The Lived Experience of People with Physical Disabilities

in Timor Leste

Thesis submitted by

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Abstract

There is a growing interest amongst occupational therapists and occupational therapy students regarding working or volunteering in developing countries. In Australia we live in a region together with vastly populated countries of Asia with old cultures, very different to our hybrid Australian society. However, there is not a lot of information relevant to how occupational therapists could work in other cultures within our region. In the field of disability there are large data-sets reporting prevalence and incidence of disability, however, as the definition of disability varies considerably from country to country, this information has broad application only.

Timor Leste is a small developing country with a recent history of occupation and violence, to the north of Australia. I visited and worked as an occupational therapist in a number of projects in Timor Leste over many years and I wanted to more deeply understand the experiences of people with disabilities. I wondered what the barriers to participation were, and what factors helped a person with disabilities live a satisfying life in the country of Timor Leste. I wanted to understand how the complex cultural context of Timor Leste influenced those with disabilities and how people with disabilities managed in times of civil unrest. I wanted to know ‘what is the lived experience of physical disability in Timor Leste’.

The data collection for this investigation was undertaken using photovoice. This is a participatory method of data collection; participants borrowed small cameras and took photographs to illustrate their daily lives and to answer the research question. The participants explained their photographs in both individual and group settings and a collection of themes was revealed in each of the three photovoice projects which made up this research.

Findings showed a wide spectrum of experiences in the lives of people with disabilities and the research method, photovoice gave depth and understanding of the details of daily life. Photovoice provided other benefits as a tool for cross-cultural research, such as
photographs being the focus of the interviews rather than the unfamiliar foreign researcher, and the participants themselves chose the material which they wanted to discuss in the research.

The findings, based on a range of experiences of people with disabilities, pointed to the effectiveness of people with disabilities themselves actively engaging in the disability sector. In Timor Leste people with disabilities acted as advocates, raising awareness of disability rights and explaining newly emerging disability services to people in remote districts. They were also seen to be effective as trainers as they based trainings on their own experiences to illustrate the need for inclusive policies and inclusive practices.

Another major finding was the overarching effect of poverty which penetrated the lives of people with disabilities. Poverty affected their ability to maintain good health, to achieve an education, to participate in family and community activities and to purchase food and essentials for life. The photographs and discussions showed the effect of poverty in detail, and showed that for many people, poverty is as much a limitation as physical impairment; poverty compounded all the other difficulties which an individual experienced on a day to day basis.

The significance of the research is that it is based on descriptions, commentaries and reflections of people with disabilities themselves where the detail of the experiences in the daily lives of people with disabilities in Timor Leste. The research also reinforces the value of the work being undertaken by people with disabilities who share the same experiences as their clients. These people were working in the disability sector as advocates, trainers and role-models for others with disabilities, and the research highlights the importance of their continuing engagement as this level. The research also points to the importance of inclusive policies and practice in disaster planning and disaster management in a post-conflict, fragile state.
The research had implications for occupational therapy practice. It highlighted factors in occupational therapy practice such as the need to consider poverty, the need to have strategies to help people with disabilities to manage violence in the home, the gendered differences in East Timorese society, the importance of family and significant others in the lives of people with disabilities, the relevance of cultural understandings of health, illness and disability, the importance of mentoring people with disabilities as they experience changes in their lives, and the value of an active disabled people’s organisation (DPO). The research also suggested a model of the experience of living with physical disabilities, as a framework by which to understand the lived experience of disability in a cross-cultural setting.
Declaration of Originality

I declare that this thesis is my own work and has not been submitted in any form for another degree or diploma at any university or other institution of tertiary education. Information derived from the published or unpublished work of others has been acknowledged in the text and a list of references is given. Four of the six articles are jointly authored and details of the contribution of each has been supplied.

H. Jane Shamrock

30th November 2015
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I would like to acknowledge some of those who were a part of my research journey. Firstly, I would like to thank my first supervisor, Dr. Mike Lyons who convinced me that I could undertake a PhD, and believed that I could make the cross-cultural journey from being an occupational therapist to a PhD candidate. Many thanks to my subsequent team of supervisors, Professor Marion Gray, my principal supervisor, as well as Associate Professor Melanie Cameron and Dr. Florin Oprescu who provided skilful support and encouragement along the way. Next I must thank the Leprosy Mission of Timor Leste, and especially Natalie Smith, for making the wonderful offer to provide me with everything I could possibly need in Timor Leste. This included accommodation, transport, interpreters, contacts and fun in between the research activities. I also thank my mentor, Dr. Jenny Hughes, who provided me with excellent guidance and insights into cross-cultural research from her many years as an academic and anthropologist in Papua New Guinea.

I would like to thank all the participants in the research project, both *malae* (foreigners) and Timorese. I felt very privileged to be able to sit with people who were willing to share their thoughts and some of the details of their everyday lives. I hope they are pleased with the results of their time with me and can find some way to make this document useful. I wish this for both the people with disabilities in Timor Leste, and those who spend time with them, either at work or in families.

The University of the Sunshine Coast provided me with everything I needed in Australia; training, a space in which to base myself, and the expertise and concern of many different people along the way such as the librarians, especially Roger Carter with his calm and skilful approach to the vagaries of Endnote, the Office of Research staff who kept the administrative
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List of original publications

Shamrock, H. J., Gray, M., Cameron, M., Oprescu, F. Disabilities in Asia: A Metasynthesis of Qualitative Literature Written in English. British Journal of Occupational Therapy (Published)

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Shamrock, H. J. The power of pictures: Using Photovoice to investigate the lived experience of people with disability in Timor-Leste. Development Bulletin, 63. (Published)
### Statement of authorship

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Prof Marion Gray  
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Chapter One: Introduction

Key to the thesis

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This thesis is an investigation of the lived experience of people with physical disability in Timor Leste. Timor Leste is one of the world’s newest countries and has been the recipient of many foreign aid programs since independence from Indonesia (McGregor, 2007). Despite the large amount of foreign aid in the country, people with disabilities frequently miss out in the processes of consultation and planning and may subsequently miss out on the benefits from foreign aid (MacLachlan & Swartz, 2009).
Data are readily available on prevalence and incidence of disability (Chapter Two). However, data about daily life as a person with disabilities in Timor Leste are limited. Knowledge about the experiences of people with disabilities is important because firstly, it can inform the development of inclusive legislation within the country; and secondly, it can inform foreign aid programs to help ensure they are operating with an inclusive approach.

1.1 Introduction to present day Timor Leste

My intention in this chapter is to provide background to this cross-cultural research on the ‘lived experience of physical disability in Timor Leste’, and to examine some of the historical influences within East Timorese society. I then introduce issues within cross-cultural research, and finally, I present the outline of the thesis. To this end, I start the thesis with a description and reflection on the experience of arriving in the country and to introduce Timor Leste.

I first visited the country now known as Timor Leste in 1972, when it was a colony of Portugal, and known as Portuguese Timor. My second visit to Timor Leste was many years later, in 2000, as a volunteer following the violence of the 1999 referendum, when Timorese citizens voted for independence from 26 years of Indonesian occupation. Since then, I have been associated with projects relating to disability and services for people with disabilities. During these visits, significant changes were noted within Timorese society which have impacted on the lives of people with disabilities. Each time I return, I find myself searching for familiar landmarks, to see if they have changed or have disappeared in the recent rapid developments within the country.

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1 The country was known in English as Portuguese Timor during Portuguese colonial times, until 1975, and as East Timor during the Indonesian occupation, up until 1999 referendum. The country was sometimes known as Timor Lorosae or East Timor from then until independence in May 2002, and since that time as Timor Leste or East Timor. I use the name Timor Leste in preference to East Timor in this thesis to help retain a focus on the experience of a group of people within the country. However, for ease of language in this thesis, reference is made to citizens as East Timorese, or Timorese, in line with Hughes (2009).
The following description depicts the journey that may be taken by a foreign visitor, such as myself, from the airport, through the centre of Dili to the *Cristo Rei* statue at the opposite end of the bay. This journey presents a verbal panorama of the cultural influences operating in Timor Leste, which can be seen in the architecture and road infrastructure of the capital. It should be noted that this is only a part of the cultural influences on Timorese life. The influences coming from the natural environment are suggested when the foreign visitor considers the high central range of mountains visible behind Dili. The steep mountain villages, the many coastal communities and the beautiful undulating lands to the east of the country, where people live more traditional lifestyles, rest out of sight of the vignette described below.

On arrival at Dili airport, or Presidente Nicolau Lobato International Airport, I step onto the runway in thick tropical heat and walk towards the two large buildings with high thatched roofs. These are reminiscent of Indonesian architecture, although typical of Timor Leste. After passing through the customs and baggage check, I travel from the airport to the centre of Dili, along the main thoroughfare, Comoro Road, with motor-cycles weaving amongst the cars and trucks. Comoro Bridge over the wide, sandy bed of the Comoro River used to have only two narrow lanes; however, since 2013, the new Comoro Bridge has been accessible for people in wheelchairs, who can now use the new pedestrian walkway. The shops expanding along Comoro Road sell consumer goods such as furniture, electrical goods and car tyres and are more numerous on each trip; but there are still some gaps between buildings where concrete rubble and weeds remain, unrestored from destruction in earlier times.

I pass the large, heavily protected Australian embassy, before turning left into a smaller chaotic street where there are closely packed, concrete Timorese homes. Many of these homes have tins with flowering plants out the front, or the top of a papaya tree may be
visible above a high fence. Turn right onto the narrow Esplanade, passing in front of the very large American embassy squatting on the ocean-front opposite the silky ocean, the *Tasi Feto*\(^2\), which is bordered by low concrete walls and a narrow grey pebbled beach. Young men often lounge on the wall, beside their parked motor-bikes; bamboo frames can be seen behind the low walls, marking the place where stalls will appear in the evenings, selling fish-on-a-stick and other evening snacks. Further along the Esplanade, gracious older buildings from the Portuguese era sit beneath large, old trees. These buildings have tightly curved, red Portuguese tiles and snowy white walls and face the lighthouse and the ocean from behind high, barred fences.

I round the lighthouse corner to see the large government building, the *Palacio do Governo*, about one kilometre away, almost opposite the Dili Port. I stood at this point watching smoke rising from burning cars in front of the Palacio during the riots and civil unrest in May 2006. I then pass the Motael Church, built during the Indonesian occupation. The architectural style is roughly Portuguese, with Indonesian-style statues of the Holy Family located out the front. The church is associated historically with the struggle for independence from Indonesia. It was the site of an attack on members of the resistance in 1991; later, during the occupation, it represented the leadership of Nobel Peace Laureate, Bishop Carlos Filipe Ximenes Belo, who regularly spoke out against the excesses of the Indonesian occupation, between 1975 and 1999.

The road along the waterfront continues past the *Palacio*, past the heavily gated building housing the World Bank, then past Hotel Tourismo, often mentioned in non-fiction books about Timor Leste. The journey continues past ocean-side suburbs and past a beach, well-known to foreigners because of the beach-side cafes and night-clubs. Around a rocky

\(^2\) *Tasi Feto*, or female sea, known as the Banda Sea in English, is the ocean to the north of Timor Leste. *Tasi Mane* or male sea, known in English as the Timor Sea, lies to the south of the island.
headland, there is another beach, yellow sand this time, with canoes for hire. The shady trees and plastic café chairs on the sand under the trees map out a favourite playground for Timorese families as well as malae (foreigners) at the weekends. The road finishes several kilometres later at a flight of steps which ascend steeply up a high rocky peninsula to the 27 meter Cristo Rei (or Jesus Statue), which looks to the west, arms outstretched, over the bay and back towards Dili. This 14 kilometre journey from the airport to Cristo Rei along the waterfront, represents the major influences in the recent history of Timor Leste: Portuguese colonial influence, Indonesian occupation and the present proliferation of Western influence and new buildings. There is an accompanying visibility of foreigners including aid-workers, advisors and adventurers and those interested in international development, especially the petroleum resources of Timor Leste.

The snapshot of Timor Leste described above is offered as a background to help link the contemporary context in which people live and work with the historical influences within Timor Leste, which still underpin life and landscape in the country today. However, these influences, clearly visible in Dili represent life in the capital only. The rural areas where more than half the population can be found, are based on traditional life-styles where change is slow and where people are more deeply influences by older cultural traditions. More details of the complex history of Timor Leste are described in the academic papers within the thesis; but below I provide an initial sketch of the context which influences the lives of people with disabilities in Timor Leste in present times.

1.1.1 Locality and history of Timor Leste.

Timor Leste is a small country with a population of 1.2 million, to the north-west of Australia, located on the eastern half of the island of Timor, see Figure 1.
There are deep cultural influences in the country coming from a 450-year period of Portuguese colonial administration, followed by 26 years of Indonesian occupation, which ended in violence, following a United Nations (UN) monitored referendum in 1999 (Leach, 2006; Molnar, 2010). UN peacekeeping forces returned to East Timor to restore order in 1999, and from then, there was a period of reconstruction and restoration of the new nation state under the United Nations Transitional Authority of East Timor (UNTAET), until the declaration of Independence on 20th May 2002.

The suppression of local population during the Indonesian occupation, and the violence in the aftermath of the referendum of 1999, left the population traumatized and quick to become fearful of further disruption and violence. For example, seven years later, I was working in Timor Leste, when tension between the the PNTL (Policia Nacional de Timor-Leste, that is, the National Police Force) and the FDTL (Forcas Armadas de Defesa de
Timor-Leste, that is, the East Timorese military), resulted in violence with snowballing factional fighting within the army, further aggravated by involvement of local gangs (Cotton, 2007). At that time, I was involved in the first community-based rehabilitation (CBR) training program in Dili, the capital. As many of the members of the traumatized population of Dili packed their belongings and fled from the city, it was possible for me to observe firsthand the difficulties of people with mobility and other impairments in times of civil unrest. I myself was frightened by the unpredictability of the violence in Dili and was eventually evacuated. I wanted to know about the lives of people with disabilities who were not assisted out of the danger as I was. Since that time, there have been further periods of civil unrest, in 2007 and 2008; the final International Stabilisation Force (ISF) was withdrawn in 2012.

