suggested that nursing in India needs to change with a focus on research and nursing knowledge and increased clinical experience. Some of the sessions focused on the need for collaborative research and this was reinforced by Mrs Tapati Bhattacharjee, the editor of the *Journal of Nursing Research Society of India* who called for articles on the collaboration of research with other countries.

Attending the conference was helpful for my understanding of nursing in general in India. It challenged any assumptions I had in terms of nursing in India not being a profession and nurses not wanting to develop nursing.

5.3.5 Observation in Orthopaedic Gym

I conducted interviews and observation in the orthopaedic gym in the outpatient department where patients went for physiotherapy. There were six orthopaedic wards for 250 patients with no room for therapy to be conducted on the wards. Each ward was a nightingale style ward where there is one large room with beds on either side without any sub-divisions. It appeared to be more crowded than the neurological ward. This meant that I was not able to observe or interview patients on the orthopaedic wards. The main problems seen on the orthopaedic wards (and therefore the orthopaedic gym) were fractured bones or spinal injuries sustained as a result of road traffic accidents such as getting knocked over as a pedestrian or off a motor bike.

The orthopaedic gym was in the outpatient department and consisted of an open area with five beds, three curtained beds and a partitioned room. Family members generally accompanied patients and helped in their treatment. There was a variety of equipment in the department, similar to equipment found in the UK, such as splints, walkers, wheelchairs, plinths, walking bars a standing frame etc. Two trained physiotherapists worked in the gym supervising a number of physiotherapy interns and postgraduate students. On the days I observed there were six to eight postgraduate physiotherapy and three to four physiotherapy interns on the ward in the morning and afternoon respectively. The trained physiotherapists confirmed that this was the normal allocation of students. The physiotherapists appeared to sit behind the desk and give advice. It was the postgraduate students who mainly treated patients and supervised the interns. One physiotherapist explained:

> "It is important that students deal with real patients. It is not the same in books for example the book will say how to treat something but the patients may have a number of problems".

This quote relates to the importance of students dealing with real life situations rather than just learning from books. The students had to explain to the physiotherapists what their plan was for the patient referring to the theory, then treating the patient and talking this through with the physiotherapist. This demonstrated their clinical reasoning and problem solving.

I observed patients in the department having physiotherapy including children with spasticity, men and women with fractures and amputations and women with back pain. I was struck by how many women were seen in the department with back pain and discussed this with the physiotherapist. She suggested that the incidence of back pain among the Indian population is mainly due to poor lifting techniques due to lack of knowledge. Places of work such as shops and factories are meant to provide back education but generally do not see it as a priority. Maybe it is not just an issue of correct lifting techniques but also an issue of working too hard. The physiotherapist suggested that there are more women with back pain as they lift heavy pans for cooking and often have to look after their own family and their in-laws. This relates to the different family structures in Indian society as previously discussed (5.1). All of the patients I saw in the department were from rural areas where the more traditional style of family structure was the norm rather than the nuclear family. This highlights two issues, one of work-related back pain and one of home-related back pain.

5.3.6 Visit with CBR Team

I had an opportunity to arrange an observation visit with the CBR (Community Based Rehabilitation) team based at the hospital. The team's work involves visiting old age homes, children at special schools, measuring children's health in schools in terms of normal development and limb deformities and visiting patients in their home following for example a stroke. The team also works with employers to raise awareness of occupational health. For example they were working with employers and employees in a tiling factory, looking at occupational health hazards and giving advice. The team I went with consisted of two physiotherapists, one junior doctor, five medical students and four physiotherapy students. The main aim of the visit was to conduct an assessment of children's mobility at a school with the aim of identifying any potential disabilities. This was also contributing to a survey conducted by the team in a nearby village where there was a high prevalence of disability.

I went on a home visit with the physiotherapist from the team to visit a 25 year old man (who I also interviewed: Pt:M7) who sustained a spinal injury in 2002 due to a road traffic accident. He lived with his mother, brother and sister-in-law in a house with other houses in a forest area (figure 5.7, page104), which reminded me in a way of a housing estate. He spent most of his time in bed unless someone was able to lift him out of it into a chair. His family had put a sliding door into the kitchen to give more room when he was up in his wheelchair, which was not very often.

Figure 5.7 : House of CBR patient (on the left)

This man had monthly visits from the team. On this visit he was on his bed watching television and the physiotherapist carried out some stretching exercises and asked his mother (who was his main carer) how things were. She stated that he was also having treatment at home consisting of oils and exercises, which she gave him. The team's monthly visits focused on monitoring the man's progress and providing equipment if needed. They had already provided him with toileting equipment, a wheelchair and a hoist for lifting.

My visit with the CBR team confirmed my understanding of CBR. The range of activities conducted by the team was varied and focused on disability prevention and rehabilitation.

5.3.7 Visit to Ayurvedic Hospital

In one of the focus groups with PG nursing students I became aware that patients accessed Ayurveda for rehabilitation for example following stroke. The Ayurvedic Hospital is situated off campus but has links with the university and medical students also spent time there as part of their training. I was introduced to the Head of the Hospital who agreed that I could speak to some of the patients and carers. I then obtained consent from the patients and their families to speak to them. Ayurveda is a traditional Indian based system of healing using massage, oils, herbs, minerals and diet. The hospital has 280 beds and consists of deluxe suites, special rooms, semi-special rooms and common wards, all varying in price. I interviewed two patients in the hospital, both in single rooms. The hospital had a nice pleasant atmosphere and smelt of oils. Patients admitted to the hospital appeared to come from different social classes and were not predominantly male or female.

Nurses in one of the focus group interviews told me that a number of stroke patients use Ayurveda after rehabilitation if they were not making further progress and because staying there was cheaper than in the hospital. One carer told me that his mother had been moved to the Ayurveda hospital for physiotherapy and massage following a stroke after spending four days at Kasturba hospital. Her family moved her to the Ayurveda hospital as the doctors said there was nothing more they could do for her. Since being at the Ayurveda hospital she had made progress in standing, sitting and was beginning to walk. I wondered if the approach in the Ayurveda hospital with a total programme designed for the person's needs and a relaxing, calm environment had been responsible for the patient's improvement. In reflecting on why some patients were moving to the Ayurveda hospital it could be that there is more time to focus on the person and what they want there than in the general ward. Rehabilitation is not a quick process and in the patient interviews a key trend was patients wanting to get home quickly because of the cost of staying in hospital.

5.4 Interpretations and Reflections

My first impression of the neurological ward was that it was not dissimilar from wards where I had worked in the UK, with its separate bays, nursing desk, treatment room etc. However, the beds were closer together and overall the ward felt cramped. I felt uncomfortable about the lack of privacy, particularly in relation to the ward round. I noted the following in my observation logbook (page 1.12):

> "Observed ward round today. Concerned that everyone listened in to what the consultant was saying. Patients, carers were obviously listening but it seemed to be the norm. No such thing as confidentiality or privacy or is that an assumption I am making. Does privacy mean confidentiality?"

Maybe I consider privacy and confidentiality to be important because of what I have become used to in the UK. Are privacy and confidentiality culturally sensitive concepts? Reflecting on wards in the UK, although there are curtains around the beds they are not always used to give privacy for conversations with doctors or other healthcare professionals. Even with curtains drawn round the bed conversations can still be heard.

I had also assumed that the ward round would be medically focused, with the emphasis being on the patient's impairments and treatments rather than on the effect of their disability on their life and their goals. This reflects my assumptions of rehabilitation in India being based on the medical model, which is the impression I got from discussions with Indian students taking the MSc Rehabilitation in the UK. However, this view was challenged when I observed healthcare professionals discussing with patients what was important to them and their family and how they could help them achieve their goals. On reflection this could have been a performance put on for me as the observer. After all, as the case of the patient in the Ayurveda hospital showed (see page 105) rehabilitation did not appear to have been provided in all cases. However, I do not think this was the case as there was triangulation of evidence between the conversations with health care professionals and students in the focus groups and individually, the patient interviews and the observations. This evidence all pointed to the healthcare professionals and students knowing and adopting rehabilitation strategies such as collaborative working and patient goal planning.

Interactions between the healthcare professionals and patients also included the family. Generally there were family members on the ward most of the time. I found it interesting that families were seen as key caregivers, helping their relatives with the activities of daily living, exercises, bringing in food. The dynamics seemed to be different from those I have seen in UK wards I have worked in. This could be due to the differences in the numbers of nurses on the ward in India and the UK. For a twenty-bedded neurological ward in the UK, there would be at least five trained nurses and healthcare assistants. One reason perhaps for families being involved in their relative's care could be because of the lack of nursing staff on the ward. Perhaps the issue here is not one of culture but of the economics of healthcare provision with lack of resources in India necessitating increased family support in order to guarantee proper care for patients.

On the other hand when thinking about Indian patients I have seen in the UK, one of the issues healthcare professionals found difficult (myself included) was relatives wanting to be around a great deal of the time, doing things for the patient and bringing in different foods. This highlights to me how integral a person's culture is to how they behave and how difficult it can be for a healthcare professional to step out of their own cultural mind set. Having the opportunity to be outside my own culture and observe different cultural practices in India has made me more aware of the differences in cultural values and to step out of my own cultural mindset: for example regarding the role of the family. I observed this with relatives being involved in giving therapy and nursing care and in being instructed in how to look after their relative at home. The majority of families I saw brought in food that they had either cooked themselves or bought from street food sellers. My assumption was that this was because of the poor ward food. Also, one patient I interviewed said that the food was monotonous. However, I think it was more to do with it being the role of female members of the family to provide food even if their relative was in hospital. It was also about providing food that they knew was good food and possibly caste appropriate, as they had cooked it, or food that they had seen cooked by the street food sellers.

Finance was a key issue for most of the patients and their families. Patients I talked to all commented on the financial difficulties of being in hospital and expressed the need to get home as soon as possible. The patients I interviewed lived outside of Manipal and their families either travelled in every day or stayed in hostel accommodation close to the hospital. So even if families received help with healthcare costs or were eligible for free health care, they incurred other costs such as the family travelling to and from the hospital, staying in accommodation, buying food as well as experiencing a loss of income. It is acknowledged in the five year plans (5.1.1.) that a challenge for healthcare in India is the availability and quality of healthcare services in urban areas and the unaffordability of tertiary health care which includes rehabilitation. Community based rehabilitation (CBR) is identified as a way of addressing some of these difficulties as discussed in chapter two (2.1.3).

Healthcare professionals and students I spoke to and interviewed noted that rehabilitation in India is directed by influences in the West. As a physiotherapist from the CBR team puts it:

> "Literature is westernised, little evidence from India. Westernised literature does not take into account different cultures e.g. in India we use a spoon not a fork, our left hand is for the toilet."

My search of relevant books in the library supported this view. I found two books written by Indian authors, one on neuro-rehabilitation (Taly et al. 2001) and a Nursing book with a chapter on rehabilitation (Basavanthappa 2004). The definitions of rehabilitation they used were those of authors from the UK or USA. I wondered why Indian authors would not see any need to discuss rehabilitation in relation to the context of India. There did seem to be a view on the part of some of the students I spoke to that Western views are the right ones, which could also be a view shared by a number of health care professionals and maybe the authors of these two books. This highlights a tension between rehabilitation as portrayed in the literature and culturally specific rehabilitation related to the individual in their cultural context.

This tension does perhaps highlight how important it is to consider rehabilitation in relation to the cultural context it is performed in. I wonder if this is why Ayurveda is popular, because it is a form of traditional Indian medicine, reflecting Indian culture. Ayurveda seems to be more than an alternative therapy; it could also be seen as part of the system of healthcare in India. It is also a cheaper alternative as discussed earlier.

It needs to be acknowledged that the length of my stay in India was all too short to allow for more conclusive and decisive statements. Observation was not easy and not being able to talk to most patients and carers without a translator because of the language barrier also made it difficult. I felt at times I may have missed opportunities and that if I had been in India for a longer period and become more immersed in the culture, the observation aspect of my research could have provided a richer contribution to my work.

5.5. Chapter Conclusion

The aim of this chapter has been to give a detailed description of the observation undertaken in Manipal and to set the context for chapter six in which the interview and focus group data are discussed.

The advantage of conducting the observation was that it challenged my assumptions about rehabilitation in one setting in India. This was vital in order to make sense of the data from the interviews and focus groups. This data set (observation, interviews and focus groups) complements the literature as discussed in chapter four (4.1), helping to establish the level of maturity of the cultural sensitivity of the concept of rehabilitation. Conducting the observation also made me more aware of the importance of understanding the methodological challenges and limitations of my research. As my observation was focused on one particular setting, it will need to be established in future research whether the insights gained are transferable across other cultural contexts in India and other non-European contexts.

Although this study is not an ethnographic study, ethnographically informed observation enabled me to become immersed into the setting to a certain extent to gain a fuller understanding of the local context and culture.

Chapter 6: Establishing Maturity

6.0 Introduction

This chapter is concerned with establishing the level of maturity of the concept of rehabilitation in relation to cultural sensitivity, using the literature and qualitative data (data from India) in terms of definitions, attributes, pre-conditions, outcomes and boundaries. Cultural sensitivity, as discussed in chapter one, is the awareness and recognition by rehabilitation professionals of the cultural differences of individuals in terms of their values, beliefs and behaviours and the understanding that these will affect the way they engage in rehabilitation. The literature also needs to be culturally sensitive as it guides rehabilitation practice.

Establishing the level of maturity is the first step, as discussed in chapter three (3.4), in selecting the appropriate concept analysis approach in order to advance or develop a concept. A mature concept (Morse 1996a, 1996b) contains the following structural features:

- A meaningful definition that enables the concept to be identifiable. Meaningful is defined in the Oxford Dictionary as “being purposeful, significant, adding value to life” (Soanes and Hawker 2008:631).
- Attributes or characteristics that must be present in all instances in which the concept appears, but there may be different strengths of association.
- Clear pre-requisites or pre-conditions that always precede the concept.
- Clearly defined boundaries which are identified by “what is and what is not part of the concept, by determining whether or not an attribute is present in the neighbouring concept” (Morse 1996b:389).
- Similar outcomes or consequences that occur as a result of the concept.

The extent to which these criteria are met indicates the level of maturity of the concept and the appropriate stage of concept analysis, which will be conducted in chapter seven.

This chapter discusses the data analysis process and then the results of the data analysis in order to establish the level of maturity of the concept of rehabilitation as discussed above.

6.1 Data Analysis Process

The sample of literature selected following the process discussed in chapter four (4.1.1, 4.1.2) consists of 120 articles published between January 1999 and May 2009. The sample includes primary research studies, systematic reviews, World Health Organisation documents and opinion papers discussing rehabilitation practices from a range of countries, for example, Australia, China, Dubai, India, Israel, Hong Kong, the Netherlands, New Guinea, Sweden, UK, USA and Zimbabwe. The articles focus on neurological, musculoskeletal and cardiac conditions, and on different settings: hospitals, rehabilitation units and the community. Following selection, I read each article at least twice, identified key terms and themes and then recorded these in a table coding each article in terms of Morse's (1995) structural features as discussed above (6.0).

The qualitative data was collected via patient interviews, focus groups with students and staff and observation as discussed in chapter four. Students were either interns who had been in full practice for the previous six months, or healthcare professionals undertaking post-graduate study. The two staff groups were made up of physiotherapy and occupational lecturers who were also practicing healthcare professionals and nursing lecturers. Seven focus groups and thirteen patient interviews were conducted (4.3.2, 4.4.2). I listened to and roughly transcribed the interviews and focus groups while in India to identify the need for further data. The tapes were transcribed again by a work colleague at a later date and then re-checked by me, cross-referencing to field notes taken after the interviews and focus groups. This re-checking helped ensure the accuracy of the transcriptions and identify any contextual factors. The data from the interviews, focus groups and observation were managed and analysed in the same way as the literature: identifying common words, ideas and coding them under Morse's features. The observation data included descriptions of activities and conversations and were coded in the same way. Refer to appendix 12 for examples of coded data.

NVivo was used to organise and code the data as it enabled easier management and analysis of all the data as discussed in chapter three (3.6). Following input of the literature and qualitative data into NVivo a list of key words and themes across both sets of data were identified and then the data was coded under Morse's features to enable analysis of the data.

6.1.2 Achieving rigour and transferability

The following strategies were used in collecting and analysing the data to ensure reliability and validity and achieve rigour and trustworthiness.

The Literature

- Different databases were accessed to access articles from different disciplines.
- Categorising the literature under the ICF categories as discussed in chapter four (4.2.2) was discussed in supervision meetings, which included the rationale for including or not including articles.
- The literature was read more than once so that I was familiar with the content and it was appraised using an appraisal tool as discussed in chapter four (4.2.2).
- A reiterative process was used where articles were read a number of times in response to ideas from subsequent articles.

The Qualitative Data

- Transcribing the interviews and focus groups immediately after data collection enabled gaps to be identified for example identifying the need to interview more patients.
- Sending the first transcripts of interviews and focus groups to a colleague and supervisors for feedback on the reliability of the questions as discussed in chapter four (4.3.2, 4.4.2).
- Having an independent person transcribe the qualitative data from the tapes on return to the UK. It would have been helpful if the participants in India had checked the transcripts but this was not possible to organise.
- Keeping field notes of the interviews and focus groups helped in putting the data into context, for example, comments on the environmental conditions and on the interactions in the focus groups. This compensated to a degree for not having a second person in the focus groups to record interactions and take notes.

Using NVivo enabled me to manage the literature and qualitative data together in a more rigorous, methodological way, identifying common themes in the data and coding the data in terms of the features identified by Morse as discussed above (6.0).

There are ways that the reliability and validity of the data analysis processes could have been improved for example, by having a second person categorising and appraising the literature; undertaking the focus groups with a second person recording the interactions and taking notes; sharing and checking the data with the participants and the interpreters. However, I felt it was difficult to implement these strategies because of the environment I was in, in India and not having access to an independent people who could double check the data. I did however implement strategies to compensate for not having a second person checking the data as discussed above. I shared my initial findings with some of the students I interviewed in the focus groups in a seminar at the end of my visit which enabled them to share their views. I also shared findings back in the UK with MSc students, which included Indian students and rehabilitation professionals and with supervisors and colleagues. This helped in checking and challenging my interpretations of the data.

6.2 The Literature

The following section analyses the sample of literature under the values/features identified by Morse: definitions, attributes, pre-requisites, boundaries and outcomes in order to establish the level of maturity as discussed in 6.0.

6.2.1 Definition

Rehabilitation is defined by different authors working in the area and by the World Health Organisation (WHO). The WHO has been key in producing definitions of rehabilitation since 1958 (2.2.1), which other authors commonly refer to. The WHO definitions are discussed below, followed by other definitions in the literature and comparisons are then made.

6.2.1.1 World Health Organisation definitions

The World Health Organisation Expert Committees on Rehabilitation (2.2.1) defined rehabilitation in 1958, 1969 and 1981. After 1981, there were no new definitions of rehabilitation produced by the WHO until the introduction of the ICF (International Classification of Functioning, Disability and Health) in 2001 (2:4). Although the World Report on Disability was published in 2011 (which is beyond the parameters of the sample of articles for this study), it has been included because development on this report began in 2006, following the adoption of the United Nations Convention on the Rights of Persons with Disabilities (UN 2006). The Convention came into force in 2008.

The ICF definition (WHO 2001) identifies the achievement of optimal social integration as being the aim of rehabilitation, which reflects the relationships identified in the ICF of all the factors that can impact on the life of an individual with a disability. These might include, for example, body functions, body structures, activities, participation and contextual factors. Elements of the ICF are also reflected in the other definitions in table 6.1 (page 114): activities and participation (UN 2006); interaction with the environment (World Report on Disability 2006-2011); achievement of "physical, sensory, intellectual, psychological and social functional levels" (WHO 2008).

Table 6.1: World Health Organisation and United Nations definitions of rehabilitation

Authors	Definition
WHO: ICF (WHO 2001)	"The use of all means aimed at reducing the impact of disabling and handicapping conditions and at enabling people with disabilities to achieve optimal social integration"
United Nations Convention on the Rights of Persons with Disabilities. (UN Adopted 2006: article 26)	"Appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain their maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life"
World Report on Disability (WHO 2011:96) Report developed from 2006-2011	"A set of measures that assist individuals who experience, or are likely to experience, disability to achieve and maintain optimal functioning in interaction with their environments"
WHO website (no date)	"Rehabilitation of people with disabilities is a process aimed at enabling them to reach and maintain their optimal physical, sensory, intellectual, psychological and social functional levels. Rehabilitation provides disabled people with the tools they need to attain independence and self-determination"

All of the definitions (table 6.1, page 114) demonstrate affirmative views of disability by focusing on "enabling or assisting people to achieve their maximum potential or ability" rather than on "the reduction of disability" as identified in the earlier WHO definitions of rehabilitation (2.2.1). This is a shift in thinking about rehabilitation, which reflects the implementation of the ICF (WHO 2001). The latest WHO (no date) definition also identifies rehabilitation in terms of giving people the tools needed to attain independence and self-determination, which implies a shift of control to the person with the disability.

The WHO (2001) definition is commonly referred to by other authors, for example, Wressle et al. (1999), Renstch et al. (2003), Hurn (2006), Sahni (2006) and by Gutenbrunner et al. (2007) in the White Book on Physical and Rehabilitation Medicine. The reason for this could be due to it being related to the ICF, which is identified as a key rehabilitation framework as discussed in chapter two.

In considering the definitions in relation to cultural sensitivity, terms such as 'social integration', 'attaining independence' or 'self-determination' can be considered as being concepts in themselves and could have different meanings to different people and different cultures. None of the WHO definitions explicitly recognise the role of family or significant others, which could limit them in terms of cultural sensitivity, which is surprising as the WHO definitions have been developed by service users and stakeholders from different countries. While the WHO definitions have adapted over the years in response to changes in perspectives to disability, cultural implications have not been explicitly addressed.

6.2.1.2 Definitions from the literature

The sample of literature contained a number of definitions of rehabilitation (table 6.2, page 115) written by a variety of authors mainly from the disciplines of medicine and nursing.

Table 6.2: Definitions of Rehabilitation from the Literature

Authors	Definition/Aim
Sinclair and Dickinson (1998:1) Medicine: UK	"A process aiming to restore personal autonomy in those aspects of daily living considered most relevant by patients or service users, and their family carers"
Thomas and Thomas (1999:3) Medicine: India	"A gradual and long process that cannot escape the influences of local cultural factors, and hence it is difficult to propose a universal theory for all aspects of rehabilitation"
Burton (2000a:307) Nursing: UK	"The real work of rehabilitation described by informants was the translation of learning from the institutional setting to their home environment"
Pryor (2000:14) Nursing: Australia	"About people's lives and often the reconstruction of those lives in the wake of injury, illness, or surgery. Rehabilitation is about lives that are lived in broken or damaged bodies"
Wade and deJong (2000:1386) Medicine: UK, The Netherlands	"A reiterative, active educational, problem-solving process focused on the patient's behavior (disability) with the following components: assessment, goal setting, intervention and evaluation"
Stucki et al. (2002:932) Medicine: Germany	"A continuous process and involves the identification and problems and needs, the relation of problems to impaired body functions and structures, factors of the person and the environment, and the management of rehabilitation interventions"
Ward et al. (2003:10) Medicine: UK	"Rehabilitation is not merely a single intervention, but a transformation process consisting of a number of interventions and can be described as a family of complex services"
Venkatakrishna-Bhati (2003:12) Medicine: India	"The process by which a patient is restored to as full, a life as possible after illness or injury and thus a way to educate handicapped and enable them to add their mite to society"
Cott (2004:1418) Physical therapy: Canada	"A status passage in the career of chronic illness and disability that is directed to helping people function as best they can within the limitations of their conditions and to prepare them to function in their homes and communities"
Hawker (no date) Disability advisor: New Zealand	"Enabling a person to engage in their world in a meaningful way"
Wade (2009:387) Medicine: UK	"A problem-solving process focused on activities and aiming to optimise social participation"

Three of the definitions identify rehabilitation as helping the individual, patient or person to regain or restore some aspect which will help contribute to their life, for example, restoring autonomy (Sinclair and Dickinson 1998); restoring to as full a life as possible (Venkatakrishna-Bhati 2003); regaining function (Cott 2004).

Other definitions focus on what rehabilitation entails, for example, Burton (2000a) undertook a phenomenological study exploring the experience of six stroke patients. The participants identified translation of learning from the institutional setting to their home environment as being the real work of rehabilitation. Stroke was identified by the participants as being an “intensely personal experience, involving the rebuilding and restructuring of an individual’s world” (Burton 2000a:307). This view is supported by Pryor (2000) who identified rehabilitation as being about the reconstruction of lives. Wade and DeJong (2000) identified rehabilitation as an education and problem-solving process, which Stucki et al., (2002) and Ward et al (2003) identified as consisting of rehabilitation interventions. The definition by Wade and deJong (2000) is commonly referred to in the literature (Wressle et al. 1999, Wressle et al. 2002, Turner-Stokes et al, 2005). In a later definition, Wade (2009) added the component of social participation as being the aim of this problem-solving process. Participation is a component of the ICF, which could explain its inclusion.