1.1.2 Timor Leste in 2015.

Timor Leste is a country of rapid societal change and urbanisation (Barbara, Cox, & Leach; Harris & Goldsmith, 2012; Streicher, 2011) and is now considered by some to be a post-colonial, post-conflict fragile state (Browne, 2007; Simonsen, 2006). This fragility was reflected in the World Bank survey (2010) where 40% of the population were living below the poverty line and extreme poverty was combined with health problems such as malaria, malnutrition and high child mortality rates (Martins & Hawkins, 2012), together with a very high birth rate of 5.7 births per woman (National Statistics Directorate, 2010). The high fertility rate and high birth-rate are consistent with other countries in Melanesia and Micronesia where high population growth is assumed to be based on high fertility rates and declining mortality (Zhang, Rao, Taomia & Duncan, 2006). The young population of Timor Leste is also consistent with the demographic transition as described by Kirk (1996) where

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3 Kirk (p361) describes demographic transition as ‘societies that experience modernization progress from a pre-modern regime of high fertility and high mortality to a post-modern one in which both are low’
societies are seen to transition from a ‘pre-modern’ status characterised by high mortality and high fertility to a ‘post-modern’ status with low mortality and low fertility. In the case of Timor Leste the large population of young people is accompanied by low levels of work opportunities and civil instability, a feature also consistent with countries undergoing demographic transition (Neupert & Lopes, 2006). Although the population growth in Timor Leste is considered consistent with the regional trend, this trend is considered cause for concern where a population growth of 3 per cent per annum means that the population will double in 17 years and subsequently poverty is expected to increase (Lundahl & Sjöholm, 2009).

Planning and change is most apparent in Dili, the capital. However, change is occurring at a slower rate and with different emphasis in the rural and remote districts. McWilliam, (2008) noted a Timorese informant who stated that ‘We are modern now … but custom remains strong’ (p 217) and in rural areas, and even in Dili, sacred houses, uma lulik, associated with traditional community values and association with deceased family members, are being rebuilt (Hicks, 2008). In the eastern part of the country McWilliam noted the return of customary practices which included intricate practices relating to kinship and ritual exchange of gifts associated with marriage which were weakened during the Indonesian occupation. In contrast, traditional practices were used in Ermera district in the West of Timor Leste to manage social practices which contributed to local poverty. In particular, the extensive gift-exchanges associated with marriage and the elaborate offerings connected with harvest were banned by a traditional prohibition, tara bandu, declared by local leaders (Palmer, 2007). Traditional health care practices also remain popular and many Timorese like to choose between, or combine traditional health practices with biomedical service delivery, while other Timorese are reluctant to attend biomedical health services, (Wild, Barclay, Kelly & Martins, 2010).
Change has also occurred with some acceptance of people with disabilities, in Dili at least. During the period of data collection for this thesis, a small but visible change occurred when the first traffic lights were installed in the city, with audible warnings for the hearing impaired. Timor Leste is developing inclusive legislation regarding access and inclusion of people with disabilities, together with practical steps as to how this should be carried out. Further details of this process and the involvement of people with disabilities can be found in Chapter Eight of this thesis.

1.1.3 **Disability in foreign aid.**

A long association with Timor Leste has put me in the privileged position of being able to observe the long term outcomes of different types of medical aid and foreign aid, and the accompanying efforts to include people with disabilities. As an occupational therapist, I am deeply concerned about equality of opportunity; I am equally concerned about imposing the values of another culture, which is one possible outcome when working as a foreigner in a developing country, and similar concerns have been voiced by many authors such as Grech (2012), Katsui (2006) and Bichenback (2009); the experience of disability varies when viewed as the impact of disability on the differing domains of life and the impact of differing domains of life impact differently on differing disabilities (Warren & Manderson, 2013). Foreign aid continues to support Timor Leste and foreign aid programs usually have a mandate of inclusivity, to ensure that no vulnerable people are left out of preliminary negotiations. However, non-government organisations (NGOs) are constrained by their own agendas (Chambers, 2014); for example, many insist on a particular gender balance within their program, or program planners may work from an over simplified basis, assuming that all people with disabilities have similar aspirations regardless of their culture (Grech, 2012; Miles, 1995).
There are influences at work in the planning of foreign aid programs. Foreign aid programs may be bound by timeframes and limited by logistical issues, such as poor roads and lack of infrastructure, particularly in remote districts. Programs may also be influenced by the ability of nationals to take up the technology or changes which are being thrust upon them, at the speed of change determined by the funders, rather than the pace of the learners. Best practice dictates that foreign aid programs should have an approach of ‘beneficence’ which at very least should be an attitude of ‘do no harm’ (Fluehr-Lobban, 2008, p. 20). However, an approach of beneficence should set parameters to ensure that societal prejudices are not replicated in aid programs and that aid programs should include the intention to change policies of oppression (Durham, Brolan, & Mukandi, 2014).

Furthermore, there are often mismatches between aid providers and beneficiaries, and in particular people with disabilities. The oppression of people with disabilities has been described as oppression based on power and control, and that people with disabilities are frequently powerless and poor, without control within their own lives (Charlton, 1998). It is not uncommon for rehabilitation professionals to assume that the Western, biomedical, individualistic understanding of disability is universal, and cultural perceptions of disability may never be considered (Barnes & Mercer, 2003). Frequently, people with disabilities are excluded from planning foreign aid programs (Cramm & Finkenflügel, 2008; Mitra, 2006; Toribio et al., 2014; Yeo & Moore, 2003) and lack of consultation has resulted in failures in practical aspects of aid. One example is a toilet block built in a school where a row of small cubicles was mounted on a concrete base, approached by two concrete steps. A structure such as this is not accessible for those with mobility impairments, and difficult for those with vision impairments.

Following my experiences working in projects providing services and training in the disability sector, I believed more needed to be known about the experiences of people with
disabilities, as people in non-Western cultures may have significantly different views on health, illness and even on the sense of self (Iwama et al., 2009; Meekosha, 2008). These differences may determine how programs and services are experienced, and whether proposed beneficiaries perceive them as relevant.

1.1.4 Disability and policy in Timor Leste.

When I first visited the present Timor Leste in 1972, known at that time as Portuguese Timor, I stayed with a family in a village on the edge of Dili. One of the children, a boy of about 10 years of age, was described as ‘this one no good’ as he appeared to have developmental delay and as such he had little status in his family, apart from simply being a family member; I don’t recall seeing any other people, adults or children with disabilities in the fishing community where stayed for about a month.

The country now known as Timor Leste is relatively new, with the republic being declared in May 2002, thus the constitution and associated legislature is based on relatively new understandings and consequently, Timor Leste is not restricted by long-standing legislation representing entrenched attitudes towards people with disabilities which can be found in older societies. The following extracts from Section 16 of the Constitution of Timor Leste: ‘Universality and Equality’ demonstrate an intention to present a grounding represented by non-discriminatory rhetoric.

1. All citizens are equal before the law, shall exercise the same rights and shall be subject to the same duties.

2. No one shall be discriminated against on grounds of colour, race, marital status, gender, ethnical origin, language, social or economic status, political or ideological convictions, religion, education and physical or mental condition.

Under Section 21 of the Constitution of Timor Leste:
‘Disabled Citizens’

‘A disabled citizen shall enjoy the same rights and shall be subject to the same duties as all other citizens, except for the rights and duties, which he or she is unable to exercise or fulfil due to his or her disability’ (Constitution of the Democratic Republic of East Timor, 2002).

In late 2012, the National Disability Policy was approved by the Council of Ministers and government ministries, which included Ministries of Health, Social Solidarity, Education, Sport, Cultural life, Transport, Employment and Vocational training. Local people with disabilities as members of the Asosiasaun Defisiensia Timor-Leste (ADTL) met with each of these ministries for discussions and practical training sessions to help policy-makers understand the barriers which disability imposes on disabled East Timorese. Nevertheless, although inclusive policies are being developed, the research demonstrated that the lives of people with disabilities in Timor Leste, especially in rural areas, are generally difficult. The lives of people with disabilities are generally characterised by exclusion, isolation and limited opportunities for participation, based on stigmatising family and community attitudes and lack of information.

1.2 Overview to the Study

This study was undertaken in a cross-cultural setting where most participants did not speak English. The study was based on a Western methodology, phenomenology, described in more detail in Chapter Four, therefore, an attempt to reach across cultures to understand lived experience needed to be carefully mapped out. An outline of how the research was undertaken is now provided.

4 Known as the Disability Working Group (DWG) up until the end of 2013.
1.2.1 The aim and objectives of the study.

With the long term vision of being able to positively influence the lives of people with disabilities, the aim of this research project was to understand the lived experience of disability in Timor Leste. By doing so, I aimed to clarify what is needed to stop the exclusion of people with disabilities in East Timorese society and to maximise opportunities for building capabilities and support. Understanding the lived experience of physical disability, that is, from the viewpoint of people with disabilities themselves, was the most direct way to understand the barriers to exclusion and to understand what is needed to enable full participation in Timorese society.

The over-arching aim of the research was therefore to investigate the lived experience of physical disability in Timor Leste. The following aims were designed to answer the research question:

1. What are the barriers and facilitators as perceived by people with disabilities in Timor Leste?
2. What are the contextual and cultural factors which influence the daily lives of people with disabilities in Timor Leste?
3. As a result of the discoveries from questions one and two, to identify implications for policy and practice which will enable people with disabilities to develop capacity, to participate in their communities and to realise their potential.

1.2.2 Overview of methodology and methods.

Next, an overview of the methods and methodology of this research is presented. A detailed explanation of the choice of phenomenology is provided in Chapter Four and the method of data collection, photovoice is primarily explained in Chapter Five with further examples in Chapters Six, Seven and Eight. Phenomenology is a methodology which places human experience at the centre of the research, based on a premise that human beings will be
best understood by considering the experience of their ‘life-worlds’ (van Manen, 1990, p.67), by asking ‘what is the meaning, structure, and essence of the lived experience of this phenomenon for this person or group of people?’ (Patton, 2002, p.104).

As I planned to investigate the multiple realities of the participants, interpretivism was the logical conceptual framework for this investigation, as the interpretivist approach ‘looks for culturally derived and historically situated interpretations of the social life-world’ (Crotty, 1998, pp. 66-67). I considered photovoice to be a suitable participatory method of data collection. Firstly, the participants could lead the enquiry by choosing who or what to use as photographic subjects, and thus present their own views of what was important to them in their daily lives (Brunsden & Goatcher, 2007; Hurworth, 2004). This was important as the impact of different conditions causing disability vary widely from country to country and from culture to culture (Allotey, Reidpath, Kouamé, & Cummins, 2003). Secondly, the photographs themselves would help reduce ambiguities in the cross-cultural research process; and thirdly, I hoped that participants would better understand the intentions of a foreign researcher in their midst by their active engagement as photographers. Photovoice met these requirements and provided a rich picture of the lives of a range of people with disabilities to help understand the phenomena of living with disabilities in Timor Leste.

To help develop a picture of the context of the research, that is, the contemporary culture of Timor Leste, I planned to interview key informants who were connected to people with disabilities, these were mostly associated with people with disabilities during the course of their work and the place of stakeholders is explained further in the Chapters relating to the different studies, especially Chapter Eight.

1.2.3 Key Concepts

I now set out some key concepts in use in the thesis which are based on my background as an occupational therapist and development worker. I follow this with an
overview of the thesis and a broad description of how the photovoice projects and the
subsequent analysis were carried out. The key concepts are explained in Table 1. Key
Concepts.

Table 1. Key Concepts

<table>
<thead>
<tr>
<th>Key concept</th>
<th>Conceptual definitions</th>
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<tr>
<td>International development or development</td>
<td>A process of enabling people’s choices and increasing the opportunities available to all members of society (United Nations Development Program, 2002).</td>
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<tr>
<td>Occupations</td>
<td>‘Groups of activities and tasks of everyday life, named, organised and given value and meaning by individuals and a culture. Occupation is everything people do to occupy themselves, including looking after themselves (self-care), enjoying life (leisure), and contributing to the social and economic fabric of their communities (productivity)’ (Law, Steinwender, &amp; Leclair, 1998).</td>
</tr>
<tr>
<td>Occupational engagement</td>
<td>The degree to which an individual is engaged in an occupation. This may range from disengagement to full-engagement and increased Occupational engagement is associated with increased happiness and sense of well-being (Sutton, Hocking &amp; Smythe, 2012)</td>
</tr>
<tr>
<td>Occupational form</td>
<td>‘The circumstances that elicit, guide and structure’ particular activities; for example the occupation of food preparation has a particular occupational form when carried out for Songkran, the Thai New Year (Hocking, 2011) or for a traditional Timorese wedding, and the clothing and ornaments worn in Timorese traditional dance</td>
</tr>
<tr>
<td>Occupational justice</td>
<td>Occupational justice is concerned with ‘economic, political and social forces that create equitable opportunity and the means to choose, organise and perform occupations that people find useful or meaningful in their environment’ (Townsend, 1999, p. 154).</td>
</tr>
<tr>
<td>Occupational marginalisation</td>
<td>‘Exclusion from participation based on ‘invisible’ norms’ or people relegated to less prestigious occupations, or given little choice or control and limited from resources and opportunities (Durocher, Gibson &amp; Rappolt, 2014, p. 422)</td>
</tr>
<tr>
<td>Occupational performance</td>
<td>Representing ‘the actual execution of an activity and the personal experience of engagement in activity within an environment’ (Iwarsson &amp; Ståhl, 2003)</td>
</tr>
<tr>
<td>Participation</td>
<td>Participation is difficult to define (Hoogsteen &amp; Woodgate, 2010) ‘In the ICF, a person’s involvement in a life situation, representing the societal perspective of functioning’ (WHO, 2011, p. 307). Participation is important to be able to achieve competence, to build relationships and to achieve satisfaction in one’s life (Hoogsteen &amp; Woodgate, 2010).</td>
</tr>
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</table>
1.2.4 **Overview of the thesis.**

An overview of this qualitative investigation of the lived experience of physical disability in Timor Leste is set out next.

**Chapter One:** The background and context to the research was described in a brief summary of the history of Timor Leste, followed by consideration of the place of disability in the development of foreign aid programs. An introduction to the research was provided and this was followed by an outline of the aim of the study, the research questions, the research design and the overall structure of the thesis.

**Chapter Two** is the literature review. Historical approaches to disability, followed by recent approaches to disability, are considered. The development of understanding of lived experience is explored in contrast to other forms of data collection relating to disability, including how understanding disability is reflected in research and practice. Lived experience of disability in three differing countries is presented to provide contrast to the experiences of living in Timor Leste.