Hawker’s (no date) definition is not specific as to what rehabilitation is. It could be presumed that rehabilitation is whatever it needs to be in order to enable the person to engage meaningfully in their world, which puts the person at the centre. This definition being focused on the ‘person with a disability’ may reflect the background of the author: that of Principal Disability Advisor for the Ministry of Social Development in New Zealand and past president of Rehabilitation International: a global disability non-government organisation discussed in chapter 2 (2.2).

Thomas and Thomas in a paper presented at a conference in Israel in 1998, highlight the influence of cultural factors such as traditional and religious beliefs and the importance of recognising the implications of these on rehabilitation in developing countries. Rehabilitation is more likely to fail if western stereotypes of community are used when planning community based rehabilitation (CBR) programmes (Thomas and Thomas 1999). Although Thomas and Thomas (1999) are referring to CBR, the point they make about Western stereotypes could apply to rehabilitation, whatever the setting. Cultural factors influence individuals’ attitudes concerning rehabilitation and, therefore, it is important that professionals take these into account if rehabilitation is to be successful.

As discussed in chapter two (2.1.3) CBR is a relatively new development in rehabilitation, which grew out of the inequalities of rehabilitation provision in developed and less developed countries.

6.2.1.3 Summary of definitions

The majority of the definitions in tables 6.1 (page 114) and 6.2 (page 115) have similarities in that rehabilitation is generally described as a process and there is an element of the process causing a change for the individual. In considering the origins of the definitions, consensus from professionals and stakeholders from different countries formulate the WHO definitions; however, the definitions in table 6.2 (page 115) are predominantly from Europe and Australia and could be seen as representing those cultures. There is evidence that some of these definitions draw on the WHO (2001) definition in that they refer to the level of participation, which is a component in the ICF (WHO 2001).

The two definitions from India (Thomas and Thomas 1999 and Venkatakrishna-Bhati 2003) have similarities to other definitions in that they both identify rehabilitation as being a process and Venkatakrishna-Bhati (2003) identifies rehabilitation as being concerned with restoration and education. The key difference is that Thomas and Thomas (1999) make reference to cultural factors, which are not addressed explicitly in the WHO definitions (table 6.1, page 114) or the definitions in table 6.2 (page 115).

In considering the cultural sensitivity of the definitions, autonomy is identified in the definition by Sinclair and Dickinson (1998) and can be questioned as to whether it is culturally sensitive in that it may not be appropriate in all cultural contexts as it may not be consistent with all individuals' values and beliefs, whereas 'meaningful' (Hawker no date) is a term that could apply to individuals regardless of their cultural context. Whatever is meaningful to the person will be based on their own cultural context, including their own values and beliefs. The terms of 'autonomy' and 'meaningful' will be explored in more depth in this chapter.

In order for a concept to be mature, according to Morse (1996b), it requires a meaningful definition, which makes it identifiable and functional. Meaningful as discussed earlier in this chapter is defined as being significant and adding value. Using these criteria at this stage in the analysis, although it could be said that the definitions do make rehabilitation identifiable, there are different definitions, each with a slightly different focus. Therefore, according to Morse's (1996b) criteria, this demonstrates a lack of maturity of the concept of rehabilitation in terms of cultural sensitivity. It could be argued, however, that not all of the definitions will be meaningful or significant to individuals undergoing rehabilitation in their cultural context and therefore maturity may not be desirable which can be seen as a flaw in Morse's approach. This argument will be developed in this and subsequent chapters.

6.2.2 Attributes

Attributes are characteristics that define a concept and, according to Morse (1996b), these must be present in all instances, although they may be in varying strengths**.** Morse does not state explicitly that the attributes should be evident in definitions of a concept. However, if attributes define a concept, then maybe one would expect definitions to contain them. In relation to rehabilitation, there are some characteristics that are not represented strongly in the definitions, which is why the following attributes (table 6.3, page 118) are identified from the definitions in tables 6.1 (page 114) and 6.2 (Page 115) and from other literature in the sample.

Table 6.3: Attributes of Rehabilitation from the Literature

Attributes	Definitions	Other Literature
Process	Sinclair and Dickinson (1998) Thomas and Thomas (1999) Wade and deJong (2000) Ward et al. (2003) Venkatakrishna-Bhati (2003) WHO website (2008)	Myeza and M'kumbuzi (2003) Soderberg et al. (2004)
Teamwork		Sinclair and Dickinson (1998) Wade and deJong (2000) Kendall et al. (2003) Soderberg et al. (2004) Hawker (no date)
Goal setting	Wade and deJong (2000)	Wressle et al. (2002) Siegart and Taylor (2004) Hurn (2006) Turner-Stokes et al. (2006)
Enabling and meaningful	WHO (2001) Venkatakrishna-Bhati (2003) Hawker (no date) WHO (no date)	Burton (2000) Herhenson (2000) Mpofu (2001) Cott (2004)
Restoration	Sinclair and Dickinson (1998) Ventakrishna-Bhati (2003)	Mishra (2003) Renstch et al. (2003)

6.2.2.1 Process

The most common attribute of rehabilitation is that it is generally described as a process that people go through. It is discussed in slightly different ways in the literature; for example, as an educational, problem-solving process (Wade and deJong

2000); a process aimed at enabling individuals to achieve their optimum levels (WHO no date); a process concerned with personal autonomy (Sinclair and Dickinson 1998); and a process affected by cultural influences (Thomas and Thomas 1999). Myeza and M'kumbuzi (2003) also discuss it as a process in relation to CBR.

Rehabilitation is identified (Soderberg et al. 2004:419) as being "a long process involving several phases and taking place on several levels and in a variety of settings" and consisting of different components, for example, assessment, goal setting, interventions and evaluation (Wade and deJong 2000). This highlights the complexity of rehabilitation in that it may start from the onset of a chronic condition (for example, multiple sclerosis, stroke), or an incident (for example, heart attack, road traffic accident) and may carry on through the individual's life. The process of rehabilitation is generally described as following this trajectory, starting from the onset and continuing into the community. However, some individuals may never leave the community so may not go into hospital. Individuals may or may not receive rehabilitation services depending on resources in terms of facilities and staff and due to the financial cost of rehabilitation services.

Rehabilitation can take place in a variety of settings, for example, acute wards, rehabilitation wards and in the community and it may consist of different interventions involving different professionals. The intensity of rehabilitation interventions is more likely to increase as the individual moves through the process, with goals being identified and decisions being made by the individual and possibly significant others, for example, family and friends rather than the professionals (Schofield 1993). Given this complexity, it is important that patients and their family (or significant others) understand the nature of the process. This is supported by Holiday et al. (2007) who, in their study looking at goal setting in a neurological rehabilitation unit in London, identified that patients had no idea of what was involved in the process to enable them to achieve their goals.

How patients are involved in the rehabilitation process needs to take account of what is culturally appropriate for them. For example, the degree of involvement of the family in the rehabilitation process may depend on the patients' and families' cultural values and beliefs.

6.2.2.2 Teamwork

Teamwork is not explicitly mentioned in the definitions. However, the literature discussing aspects of rehabilitation does not identify rehabilitation as being a typically uni-professional endeavour. It is described as a multidisciplinary or interdisciplinary process (Sinclair and Dickinson 1998, Wade and deJong 2000, Kendall et al. 2003, Soderberg et al. 2004, Hawker no date). The World Report on Disability, developed between 2006 and 2011 (WHO 2011), identifies rehabilitation as involving multiple interventions delivered by a team, which should include people with disabilities and their families as partners. One of the strengths of the ICF (WHO 2001) as discussed in chapter two (2.4.2) is that it provides a common language for health care professionals, enabling teamwork to be more effective. Undoubtedly, teamwork can be identified as an attribute.

In describing teamwork, the terms 'disciplinary' (the knowledge and skills required by each professional group) and 'professional' (the functions and activities of different professional groups) are used (Payne 2000). These terms can be used interchangeably, which can be problematic as they mean different things and could affect the way professionals communicate with each other. It is therefore important that rehabilitation professionals use the same terminology with the same meaning. In practice, this terminology tends to be multi or interdisciplinary.

Multidisciplinary rehabilitation teams generally work together within the confines of their own knowledge base (Barr 1997). Goals tend to be more professional-led, whereas interdisciplinary teams have a shared responsibility for individual-centred goals (which are more focused on what the client wants) across professional disciplines (McGrath and Davis 1992, Schut and Stam 1994). Interdisciplinary teamwork is difficult to fully achieve as it relies on teams being consistent and comfortable in working across boundaries and in communicating effectively with each other (Molyneux 2001). In reality, teamwork in rehabilitation tends to be multidisciplinary where there is little overlap of roles. However, there may be a focus on client-centred goals involving the client and family as part of the team.

There are challenges for different professionals in working together with a focus on patients' goals. Soderberg et al. (2004), in their study of clients' experiences of a work rehabilitation process in Sweden, identified that clients' values can clash with traditional medical values in relation to optimal wellness and healthy behaviour and that some clients felt that the content of the rehabilitation was not adjusted to their needs. In conclusion, the study recommends that professionals should ask themselves whose interests are being satisfied or denied. This relates to the need for professionals to reflect on their own values and beliefs and their own practice.

Whether teamwork is culturally sensitive or not may depend on how client-centred it is and how much involvement the client and their family have in the rehabilitation process. Another factor could be how aware the team is of the importance of understanding the patients' cultural context.

6.2.2.3 Goal setting

Goals and goal setting are identified by a number of authors as being central to rehabilitation (Wressle et al. 2002, Siegart and Taylor 2004, Turner-Stokes et al. 2005, Hurn 2006) and are included in the definition by Wade and deJong (2000). This focus on client-centred goal setting fits in with the ethos of client centred care (Cott 2004) and with the idea of rehabilitation being meaningful to the individual as long as the goals are client centred. Client-centred goal setting can improve client participation, which can be identified as a characteristic of multidisciplinary teamwork in rehabilitation, with the team working with the individual and their family (or significant others) towards their own goals (Wressle et al. 2002).

In a systematic review of the effectiveness of goal planning, Levack et al. (2006) concluded that, although goal setting is key to rehabilitation, there is limited evidence showing a positive link between goal setting and a patient's adherence to treatment and inconsistent evidence in linking goal planning to improved outcomes. Nineteen studies were included in the review, covering a range of conditions including neurological and musculoskeletal. However, it is not clear in which countries these studies were undertaken and there is no specific mention of cultural issues related to goal setting.

Wade (2009) cautions that goal setting can be harmful in terms of de-motivating the patient by setting goals that are not relevant to them or which are not sufficiently challenging. If goals are meaningful to the patient, then they are more likely to be motivated towards the rehabilitation programme. However, achieving meaningful patient-centred goals is complex, affected by a number of factors, including the patients' experiences and expectations of goal planning (Holliday et al. 2007). In considering whether goal planning is culturally sensitive, it is interesting to note that there is no discussion in the literature of the effects of different cultures on goal setting and no apparent studies on goal setting in developing countries. Maybe the key is that goals need to be meaningful to the individual in their culture. This could be more problematic when the professionals working with the patient are not of the same culture and therefore have different cultural values and beliefs. This then depends on professionals being aware of and recognising these differences: in other words, being culturally sensitive.

6.2.2.4 Enabling and meaningful

Rehabilitation is generally seen as an enabling process rather than a 'doing to' process, in the sense of enabling the individual to reach their full potential (WHO no date), to achieve optimal social integration (WHO 2001, Venkatakrishna-Bhati 2003) and "enabling the person to engage in the world in a meaningful way" (Hawker no date: 2). Hawker identifies this as the essence of rehabilitation. This does not come through in any other definitions, but it is indicated in studies looking at the experience of rehabilitation for the individual.

A study conducted in Canada looking at the components of client-centred rehabilitation (Cott 2004:1416) found that participants felt the rehabilitation did not prepare them for "life in the real world". That is, rehabilitation did not teach them the skills needed to live outside of hospital, such as managing personal relationships and dealing with having a chronic condition. Cott (2004) concluded that, in order for rehabilitation to enable clients to 'live in the real world' they must be involved in managing their own rehabilitation process so that outcomes are meaningful to them. This is supported by Burton (2000a:308) who, in their UK study looking at how people experience stroke, concluded that rehabilitation programmes must enable individuals to "shape their future lives in a meaningful way" so that they can deal with the challenges of living with a stroke.

This notion of rehabilitation being meaningful is highlighted by a number of authors (Herhenson 2000, Mpofu 2001, Hawker no date) who refer to the views of Banja (1996). Banja (1996:282), in his article on ethics, values and world culture, talks about rehabilitation meaning different things in different cultures. However, there may also be something in rehabilitation that remains the same regardless of client group, diagnosis or rehabilitation setting: an essence or identity that remains unchanged (Banja 1996).

Banja (1996:283) identifies this essence as possibly being the expectation from patients that “rehabilitation will help them to engage in the world in a meaningful way”, maybe to enable them to live in the real world, as suggested by Cott (2004). The issue then to be considered is whether rehabilitation professionals view their role as helping or enabling patients to engage in the world in a meaningful way. This will be explored further in chapters seven and eight.

The term ‘meaningful’ in relation to rehabilitation appears to come from authors taking a more cultural perspective, drawing on anthropology (Herhenson 2000, Hawker no date) and ethical diversity (Banja 1996). This seems to be a different way of viewing rehabilitation, which identifies rehabilitation as being whatever is meaningful to the individual.

6.2.2.5 Restoration

Restoration is a term used in two of the definitions (Sinclair and Dickinson 1998, (Venkatakrishna-Bhati 2003) and other literature in relation to the rehabilitation process restoring autonomy, or restoring to a full life or capacity (Mishra 2003).
Renstch et al. (2003:412), in their report on a project to implement processes based on the ICF (WHO 2001) in a rehabilitation unit in Lucerne, Switzerland, conclude that “the restoration to health of improvement of function is the main responsibility of rehabilitation, especially in the components of activities and participation”, meaning, for example, restoring the activities of daily living and social activities.

The Oxford Dictionary definition (Soanes and Hawker 2008:877) of restoration is to “return to a former condition”, re-establish, renew or repair. In relation to rehabilitation, “returning to a former condition” may not be achievable in light of the individual’s disabilities. However, restoring function or restoring to health, as identified by Renstch et al. (2003), will be achievable, although this may be at varying degrees depending on the individual’s impairments and disabilities. Renewal or repair implies that something is broken and needs repairing whereas it may be more about living and adapting to that which is broken. This is supported by Pryor’s (2000:141) view of rehabilitation being “about lives that are lived in broken or damaged bodies”.

6.2.2.6 Summary of attributes

The attributes identified are drawn from the definitions and other literature. Teamwork is not in the definitions. However, it is discussed as being essential to rehabilitation and is reflected in literature from different countries. In terms of cultural sensitivity, the attributes of process, teamwork, goal setting and restoration could be identified as being culturally sensitive, but, as discussed above, this will depend on whether they are client and family-centred. Perhaps the crucial point is that these attributes need to be focused on what is meaningful to the individual and their family. This points to ‘meaningful’ being a key culturally sensitive attribute with the cultural sensitivity of the other attributes depending on it. It is interesting that the views around ‘meaningfulness’ are identified from authors who are not predominantly rehabilitation professionals: Herhenson (2000) giving an anthropological view and Banja (1996) and Hawker (2005) and giving a sociological view.

There seems to have been a shift in thinking over the years, away from focusing on disability to considering what is important to the patient with the relatively new recognition of the importance and relevance of goal setting. This suggests that the concept of rehabilitation is constantly adapting and therefore needs to be flexible in order to ensure it is culturally sensitive. This could mean that the key attributes may vary in terms of importance depending on what is meaningful to the patient and their family and that, in some cultural settings, the attributes may not be present, for example, in the case of goal setting. This further supports the view that, in terms of cultural sensitivity, it may not be desirable for the concept of rehabilitation to be mature as it needs to be responsive to the patient and their family or significant others in their own culture.

6.2.3 Pre-requisites

Two pre-requisites for rehabilitation are identified in the literature: disability and input from healthcare professionals.

Rehabilitation is identified as being required for individuals with a disability to enable them to live a changed life (Hawker no date), to experience client-centred care (Nordholm and Lundgren-Lindquist 1999, Cott 2004) and to “lead the life they would wish” (Gutenbruner et al. 2007:7). The United Nations Convention on the Rights of People with Disabilities, adopted in 2006, requires countries to ensure that habilitation and rehabilitation services are available for people with a disability. In the past, disability has been viewed in terms of the disease process (French 1994), with an assumption that the difficulties faced by people with a disability are a direct result of their impairment. However, the ICF (WHO 2001) identifies disability as an umbrella term covering impairment, activity limitations or participant restrictions and the interaction of these with contextual factors such as the environment. For example, a person's activities of daily living may be caused by their environment and therefore may only require rehabilitation in the form of adaptations to the environment.

In looking at the definitions and the discussion around the attributes, it is clear that rehabilitation relies on the input and interventions from a variety of healthcare professionals (WHO 1958, Wade and deJong 2000, Wressle et al. 2002, Ward et al. 2003, Turner Stokes et al. 2005). Therefore, healthcare input can be seen as another prerequisite. The level of input may vary from being minimal (for example, one or two encounters) to being more intense, with a number of instances of professional input. However, this raises the question of whether rehabilitation can take place without professional input as some people with a disability who require rehabilitation may not have access to healthcare services due to the lack of availability of services or due to cost. Perhaps the key point is that, for rehabilitation to take place, some kind of intervention is required and in some circumstances, this may be from a relative or healthcare assistant who has gained training in what is needed from a healthcare professional. How rehabilitation interventions are delivered may be different depending on the country and context they are delivered in. For example, CBR (community based rehabilitation), discussed in chapter two, which occurs mainly in developing countries may be delivered by a rehabilitation team, relatives, other members of the community and/or alternative practitioners, for example, acupuncturists, ayurveda practitioners and herbalists.

If rehabilitation relies on healthcare professional input, then this could limit its flexibility and may prevent it from being person and family-centred and from being culturally sensitive. In relation to Morse's (1996b) criteria of clear pre-requisites always preceding the concept in order for it to be mature, then, as discussed above, healthcare professional input may not always precede rehabilitation, which may indicate some immaturity of the concept.

6.2.4 Boundaries

In order for a concept to be mature, according to Morse (1996b), it should have defined boundaries, which are determined by the same attributes not being present in related concepts. A boundary is defined in the Oxford Dictionary (Soanes and Hawker 2008) as a limit or a control, which could imply that boundaries limit or control a concept.

Rehabilitation is a concept, which is discussed in relation to other complex concepts, for example, autonomy, teamwork and quality of life. However, the relationship between these concepts can be clearly defined. For example, teamwork is how the process of rehabilitation is achieved. Conneeley (2003), in her study looking at quality of life and traumatic brain injury, concluded that factors related to quality of life are interlinked, complex and diverse, involving functional ability, premorbid life roles, relationships, activity and wellbeing. There is a distinct link between rehabilitation and quality of life, in that rehabilitation can help people restore their autonomy, which in turn can influence their quality of life (Conneeley 2003). Therefore, quality of life can be seen as being an outcome of rehabilitation (Edwards 2002, Davis 2006).

The attributes identified in table 6.3 (page 118): process, teamwork, goal setting, enabling, meaningful and restoration are not clearly evident as attributes in the related concepts of autonomy, teamwork and quality of life. Teamwork in itself is identified as an attribute of rehabilitation and autonomy and quality of life as outcomes. However, there are links between the related concepts and the concept of rehabilitation as discussed above. For example, setting meaningful goals and restoring lost roles could be factors related to quality of life. The pre-requisites of rehabilitation, as discussed in this chapter, are not the same as other closely related concepts. Other concepts, such as quality of life, do not relate only to individuals with disabilities and do not rely on the input from a multi-professional team.

Boundaries differentiating what and what is not rehabilitation are inferred from the pre-requisites and attributes, as discussed above. Rehabilitation could be inadequate if there are not interventions from a range of professionals and if all or some of the attributes identified are not evident, for example, if rehabilitation is not a process, if goal setting is not evident or if there is not some aspect of restoring the patient to their former roles or activities. However, in relation to cultural sensitivity, having boundaries that are clearly defined to such an extent that they are not flexible could inhibit rehabilitation being adaptable to different cultural contexts. Boundaries could be seen as limiting rehabilitation in meeting individuals' needs. Therefore, the boundaries of rehabilitation may need to change depending on an individual's cultural context, for example, in terms of the pre-requisites and attributes.

6.2.5 Outcomes

Morse (1996b) identifies that, in order to be mature, concepts needs to produce similar outcomes or consequences in different contexts. In the literature, a number of outcomes are identified in relation to rehabilitation as identified in table 6.4 (page 127).

Table 6.4: Outcomes of Rehabilitation from the Literature

Outcome of Rehabilitation	Authors
Quality of life	Mackenzie and Chang (2002) Zhang Hampton and Quin-Hilliard (2004) Gutenbruner et al. (2006) Whalley-Hamell (2007a)
Maximising participation	Wade (2000) Gutenbruner et al. (2006) United Nations (2006) Wade (2009)
Social integration	WHO (2001) Venkatakrishna-Bhati (2003) Sahni (2006)
Achievement of goals	Wressle et al. (2002) Sivaraman Nair (2003) Hurn et al. (2006) Levack et al, (2006)
Motivation: a predictor of outcome	Grahn et al. (2000) Pryor (2000) Wade (2000) Maclean et al. (2002) Saadah (2002)
Autonomy	Sinclair and Dickinson (1998) Cardol et al. (2002a)

Quality of life is identified as being the ultimate rehabilitation outcome for people with a disability (Mackenzie and Chang 2002, Hampton and Qin-Hilliard 2004, Hamell 2007a). However, it needs to be "quality of life that is important to the individual, not what professionals think it should be" (Davis and Madden 2006:17). This focus on quality of life is a recent trend in relation to rehabilitation. Gutenbruner et al. (2007) identify that wellbeing, social and vocational participation are fundamental outcomes related to an individual's quality of life and suggests that wellbeing is a better indicator of success than quality of life. Wellbeing can be seen as a component of quality of life; however, it does not fully explain quality of life (Taylor et al 2008), although this contradicts the ICF (WHO 2001), where quality of life is postulated as a construct of subjective wellbeing.

Wade (2000, 2009) supports the view of Gutenbruner et al. (2007) of participation being an outcome of rehabilitation. Participation, a component of the ICF (WHO 2001:123) is described as being "involvement in a life situation" or "the lived experience of people in the actual context in which they live" which needs to include the individual’s cultural context. Increasing participation, (involvement in life situations), is suggested by some authors as being the aim of rehabilitation (Wade and deJong 2000, Renscht et al. 2003, Rimmer 2006).

The idea of social integration as an outcome is explicit in the WHO (2001) definition in terms of integrating people who are disabled into society, which reflects the focus of the ICF being on a psychosocial model. This is supported by Venkatakrishna-Bhati (2003:12) who, in appraising the placement of disabled and handicapped people in India, defined social integration in terms of “disabled people contributing to society”. However, Sahni (2006) makes the point that patient, family and public education is needed so that patients can take their place in society.

The achievement of patient goals is also described as an outcome of rehabilitation (Wressle et al. 2002, Levack et al. 2008). Although, as previously discussed (6.2.2.3.), there is not an obvious link between goal setting and successful outcomes, there is evidence to support the use of goal attainment scaling as an outcome measure (Hurn et al. 2006). Goal attainment scaling measures the achievement of an individual’s goal and is used in rehabilitation to give a structure to goal setting. Motivation, although not identified as an outcome of rehabilitation, does influence outcomes (Saadah 2002), including the achievement of goals (Wade 2009). Maclean et al. (2002) conclude in their study that clinical, family, cultural and environmental factors influence a patient’s motivation. Pryor (2000) also suggests that a number of factors contribute to a positive outcome, including the participants, the activities and the setting in which the activities take place.