**Chapter Three** is a metasynthesis of literature of lived experience of physical disability in East and South East Asia. The limited literature which met the criteria for inclusion for in this study highlighted the overall lack of published literature available written in English in the field. This article has been published.
Chapter Four considers the use of phenomenology and the theoretical perspective of interpretivism used in this study as well as the ontology and epistemology of an occupational therapist as a researcher.

Chapter Five describes position of the researcher, the research design, rigor in research, cross-cultural research issues and translation, and explains the method of data collection.

Chapters Six is an academic paper which contributes to the Method section of the thesis. This paper was a pilot study and describes photovoice in detail.

Chapters Seven and Eight contribute to the Findings section of the thesis and describe two photovoice projects with emphasis on the findings in these two projects.

Chapter Nine is the Discussion section in which photovoice as a method of data collection is discussed, together with an overview of the lived experience of physical disability and the context in which Timorese people with disabilities are living. Limitations in the research are also examined in this chapter.

Chapter Ten presents my contribution to the forthcoming book Occupational Therapy without Borders. My chapter, Chapter 49, has been accepted and the book will be published in 2016. This book chapter considers the place of an occupational therapist working in the cross-cultural context of Timor Leste. The book gives some practical explanations of how to work skilfully and safely in a cross-cultural context.

Chapter Eleven is the Conclusion and also outlines Implications for policy and practice.

Appendix P consists of a published article which is a commentary on the pilot study. The article was published in the Development Bulletin following a presentation at the Australian National University. The citation is Shamrock, J. (2013) The power of pictures: Using
Photovoice to investigate the lived experience of people with disability in Timor-Leste.

Development Bulletin, 63.

1.3 Summary and Conclusions to Chapter 1

This chapter provided an overview of the research, and the context to the research, by describing Timor Leste past and present. This was followed by examining disability and foreign aid, especially in Timor Leste. Finally, the outline of the research questions and objectives, the research design, and the overall structure of the thesis was laid out.

Chapter Two, the literature review, follows and a range of approaches to disability are considered. The development of understanding of lived experience is explored, as a means of data collection, in contrast to other forms of data collection relating to disability. This includes how understanding the lived experience of disability provides additional important information in research and practice.
Chapter Two: Literature Review

Key to the thesis

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<tr>
<th>Chapter</th>
<th>Description</th>
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<td><strong>2. Literature review</strong></td>
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<td><strong>3. Literature review</strong></td>
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<td><strong>4. Methodology</strong></td>
<td>Methodology, research framework</td>
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<td><strong>5. Methods</strong></td>
<td>Research method, research details</td>
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<td><strong>6. Methods</strong></td>
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<td><strong>11. Implications for practice</strong></td>
<td>Implications for practice</td>
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<tr>
<td><strong>Appendix P</strong></td>
<td>Descriptive article</td>
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In this chapter, I review the literature relating to different aspects of disability, which may influence the way in which disability is experienced in Timor Leste. In this chapter, historical views of disability within different cultures are considered, followed by an investigation of views of disability in contemporary times. Next, I consider disability as it is conceived by the World Health Organisation (WHO) and the United Nations (UN), as these viewpoints influence the way in which foreign aid agencies, working in developing countries, include disability within their aid programs.
Finally, the lived experience of people with disabilities in three developing countries is examined, in preparation for Chapter Three which is a metasynthesis on the lived experience of physical disability in East and South-East Asia.

2.1 Approaches to Disability

Views of disability depend on the paradigm or context under consideration (Braithwaite & Mont, 2009; Iwarsson & Ståhl, 2003), and religious beliefs within society often provide a context which has influence on attitudes to people with disabilities. Throughout history, in both Western and non-Western cultures, there has been a variety of approaches to disability based on differing cultural and religious understandings; some major influences at different times and in different places are presented below. The majority of people in Timor Leste are Christian with an overlay of ancestor-based beliefs and systems of rituals (Molnar, 2010). Religious affiliation is evident in Timor Leste on Sundays where street-scenes usually feature well-dressed families walking to church or going to cemeteries to visit the graves of family members who have recently died.

2.1.1 Early approaches to disability.

Culture is not an isolated phenomena, rather it is located on a continuum consisting of layered processes, and an understanding of the layers relating to disability helps to understand the prevailing attitudes to disability in Timor Leste today (Fontes, 2008). Religion influences societal attitudes to disability and also influences attitudes of some of the NGOs providing services to people with disabilities in Timor Leste, most commonly Christian organisations. Timor Leste is a predominantly Christian country, as a result of Portuguese colonial influence (see below) therefore I present a brief look at early Christian ideas about disability as background to present attitudes to disability, both by service providers (both Timorese and foreign) and by Timorese in general. I give examples of attitudes of early non-Christian
attitudes to disability to present a sense of the range of attitudes to disability through the ages and within different cultures.

Christian writing from biblical times describes people as clean or unclean, whole or defective, beautiful or ugly, and a person with a defect such as blindness was seen as cursed for being different and unequal to others (Olyan, 2008). Early Judaism viewed impairments as disease and a sign of sin or wrong-doing, early Christianity saw disease as a punishment or curse (Barnes & Mercer, 2010), and this view was prevalent in Catholic Portugal, of which East Timor was once a colony (Fontes, 2008; Loja, Costa, & Menezes, 2011). In contrast to negative attitudes associated with disability, some early edicts concerning the care of people with disabilities can be seen in the Old Testament. For example in Leviticus 19:14, citizens are advised not to cause hazards for those who are deaf or blind; in Deuteronomy 15:11, there is a reminder to be generous to those who are poor or needy (Albrecht, Seelman, & Bury, 2001). In Europe, there are reports of Christian hospices for the blind set up in the fourth century; and there is record of the first sheltered workshop known as the Congregation of the Three Hundred, to provide help to a group of 300 hundred crusaders who had been blinded by the Saracens (Selway & Ashman, 1998). Additionally, ideas about how the human body should be viewed have changed over times, and medical historians have concluded that ‘normality’ and ideas about the normal body, have changed in tandem with cultural and social changes (Bickenbach, 1993; Davis, 1995).

There is little acknowledgement of non-Western historical origins of attitudes to disability in Western literature. This lack of acknowledgement occurs, despite Disability Studies appearing in the West as a discipline during the 1960s and 1970s, at the same time as the study of world religions and cross-cultural interests became popular (Miles, 2002). Although Timor Leste is predominately a Christian country, it is important to consider non-
Western religious influence on ideas about disability, in order to compare the influence of religion on societies.

In Timor Leste the majority of the population is Christian however, worldwide, at least 70% of the people with disabilities do not live in Judaeo-Christian cultures (Miles, 1995). To demonstrate the importance of religion in societal responses to disability, two viewpoints from non-Christian religions are briefly considered. Examples include the early Zoroastrian prophetic vision of an ideal state at some time in the future where no-one would have disabling conditions such as lunacy, maliciousness or would be humpbacked or leprous. Conversely, the early Jaina communities of South Asia were advised not to comment on visible disease or disability in the vicinity of those with disabilities, and laws were written to fine those using abusive language towards such people (Miles, 2000).

Islam is one of the major world religions and there is a small Muslim community in Timor Leste. There is no single Muslim viewpoint regarding disability although it is seen as ‘morally neutral’ and a natural part of the human condition (Hasnain, Shaikh, & Shanawani, 2008, p. 32). Islam itself has varying views as reported by these authors who note that in some Islamic cultures, disability is seen as the result of a curse by a spirit or djinn. The authors above see a parallel with Christian beliefs stemming from stories of Jesus expelling evil spirits from people with disabilities, and these beliefs can be found in minority groups in both these faiths today.

People living in some Islamic cultures base their views and attitudes to disability on the Islamic Jurisprudence or Fiqh. The Fiqh consist of Muslim jurists who interpret the laws for the benefit of the general population, and the jurists have made statements based on interpretations of the Quran through the ages, regarding what actions can be undertaken to prevent or manage disability, with charity strongly advised as a spiritual treatment for disability (Ghaly, 2008). People with impairments or illness with functional difficulties have
a range of instructions from the jurists, for example, if it is necessary to omit or make changes in undertaking rituals relating to daily prayers. These instructions also include any problems relating to undertaking the Hajj (the obligatory pilgrimage to Mecca) (Rispler-Chaim, 2006)

2.1.2 Origins of recent Western perspectives of disability

In recent times in Western cultures, ‘Disability Studies’ emerged as a cross-disciplinary phenomenon as a result of changing social trends, such as the beginnings of the scientific method during the Renaissance (Albrecht, Seelman & Bury, 2001), the civil rights movement in the United States, and becoming formalised at the time of the first course in Britain offered by Zola in 1977. This specific course focused on ‘living with a disability’. It was the base for the Society of Disability Studies (SDS) and the Disability Studies Quarterly, a journal edited by political scientist, David Pfeiffer (Rogers & Swadener, 2001). Disability studies investigates the historical, social and political environments in which disability can be found, moving beyond the medical model of disability described below, to consider the disabling nature of communities and of the environment where people live (Block, 2004). Disability studies deconstructs and rethinks the dominant view about disability (Kielhofner, 2005) and closely considers the socio-political and social context in which disability is set (Titchkosky & Michalko, 2009).

Qualitative research grounded in the human experience in Western countries is proliferating, including research on cultural considerations relating to disease and disability (Sandelowski, 2004). However, culture originates from collective social processes which arise from common shared experiences (Iwama, 2006). The majority of the global population with disabilities come from non-Western countries, where local views on health, illness, disability and the sense of self are significantly different from Western cultures (Iwama et al., 2009; Meekosha, 2008). Therefore, Western concepts of disability cannot be applied to
cultures in developing countries (Meekosha, 2008; Mira, 2012). Western concepts of disability in English-speaking countries are based on a biomedical model where disability is medicalised and individualised (Barnes, 2009). Consequently, Western concepts of disability play a part in influencing the lives of people with disabilities in non-Western countries, if foreign aid originates in the West. The evolution of Western views of disability is now presented to provide background to Western attitudes to people with disabilities.

2.2 Models of Disability; a variety of lens on disability

Models of disability in disability research are considered to represent a type of theory about disability, while not representing the theory itself (Llewellyn & Hogan, 2000); and models are also seen as ‘ways of translating ideas into practice’ (Oliver, 2004, p. 19). Models of disability are therefore important as they form the platform on which people with disabilities are viewed. In general terms, earlier Western models of disability were discriminatory and based on the attributes or deficits of the individual as the problem. In contrast, later models considered the context in which the individual was located as the problem, or as a part of the problem. (Bickenbach, Chatterji, Badley, & Üstün, 1999; Marks, 1997). The Capability or ‘Human Development Approach’ (Nussbaum, 2007, p. 21) is used in the United Nations Development Programme and is becoming recognised by those working in the development sector as well as occupational therapists as an important theoretical basis by which to examine vulnerable people. These main models will now be discussed in more detail.

2.2.1 Medical models of disability.

The medical model of disability is the earlier Western approach to disability, it is based on impairment, and is accompanied by diagnoses and medical categories, with the intention of devising treatment (Smart, 2001; Toboso, 2011). The medical model is used in disability literature relating to developing countries where disability is usually considered in
terms of medical treatment and rehabilitation. For example, community-based rehabilitation (CBR), is an approach to rehabilitation commonly used in developing countries and based on the medical model (Finkenflügel, Wolffers, & Huijsman, 2005). CBR was developed as an approach which provided assistance to people with disabilities in their communities, however the earlier forms of CBR were considered to be simply the application of the medical model in a community setting. CBR has since expanded into many broader approaches which may include a human rights agenda and projects intended to promote economic empowerment, such as micro-credit and income generation for people with disabilities (Lang, 2011). Despite changes in the way CBR is carried out, discussion remains whether CBR operates under a more inclusive social model or as a version of the medical model of disability (Finkenflügel, Cornielje & Velema, 2008). Further criticisms of the medical model of disability include:

- an understanding that disability is abnormal or ‘deviant’ (Helman, 2007; Smart, 2001)
- the model’s authoritarian approach towards disability (Koch, Jenkin, & Kralik, 2004; Stambolovic, 2003)
- When disability is seen as a medical problem in developing countries, it then becomes one of the many problems relating to health care and is prioritised below other pressing health issues, such as availability of basic health care funding, infant mortality, clean water and sanitation (Coleridge, 1993).
- an understanding that disability is the result of misfortune or tragedy which calls for charity and/or medical intervention (Oliver, 1986, 1990)
- An understanding that the individual is sick with an impairment or deficit which requires correction (Kudlick, 2003; Whitehurst, 2007).
• The medical model is also known as the individual model, as the focus is on the individual patient who is not expected to play an active role, apart from complying with the directions or prescriptions of the doctor (Davis, 2012).

The medical model has been roundly rejected as a way of understanding disability by Western disability movements. It is seen as limiting, blaming, discriminatory and disempowering, and disability movements have gradually, and mostly successfully worked to broaden the understanding of people with disabilities in their societies (Bickenbach, Chatterji, Badley & Üstüน, 1999; Oliver, 1990).

2.2.1.1 The charity model; a charity lens.

Building on the medical model is the charity model which has roots in the Western, Christian, colonial past (Dalal, 2002; Miles, 2000). The charity model evolved from Western historical explanations of disability, often with disability understood to be the result of divine punishment or moral failing. Western organisations such as the Christian Church or medical organisations (Grech, 2008) assumed that people with disabilities were objects of pity (Bogusia & Alys, 2004).

Those working in an environment derived from the medical or charity model frequently decided what the patient needed (Ingstad & Whyte, 1995), without searching for the capabilities of the beneficiaries (Temple & Edwards, 2002). The model assumes that people with disabilities are excluded from society and, for this reason need charity derived from the benevolence of donors (Bhanushali, 2007). The associated belief is that people with disabilities are generally best managed by separation into specialised services and institutions with an understanding that, if they are out of sight, the problem is solved (Coleridge, 1993; Rioux, 2011). The charity model was in place in Britain where disabled people were institutionalised in colonial times (Meekosha & Soldiac, 2011). Aspects of the charity model can still be seen today in non-government organisations (NGOs) in developing countries such
as Timor Leste, for example an NGO which provided services for people with disabilities in a small community on the outskirts of Dili is described in more detail in Chapter Seven on page 153.