The restoration of personal autonomy (Sinclair and Dickinson 1998) and the regaining and retaining of the highest level of autonomy (Cardol et al. 2002a) are identified as aims and consequences of rehabilitation. Autonomy can be defined as decisional autonomy (the ability to make decisions without external restraint or coercion) and executional autonomy (the freedom to act on the basis of decisional autonomy) (Cardol et al. 2002a). For an individual with a disability, decisional autonomy may be affected by a number of factors associated with their disability, for example, cognitive or communication impairments (Chan 2002). In response to the view by Cardol et al. (2002a:970) that “autonomy, conceived as a basis for participation, is the ultimate aim of rehabilitation”, a discussion in the literature ensued, involving a variety of authors from different countries (Hong Kong, Israel, Netherlands, Dubai, UK, Australia). Catz and Itzkovich (2002) and Clapton and Kendall (2002) argue that identifying autonomy as a rehabilitation aim may conflict with the interests of family and society, a view which is supported by Kerston (2002) who observes that not all individuals who engage in rehabilitation are able or willing to be autonomous. In considering autonomy for countries where there are strong family relationships and different cultural backgrounds, Saadah (2002:981) advocates a “family-centred deliberative process based on accommodation and negotiation” as being a more acceptable, culturally sensitive aim of rehabilitation than autonomy.

For a concept to be mature (Morse 1996b), there needs to be similar outcomes or consequences. The outcomes identified above link to each other. For example, quality of life may be enhanced for the individual if goals are meaningful to them and their family and if participation in life situations is maximised including integration into the community and society. Motivation is more likely to be increased if goals are meaningful and relate to the individual’s life situation. Catz and Itzkovich (2002) advocate that rehabilitation should focus on as many factors as possible affecting the individual’s quality of life rather than focus on one single aim such as autonomy. If rehabilitation is to be culturally sensitive, then it needs to focus on the factors that are significant to the individual.

6.2.6 Conclusion: Literature

According to Morse et al. (1996b), a mature concept has a meaningful or significant definition and attributes that define the concept. In considering whether the definitions of rehabilitation in relation to cultural sensitivity are meaningful, it is useful to refer back to the term ‘meaningful’ and identify whom the definitions and attributes should be ‘meaningful to’. It is reasonable to expect the definitions and attributes of rehabilitation in the literature to be purposeful and significant to individuals (and their family or significant others) undergoing rehabilitation. As already discussed, to be meaningful, rehabilitation needs to take account of the individual and their family in their cultural context.

The definitions in tables 6.1 (page 114) and 6.2 (page 115) are by the World Health Organisation and other authors. In considering these definitions in relation to ‘meaningful’ as described above, a key observation is that it is mainly healthcare professionals and stakeholders from Europe and Australia who have developed them. This could put into question their meaningfulness to individuals from other countries. In contrast, the definition by Hawker (no date) is not specific about what rehabilitation is in the way the other definitions are. She identifies that rehabilitation is whatever is meaningful to the individual.

Examining the key attributes of rehabilitation in the definitions and other literature allows a more informed decision to be made on meaningfulness. The more commonly cited attributes (6.2.2) are process, teamwork, goal setting, enabling, meaningful and restoration. These attributes can be seen as being culturally sensitive if they are implemented in a culturally sensitive way. In order for this to happen, definitions and attributes may need to change in response to individuals' needs and to promote cultural sensitivity.

Morse (1996) also states that a mature concept should have clear pre-requisites, boundaries and outcomes. Two clear pre-requisites for rehabilitation are identified (6.2.3): disability and input from different health care professionals. The evidence in the literature for the pre-requisites comes from different countries indicating potential cultural sensitivity. In terms of boundaries, rehabilitation links to a number of concepts, for example, autonomy, teamwork and quality of life, which could cause the boundaries of rehabilitation to appear to be unclear. However, the relationship between rehabilitation and these concepts can be clearly defined (6.2.4). According to Morse (1996b), the outcomes or consequences should be similar. The outcomes discussed (6.2.5) are quality of life, maximising participation, social integration, achievement of goals, motivation and autonomy. They all link together, which demonstrates unity.

There is a view in the literature of the importance of rehabilitation being meaningful to the individual and their family, which has to take into account the individual's context and how they are participating in society. Interestingly, this literature is mainly from less westernised countries where there is inter-dependence within and between families. Banja (1996) makes an important point about the essence of rehabilitation. Is there something that remains the same regardless of culture? Maybe that something is meaningfulness. The views from the literature on rehabilitation being meaningful come from authors who are not from the medical profession, for example, Banja (1996) is a professor of clinical ethics and Hawker (no date) is a disability advisor.

On the basis of the findings from the literature as to the cultural sensitivity of the concept of rehabilitation, it can be suggested that the concept does not achieve maturity (using the criteria identified by Morse 1996b) for the following reasons:

- There is no single meaningful definition that is culturally sensitive and appropriate for all cultural contexts. Maybe it is not feasible to have a single definition.
- Different attributes may be present in different cultural contexts.
- Although there generally seem to be two clear pre-requisites in order for rehabilitation to be culturally sensitive, there may not always be input from healthcare professionals.
- There are clear boundaries between the concept of rehabilitation and other related concepts. However, having limiting boundaries may inhibit the cultural sensitivity of rehabilitation.
- Similar outcomes or consequences can be identified. However, the outcomes need to be whatever is meaningful to the individual in their cultural context.

Issues in using Morse's approach and in identifying whether the concept of rehabilitation is mature or not will be discussed in more depth at the end of this chapter following analysis of the qualitative data.

6.3 Qualitative Data

6.3.1 Definitions

Students and staff discussed the meaning of rehabilitation in the focus groups (table 6.5, page 131).

Table 6.5: Meanings of Rehabilitation from the Focus Groups

Students	
FG1:PT	"Returning the patient back to what they were"
FG1:PT	"It is about getting the patient back to the best form he can be after the disease like he can get or the maximum we can get by rehabilitation so he can be as normal as possible after the disease"
FG1:OT	"I feel like rehabilitation is bringing the patient to their previous level of functioning, and I feel like psychological aspects are of great importance because once they go back, once they are compromised with their functioning, they will be doubting whether they will come back to their previous level"
FG2:PT	"Make them independent as much as normal"
FG2:PT	"Bring them back to the activity level he was doing pre-accident state, pre-trauma state"
FG3:N	"Promote his normal life"

FG3:N	“It is helping a person who is having some difficulty or some deformity maybe secondary to some damage, accident, helping him function to the maximum as possible within his limitations”
FG3:N	“Maybe to settle him again back to a social life”
FG4:PT	“Helping a person achieve the goal that they want”
FG5:OT	“Helping them improve”
Staff	
FG6L:OT	“In our socio economic context, we try to restore as much as possible to their fullest physical extent”
FG7L:N	“To bring back the person to his normal limits”
FG7L:N	“Helping them gain back their strength and abilities”

There was consensus in the focus groups, both from students and staff that rehabilitation is about returning the patient back to how they were:

> “It is about getting the patient back to the best form he can be after the disease” (FG1:PT). “Helping them to gain back their strength and abilities” (FG7L:N).
>
> “I feel like rehabilitation is bringing the patient to their previous level of functioning” (FG1:OT). “Giving patients independence” (FG2:PT). “Bring them back to the activity level he was doing pre-accident state, pre-trauma state” (FG2:PT). “Bring back the person to his normal limits” (FG7L:N).

These views related mainly to functional improvement but there was the recognition of the need to work with patients within their limitations.

> “It is helping a person who is having some difficulty or some deformity maybe secondary to some damage, accident, helping him function to the maximum as possible within his limitations” (FG3:N).

Preventing complications was also identified as an aim of rehabilitation.

> “Assisting to prevent further complications or problems, trying to prevent a disease getting further complications. We teach it as part of prevention of a disease also it is helping them to live life with whatever limitation they have because of physical illness” (FG7L:N).
>
> “So depending on that we start rehabilitation maybe dietary as well as behaviour modification, physical therapy, exercise, yoga. These things will promote his normal life so he may not be having full functioning normal life as before, but within whatever is possible to reduce the complications and restore his life” (FG3:N).

These views of rehabilitation, reducing and preventing complications, were identified by the nursing lecturers (FG7L:N) and the focus group of postgraduate nursing students (FG3:N) as a key area for nurses in relation to health education. During the observation, there was evidence of nurses teaching patients and relatives about diet and managing their diabetes.

However, these views could be a result of their understanding gained from textbooks from Western countries, which was highlighted in other focus groups.

> "What we know with respect to physical rehabilitation it is from the books of West origin, predominately USA. What we gather is that rehabilitation is the process of restoring a person to his maximum functional potential. The type of patients we see here there are commonalities in terms of their stroke rehabilitation or head injury, spinal injury. In our socio economic context, we try to restore as much as possible to their fullest physical extent' (FG6L: OT).

In this focus group of occupational and physiotherapy lecturers/practitioners, participants agreed with this view and another occupational therapist added to it by emphasising that Western books also highlight psychosocial aspects. In considering this in relation to rehabilitation in India, there was however a view that rehabilitation is primarily about physical aspects.

> "In a rehabilitation point of view in India it is more about bringing him back to the normal level which is why the focus is on physical. We do look at emotional and cultural aspects but the main focus is on physical" (FG6L:OT).

This emphasis on functional aspects was prominent in the focus groups. However, it was also evident that other aspects were considered.

> "Maybe to re-settle him again back to a social life" (FG3:N).
>
> "I feel like psychological aspects are of great importance" (FG1: OT).

There was discussion in the focus groups of the effects of other factors on rehabilitation, such as a person's occupation, whether they lived in an urban or rural area, the input of the family and so on.

> "In the urban set up with the son and wife working, consider the mother-in-law sick at home, son-at-work, daughter-in-law at work, they have no choice but to hire maids, and care from maids is definitely different from a family person. This becomes a problem in those areas. They have a tremendous amount of money but no-one to look after them" (FG1:PT).

> "In the rural areas of India the head of the family is usually the wage earner, so the rehabilitation when it comes to it as she said, there are no rehabilitation centres like in the book, so what they do is just take care at home, whatever instructions have been given in hospital that is being followed in the home setting" (FG3:N).

This difference between rural and urban areas was highlighted in all focus groups, with families in urban areas generally being seen as having more money because more members of the family would be working. Families would also not necessarily be living together, whereas in rural areas, all of the family seemed to live close together, if not together, with the man being the wage earner. This highlights social and cultural differences in the same country.

6.3.1.1 Patient interviews

In the interviews, patients identified what their expectations were of their stay in hospital (table 6.6, page 134).

Table 6.6: Patients' Interviews

Source	Rehabilitation
Pt.F1	"To be able to read and have physiotherapy every day". I think being here I'll be taken care of for everything because I have pressure sore". "I would like to walk, but then I don't know"
Pt.F2 (translated)	"The pain has decreased it is manageable. Wants to go home and possibly return to work"
Pt.F3 (translated)	"Return home and spend time with children".
Pt.F4 (translated)	"Wants to go home. Family worried about expense of staying in hospital".
Pt.F5	"To get improvement in my legs".
Pt.M1	"Bike reading and writing". "I have to meet a minimum five government officers a day. Which is why I need a bike, I can't buy a car".
Pt.M2 (translated)	"Wants to improve. Return to family and go to college".
Pt.M3 (translated)	"To move round independently and return home".
Pt.M4 (translated)	"To be physically and mentally fit to return to work".
Pt.M5 (translated)	"Return to pre-accident state".
Pt.M6 (translated)	"Return home and return to work".
Pt.M7 (translated)	"To continue to live at home".
Pt.M8	"Rehabilitation starts with individual person, I don't look to institution I feel it comes from me not the outsiders, I have to do it".

As discussed in chapter four (4.2.2), the patients came from rural areas except for three patients who came from Mumbai (Pt.F1, PT.F5, Pt.M8). Patients ranged in age between 20 to 74 years. All patients except for Pt.F1 were being rehabilitated towards going home and some were in the process of being imminently discharged. Pt.M7 was already at home, being visited by the CBR (Community-Based Rehabilitation) team.

In the patient interviews, it was implicit that rehabilitation was seen as a way of enabling individuals to achieve goals, which were important to them, for example:

> "To be able to read and have physiotherapy every day" (Pt.F1).
>
> "To walk independently and return to work" (Pt.M4).
>
> "Return to pre-accident state" (Pt.M5).
>
> "Return home" (Pt.F2, Pt.F3, Pt.F4, Pt.M2, Pt.M3, Pt.M6)

The expectations that the patients had of the rehabilitation process appeared to reflect their condition, for example, Pt.F1 was a lady who was severely disabled and who needed help with all activities of daily life. Therefore, her goals can be identified as being realistic and meaningful in terms of her disabilities, adding to her quality of life, for example, having daily physiotherapy helped the mobility in her limbs, lessening her discomfort. Reading was an activity she enjoyed and also had some control over. Pt.M4 was a former teacher who now worked in a business as a resource person. He was married with two children and was hit by a motorcycle, resulting in a leg fracture. His main concern was returning to work to enable him to support his wife and children which, given his injury, was a realistic goal.

The expectation of the majority of the patients was to return home. However, this was sometimes a result of other reasons, such as not being able to continue to afford the costs of rehabilitation. For example, Pt.F4 was a married lady with two young children and she and her family was anxious about the cost of her staying in the hospital. Her husband and her mother were taking care of her in the hospital, which may also have incurred higher financial costs. Most of the patients interviewed had members of their family staying with them, helping in their care and providing food for them. One of the reasons for this was because they lived far away from the hospital and it was cheaper to stay near the hospital than travel there every day. Other reasons were that, although food was provided by the hospital, it was described as being poor and did not cater for all the patient's dietary cultural needs.

Pt.M8 was a male food technologist from Mumbai receiving ayurveda treatment for paralysis due to the removal of a brain tumour six years ago. He saw himself as being responsible for how well his rehabilitation went.

> "Rehabilitation starts with the individual person, I don't look to institution I feel it comes from me not the outsiders, I have to do it. They may give a solution from their point of view, which may not be a good solution for me. I am the best solution. I have to realise my strengths, weaknesses and opportunities and how o make best use of them. I think it started with me. I think for example at job interviews they just see the paralysis, it is their paralysis. They think will he be a liability. Other outside influences can help but it is me. People are helping me get what I need but I am in control. It is down to me" (Pt.M8).

This patient spoke English and was able to articulate well his own feelings and ideas about rehabilitation. He did not identify added financial factors, but, as a result of his tumour, he had looked towards other opportunities and, with the help of friends, he had started a business as a chocolatier. This could be considered to be an example of a patient wanting and accepting autonomy, wanting to feel that he is in control and recognising that he can influence this.

Although the idea of control and autonomy was not expressed in the other interviews, it is not possible to say that patients did not want control or autonomy. This may have been at different levels, for example, making the decision to go home. They may not have expressed it in the same way due to not being able to speak English at all or well. However, they were all clear in expressing what their expectation was of rehabilitation.

In summary, common meanings or aims of rehabilitation were identified from the focus groups. As seen in table 6.5 (page 131) these focus on returning patients to how they were in relation to their previous level of functioning, strength and abilities, independence, social integration. However, it may not always be realistic for an individual to return to their previous level of functioning, depending on the level of their disability. This was acknowledged in the focus groups with discussion of how professionals need to collaborate with patients and their families in working towards realistic aims. The aims identified cannot be provided by one professional group, which indicates the importance of teamwork. In the interviews, the focus for patients was generally on returning home and, in some cases, returning to work. There did seem to be an expectation by some of the patients of returning to their previous level of functioning, although there was also acknowledgement by patients that they may need to make some adaptations in this thinking, for example, using a mobility aid or considering other ways of getting to work. An additional factor for patients was the need to return home as quickly as possible due to the cost of staying in hospital. The majority had their family staying with them, which may have added a financial burden. Therefore, socio-economic factors were identified in the focus groups as influencing the rehabilitation process.

6.3.2 Attributes

In looking at the qualitative data, the following attributes or characteristics of rehabilitation are evident from the focus groups and interviews: returning/restoring; meaningful; family; teamwork; goal setting. Some of these attributes are evident in the meanings of rehabilitation as identified in table 6.5 (page 131) and some are identified in the remaining interview data.

6.3.2.1 Returning/restoring

The most common attribute identified is the notion of rehabilitation returning or restoring, which was evident in all of the focus groups. This was referred to in terms of the patient returning or restoring to their pre-accident state, to how they were before and to their fullest physical extent. However, this was stated in the context of the person's abilities and limitations, recognising that restoration in terms of returning to a former condition might not always be achievable. There was acknowledgement of this in the focus groups with participants talking about helping patients identify what is achievable and working with them in relation to their limitations.

> "It is about getting the patient back to the best form he can be after the disease like he can get or the maximum we can get by rehabilitation so he can be as normal as possible after the disease" (FG1:PT).
>
> "It is helping a person who is having some difficulty or some deformity maybe secondary to some damage, accident, helping him function to the maximum as possible within his limitations" (FG3:N).

In the interviews (6.3.1.1), some patients identified their expectations of returning to their 'pre-accident' state and resuming former roles such as work roles or their role as a parent, wife, father. However, as discussed (6.3.1.1), there was also a realisation that adaptation and changes may be needed to make these expectations realistic; for example, one of the male patients was being discharged with a walking frame.

> "He says since he is weight bearing only 20% he is not confident. Walking in the house is not a problem but there are a few steps. But then after he has got 50% weight bearing he will be confident. He can modify the step to the entrance, use a plank and then he can manage" (Pt.M3).

This patient was being discharged with a home programme of exercises and a follow up appointment to monitor progress. As patients were not followed up after the interviews, it was not possible to determine whether their expectations changed over time as they began to live with the impairments and disabilities that they had incurred. Similarly, as families were not included in the study, their expectations were not identified which could be seen as a limitation to this study.

In discussing what rehabilitation is, a number of factors were identified in the focus groups which affected an individual's rehabilitation and therefore made returning to work or home difficult.

> "Patient's adherence is not very good, once they start recovering they want to go home, so rehabilitation completely becomes a difficult task. Also economic status is also very important. It (adherence) can do with psychological factors also. He doesn't understand what you are doing, or he is not willing to do, he doesn't have the confidence in the physiotherapist"(FG 4:PT).
>
> "It can also be that he wants to go for a job very fast, and doesn't want to stay in hospital" (FG4:PT).
>
> "Lack of awareness and I think financial are the two most important things" (FG4:PT).
>
> "Sometimes the chronicity of the problem is the major thing. By the time the subject comes to us he has developed all the wrong patterns, he has chronic pain or whatever there is and because of that we cannot get the good results" (FG 4:PT).

In this focus group, there was a conversation among the students about the reasons why patients may not be able to return to former activities or a normal life. This was viewed as being due to patients not adhering or complying with the rehabilitation process, which then affected their progress. A number of factors were identified as causing lack of adherence, for example, financial resources and the illness or disease itself.

6.3.2.2 Meaningful

The idea of rehabilitation being meaningful or significant to the individual was discussed in the focus groups.

> "If a teacher comes in and there is some complaint of muscle strength weakness we would give him writing on the board, he would find that meaningful, that is the activity he has to do the whole day, that is his living so if he does that he will be motivated, then we will grade and adapt the environment to facilitate all the possible deficits he has" (FG1:OT).
>
> "If you have to get the patient to do strengthening exercise. Can't just tell them to do the exercises. Tell him to fill up bag of sand or hold water bottle. Makes it more realistic. If it is something he already has to do he will do it" (FG2:PT).

Creating meaningful activities that reflect the individual's real life situation was recognised as a way of increasing motivation. As part of the observation, a physiotherapist informally talked about a patient who would not comply with the exercises given to him so the physiotherapist incorporated the exercises as part of the patient's hobby, which was fishing.

When talking about rehabilitation and what it means, participants talked about modifications to help make rehabilitation meaningful to the patient. They identified how the family helped in these modifications.

> "In adaptation we might modify his treatment" (FG 2: PT).
>
> "Sometimes the family will modify their surroundings, their work areas. Sometimes we can learn something really new, how they have modified something" (FG2:PT).
>
> "We gave him a slipper for outside and later and tying it to the leg with some other modifications where he may not wear a slipper to the temple as such" (FG1:OT).

This last comment highlights the consideration of cultural factors in relation to modifications to enable the patient to have an easy way of meeting the requirements for the temple. Participants discussed a major part of their role as making the modifications needed for patients rather than purchasing adapted equipment.

> "It depends on the patient's financial status whether they can afford it or not. If they can afford it they do, otherwise you modify what they have" (FG2:PT).
>
> "Educating the family. It takes a lot of convincing them. The patient has beliefs about using certain things. There are devices to help make them independent, but

> the family may not like them or it is expensive. They say what do they need that device for" (FG6L:OT).

In this focus group, the lecturers talked about education as a way of convincing patients and their families to make adaptations and modifications.

Motivating patients was also discussed as a way of engaging them in rehabilitation. If patients were not motivated, this was viewed as a barrier to rehabilitation. A link was clearly identified in the focus groups between motivation and meaningfulness and between patients' adherence and their motivation.

> "Disability depends on the motivation of the patient and what their requirements are so they are not willing to go out from their family, so the youngest in their 30's have to go to work at home. Depending on their years and what they need, their motivation and rehabilitation is mostly based on that" (FG1:PT).
>
> "The patients can define what they want to achieve. They will be focused on their physical impairment like walking. They may not be aware of limitations. They still want to recover completely. It may take time for them to accept their limitations. They may get de-motivated" (FG6L:PT).
>
> "Motivation is required, and lots of help from the family and friends is required. We need to get family members to explain the process and explain how important it is to work towards rehabilitation" (FG2:PT).

Healthcare professionals discussing and explaining things to the patients and their families was observed on the wards. There was acknowledgement in the focus groups that the family knows the patient better and can therefore explain things in a more meaningful way. However, this could be problematic in light of the concerns expressed in the focus groups (as discussed earlier) regarding lack of awareness and the need for education. Families may not be fully aware of the implications for their relative and therefore this may affect how they explain things. A limitation of this study could be seen as not exploring in more depth what 'meaningful' means for families, patients and professionals. (The limitations of this study are discussed in more depth in chapter nine: 9.4).

The patients identified that rehabilitation was meeting their expectations. However, there seemed to be a feeling of patients following doctors orders.

> "He says he never had base line expectation, because he does not know about the whole thing, he just trusts the doctors, whatever they say will be to his benefit. So far it has been to his benefit, so it is okay" (Pt.M5).

Although this patient put his trust in the doctors, it was with the proviso that it needed to be to his benefit. His aim was to return home and possibly to return to work, but he acknowledged that his level of activity was less than before the accident. It could be that 'meaningful' connects to what the individual identifies as being of benefit to them.

6.3.2.3 Family

The role of the family in rehabilitation was prominent in the data. Most of the patients had physiotherapy, exercises or activities such as walking with the walker to practice on the ward. The family was involved in these exercises in terms of instruction by the therapists. Educating the family to look after their relative, particularly on discharge, was seen as being a key role of the physiotherapists, occupational therapists and nurses.

> "We teach them home care, at discharge time. If the patient is having some fractures or spinal injury so they have instructions about that, their family should know how to move the patient" (FG1:N).
>
> "We have care giving training. We teach education to families what is good for them, what is not good. How they can help if the patient cannot do it themselves" (FG2: PT).
>
> 'Educating the family. It takes a lot of convincing them. The patient has beliefs about using certain things. Relatives find it easier to help them out themselves. There are devices to help make them independent but if the family do not like it or it is expensive. They say we can help, what do they need that device for" (FG6L:OT).

There was discussion in the focus groups about the way the family functions in India. This discussion highlights the role of the head of the family and the importance of that role.

> "Sometimes the head of the family might decide upon the choices available for treatment. If he is the breadwinner he has more authority, if both are literate, economically sound they both may choose, but the head of the family chooses mostly" (FG6L:PT).

Social and economic factors that affect the family and rehabilitation of the patient were also mentioned. For example, finances and the environment, which can be challenging for people in a wheelchair:

> "India is different. Most is on the ground. Thinking of patients in the rural area, their cooking is also about squatting, where can they put their stove, there is no platform, nothing" (FG1:OT).
>
> 'Some of them travel 1KM for their toileting every day. How can a wheelchair patient do that'? (FG1: N).
>
> "Economic, literacy and social circumstances, that is where the differences are in rehabilitation concepts between Western and Indian society" (FG7:OT).

These last quotes highlight the importance of professionals recognising and addressing, where possible, severe socio-economic obstacles such as lack of toilet facilities and inadequate cooking facilities.

6.3.2.4 Teamwork

The notion of rehabilitation being performed by a number of different professionals was evident in the focus groups, interviews and observation.

> "In the neurology wards, we have a rehabilitation therapy area and people are working on the ward, that is one specialisation they have, with a team approach, the team also comes and educates" (FG3: N).
>
> "When there is like a co-ordination with what the physiotherapist and occupational therapist are doing, like with a stroke patient: functional activities, strength training and all that" (FG3: N).
>
> "All of the Heads of the various departments meet up and discuss the patients as each staff is allocated to medical surgical areas, they are in charge, they know about the patients, so each one they discuss with the main doctor" (FG1: PT).
>
> "It is a team approach but we don't really interact with each other as such. Our department will work on their own" (FG1: OT).