2.2.2 Social models of disability.

The original social model of disability emerged during the 1960s and 1970s in Britain, based on the Union of the Physically Impaired Against Segregation (UPIAS) and led by disabled academic Michael Oliver (Barnes, 2003; Finkelstein, 2002; Lutz, 2003). In the United States, the forerunner of the social model was known as the ‘independent living movement’ which was developed to resist the dominance of health professionals and government services, and which was based on the attitudes and approaches of the medical model (Toboso, 2011). The model was based on the experiences of disabled activists living in a Western culture, for example Great Britain and the USA, and was devised as a tool to understand the disabling features of modern Western society (Barnes, 2012).

The social model has two important viewpoints:

- Disability seen through the lens of the social model is a limitation or inability to participate because of barriers which may be physical or social. Thus society is seen as the cause of disablement, and an end to the oppression of discrimination is seen as vital for people with disabilities. (Masala & Petretto, 2008).

- The social model declares that people with disabilities have a right to participate in policy and initiatives for change which are related to their lives; and that they have a right to participate in all levels of society, rather than being dependent on services provided by the able-bodied (Lutz, 2003; Oliver, 1990).

However, other writers were concerned that the social model did not adequately cover all the concerns of people with disabilities (Goodall, 1995; Lutz, 2003; Titchkosky & Michalko, 2009). Disability is complex and multi-dimensional; and for this reason the person,
the impairment and the problems caused by environment must all be taken into consideration, not one at the exclusion of the other (Bickenbach, et al., 1999; Goodall, 1995). According to Thomas (2004), the social model has an ‘almost iconic status’, as the model is seen as the key to discussion about disability in society, with attitudes either for or against it and the social model of disability has been described as a product of the concerns of ‘Western white, urban, educated disabled academics in industrialised settings’ (Grech, 2009, p.775). However, ideas about the place of disability in society are changing, together with the changes within societies. (Gabel & Peters, 2004).

At the time when the social model was evolving in Britain, Saad Nagi put forward the Nagi model in the USA (Fuiiura & Rutkowski-Kmitta, 2001). Nagi, a sociologist, was concerned about the semantic and conceptual ambiguities in the disability literature regarding disability and its associated concepts. He acknowledged the importance of family, society, community and environment as influences on disability, and his conceptualisation gave development practitioners a common language with a broader base from which to consider people with disabilities (Jette, 1994). The Nagi model promoted a social and cultural view of disability (Masala & Petretto, 2008), which could also include the influence of cultural factors (Mitra, 2006). For example, the Nagi model helped inform a study of physical disability and functional limitation amongst aging Nigerians (Abdulraheem, Oladipo, & Amodu, 2011). The Nagi model was a building block for further understanding of the ‘main pathways’ in the process of disablement (Jette, 2006) however, this model has not been widely used in writing about disability as the taxonomy and language of the ICF is preferred as a universal language for describing disability and the issues associated with disablement (Stucki, 2005).
2.2.3 The capability approach (CA).

Nobel Laureate, Amartya Kumar Sen, the author of the capability approach (Sen 1985, 1999, 2005) originated from Bangladesh and his early experiences included the great famine of Bengal and the partition of India. His many publications included writings on savings and capital in developing countries, and issues of property and inheritance in rural India. Sen’s model (1985) addressed the place of well-being, inequality and the issues of livelihood and poverty, in interaction with an individuals’ personal characteristics, such as age or impairment. This was in contrast to the more common approach in development, of primarily considering disability as a national economic factor (Greig, Hulme, & Turner, 2007).

Sen asked questions about quality of life as could be seen by the opportunities actually available, based on three interconnected elements: ‘functionings (what a person are capable of being and doing), capabilities (the functionings a person has the opportunity and ability to achieve), and agency (the freedom to choose the functionings one values)’ Hammell, 2015 p81). He saw ‘development as freedom’ and he acknowledged the value of ‘human and social capital’; for example he described the value of the web of relationships within poor communities (Corbridge, 2002, p. 192). The model aligns closely with the World Health Organisation (WHO) International Classification of Functioning, Disability and Health (ICFDH) (Sen, 1985), upon which disability is conceptually positioned within society from the point of view of the WHO.

The capability approach to disability is not considered to be a definition of disability; rather it attempts to view the potential for the individual with disability to function within a complete context. The impairment is only one factor which is considered together with other significant factors such as age, stigma, race or gender (Mitra, 2006). An example could be the use of the model when considering the impact on a blind woman of child bearing age, with only remnants of her community and family intact, following the 2004 and 2005 earthquakes in Sumatra (Bradby, 2002). The writings of Sen have had a significant impact on the foreign aid and international development sector, leading to the establishment of development indicators such as the Human Development Index, the Gender Empowerment Index and the Human Poverty Index, all of which arose within the UN Development
Sen’s influence is extensive in development circles, although his model is seen by some as less relevant when more urgent issues such as acute medical care are considered to be of primary importance such as when dealing with major issues such as famine, freedom, security and stability (Corbridge, 2002). Sens work has at its core the question: ‘what are people actually able to do and to be? What real opportunities are available to them?’ (Nussbaum, 1997, p12).

The capability approach is seen by Hammell (2008, 2015,) as a significant way for occupational therapists to view their engagement with people with disabilities. Hammell (2008) suggests that the occupational therapist using this approach would view the impairment as a prerequisite to disability, however, the impairment must be considered together with other factors such as personal characteristics (which include gender, race and age), environmental factors such as access which may influence function, and other resources which can support the individual to make choices and take up opportunities to achieve well-being. Burchardt (2004) highlights Sen’s insistence that well-being and inequality cannot be estimated simply on income as there may be extra costs associated with impairment, such as the need to pay for personal assistance or for extra heating as well as noting that other variations to the amount of resources that an individual requires may also be dictated by conditions such as pregnancy or age.

Sen was influenced by Eastern and Western thinkers who rejected a reductionist approach with an accompanying list of capabilities required for wellbeing. Sen sought a more holistic view instead, supported by research in non-Western countries such as Afghanistan, where local context which included belonging and inclusion in community life, were identified as important, rather than an individual’s performance of particular activities (Hammell, 2015).
2.3 Disability in Foreign Aid

In my research on the lived experience of physical disability in Timor Leste, I worked closely with an NGO which provided support in the form of facilitating access to people with disabilities. As this NGO is a part of the landscape of services being developed in Timor Leste for people with disabilities, a background to international aid and development in developing countries is presented below.

Development is a broad term in use, when foreign development aid is provided to developing countries by governments, international agencies and non-government organisations (NGOs) (Riddell, 2007). Little agreement can be found about the original meaning of the term ‘development’ (Power, 2004) although the term can be traced to the Marshall Plan which aimed to assist poorer countries in Europe following the Second World War (Fukuda-Parr & Lopes, 2013; Mills, 2008). The Marshall Plan was devised to develop a prosperous Europe after the Second World War. The intention was that Europe would become a partner of the United States based on ‘the creation of a large market in which capital, labor, and goods could move freely across open internal borders’ (Chollet & Goldeier, 2005, p, 11) and use of increasing technology would be the means of production.

These ideas of economic recovery were applied to issues such as poverty in developing countries, with the expectation that technological advancement would resolve these problems as well. However, by the 1970s, this approach was being acknowledged as a failure (Munsaka & Charnley, 2013). Instead, the gap between the wealth and health of the few rich nations compared to that of the many poor nations was being described as one of the biggest problems of the time and an economic scandal (Greig et al., 2007). Despite these views, the success of the Marshall Plan in Europe following the Second World War is not forgotten and there have been continued calls for further ‘Marshall Plan-style’ interventions.
such as using this approach for the ‘Make Poverty History’ agenda in aid delivery to Africa (Lockwood, 2005, p. 785).

Disability has been linked to the Western preoccupation with either the medical model or the social model of disability above the practicalities and difficulties of day to day life in a poor country where the efforts imposed by poverty are magnified when disability is also a part of day to day life (Yeo, 2005). However disability issues are becoming a part of agendas within development practice, based on changing views of disability. A significant stage in raising the profile of disability is represented by the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) which was put forward in May 2008. Article 31 on the UNCRPD states that accurate statistical data is needed to enable effectively inclusive policies and practice and article 32 of the UNCRPD states clearly that:

States parties recognise the importance of international cooperation in the present Convention, and will undertake appropriate and effective measures in this regard, between and among States and, as appropriate, in partnership with international and regional organisations and civil society, in particular organisations of persons with disabilities (page 24).

Disability has broad associations which needed to be addressed and the most significant association was seen as poverty, with disability and poverty seen to be the causes and consequences of each other (Yea & Moore, 2003). Yet there are problems associated with definitions of poverty, problems obtaining robust statistical data within signatory countries and limited consideration of, or funding for research into disability within international development. Groce, Kett, Lang & Trani (2011) state that these factors result in the links between poverty and disability now being considered as significant yet fragile. Furthermore, these authors report that closer examination of data relating to disability from very poor countries using Amartya Sen’s capability approach reveals that while poverty...
overall may not greater for those with or without disabilities in the lowest ranking countries in the UNDP’s (United Nations Development Programme) Human Development Index (HDI), the results of poverty are more severe for those with disabilities, and the severity may vary depending on the disability. For example, Afghanistan is one of the lowest ranking on the HDI where school attendance varied depending on whether a child had a disability or not, and varied further depending on the nature of the disability, on whether the child was male or female, whether the child lived in an urban or rural setting or whether the family was from an ethnic minority.

Despite the emergence of development practice as a field of endeavour with a body of research and policies at all levels, disability is still marginalised and poorly represented in written English academic literature relating to poor countries (Albert, McBride, & Seddon, 2004). According to Grech (2009), some of the major issues not addressed in disability literature, as it relates to poor communities in the majority world, include:

- the importance of physical strength for poor workers
- the lack of voice amongst those with disabilities
- the conflict of managing disability against the many other claims for health services
- the impact of faith on people with disabilities
- the assumption that all people with disabilities are excluded and oppressed
- the impact of singling out people with disabilities and subsequently excluding them from their communities (Grech, 2009).

Further problems stemming from the small representation of people with disabilities living in poor countries are considered below in the light of the International Classification of Functioning, Disability and Health (ICF), the United Nations Convention on the Rights of People with Disabilities (UNCRPD) and the Millennium Development goals (MD), all of

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which are overarching structures associated with the United Nations (UN) which have a bearing on how foreign aid is undertaken in poor countries.

2.3.1 Disability and the International Classification of Functioning, Disability and Health (ICF).

A review of the evolution of approaches to disability within the World Health Organisation (WHO) is included here, as these views broadly reflect the understandings of disability in Western societies; and which are further reflected in approaches to inclusion of people with disabilities in foreign aid.

The WHO first attempted to define disability with the publication in 1980 of the first version of the International Classification of Impairments, Disabilities and Handicaps (ICIDH) (Wong, 2011). The publication of the ICIDH was seen to be a breakthrough at the time, as it aimed to classify the consequences of diseases and injuries by using a linear approach; that is, at the organ level, disease could cause an impairment (abnormality or loss or of bodily structures or function) which was seen to cause a disability (a lack of ability to perform a normal activity) at the person level. This approach also included the impact on the individual at the societal level, where a handicap could be observed (defined as a limitation with regard to fulfilling a role in life) (WHO 1980).

The linear and causative view of disability was challenged by the Western disability movements; and in 2001, the ICF replaced the ICIDH. The aims of the ICF took a broader view again of health and disability, and were designed ‘to provide a unified and standard language and framework, for the description of health and health-related states. It defines components of health and some health-related components of well-being (such as education and labour) (WHO, 2001, p.3). The ICF was intended to parallel the publication of the International Classification of Diseases (ICD), which was a new and important tool providing information about diseases, disorders and injuries. However, the medicalised approach to
disability still prevailed; the ICF presented one viewpoint from that era which expected that the individual must fit into a normal world and failure to do so came from the individual herself (Haglund, 2003). According to the WHO:

Disadvantage accrues as a result of [the individual] being unable to conform to the norms of his universe. Handicap is thus a social phenomenon, representing the social and environmental consequences for the individual stemming from the presence of impairments and disabilities. (WHO 1980)

This statement clearly places the responsibility of the individual with disabilities to fit into society, and further problems were expressed in relation to this first draft of the ICF. These included:

- A ‘disabled’ person is the recipient of a value judgement as he/she is unable to perform in a way that is normal (Goodall, 1995)
- ICF still has a linear approach with its direct links from disease, to impairment to disability to handicap, is a causal and linear model based only on details of the body, it does not take into account the role of the environment (Imrie, 2004; Masala & Petretto, 2008)
- Disability was seen as a disease process creating abnormality and personal tragedy (Oliver, 1990).
- The ideas of abnormality were narrow and had two significant implications. Firstly, cultural differences were ignored; and secondly, changes leading to difference found in normal aging were left in the ‘not normal’ category (Wendell, 1996).
- Criticism was expressed by members of the Union of the Physically Impaired against Segregation (UPAIS), who insisted that disability does not come from the limitations of individuals, rather it reflects society’s failure to adequately accommodate the needs of people with disabilities (Oliver, 1996).
In 2001, the ICF was revised to define health conditions and the states that impact on them. This represented a shift from the previous traditional focus on infection control and reduction of mortality (Stucki, 2005). The ICF considered a health condition to be any of the range of circumstances which impacts on function such as disease, injury, pregnancy, aging, genetic conditions or stress. (Imrie, 2004). The ICF claimed not to describe persons as units to be classified, rather it described situations as they apply to the individual, and always considers the environmental and personal factors.

The ICF suggests that disability is about ‘variation of human functioning caused by one or a combination of the following: the loss or abnormality of a body part (for example impairment); difficulties an individual may have in executing activities (for example activity limitations); and/or problems an individual may experience in involvement in life (for example participation restrictions)’ (Imrie, 2004, p.292). The latest draft from 2001 has been hailed as a valuable tool for research, clinical practice, education and for planning and designing social policy. The document is more able to communicate an individual’s abilities to participate in everyday life, and to describe an individual’s limitations of function, activities or participation (Haglund, 2003). Despite this enthusiasm for the ICF some significant concerns remained (Masala & Petretto, 2008). Particular concerns included:

- Criticism from disability self-advocacy and activist groups who were concerned that the categories within the ICF would provide fuel for further discrimination against people with disabilities (Masala & Petretto, 2008).
- Comments from Hurst (2003) who was concerned that Disability Adjusted Life Years (DALYS) was being used by the ICIDH to measure the health status of countries. DALYS counts people based on their impairments and excludes environmental impacts such as wars, famine, or civil violence.
• Concerns by Hammel et al., (2008) that the term ‘participation’ has not been clearly defined or conceptualised.