When asked if this was really a team approach, the answer was 'yes it is' and that this was important as different professionals focus on different aspects related to the patient, for example, mobility, dressing and medication. The participants equated working as a team with working on their own, with little interaction with each other. However, communication was observed between different professionals concerning the progress of patients.

As discussed in chapter five (5.3.2) in an interaction observed on the ward round between the consultant and a newly admitted male patient with Parkinson's Disease, the consultant appeared to focus on the patient as a person rather than the symptoms. This focus was also evident from the interactions between other professionals on the ward round which included doctors, a physiotherapist, an occupational therapist, a speech and language therapist, a psychologist and the nurse-in-charge. There was evidence of teamwork with members of the team discussing patient's progress, identifying and agreeing rehabilitation interventions focused on the patient, discussing with the patient and their relatives.

Patients, in discussing their day, identified that they had received input from different professionals, for example, in helping them with their mobility, dressing or continence needs. Different professionals working with patients and their families were observed and this sometimes involved more than one professional, for example, a physiotherapist and a nurse working together with the patient and their family.

6.3.2.5 Goal setting

Setting goals was identified in the focus groups as being an important way of helping patients achieve what they want out of rehabilitation. This then guided treatment plans.

> "When the patient initially comes, and we are assessing the patient, we ask them what are you looking for at the end of this treatment, what do you want out of it, what is your main complaint, what do you want to achieve that is how we set out our treatment plans based on the patient apart from what we feel the patient needs, it is what makes the patient happy. We look at the patient" (FG1:PT).
>
> "It may start from the beginning when the patient is in hospital. The patient may not come for rehabilitation he has come for some problems. He has been treated for that. Once the treatment has come to a particular point we will help him. This is what you need to question. This should be with the health team and the patient, so the patient knows what is his goals to be performed, and the nurses and the health team what is to be provided to achieve it" (FG3:N).

This last quote acknowledges that some patients are admitted for a specific health problem and rehabilitation starts after initial treatment of that problem, for example, following acute treatment of a stroke or surgical procedure.

The following is an interaction by different students in the same focus group talking about the process of goal setting and the strategies they use to help patients identify their own goals.

> "Some patients are able to understand, some patients are not able to understand that. We have to make them understand" (FG2:PT).
>
> "We work with them, tell them what they can do to improve themselves" (FG 2:PT).
>
> "We have to keep explaining them the same thing again and again, better to explain something" (FG2:PT).
>
> "Goals with the patient play a major part according to the progress we set the goals. If getting discharged … so we decide goals and we help him. Step by step depends on what the patient wants e.g. an amputee might be happy with crutches, another amputee might want to go on the bus, climb stairs" (FG2:PT).

In discussing difficulties with setting goals, the focus groups discussed strategies such as modifying goals with the patient and their family; being clear what the patient's and family's expectations are; exploring what their home environment is like and modifying treatment accordingly. The importance of the cultural and social background of the patient and family was also discussed and there was acknowledgement that there are differences in cultural beliefs and practices from people from different areas of India.

> "For many times what happens is what we feel is important for the client, may depend on their cultural background. So the family and patient himself may come up with options in regard to their cultural background" (FG1:OT).

Setting goals was identified as happening throughout the rehabilitation process, including at assessment and on discharge. There was evidence of short and long-term goal setting with the patient and their family from the observation. In the interviews, although patients did not refer to the terms 'goals' or 'goal setting', they did identify goals such as returning home, returning to work and walking again.

In summary, the attributes identified arise from the patient interviews, different focus groups and the observation, indicating a consensus of opinion. The attributes of 'meaningful' and 'the family' came through strongly, maybe reflecting cultural values and beliefs. Goal setting was identified as a way of making rehabilitation meaningful, with teamwork being key in delivering rehabilitation. Although in the focus groups, teamwork was identified as professionals working generally on their own, in practice, professionals did work together with patients and their families as a team.

6.3.3 Pre-requisites

The main pre-requisite for rehabilitation apparent from the qualitative data is disability. The meanings of rehabilitation discussed by the focus groups (table 6.5, page 131) highlight that rehabilitation is required following disease (FG1:PT) and deformity (FG3:N) and when a patient's functioning is compromised due to disability. The patients interviewed were all limited in some way in relation to activities of daily living due to conditions such as stroke, blood clot, back pain, spinal cord injury or trauma.

Another key pre-requisite identified from the qualitative data is the input of healthcare professionals and the family. The patients interviewed, the patients discussed in the focus groups and the patients observed all required this input. For example, Pt:M7, although living at home, was still intermittently seen by the CBR team six years post accident to check that no professional input was needed. The mother of this young man went through daily exercises with him as instructed by the rehabilitation team and helped him with daily living tasks, such as eating, washing and dressing. In other cases, discharged patients were followed up at home if needed and also attended follow up appointments until input was no longer needed. This input varied depending on the patient's needs. For example, nursing input for dressings or monitoring diabetes; physiotherapy input for mobility exercises.

6.3.4 Boundaries

It was not apparent in the focus groups or interviews that the boundaries between rehabilitation and other concepts, such as teamwork and quality of life, were not clear. Participants did not use terms such as 'quality of life' and 'autonomy' in the focus groups. However, there was evidence of recognition of these concepts, with participants identifying what was meaningful and important to them, which could be identified as relating to their quality of life. For Pt.M8 (5.2.1.1) this included being autonomous.

There was no evidence of concepts being confused with each other. The meanings of rehabilitation were clearly identified in the focus groups and interviews and they fit in with the attributes and pre-requisites previously identified.

6.3.5 Outcomes

Different outcomes or consequences of rehabilitation were identified in the interviews and focus groups (table 6.7, page 146).

Table 6.7: Outcomes of Rehabilitation from the Qualitative Data

Outcome of Rehabilitation	Patient Interviews	Focus Groups
Independence		FG2:PT,
Control over life/achieving autonomy	Pt.M8.	
Regaining function	Pt.F5, Pt. M3, Pt.M4.	FG1:OT, FG3:N, FG7L:N.
Returning home	Pt.F2, Pt.F3, Pt.F4, Pt.M2, Pt.M3, Pt.M6	
Returning to work	Pt.F2, Pt.M1, Pt.M2, Pt.M4, Pt.M6.	
Setting back to social life		FG3:N.
Return to pre-accident state	Pt.M5.	FG2:PT.
Achieving goals		FG1:OT, FG1:PT, FG2:PT, FG4:PT, FG7:PT.

The main outcomes generally identified by patients was returning home and returning to work. In order for this to happen, some patients identified the need to regain physical function (Pt.F5, Pt.M3, Pt.M4) and some patients identified adaptations required to enable them to return home. Pt.M8 identified a main outcome of rehabilitation for him as regaining control over his life (6.3.1.1), which can be viewed as achieving autonomy.

In the focus groups, the main outcome was the achievement of meaningful and realistic goals (6.3.2.5) for the patient to enable them to return home and to work, if appropriate, which links in with the outcomes identified by patients. The focus on returning home and achieving realistic goals can be seen as relating to an individual’s quality of life.

6.3.6 Conclusion: Qualitative data

Like the literature, the qualitative data has been examined in terms of definitions, attributes, pre-requisites, boundaries and outcomes. In looking at the definitions and attributes, the same criterion has been used (6.2.6): significance to the individuals undergoing rehabilitation (and their family or significant others).

Participants in the focus groups generally identified rehabilitation as being to return or restore people to their previous level of functioning as much as possible, incorporating psychological and cultural factors. Patients generally saw rehabilitation as being a way for them to achieve what was important to them in relation to their lives. As discussed in 6.3.2, the attributes of returning/restoring, meaningful, family, teamwork and goal setting were identified from the data more explicitly in the focus groups than in the interviews, which could be due to the professionals' knowing what language to use. Although returning/restoring was identified in terms of returning the patient to their previous life, the main attribute appeared to be meaningful rehabilitation for the patient and their family, with meaningful goals and teamwork facilitating that.

Using Morse's (1996) criteria of clarity of pre-requisites, boundaries and outcomes as in section 6.2, the pre-requisites for rehabilitation are clearly identified from the data as being disability and healthcare professional and family input. The boundaries of rehabilitation are identified in the data as being clear, without confusion with other concepts.

On the basis of the findings from the qualitative data as to the cultural sensitivity of the concept of rehabilitation and the above discussion, the concept appears to achieve maturity because the definitions and attributes can be considered to be culturally sensitive, with a clear focus on 'what is meaningful' to the patient and their family. Clear pre-requisites, boundaries and outcomes are identified. However, this apparent achievement of maturity could be because the data is from one cultural setting and may also be limited in terms of the questions asked of the participants and lack of interviews with family members. It is important to compare this data with the literature (6.1) to make a more informed decision about the cultural sensitivity of the concept of rehabilitation.

6.4 Comparison of Data

Having examined the literature and the qualitative data, comparisons between these two sets of data will now be made. These comparisons will mirror the previous sections by being discussed under definitions, attributes, pre-requisites, boundaries and outcomes.

6.4.1 Definitions

Definitions of rehabilitation in the literature come from the WHO and different authors. The WHO definitions (table 6.1, page 114) have been developed by a consensus of people from different countries, whereas other definitions (table 6.2, 115) are mainly from Europe and Australia. There is no consensus of opinion in the definitions as to what rehabilitation is, although it is generally agreed that it is a process, which focuses on more than dealing with impairment and disability. In contrast, the definitions of rehabilitation from the qualitative data agree that rehabilitation is about returning patients to what they were or helping them achieve the maximum level possible.

6.4.2 Attributes

There are some commonalities in the attributes across both sets of data. However, some attributes are unique to either the literature or the qualitative data. These are identified in table 6.8 (page 148) in order of priority of how common they are in the data.

Table 6.8: Comparison of Attributes from the Literature and the Qualitative Data

Literature	Qualitative Data
Process	Returning/restoring
Teamwork	Meaningful
Goal setting	Family
Enabling and meaningful	Teamwork
Restoration	Goal setting

6.4.2.1 Process

The most common attribute in the literature is ‘process’, with different authors describing it in different ways, for example, as an educational process (Wade and DeJong 2000) or a process aimed at individuals achieving their maximum levels (WHO no date). The term ‘process’ is not mentioned in the qualitative data, although it is implicit in the focus groups and interviews that rehabilitation is a process that patients go through with education being identified as a way of helping patients.

6.4.2.2 Returning/restoring

Returning/restoring is the most common attribute from the qualitative data in the sense of restoring maximum function or returning people to what they were. This is echoed in the literature, but is not given the same priority as in the qualitative data. Whether returning people to what they were is achievable or not will depend on the level of their disability, which is identified in the literature (Mishra 2003, Renstch 2003,). In further discussion in the focus groups, it was apparent that the participants recognised this and worked with patients and their families in identifying achievable goals.

6.4.2.3 Teamwork

Although teamwork is not explicitly identified in the definitions, it is discussed in the literature as being key to rehabilitation and this is supported in the qualitative data. The focus groups discussed the importance of working with different professionals as a team and receiving input from different professionals was identified in the interviews.

Team working was observed on the wards with different professionals interacting with each other and working together with the patient and their family. There are a number of challenges in working as an effective team, which are detailed in the literature and seem to be reflected in the focus groups. One such challenge is the importance of professionals reflecting on whose interests they are working towards. This is identified in the literature and supported by the qualitative data, where focusing on the patients' goals was identified in the focus groups and observed on the wards.

6.4.2.4 Meaningful

Meaningful is an attribute that is strongly evident in the qualitative data in terms of making rehabilitation meaningful to the patient. Making adaptions or modifications, meaningful activities and involvement of the family were identified in the focus groups as strategies to facilitate meaningfulness. In the literature, enabling and meaningful are identified by some authors, for example, in terms of enabling individuals to live their lives in a meaningful way (Banja 1996). Enabling is not a term used in the qualitative data, although supporting and helping patients was discussed in the focus groups and observed on the wards.

6.4.2.5 Goal setting

In the literature, client-centred goal setting is identified as being central to rehabilitation and a characteristic of multidisciplinary teamwork (Wressle et al. 2002). Goal setting was discussed in the focus groups as being integral in the rehabilitation process, happening at the assessment stage and going through to discharge. There was also evidence of this taking place in the observation. The potential harm of goal setting is discussed by Wade (2009) in terms of setting goals which are not meaningful to the patient which may then result in them becoming demotivated. Strategies were identified in the focus groups to address these challenges, such as modifying goals with the patient and their family and being clear as to what their expectations are.

6.4.2.6 Family

The role of the family was key in the qualitative data, being seen by professionals as crucial to the rehabilitation process. The term 'family' can include significant others as well as immediate family members. For example, neighbours, friends or a member of the community might be closely involved in the rehabilitation process. In the focus groups, the family was seen as integral to goal setting and in instructing and supporting the patient in their rehabilitation programme. The presence of families was prominent on the ward, with some of them staying in hostel accommodation, bringing in food, giving care and assisting with exercises. The health care professionals saw a key role as being to educate the family and the patient. They identified the family as being valuable in motivating the patient and helping in identifying and achieving meaningful goals.

In the literature, family is not identified as a key attribute. The focus is predominantly on the individual. Family is referred to as needing to be considered but not as being fundamental. This could reflect the fact that the literature is mainly from countries where values around individualism (as discussed in chapter two) are more prominent, with the focus on the individual rather than the family.

6.4.3 Pre-requisites

The presence of disability (the lack of ability to perform tasks and to participate in life situations) is the main pre-requisite for rehabilitation identified from both sets of data. In the literature, rehabilitation is discussed in relation to a variety of different conditions or situations that result in disability, for example, neurological, musculoskeletal and cardiac conditions. Countries are required to provide rehabilitation services for people with a disability (United Nations Convention 2006). In the focus groups, participants identified that people with a disability require rehabilitation and this was supported by the patient interviews and the observation. The patients observed and discussed in the interviews were all receiving rehabilitation because of short- or long-term disability.

The second clear pre-requisite identified from both sets of data is the need for input from a variety of healthcare professionals. This is identified in the literature with examples from practice and research studies (Ward et al. 2003, Turner Stokes et al. 2005). Input from different health care professionals was identified as being key to rehabilitation in the focus groups, the patient interviews and from the observation. A key difference in the qualitative data is that input also included the family. Therefore, a pre-requisite in the qualitative data was input from healthcare professionals and the family. The families were taught techniques by healthcare professionals and participated in care and rehabilitation interventions on the ward, which, if needed, they then carried on at home.

6.4.4 Boundaries

In the literature rehabilitation is identified as a concept, which although it links with a number of other concepts such as quality of life and teamwork, has clear pre-requisites and its relationship to these other concepts is clearly defined. Participants in the focus groups did not confuse rehabilitation with other concepts and they were clear how other concepts, such as teamwork and goal setting, linked to rehabilitation.

6.4.5 Outcomes

A number of outcomes are identified in the literature as a result of rehabilitation: improved quality of life, maximising participation, social integration and achievement of goals. This relates to the qualitative data, where the outcome of rehabilitation is whatever is meaningful to the patient and their family. In terms of cultural sensitivity, it is important that the outcomes of rehabilitation are meaningful to the person in their cultural context. The challenge for rehabilitation professionals is in maintaining a balance between the achievement of meaningful outcomes for the individual and the need for outcomes to be realistic. This is important so that individuals do not become de-motivated when they cannot achieve identified outcomes because they are not realistic. However, outcomes also need to be meaningful to them, otherwise they will not be motivated to achieve them.

6.5 Chapter Summary

The aim of this chapter has been to establish the maturity of the concept of rehabilitation in relation to cultural sensitivity. In order for a concept to be deemed to be mature, it needs to have a meaningful definition and attributes, clear pre-requisites, outcomes and boundaries (Morse 1995). Firstly the literature and then the qualitative data have been examined using these indicators and then compared to each other using the same indicators.

Using these indicators has enabled the concept of rehabilitation in relation to cultural sensitivity to be deconstructed or taken apart to examine its components (definitions, attributes, pre-requisites, boundaries, outcomes). This process has enabled a structured analysis to be undertaken, resulting in a decision on whether the concept of rehabilitation in relation to cultural sensitivity is a mature concept. There is some overlap in these components in terms of the attributes present in the definitions (table 6.5, page 131), which is not really addressed by Morse (1995). This could be seen as a limitation of Morse’s approach, however, it challenges further critical thinking in considering why this is and whether it is appropriate or not. Conducting a maturity check of the literature and the qualitative data has facilitated a systematic focused enquiry raising questions and challenging assumptions in a more structured way than a critical review of the literature would have allowed without a specific framework.

A decision now needs to be made on whether the concept of rehabilitation is an immature, partially mature or mature concept. This will then determine the type of concept analysis enquiry (3.4.1) required to further advance or develop the concept in relation to cultural sensitivity.

6.5.1 Morse's Indicators

The first indicators to be considered, as identified by Morse (1996b), are whether there is a meaningful definition and meaningful attributes. There are many definitions of rehabilitation in the literature and some of these identify concepts, such as autonomy, which can be considered as not being culturally sensitive. The most recent definition in the literature is by the WHO (no date: the current definition on the WHO website) that uses terms like independence and self-determination, which may not be culturally sensitive. The definitions of rehabilitation in the qualitative data are less specific, focusing on rehabilitation as helping patients achieve the maximum level of functioning possible within their socio-cultural context. These definitions could apply to any culture so can therefore be identified as being culturally sensitive. However, in looking at the literature and the India data together, not all of the definitions are culturally sensitive.

The attributes are clear from the literature and the qualitative data, with some of them being the same: teamwork, goal setting, meaningful, restoring. In the literature, whether the attributes are culturally sensitive or not relies on whether they are meaningful to the individual and their family, taking into account their cultural context. In contrast, the same attributes identified in the qualitative data: teamwork, goal planning and restoring were in the context of what was meaningful to the individual and their family. The attribute of 'meaningful' was more prominent in the qualitative data in terms of rehabilitation being meaningful to the patient and their family and 'family' was also identified as a key attribute, which is not really reflected in the literature. Therefore, looking at the data as a whole (the literature and the qualitative data), some of the attributes may not be considered in a culturally sensitive way, which indicates lack of maturity.

Morse (1995b) identifies clear pre-requisites as needing to precede a concept in order for it to be mature. The literature and the qualitative data identify the same pre-requisites for rehabilitation: disability and input from healthcare professionals; in addition, input from family members appears in the qualitative data. These pre-requisites are clear and there is consensus about them, which indicates maturity.

However, in some instances, input may be from one professional rather than different professionals, or from community members or volunteers so, therefore, there needs to be flexibility in terms of professional input depending on the cultural context. This is demonstrated in the qualitative data with the input of family.

Clearly defined boundaries should be evident in a mature concept (Morse 1995b), with attributes that are not present in related concepts. Although rehabilitation is associated with other complex concepts and the boundaries could appear to be blurred, on examination, this is not the case. As already stated, the pre-requisites for rehabilitation are clear and the attributes identified in the literature and the qualitative data are not key attributes in the related concepts of teamwork, autonomy and quality of life. The relationship of rehabilitation to other concepts is clearly described in the literature. In the qualitative data, there appeared to be no confusion of rehabilitation with other concepts.

In order for a concept to be mature, according to Morse (1996b), outcomes or consequences need to be similar. As discussed, the outcomes identified in the literature (quality of life, maximising participation, achievement of goals, motivation and autonomy) are similar in that they can all be seen as relating to what is meaningful to the individual. In the qualitative data, the outcome of rehabilitation was identified as whatever is meaningful to the patient, for example, returning home, regaining function or regaining control over life.

6.5.2 Decision on Maturity

Based on the evidence (the literature and the qualitative data), the concept of rehabilitation in relation to cultural sensitivity can be considered as being partially mature. Maturity appears to be achieved in relation to pre-requisites, boundaries and outcomes, but only partially achieved in respect of definitions and attributes. If the conclusion was only being made on the qualitative data, then it could be said that the concept in relation to cultural sensitivity is mature. However, this evidence is only based on a snapshot from one area of India so it can only ever be seen as relating to that particular context.

In contrast, the literature is from a number of different contexts. However, these are predominantly countries with a western view, which then raises the question of cultural sensitivity in relation to other countries with a less western view. Focusing only on the literature would not have brought in a detailed view from a country where there is a less western view. Combining the data enables a more informed decision to be made on the cultural sensitivity of rehabilitation and identification of what is required to ensure that the concept of rehabilitation is culturally sensitive. What this is will be explored in more depth in the next step of concept analysis.

6.6 Concept Clarification

Having established that the concept of rehabilitation in relation to cultural sensitivity is partially mature, the appropriate type of concept analysis enquiry now needs to be identified. In looking at the different types discussed in chapter three (3.4.1) as identified by Morse (1995) and Morse et al (1996b), concept clarification seems the most appropriate next step. Concept clarification is suitable when a concept appears to be well developed and well described by a large body of literature, however, on looking at it more closely the concept appears to be murky with competing assumptions. It has now been confirmed by establishing the level of maturity that, despite the large body of literature on rehabilitation, assumptions are made that this literature is appropriate across cultural contexts when this does not appear to be the case.

The first step in concept clarification consists of examining the literature in terms of underlying values. In establishing the level of maturity, this first step has taken place with examination of definitions, attributes, pre-requisites, boundaries and outcomes. The development of critical or analytical questions is the next step in concept clarification. The questions are used to develop or advance the concept further, which, in this case, is the concept of rehabilitation in relation to cultural sensitivity.

6.6.1 Critical Questions

Morse advocates that analytical questions are identified once the researcher is familiar with the literature (Morse 2000, Hupcey 2002). Through examination of the definitions, attributes, pre-requisites, boundaries and outcomes I became familiar with the literature and the qualitative data, identifying common words and themes as discussed in this chapter (6.1). After analysis of the literature and qualitative data in order to establish the level of maturity of the concept, I identified a number of themes from the data (refer to appendix 12), which I then categorised into preliminary questions. These were discussed with the supervisory team and combined into five main critical questions (table 6.9, page 155), which is in keeping with the process of concept clarification (Morse 1995, Hupcey et al. 2002, Whitehead 2004).

Table 6.9: Critical Questions

Preliminary Questions	Final Critical Questions
1. What does meaningful mean?	**Question 1** **What makes rehabilitation meaningful?**
2. What makes rehabilitation meaningful to the patient and their family?	
3. How does the multidisciplinary team make rehabilitation meaningful for the patient and their family?	
4. How does client-centredness fit in with meaningful rehabilitation?	
5. What is the intention or aim of rehabilitation?	**Question 2** **What is the intention of rehabilitation?**
6. Whose aim is it?	
7. How does quality of life link with rehabilitation?	
8. What is the role of culture?	**Question 3** **What is the relationship between culture and rehabilitation?**
9. Is culture enabling or disabling?	
10. What is the relationship between context and culture?	
11. What is culturally safe rehabilitation?	
12. What or who is the unit of decision-making? Is this time dependent or does it change over time?	**Question 4** **What or who is the unit of decision-making in rehabilitation?**
13. What is the role of family in decision-making?	
14. What is the relationship between autonomy and rehabilitation?	
15. What are the socio-economic influences on rehabilitation?	**Question 5** **What are the external factors that impact on rehabilitation?**
16. What are the different types of rehabilitation delivery models? What are the implications of these?	
17. Does rehabilitation reflect a medical or social model or both? Do these promote culturally sensitivity?	

The five final critical questions will be used in the next chapter to advance the concept of rehabilitation in relation to cultural sensitivity.

Chapter 7: Concept Clarification

7.0 Introduction

The aim of this chapter is to advance the concept of rehabilitation towards maturity in relation to cultural sensitivity, by using the technique of concept clarification as identified in chapter five. Adopting this concept analysis technique enables more detail to be gathered on the concept than would be possible from a critical review of the literature; Following the maturity check in chapter five, there are areas that need further exploration in order to enhance the concept in a culturally sensitive way.

As identified in chapter six (6.6.1), the following critical questions, arising from the maturity check, were condensed from the original list.

1. What makes rehabilitation meaningful?
2. What is the intention of rehabilitation?
3. What is the relationship between culture and rehabilitation?
4. What or who is the unit of decision making in rehabilitation?
5. What are the external factors that impact on rehabilitation?

This chapter further analyses the sample of literature and the qualitative data using these questions in order to gain increased understanding of the cultural sensitivity of the concept of rehabilitation. Additional literature will be used as required to further develop the analysis, as advocated by Morse (2000). Morse (1995) advocates that literature is explored from different disciplines to identify whether the concept under investigation has different meanings in different disciplines. The literature used for the concept clarification questions is identified in table 7.1 (pages 157-158) and divided into different disciplines. The responses to some of the questions are from more than one discipline.