• Concerns that the ICF focuses on the individual and his/ her unique circumstances without recognising that the environment including the social, legal, political or economic environments can create impairment or that inequities can be created by discriminatory government policies (Hammel, 2006) DOI: 10.1080/09638280601129181

The ICF is still evolving (McDougal, Wright & Rosenbaum, 2010; McIntyre & Tempest, 2007) and is supported by occupational therapists for its associating with standards for measuring the outcomes of health-related states. However the ICF has limitations, as has been outlined above and is problematic when considering the lived experience of people with disabilities; for example, it excludes subjective experience and excludes whether individuals are doing that which they actually choose to do (Hammel et al., 2008).

2.3.2 Disability and the United Nations Convention on the Rights of People with Disabilities (UNCRPD)

There are further influences within the development industry, which affect approaches to people with disabilities living in developing countries. The United Nations Convention on the Rights of People with Disabilities (UNCRPD) is a significant milestone within the UN, built on a previous milestone, the Standard Rules on the Equalisation of Opportunities for Persons with Disabilities (United Nations 1993). The Standard Rules stated that the individual with disabilities will be provided with tools for rehabilitation to change his/her life. While the intention to provide help for people with disabilities was embedded in this legislation, the implication remained that the individual needed to make the changes, rather than the environment being adapted to the individual’s needs (Stucki, Cieza, & Melvin,
The UNCRPD therefore represented important progress when considering disability within a social context, as opposed to the epidemiological view of the medical model.

The UNCRPD was pronounced by Kofi Annan on 13th December 2006 who declared that:

Today promises to be the dawn of a new era – an era in which disabled people will no longer have to endure the discriminatory practices and attitudes that have been permitted to prevail for all too long. This Convention is a remarkable and forward-looking document (Kanter, 2006, p. 293).

The UNCRPD was considered to be a paradigm shift with a change from ‘non-interference’ or negative rights, such as the right to live free of discrimination, to the positive obligations of states (Kayness & French, 2008; Meekosha & Soldiac, 2011). Examples of positive obligations of states include the obligation to provide information in formats which are understandable to those with communication impairments, as well as the obligation to provide justice in the form of assistance for people with disabilities to interpret information.

The UNCRPD is to be considered a work in progress with the following considerations not yet resolved:

- There is a controversial relationship with the ICF, which is not mentioned in the UNCRPD at all, even though the ICF is a prominent analytical, statistical and planning tool in the United Nations and other national and multinational agencies.
- The document makes use of the social model of disability and makes no mention of treatment or prevention of impairment.
- The UNCRPD does not refer to family members except to privilege the rights of people with disabilities over their family members, with the intention to ensure that people with disabilities are not passive within family life.
• The UNCRPD makes use of human rights approaches which do not originate in developing countries.

• The UNCRPD is expected to make the most difference where approaches to human rights come from ‘symptoms of deeper pathologies of power and are linked intimately to the social conditions that so often determine who will suffer abuse and who will be shielded from harm’ within societies (Farmer, 2004, p. 7).

The UNCRPD is a ruling from the UN which is significant in this research project, because of an important coincidence at the time of the data collection. In September 2013, five members of the Disability Working Group (DWG) from Timor Leste flew to Geneva to attended sittings of the UN assembly, with the intended purpose of finding out what commitments would be needed from Timor Leste when the nation became a signatory of the UNCRPD. In 2015, as this thesis is being written, the UNCRPD is still considered as the beginning of a paradigm shift with further work needed on some difficult aspects such as, bioethics and quality of life (Kayess & French, 2008). Nation-states which are currently (2015) ratifying the UNCRPD, also have to decide how to interpret the UNCRPD within their own frameworks, and how to punish offenders (Meekosha & Soldatic, 2011). In Timor Leste in 2015, consultation continues as the UNCRPD is still under consideration, meanwhile some of the basic requirements, such as implementation strategies are becoming embedded in local legislation.

2.3.3 Disability and the Millennium Development Goals (MDG)

A brief background and description of the Millennium Development Goals (MDG) is now considered, as the MDGs are a part of the background to foreign aid and development in poor countries such as Timor Leste (Saith, 2006). The MDGs were a result of joint consultations between the UN, the World Bank, the International Monetary Fund (IMF) and the Organisation for Economic Co-operation and Development (OECD) and were developed as a
platform from which to base policies relating to international development and foreign aid. The leverage within the MDGs came from pressure on poor countries to attempt to address their own development problems, making this a requirement of foreign aid (Saith, 2006). The MDGs reflected the sidelining of disability as a significant part of foreign aid and the MDGs do not specifically mention disability. They did focus on poverty (Yeo, 2001) and one of the goals was to halve poverty by 2015. As poverty and disability are closely linked, the assumption was that disability would have to be included in programs designed to reduce poverty.

Chopra & Mason (2015) consider the MDGs were mostly successful due to markers such as reduction in child and maternal mortality, improved access to education of primary school children and reduction of HIV/AIDS, tuberculosis and malaria. These changes occurred despite the omission of disability and despite approximately 15% of the world’s population living with some form of disability (Chopra & Mason, 2015). The MDGs were hailed as remaining relevant for their fifteen years duration; but they have now (2015) reached the end of their timeframe. The quantitative targets can now be reviewed by agencies such as the World Bank, the IMF and others considering the outcomes from the data sets resulting from the MDGs. It could be posited that the use of data in relation to the MDGs may possibly not be utilised effectively, as MDGs were set without consultation with all the institutions or countries planning to use them as planning targets (Fukuda-Parr, Greenstein, & Stewart, 2013).

The MDGs were replaced in 2015 by the Sustainable Development Goals (SDG), with a health promotion focus, including an emphasis on, education for all, developing social protection, eliminating systemic poverty and promoting access to gainful employment and healthcare (Geiger, 2015). The Sustainable Development Goals are based on expectations of increased involvement in the business sector where business is seen as a driver for prosperity.
and where thoughtful application of business principles is supposed to be of benefit to the poor (Kharas & Zhang). At this point in time, the Sustainable Development Goals seem to contain many questions, rather than guidance or answers relating to people with disabilities; issues such as human rights, rights of the disabled child and education need more consideration at this time (Yeates, 2015).

The overarching policies established by the United Nations and the World Health Organisation have Western underpinnings, a detail which is not widely acknowledged. A response to the Western dominance in approaches to development, in this case in the South Asian context, is addressed by Miles (2002). Miles was concerned that foreign aid comes not from Asian organisations but from European and North American funded programmes, which follow trends. He writes:

In the 1970s the foreigners were funding special schools and talking about training specialised teachers and therapists. In the 1980s they offered Normalisation, Integration, Community Based Rehabilitation, and the eradication of smallpox. In the 1990s, the buzz has been Inclusion, Social Model, Leadership by Disabled People, and elimination (maybe) of polio. None of these offers or ideologies came with even the slightest recognition that South Asia might have some interesting indigenous experiences with which to contribute to its own future (Miles, 2002, p.113).

In summary, the development industry generally operates from a Western perspective, is guided, but not governed by Western superstructure, is reported on by Western visitors or reporters which include the World Bank, the World Health Organisation; and is frequently administered by professionals from Western origins. In the search for information which may be out of sight to a Western researcher in the predominantly Western-based development industry, this thesis is centred on the lived experience of people with disabilities in the Asian
country of Timor Leste and the participants themselves presented the issues that were important to them.

2.3.4 Data collection in developing countries.

The variety of understandings and definitions of disability ultimately result in a variety of findings when researching disability, leading to limitations to the depth of data collection regarding disability in developing countries. Definitions of disability vary from country to country (WHO, 2011), as was seen in Chapter Two and is discussed at length in Chapter Six. For example, data collection relating to disability in developing countries is generally medicalised, despite the impact of broader factors, such as those discussed above (Albert, 2004; Oliver, 1996). There is a range of considerations within an exercise to define disability for the purposes of data collection. For example, Brandsma et al., (2009) present a table which offers nine differing definitions of disability. Snyder and Mitchell (2010) note that historically, definitions of disability have been linked to various views of civil rights, and Ingstadt and Whyte (2007, p.11) ask the question ‘what kinds of conditions count?’ as they consider variations to the human condition such as disability arising from chronic conditions or obesity.

Data collection and research undertaken in developing countries - such as surveys prior to establishing new aid projects - often exclude people with disabilities. Examples here include those who cannot write excluded from written data collection, and those with visual or hearing impairments may not receive the needed extra help required to participate in research or surveys. Scholars, policy makers or those planning development activities frequently assume that ‘disabled people have a set of uniform needs and as a result of this broad and inaccurate assumption their needs cannot be adequately met’ (Yeo & Moore, 2003, p.577). There is a further concern that data collection may be undertaken with the internal agendas of the data-collectors influencing the type of data to be collected (Chambers, 2014).
The Washington Group on Disability Statistics was a group established within the United Nations Statistical Division, starting in 2001, to attempt to establish a culturally neutral definition of disability amongst UN member states to provide a framework from which to monitor the UNCRPD. The categories and methods of questioning established by the Washington group are still evolving and being tested (Madans, Loeb & Altman, 2011) meanwhile anomalies remain in the definition of disability which continue to create difficulties for those seeking robust data for disability research.

2.4 Occupational Therapy and Disability

As an able-bodied occupational therapist working and researching in the development industry in Timor Leste, I needed to consider my own views and biases regarding disability in an Asian country. I have an outsider’s view of disability coloured by my white Australian origins and my Western professional training and experiences, both in Australia and in Timor Leste. Occupational therapy is a profession concerned with the spectrum of activities or ‘occupations’ and occupational roles that an individual undertakes during the course of the day, or during a period within his or her life. Occupational therapists believe that ‘involvement in occupation is closely linked to human development, life satisfaction, and health’ (Hemmingsson & Jonsson, 2005, p.572); and that all people have a right to a life of meaning and satisfaction prescribed by what the person does during the day, the occupational roles that the person undertakes and the environment where people engage in occupation (Hemmingsson & Jonsson, 2005).

The Occupational Functioning Model (OFM) is one of several models within occupational therapy and is a model which roughly corresponds to the International classification of Functioning (ICF) (Radomski & Latham, 2008). Parallels include the views of the OFM regarding satisfaction with life roles, family and home maintenance, and activities which increase skill such as hobbies and learning, and are similar to the term
‘participation’ used in the ICF, where involvement in life and societal functioning are considered. The occupational therapist considers competence within life-roles, mastery of the required activities to undertake life roles, and the skills and abilities which underpin both competence and mastery. In parallel, the ICF makes use of the term ‘activity’ to describe the extent to which an individual can engage. The OFM and the ICF are closely aligned in consideration of the spaces where people operate. The OFM uses the terms ‘environment and context’, while the ICF makes use of the term ‘contextual factors’ when considering the natural, built, social and attitudinal environment where an individual lives (Radomski & Latham, 2008). Occupational therapists therefore work in the space ‘between what a person needs to do, wants to do and can do … then uses various occupational, adaptive and adjunctive therapies to intervene.’ (Radomski & Latham, 2008, p. 12).

Timor Leste is located in Asia where views and values differ from Western views. Occupational therapy comes from a Western background and has Western cultural norms embedded in it and Western-based occupational therapy practice may be experienced as oppressive or counterproductive if culture is not a part of occupational therapy (Iwama, 2004). To begin to address cultural differences in occupational therapy, Michael Iwama put forward a model of occupational therapy, the KAWA model, adapted to the Asian context, based on his understanding that ‘Asian peoples may perceive the world quite differently from their Western counterparts. In the KAWA model the world is not seen in the Western manner as rationally separate, instead Iwama introduces the East Asian cosmological perspective placing nature, self and society in a closed, tightly integrated whole…’ (Iwama, 2005, p. 135)

Iwama suggested that, for Asian peoples, and Japanese people in particular, social roles within a group are of paramount importance; the collective is more important than the individual and that individual striving is an anathema, in other words, ‘belonging rather than
doing becomes the social ethos’ (Iwama, 2005, p. 137). East Timorese society has similar concerns where the family unit is a unit of mutual obligation (Brown & Gusmao, 2009), especially in more traditional rural areas. This means that people with disabilities have relationships within their primary groups, family and community, which differ from Western relationships and expectations within families. Thus, I hypothesised that the different balance of relationships in Timorese families is one of the factors resulting in a different lived experience of disability in Timor Leste. As there is no published research on the lived experience of disability in East Timor, this thesis begins to address this deficit, with the intention of contributing to making foreign aid and development more appropriate to people with disabilities in Timor Leste.

Occupational therapists work from a viewpoint of client-centred practice and this requires therapists to help their clients define the outcomes that the clients want for themselves. However, an occupational therapist may face ideological difficulties by only working with the individual in relation to their disabilities (Kielhofner, 2005.) Where a culture values a person for their individual achievements and abilities, an ‘egocentric’ view of what it is to be a person is said to exist and this is the Western approach. Where a culture values a person for their relationships with others, a ‘sociocentric’ view is said to exist, and aspects of both these views are seen in all societies. In a primarily ‘sociocentric’ society, which includes Asian cultures as well as Timor Leste, the independence valued by the Western world, and by occupational therapists (Whiteford & Wilcock, 2000), is not always of primary importance, and dependence on others may be considered more as mutuality and/or love (Tervalon & Murray-Garcia, 1998, p. 10).

Occupational therapists have developed the terms ‘occupational marginalisation’, ‘occupational injustice’ and ‘occupational apartheid’ to denote fields of concern regarding people who are unable to, or who are prevented from, participating in their communities.
(Hemmingsson & Jonsson, 2005; Townsend, 2004). It is tempting, as an occupational therapist, to try to construct an ‘occupational’ model of disability where the barriers and enablers to ‘occupation’ are considered, where the rights of an individual to engage in occupation and the problems caused by occupational apartheid as described above are a part of a conceptual framework. However, Molke (2004) argued that ‘occupational’ literature does not accurately consider the full range of human experience and is biased towards a Western view of occupation.

Other critics of occupational-based thinking note that ‘current conceptualisations of occupation reflect a direction in thinking that addresses societal and political needs rather than how occupation relates to human development and well-being’ (Jonsson, 2008, p. 3). There is a risk that occupational therapists may try to make people from developing countries ‘become citizens of an ‘advanced’ liberal world, consuming and producing Western beliefs to order life to reflect Western notions of freedom, justice and occupational perfection’ (Molke and Rudman, 2009, p.245). To help draw attention to a Western bias, and to highlight the importance of considering cultural environments in relation to the lives of people with disabilities a study of lived experience of disability will provide occupational therapists with a better understanding of life in a developing country, such as Timor Leste. This thesis will also demonstrate that the capabilities approach (Sen, 1987; Nussbaum 2002; 2005) will be an appropriate tool for investigating and addressing the lived experience of people with physical disabilities in Timor Leste.

2.5 Lived Experience of Disability

Increasing importance has been attributed to the collection of literature from an insider’s perspective (that is, from the perspective of people living with disability) (Awaad, 2003; Paterson, 2001). In Western literature, within the field of disability studies, academics with disabilities have provided personal narratives as well as articles, books and reports,
based on reflections on their personal experiences of their disabilities (for example Titchkosky & Michalko, 2009; Toombs, 2001; Overboe, 1999 and Robillard, 1999). However, there is little literature on the lived experience of people with disabilities living in non-Western countries (Albert, McBride & Seddon, 2004; Ghosh, 2012; Meekosha, 2011).

The result of this deficit is that little is known about the lived experience of physical disabilities in non-Western cultures; culture and context play an important part in the life experiences of people with disabilities (Misajon, Pallant, Manderson, & Chirawatkul, 2008), and this was revealed in the metasynthesis written up in Chapter Three. As culture has important impact on the lived experience of physical disability so too does the ability of a researcher to understand the lived experience of physical disability and the researcher needs to be able to reflect on her status within another culture. The ways in which this was addressed is dealt with in more detail on Chapter Five of the thesis.

In this section a range of lived experience of disability from other cultures is presented so that the experiences of people with disabilities in Timor Leste can be seen in context. Some examples from the literature available in English, from non-Western cultures includes exploration of the complexities of gender and marriage for men with disabilities in Jordanian society (Jalal & Gabel, 2014) and a Master’s Thesis by Tulasi Acharya examining the lived experience of two disabled Nepali women writers, Bishnu Kumari Waiwa and Jhamak Ghimire (Acharya, 2012). An obvious barrier for an English speaker is the constraint of language, as literature from the English speaking Western countries is easier to access than literature from non-Western countries not written in English.

To help position the lived experience of physical disability in Timor Leste in context, three developing countries have been chosen for their differences from Timor Leste. In this way, lived experience of physical disability can be contrasted across different cultures. The three countries selected are: (a) India, because the vast population and entrenched attitudes
are a contrast to the small population of the relatively new country of Timor Leste; (b) China because of the influence of the disabled son of a prominent political figure on the emergence of a disability movement in China; and (c) Guatemala because it is a relatively small country with an aging population situated in a different cultural context to Asia, namely within the cultures of South America.

2.5.1 **Lived experience of disability in developing countries – India.**

India is a large and rapidly developing country with extremes of development and poverty and deeply entrenched ideas about disability, based on tradition and religious views. The exclusion and stigmatisation of people with disabilities in India are based on a different understanding of the types of people who are desirable in society; for example, traditionally, people with disabilities were considered unable to perform the rituals necessary for the well-being of the family (Buckingham, 2011).

Women with disabilities in India have been particularly marginalised, firstly, by the feminist movement which saw disability as a form of difference, and at the same time by the disability movement who saw women as primarily women, and discounted their disabilities. Women with disabilities are especially vulnerable and isolated and at high risk of violence, exclusion from education and abandonment (Daruwalla et al., 2013; Jakubowicz & Meekosha, 2002). There are few schools for children with disabilities in India and places reserved for children with special needs in mainstream schools are seldom filled (Buckingham, 2011). A disability rights movement is gradually becoming more visible in India although acceptance of disability is usually based on a ‘charity or pity approach’ (Mehotra, 2011. p71)

The vast Indian subcontinent is represented by a handful of academics with disabilities who write from their informed perspective of lived experience of disability. Anita Ghai, an Indian academic with disabilities, noted that these attitudes are associated with the
dominant Hindu religion and supported by cultural acceptance of pain and suffering as a result of karma (Dalal, 2002). The respondent below lives with the constant daily pain imposed by her disability and her response reflects her daily distress:

Destiny, Fate, God, past sins ... call it whatever you will ... it is not justified.....It would have been better if I’d been allowed to die one day instead of dying everyday… (Lakshmi) (Ghai, 2001. p26).

Indian families care for family members with disabilities, and the family and even the surrounding community are ‘permeated’ by the disability of a family member (Vaidya, 2014, p. 32). Ghai notes that the strength of the Indian family unit is a source of support for a family member with disabilities. She also notes that family support and personal resilience is seriously eroded where an individual such as the respondent above, has to live with on-going daily pain, and where little relief of suffering is available due to minimal opportunities for health care (Ghai, 2001).

2.5.2 Lived experience of disability in developing countries – China.

China is another vast country with small but significant changes in attitudes to disability noted in some sections of Chinese society. Matthew Kohrmann, an acclaimed Western disabled academic (Bourke -Taylor & Hudson, 2005), reported on conversations with people with disabilities in China from his insider perspective. Kohrmann’s interviewee and colleague with disabilities, Hai, commented that:

Just after the Cultural Revolution: we quezi (crippled) were invisible because we hid ourselves away. That’s no longer the case. We’re out on the streets going where we want to go. The world is talking about the disabled now. ... now, most Beijingers expect to see and hear about people like you and me ... (Kohrmann, 2005, p. x)
In China, significant attitudinal changes and opportunities were partially initiated by an individual with high ranking connections. Deng Pufang, the oldest son of Deng Xiaoping, China’s leading government official during the late nineteen seventies to the nineteen nineties, is a name associated with the development of the Zhongguo Canjiren Lianhehui or China Disabled Persons Federation. This organisation’s mission is to help Chinese people with medical services, rehabilitation and publications de-stigmatising disability. People with disabilities in China attribute the improvement in the public understanding of disability to Deng Pufang’s personal and publicised experiences of injury and disability (Bowen, 2008). Despite the improving status of people with disabilities, social barriers are still evident. For example, it is difficult for women and even more difficult for men with disabilities to marry (Nakata, 2007).

Scholars writing about disability in China have noted that the internet is having a profound impact on the lives of Chinese people with disabilities. There are web-sites specifically for people with disabilities, although people with disabilities have less access to the internet than able-bodied Chinese citizens. (Nind, 2011). Sarah Dauncey, commenting on ‘life writing’ which is popular with people with disabilities, stated that this emerging narrative form is seen as a part of the Chinese Communist Party policy of showcasing the ‘triumph over tragedy’ of people with disabilities in the new Chinese environment (Dauncey, 2012, p. 312).

An example of the success of ‘life-writing’ is the author Zhang Yuncheng who lives with the progressive neurological disease, muscular dystrophy. Zhang has made extensive use of digital communication to meet peers, to record his thoughts and experiences and to help others. Dauncey stated that Zhang is but one of many people in China with disabilities who now has a voice due to decreased stigmatisation in the present cultural climate. However, scholars commenting on use of digital communication by people with disabilities note that
this form of communication is only available to a minority of people with disabilities. China is a large country with diverse populations and there is little to be found in English which describes the experiences of minority peoples or people in remote areas in China (Guo, Bricout, & Huang, 2005).

2.5.3 Lived experience of disability – Guatemala.

Guatemala is a small, poor South American country with a population of approximately 8 million people. Guatemala has high unemployment, life expectancy is less than 60 years, levels of literacy are low and 38% of children have malnutrition. Here it was noted that families care for and frequently overprotect disabled family members. Overall, people with disabilities are a source of shame for the family and not considered to be a part of mainstream society (Couch, Goetz, & Baud, 1991). Guatemala is considerably larger than Timor Leste which has a population of 1.2 million. However, there are similarities such as close family units, endemic poverty and significant environmental barriers to participation in activities common to others in the community.

Shaun Grech studied the relationship between poverty and disability in rural Guatemala and his respondents reported a range of difficulties and barriers; these included difficulties associated with poverty and meeting the extra medical expenses which are common to disability. In Guatemala, there is a mistrust of doctors who charge high fees, leading people to self-medicate or to seek cheaper, more traditional means of relief or cure. Other problems included difficulties in achieving education, significant environmental barriers and limited social participation. Grech’s respondents also commented on stigma, exclusion, shame and lack of support from government services related to their poverty and disability. These factors were evident by a note of bitterness in his respondents; for example a respondent stated: ‘What are rights? The government, the municipality or no one has ever given us anything... you are forgotten here ... (Roberto)’ (Grech, 2008).
The findings in Grech’s study highlighted exclusion and poverty as common elements in the lives of people, tempered by factors such as gender and the severity of impairment (Grech, 2008). A study of the aging population in Guatemala revealed a public health concern relating to the increasing aged population, with accompanying increased obesity and chronic conditions with associated disability (Yount, Hoddinott, & Stein, 2010). The study revealed greater disability and poorer self-reported health problems in women within the age group studied (50 years and older at the time of interview). The study provided generalised data on the functional status of the respondents as well as occupation, standard of living, health and identified chronic diseases. These details helped provide a picture of an older population with increasing impairments, although without record of the personal responses and experiences of those interviewed (Battiste, 2011). The aging population is one of the differences between Guatemala and Timor Leste; Timor Leste had 43% of its population under the age of 14, in 2007 (Lundahl & Sjöholm, 2009).

### 2.6 Summary

In this chapter, I referred to the literature which provides a background to my investigation of the lived experience of physical disability in Timor Leste. I considered literature which described some of the many different perspectives on disability from both historical and contemporary times, as these views can help define the different ways people with disabilities live in their communities.

I also addressed some of the reasons for societal attitudes towards disability. Since the Second World War, the human rights of people with disabilities are gradually becoming acknowledged as societal attitudes change. However, disability remains a minor consideration within the development field as the problems identified in the Sustainable Development Goals - systemic poverty, educational opportunities, lack of social protection, access to gainful employment and healthcare needs - appear more pressing and involve a
larger demographic base. Finally, I presented sketches of lived experience in three different developing countries to provide a basis for comparing and contrasting lived experience of disability in Timor Leste.

In the following chapter, Chapter Three, a metasynthesis of literature on the lived experience of physical disability in East and Southeast Asia is presented, as a further step towards understanding disability in Timor Leste.
Chapter Three: Literature Review

Key to the thesis

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<th>Description</th>
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<td>1. Introduction</td>
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<td>11. Implications for practice</td>
<td>Implications for practice</td>
<td></td>
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<tr>
<td>Appendix P</td>
<td>Descriptive article</td>
<td>Published</td>
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</tbody>
</table>

The previous chapter was an overview of background literature relevant to this thesis. Chapter Three is a metasynthesis of literature which reports on the lived experience of people with disabilities in East and Southeast Asia, to provide a broad context in which the thesis was located. The paucity of literature which met the inclusion criteria highlighted the importance of this research.

This chapter constitutes an article which was written for and accepted by the British Journal of Occupational Therapy (BJOT). BJOT has an impact factor of .636 in 2014. BJOT was selected because of its broad readership and because it publishes both qualitative and quantitative research including literature reviews.
The Lived Experience of Disability in East and Southeast Asia: a Meta-Synthesis of Qualitative Literature Written in English

3.1 Abstract

People with disabilities make up 15% of the world’s population, but many of these people are marginalised in their communities, experiencing stigma and exclusion. There is little literature about people with disabilities describing their lived experiences, and without such understanding it is difficult to provide truly inclusive health services. This meta-synthesis is derived from a systematic review of academic articles written in English, and includes quotations from people with physical disabilities commenting on their experiences in eight Asian countries of East and Southeast Asia. Fourteen articles met the selection criteria. Six overarching themes found in the articles established that (1) primary groups are important for people with disabilities, (2) journeys in resilience vary among individuals with disabilities, (3) managing poor health makes life with disability more difficult, (4) education is important but difficult for people with disabilities to achieve, (5) poverty is closely linked to disability, and (6) values and beliefs are enmeshed in the experiences of living with disability. The meta-synthesis is valuable because it revealed differing cultural contexts within the universality of human experience.

Practical application of cultural context will make research or healthcare practice more relevant to people with disabilities in Asian countries. Further research is needed to determine the nature of culturally appropriate research, clinical practice and health promotion.

Keywords: meta-synthesis; cross-cultural practice; disability; Asia; health
People with physical disabilities make up 15% of the global population with 20% of the global poorest of the poor, said to be disabled (Grech, 2011; Groce, 2011; Yeo, 2005). Researchers are placing increasing importance on understanding disability from the insider’s perspective (Paterson, 2001; Peters, Gabel, & Symeonidou, 2009) however, there is still limited information on lived experience of disability from the perspective of people in non-Western countries, including countries of Asia (Meekosha, 2008). This meta-synthesis was part of a larger study on the lived experience of physical disability in East Timor, thus a broad understanding of the experience of physical disability within the East and Southeast Asian context was of particular interest.

International Classification of Functioning, Disability, and Health (ICF) adopted by the World Health Organization (WHO) in 2001 provides a basis for understanding disability. The ICF Handbook states that disability broadly is a ‘dynamic interaction between a person’s health condition, environmental factors and personal factors’ (p. 5). This description does not differentiate by aetiology, instead disability is described as covering a range of levels of functioning including (a) impairments in body functions and structures (b) limitations in activity and (c) restriction in participation (WHO, 2001). In this study one or more of these aspects of disability were found in all the original articles with (b) and (c) being of particular interest where contextually specific attitudes, traditions, and activities are found.

Qualitative research grounded in the human experience in Western countries is proliferating including research on cultural considerations relating to disease and disability (Sandelowski, 2004). However, culture originates from collective social processes which arise from common shared experiences (Iwama, 2006). The majority of the global population with disabilities come from non-Western countries where local views on health, illness, disability and the sense of self have significant differences from Western cultures (Iwama et
This meta-synthesis was undertaken to help Western readers understand the lived experience of disability in non-Western cultures.

3.2 An Overview of Meta-Synthesis

Meta-synthesis enables a higher level of analysis within qualitative research by taking the findings (Jensen & Allen, 1996) from studies on similar phenomena, and interpreting and transforming data to provide a broader view of that phenomena (Rice, 2008; Sandelowski, 2006). Noblit and Hare (1988) developed meta-ethnography as a way to improve the interpretation of qualitative research and to advance understanding of social phenomena. Their approach is a rigorous yet creative strategy to synthesise data from similar studies using an interpretive paradigm.

For the purposes of this study, meta-synthesis is described as:

The examination, critical comparison and synthesis of published qualitative studies that concern a common topic. The meta-synthesis aims to advance knowledge by accomplishing a greater depth of understanding and degree of conceptual development than can be attained from a single study. (Hammell, 2007, p.125)

There are three possible goals of meta-synthesis that complement and overlap each other (Zimmer, 2006). These are to either develop theory, find higher levels of abstraction by theory explication, or use a descriptive approach to gain a higher level of generalisability. A descriptive approach is the appropriate stance for investigating ‘lived experience’. The aim of this paper is to synthesise the literature in order to better understand the phenomenon of the lived experience of adults with physical disability in East and Southeast Asia.

3.3 Methods

Originally Noblit and Hare (1988) outlined a seven stage framework by which to undertake meta-ethnography. More recently, their seven stages have been modified to a five stage process as described by Campbell et al., (2003), Gewurtz et al., (2008) and Hammell...
The five stage process used in this meta-synthesis is based on the approaches used by these authors.

3.3.1 **Stage one: Identify relevant research questions.**

The principal research question for the meta-synthesis was: What does published qualitative research written in English tell us about the lived experiences of adults with physical disabilities in East and Southeast Asia? Countries examined included China, Japan, Republic of Korea, Mongolia, Taiwan, Indonesia, Malaysia, Singapore, Philippines, East Timor, Brunei Darussalam, Cambodia, Laos, Myanmar (Burma), Thailand and Vietnam (United Nations Statistics Division, 2013).

3.3.2 **Stage two: Identify appropriate inclusion and exclusion criteria.**

In order to be included in the meta-synthesis the articles must: (1) include physical disability, (2) include the perceptions of the person with disability, (3) include verbatim responses to the research questions in the original research, (4) include only peer reviewed articles and (5) be written in English. An article was excluded if: (1) there were no verbatim comments from participants, (2) the identified Asian population was located outside Asia, (3) was about minors under the age of 18 years, (4) was about an ex-patriate population living in an Asian country and (5) was only about the perceptions of others such as carers or family.

3.3.3 **Stage three: Develop search strategies to identify and retrieve relevant qualitative studies.**

A literature search was made using Search CINAHL, Google Scholar, Scopus, ProQuest and Medline. Keywords included stroke, cerebrovascular accident* and polio amongst others. The search was further limited by inserting the names of the countries of East and Southeast Asia and finally, limited again by use of terms from qualitative research methods in which lived experience can be found such as focus group, grounded theory, ethnograph* amongst others. Reference lists of articles and individual journals were hand-
searched including *Disability and Society*, *Disability and Rehabilitation*, *Development in Practice*, *Third World Quarterly*, *Asian Pacific Disability and Rehabilitation Journal*, *The Review of Disability Studies: An International Journal* (RDS) and on-line sources, such as Source at [www.asksource.info](http://www.asksource.info) and Independent Living Institute at [http://www.independentliving.org/docs7/miles200701.html](http://www.independentliving.org/docs7/miles200701.html). Finally, citation, author and footnote searches were carried out by checking the reference lists in the articles that were accepted for the analysis. Appendix O shows the flow-chart of activities related to the literature search based on the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) strategies for literature searches (Mohar et al., 2009).

3.3.4 **Stage four: Determine a framework for assessing quality and set standards for including studies.**

Evaluation for validity, reliability and credibility was not undertaken because of the complexity of evaluation across different epistemological traditions (Sandelowski, Docherty, & Emden, 1997). In this meta-synthesis the value of the peer-reviewing process for publishing academic articles was accepted at face value and a total of fourteen published, peer reviewed articles were found which met all the selection criteria. This small body of literature reflects the limited number of studies on lived experience of physical disability written in English from the vast geographical regions of East and Southeast Asia. Noblit and Hare (1988) stated that a small number of studies will suffice for a meta-synthesis, without specifying exactly how small; therefore, 14 articles were deemed adequate to better understand the phenomenon of the lived experience of adults with physical disability in East and Southeast Asia.
3.3.5 **Stage five: Synthesise findings from across studies, transform findings into a new conceptualisation.**

A range of approaches can be used to analyse and synthesise the findings from across different studies (Finfgeld, 2003; Sandelowski, Lambe, & Barroso, 2004). All approaches compare, contrast, then synthesise findings which relate to the phenomena of interest (Gewurtz et al., 2008). In this current meta-synthesis three stages were used in the analysis and synthesis of findings, based on the approach of Noblit and Hare (1988). Each of the final fourteen articles was read in depth and each description, comment or quotation relating to lived experience was given a descriptive code in the form of a word or brief phrase. The body of text was then entered in a table with the descriptors entered in a separate column against the significant piece of text. The descriptors were clustered together using the ‘sort’ function in Microsoft Word. At this point the clustered codes could be interpreted into general themes and were compared across papers (Atkins et al., 2008). Finally similar categories were collapsed into each other and the themes were assigned descriptive metaphorical titles.

**3.4 Results**

The 14 articles included responses from one hundred and seventy nine participants from eight countries listed in Table 2. The data used in this paper came from firstly verbatim responses of participants to allow the voices of the respondents with disabilities to be clearly heard and secondly from conclusions drawn by authors in their original articles.
Table 2
*Articles with Brief Findings Included in the Meta-Synthesis*

<table>
<thead>
<tr>
<th>Authors and citation</th>
<th>Title</th>
<th>Sample size</th>
<th>Method or methodology</th>
<th>Summary of findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lui and Mackenzie (1999)</td>
<td>Chinese elderly patients perceptions of their rehabilitation needs following a stroke</td>
<td>15</td>
<td>Ethnographic approach</td>
<td>Unmet patient need during recovery following stroke: information, respect as individuals, links between psychological and physical needs, importance of social and spiritual needs.</td>
</tr>
<tr>
<td>Boonpiam (2006)</td>
<td>Experience of Motherhood Among Women with Physical Disability in Thailand</td>
<td>9</td>
<td>Interviews and participant observation</td>
<td>Importance of fulfilling women’s roles: the will to become a mother, unique methods of child-care, extensive barriers, stigma and criticism, family and society.</td>
</tr>
<tr>
<td>Rukwong et al (2007)</td>
<td>Suk-Sam-Bai: The Quality of Life Perceptions Among Middle-Aged Women Living With a Disability in Isaan, Thailand</td>
<td>16</td>
<td>Qualitative method</td>
<td>Experiences of gain, maintenance, and loss, physical health, maintaining gender role and a caring and supportive environment.</td>
</tr>
<tr>
<td>Authors and citation</td>
<td>Title</td>
<td>Sample size</td>
<td>Method or methodology</td>
<td>Summary of findings</td>
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<tr>
<td>Roy (2011)</td>
<td>Beyond disability and ethnicity challenges: Narrative of a Para-Olympian Malaysia</td>
<td>1</td>
<td>Narrative approach</td>
<td>Insensitive engendered attitudes from others.</td>
</tr>
<tr>
<td>Norris et al (2012)</td>
<td>‘It burdens me’: the impact of stroke in central Aceh, Indonesia.</td>
<td>11</td>
<td>In-depth interviews, photograph-facilitated interviews and participant observation.</td>
<td>Loss of valued roles, gradual adjustment to their losses with the help of religion and supportive relationships, traditional healing, social roles.</td>
</tr>
<tr>
<td>Authors and citation</td>
<td>Title</td>
<td>Sample size</td>
<td>Method or methodology</td>
<td>Summary of findings</td>
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Six themes were identified using the methods described above: (1) the importance of primary groups for people with disabilities, (2) journeys in resilience vary with individuals with disabilities, (3) managing poor health makes life with disability difficult, (4) education and understanding are important and difficult for people with disabilities to achieve, (5) poverty is closely linked to disability and (6) values and beliefs are enmeshed in the difficulties of living with disabilities.

3.4.1 Theme 1. The importance of primary groups for people with disabilities.

Comments relating to connections to the individual’s primary groups including family, community, and work made up the largest category. Firstly many people with disabilities commented on how a person with disabilities was accommodated within the family:

‘My husband has suffering from many things. He is washing dishes, clearing room. He does anything for me. He supports me very much.’ (Hwang et al., 2004, p. 224)

Some family relationships did not survive disability such as the wives who abandoned their husbands following the husbands’ spinal cord injury:

‘I have met a lot of these cases and the fibre of love is not there, and they think they will be a burden to them … so they go to find someone to look after them and for sex (Boonmee 50-year-old with quadriplegia, urban location)’. (King & King, 2011, p. 1483)

One respondent reported guilt for being unable to undertake traditional family roles. In this case, a son could not do as his mother asked:
‘I knew my mother had devoted her life to me. In my mind, I knew my behavior was not good. When she wants me to do something for her, I can do nothing.’ (Ide-Okochi, Yamazaki, Tadaka, Fujimura, & Kusunaga, 2013, p. 6)

Community involvement was important to the respondents. Some respondents reported consolation from the acceptance of their disabilities by others in their communities:

‘Even though I cannot move outside my house, my neighbour sometimes visits me at my home … we talk together … this makes me feel relaxed.’ (Rukwong, 2008, p. 290)

Other respondents experienced the loneliness of non-acceptance:

‘I didn’t belong to the community … I couldn’t do anything fully… I always went and hid my face. Even if I could do something, I was never given the opportunity … I always thought I’m not like other people … I thought of myself as the worst rubbish (23 August 2000)’. (Gartrell, 2010, p. 297)

One perceptive respondent noted that acceptance by the community has limitations:

‘Healthy people seem to be very sorry for us... What I mean is, of course their behavior toward us and toward the healthy people is not similar. We have to understand that.’ (Schuller, 2010, p. 65)

Others experienced community expectations that a person with disabilities should be excluded from important life roles such as parenthood:

‘They talk about my pregnancy and then started to criticize and asked me why I let myself be pregnant. (Sau, Hemiplegia, 32)’ (Boonpiam, 2006, p. 91)

Joining a work group was difficult for many people with disabilities:
‘I could work as a guard or gardener but they do not ask me to work. (17 March 2001).’ (Gartrell, 2010, p. 297)

Conversely, another employed person worked with ‘normal’ people in a workplace which had accessible facilities:

‘Luckily, the factory owner provided facilities to disabled people, including toilet’ (Maew, Polio 33).’ (Boonpiam, 2006, p. 54)

3.4.2 Theme 2. Journeys in resilience vary with individuals with disabilities.

The results showed that personal strength and resilience play a significant role in living with disabilities. Variations included the journey following trauma in contrast to the journey of slow onset disability and both result in different pathways towards resilience. Many respondents who experienced sudden trauma with subsequent disability initially experienced a period of hopelessness and helplessness:

‘I was worried about my future. I didn’t know what would happen to me … after amputation, I was not the man I usually was. My son planned to send me to the institution because no family member could take care of me. There was no hope for the future.’ (Liu, Williams, Liu, & Chien, 2010, p.4)

Some people with disabilities were able to generate emotional strength and pride to make the changes needed for a meaningful life:

‘I can work and take care of myself. I gain money from my job for taking care of my grandchild and mother. I can contribute to my family’s income. I feel that this is my self-worth. I not only wait help from others. Some able people cannot do like me.’ (Rukwong, 2008, p. 288)

However, others felt humiliated and excluded:
‘In the past, everyone called me ‘woman on the farm’ because they always saw me working on our farm every day … Now, I cannot do like that because of my weakness. I have never gone outside my house since contracting this problem.’

(Rukwong et al., 2007, p. 291)

A respondent noted gendered differences in response to trauma acquired as an adult:

‘Women are very strong ... As a woman she can accept it (her impairment) even though she feels worried. In the case of men, if they get sick, it is terrible... For a woman, even though she's sick, she still has to cook. For men, they just lie down ... Women are tougher as they have to take care of their children, family and themselves (Malay, F).’ (Misajon, 2006)

Some participants found strength in engaging prayer as a way to accept their mortality, and resolve negative feelings: ‘firstly, I felt regret, but what for, so I surrender myself’ (Pramana, male, 66 years) (Norris, Allotey, & Barrett, 2012).

A respondent drew his strength from the notion that he had escaped death despite the pain of his ongoing treatment:

‘When my relatives saw me changing dressings, they couldn’t help crying while I held my tears back. They were really surprised, ‘you’re such a brave guy’ … I had stepped on the threshold of hell, and I realized that everything, compared to the marvels of life, could fade.’ (Wang, Wang, & Liu, 2012)

3.4.3 Theme 3. Managing poor health makes life with disabilities difficult.

Co-morbidities were expensive and disability was compounded by health problems:

‘I always received drugs for diabetes and hypertension … Last month, I had a problem with lung disease and diabetes. I was admitted to a provincial hospital for seven days. At that time, I think I was going to die.’ (Rukwong et al., 2007, p. 288)
A woman who was pregnant at the time of her disabling stroke had to prioritise the birth of her baby over her own health. All treatments were terminated by her husband until after the baby’s birth however, both the baby and the woman died in childbirth (Norris, Allotey, and Barrett, 2012)

3.4.4 Theme 4. Poverty is closely linked to disability.

Respondents experienced financial difficulties linked to their disabilities. A respondent was expected to try all avenues to cure the disability and this was stressful and expensive for the both the individual and his family.

‘He agreed (like other men and their carers) that he was expected by the community to use every avenue which might offer a cure—to the point where all available money was spent.’ (King & King, 2011, p. 1484)

One woman, who could not afford an artificial sphincter, reported that the ensuing odour meant that she was criticised and isolated by friends.

‘Due to the difficulty in urination control, urine made skin irritated and infected. It’s hard for me to live my life normally (respondent not named)’ (Boonpiam, 2006, p. 50).

A respondent explained his distress that the result of his disabilities would impact on the opportunities for his children:

‘Faisyal: I think about my children, three of them, because they have to go to school … I must fulfil the needs of my children.

Interviewer: What is the biggest problem you face?

Faisyal: That I cannot work again, yes it burdens me because my children need a lot of money to pay for their study.’ Faisyal. (Norris et al., 2012, p.12).

People with disabilities experience stigma when looking for ways to earn a living.
‘The money lenders don’t trust us … they think we will borrow money and waste it away … I can think, but I have no money to act on my ideas’ (Gartrell, 2010, p. 296).

The inability to work together with loss of the worker role was experienced as an insurmountable cause of poverty:

‘Before the accident I was the head of the house …. but since the accident it is difficult for me and my family… Some months we have no money and my wife must go out to work. (Surachai, 37-year-old quadriplegic, rural location).’ (King & King, 2011, p. 1482)

3.4.5 **Theme 5. Education and understanding are important and difficult for people with disabilities to achieve.**

This section identifies information seeking from two perspectives: firstly, as educational opportunities to increase capacity to earn a living and secondly, finding information to provide explanations and remove barriers. A respondent saw education as opportunity for advancement however, she experienced lack of support for her intentions to study:

‘[People used to say] why bother learning, you can’t do anything in the future… You can only dry rice in the sun and keep the chickens away.’ (Gartrell, 2010, p. 295)

A respondent who managed to attend university reported a lack of support from fellow students.

‘… I always hid from the Director… I was scared he would not allow me to study. I went to university early in the morning, went up the third floor so no one could
see me and stayed until everyone else had gone before I went home. (17 July 2000)’ (Gartrell, 2010, p. 295)

Education and information which provided explanations were needed to help people manage their disabilities:

‘Whether it’s hot or cold, I sweat. I sometimes feel cold while others feel hot. It makes me feel restless. I consulted my doctor, who told me I have menopausal symptoms. Oh! I see. I am a menopausal woman. (Mrs Chaba, a 54-year-old with arthritis)’ (Rukwong et al., 2007, p. 288)

Information about health conditions was not always easy to understand:

‘I’m not well educated … And the doctor sometimes keeps talking … but how can I remember? They should have given me some written notes’ (Lui & Mackenzie, 1999, p. 396).

3.4.6 Theme 6. Values and beliefs are enmeshed in the difficulties of living with disabilities.

Differing cultural practices present particular difficulties.

‘I did my housework when I was healthy. Since I have had an accident, I have not been able to do my household … Nowadays, my husband always washes my sarong-like lower garments (pa-sin). I sometimes try to do it myself because our ancestors’ teaching is that if a woman lets her husband touch her sarong-like lower garments; her family will have problems in generating income.’ (Rukwong, 2008, p. 62)

Maintaining traditional cultural roles after the onset of disability were often difficult:
‘I often talk about my disease with my mother, but I don’t want my husband’s family to know I am a patient with rheumatism, because they don’t like that I have a disease … They just worry that I can’t care for my husband.’ (Hwang, Kim, & Jun, 2004, p. 243)

One respondent found herself challenging gender roles when she chose the sport of powerlifting as a sport possible for her with her disabilities.

‘How can you go for that sport (powerlifting) … Only a man can lift the weights and you are a girl... Powerlifting is not for woman.’ (Roy, 2011, p. 433)

Some families combined treatment methods from different cultures:

‘My family tried many things to supplement modern medicine to solve my weakness, such as herbs, Thai massage, earning merit by setting free birds and fish, and conducting ceremonies to apologise to the household spirit. We did everything. I think all of that helped me get better. However, I relied on modern medicine for my main treatment.’ (Rukwong et al., 2007, p. 289)

Culturally specific explanations became a part of the understandings and knowledge that the individual drew on to make sense of disability.

‘In the area that I had the accident there were other accidents, and now the phi (restless souls of people killed at a particular location) wait for other people to have an accident and die, and then they can be reborn because they have been replaced. The phi find people to replace them to look after the area……. The area has a lot of accidents (Mana, 35-year-old paraplegic, rural location)’ (King & King, 2011, p. 1482)

One respondent was grateful that he lived in his modern society rather than having to live under older traditional beliefs about disability:
‘Sometimes I think that my brother and I are lucky as we don’t live in the old backward society; we were born into this civilised, prosperous, and democratic socialist New China, which has shown us warmth and given us hope.’ (Dauncey, 2012, p. 316)

3.5 Discussion

This review synthesized the literature in order to better understand the phenomenon of the lived experience of adults with physical disability in East and Southeast Asia. Fourteen articles were found meeting the inclusion criteria, involving 179 participants and the analysis of the articles produced a rich picture of lived experiences of physical disability in Asia. This is a small sample in the global picture of disability, however, the meta-synthesis of qualitative research provided glimpses of important life details not available in big data-sets by which population-based information is gathered (Singal, 2010). The six themes identified in the meta-synthesis can be summarised as: (1) belonging (2) resilience (3) health (4) education (5) poverty and (6) context, and a brief discussion is needed to examine these findings.

The over-arching themes were broad, which is consistent with a meta-synthesis although there is an accompanying risk of thrice removing the data from the experiences of those originally participating in the qualitative empirical research (Sandelowski, 2006). To counteract this risk, original quotations were used as much as possible to retain the flavour of participants’ responses, resulting in a closer understanding of the possibilities within each theme. The research did not claim to compare cultural variations from country to country or to compare Asian with Western cultures.

3.5.1 Disability and definitions.

Disability has nuanced meaning; for example the social impact of disability may vary depending on whether disability is seen to cause barriers to social relationships or is construed as a loss of independence and productivity (Ripat and Woodgate, 2011). There is
also a lack of worldwide uniform definition of disability worldwide (Ingstadt and Whyte, 1996) however, the International Classification of Functioning and Disability's (ICF) considers disability as ‘an umbrella term denoting the negative aspects of the interaction between an individual and that individual’s contextual factors’ (Iwarsson & Ståhl, 2003). Despite the ICF description being quite broad it may be inadequate at a local level across cultures. Local languages may have no word for disability, for example where disability is seen as normal such as in aging; or if the causes of disability come from supernatural forces or as a punishment or curse (Selway & Ashman, 1998; Reid-Cunningham, 2009).

This meta-synthesis considers disability within different cultures however, culture also has many definitions; culture can be briefly described as ‘comprising traditional beliefs and social practices that lead to rules for social interaction within a particular locality or social group’ (Gujral, 2002, p. 440). Cultures are not fixed and are instead described as ‘fluid, heterogeneous, hybrid systems of knowledge, institutions, discourse, and practices that vary over time and location’ (Kirmayer & Sartorius, 2007, p. 832). Culture is the source of understanding illness and disability in the explanatory models of illness described by Kleinman and associates (Kleinman, 1978; Kleinman, Eisenberg, & Good, 1978). ‘People learn from their own cultures how to be healthy, how to define illness’ (Munoz, 2007, p256). In this meta-synthesis respondents provided a range of responses and stories for their experiences of disability coming from a variety of cultural contexts and backgrounds.

3.5.2 Primary groups.

The importance of primary groups (family, work and community) was seen in the meta-synthesis, in particular the importance of the family. Unlike care for persons with disabilities regulated by the Americans with Disabilities Act or Australia’s National Disability Insurance Scheme, persons from Asian countries seldom benefited from special health programs for those with disabilities, leaving families as the primary carers.
Broad characteristics of Asian values can be contrasted to Western values. Asian collectivism is seen in subordination to group goals and aspirations for group achievement. In contrast, Western individualism emphasises personal goals and personal achievement (Triandis, Bontempo, Villareal, Asai, & Lucca, 1988). Large areas of the majority world are considered to have mostly interdependent societies with obedience important in parenting, and lifestyles reflecting structured roles (Kagitcibasi, 2005). People with disabilities in Asian cultures describe themselves in terms of their relationships and satisfaction comes from the sense of belonging to their groups (Markus & Kitayama, 1991).

3.5.3 **Resilience and the individual.**

While the importance of the sense of belonging to primary groups has been mentioned, the resilience of the individual is the other side of the story, influencing how the individual with disabilities sustains group membership. Studies on cultural variations of the individual experiences of self, show that cultural variations in the individuals’ sense of being are built on core understandings embedded within cultures (Markus & Kitayama, 1991). An example of cultural differences in ideas of self, in this case attitudes to standing out in a crowd and being noticed, can be seen in two contrasting popular sayings; firstly from the United States of America ‘the squeaky wheel gets the grease’ in contrast to Japan where ‘the nail that stands out gets pounded down’ (Markus & Kitayama, 1991, p. 224). However, it is important to note that broad generalisations based on ethnic or cultural differences are not enough, and individual level experiences still need to take precedence. For example, individuals may be fearful or brave, may have solid social support or little support and may have guilt or distress relating to their individual journey with disabilities.

3.5.4 **Health, education and poverty.**

The findings of this meta-synthesis support extensive findings linking health, poverty and education which impact on the quality of life of an individual with disabilities. Examples
include studies revealing lack of formal education of children linked to poverty in adult-hood (Groce, 2011), and a cause of poor health (Black et al., 2008), while good health is linked to education (WHO, 2002; Subramanian, Huijts & Avendano, 2010). Poverty has also been linked to poorer health status and lower levels of education in carers of people with disabilities (Chou, Chiao, & Fu, 2011). In Asia a person with disabilities and his or her family are likely to be poor, i.e. earning less than US$2 per day, as described by the Multidimensional Poverty Index (MPI). (Alkire & Santos, 2014).

Poverty also increases the likelihood that a person with an existing health condition becomes disabled (Peters et al., 2008). ‘Out-of-pocket’ payment is the most common method used by people in Asian countries to pay for health care (Somkotra & Lagrada, 2009; Van Doorslaer et al., 2007), and such payments may lead to the need to reduce food consumption or to sell possessions such as animals. Inevitably, these costs push already poor households further into poverty (O’Donnell et al., 2008; Van Doorslaer et al., 2005). Where social welfare programs are in place they may be ineffective, leaving people with disabilities continuing to rely on monetary support from families or friends as a way to manage health problems (Komardjaja, 2004). A cycle linking poverty, health, and education could be seen in both the literature and the concerns expressed by the respondents in the meta-synthesis.

3.5.5 Implications for practice and research.

Understanding cultural difference in health beliefs and health care is part of understanding people with illness or disability. However, ‘we need to examine individuals’ use of these attributions directly rather than simply using ethno-cultural identity as a proxy for the specific cultural factors that underlie the attribution’ (Kirmayer & Sartorius, 2007, p. 832). Inactive ‘respect’ or ‘sensitivity’ or ‘cultural competence’ is not enough. An approach to the cultural aspect of health care needs to include all differences in the human condition, such as gender, class, religion, and all environmental considerations that might have
influence the up-take of services, and successful service delivery must involve negotiation with the individuals involved (Bickenbach, 2009). In the words of David Werner writing about the rights of people with disabilities in Mexico (1998), ‘nothing about us without us’.

Further specific strategies have been put forward by Ripat and Woodgate (2011) to establish the impact of local contextual beliefs and attitudes on an individual with disabilities with the use of specific tools such as methodological triangulation or culturally sensitive instruments (Kao, Hsu & Clark, 2004).

As populations age in East and Southeast Asia, traditional family supports for people with disabilities will be lessened (McKee, 2006; Phillips, 2002). Where services for an aging and/or disabled population are to be developed, the cultural context must be investigated and local understandings of health and illness must be included. Where services acknowledge the importance of the broader picture as identified in the themes in this metasynthesis, that is, family, the health journey, resilience, poverty, education and context, services with effective and successful outcomes will be easier to achieve.

3.6 Conclusions

Meta-synthesis making use of quotations by participants was an effective tool to gain a broad and rich picture of the lived experience of disability within the selected Asian countries. This meta-synthesis has provided a better understanding of the phenomenon of the lived experience of adults with physical disability in East and Southeast Asia. While the sample was small, and the themes were universal, the rich context within the themes indicated that there is a range of important contextual differences within different populations based on culture. The value of the meta-synthesis was that the universality of the human experience was laid bare while the cultural context coming from differing backgrounds could clearly be seen. Building on these differences, health care practice and research will be able
to identify treatments, approaches, or skills to contribute to knowledge about what influences, and what gives a sense of meaning, and quality to the lives of people with disabilities.

3.7 Limitations of the Research

There are risks inherent in cross-cultural research (Sparks, 2002; Suh, Kagan, & Strumpf, 2009). For example, the gender, age or race of the actual interviewers was not reported but may have influenced the participants’ responses.

Use of interpreters was never identified in the selected papers so there may be anomalies occurring through translation.

The analysis did not address the abundance of material in grey literature where anecdotes of experiences of disability can be found; this meta-synthesis took a more traditional approach based on assumption that accurate data and objective interpretation results from using material from peer reviewed sources.

Finally, meta-synthesis on lived experience is a process thrice removed from the original experiences of those being researched; meta-synthesis is ‘reviewers representations of researchers representations’ (Sandelowski 2006, p.11). The intention in this meta-synthesis was to demonstrate the experiences of disability in selected Asian countries, not as the TRUTH but as a smaller truth (Sandelowski 2006, p.13). Despite the smallness of this truth, it is large enough to point out the significance of contextual differences regarding people with disabilities in East and Southeast Asia.

3.8 Further research

The study pointed to a need for further research into all the factors which influence the experience of disability in each of the diverse cultures of Asia, bearing in mind that culture is a fluctuating influence on societies. Investigation of literature found in books as well as grey literature would give further richness to the variety of experiences of disabilities
in different Asian countries; understanding the range of culturally based views of disability and illness could contribute to making health care more effective.

3.9 References


The original paper ends here

### 3.10 Key points

- Metasynthesis is a form of review of literature based on ethnography
- Fourteen articles were found concerning the selected countries of East and Southeast Asia which met the selection criteria for the metasynthesis to investigate literature concerning the lived experience of physical disability
- Findings from the metasynthesis can be grouped into six themes, each consisting of sub-themes. The themes were:
  - (1) belonging
  - (2) resilience
  - (3) health
  - (4) education
  - (5) poverty
  - (6) context
- This metasynthesis provided details of the lived experience of physical disability in the selected regions

### 3.11 Conclusions

Metasynthesis provided a rich picture of the phenomena under investigation. The sample size was small however the results were rich and detailed. The results showed that further research written in English is needed to more fully examine the lived experience of physical disability in Asian countries
Chapter Four: Research Methodology

Key to the thesis

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The previous chapter, Chapter Three, was a paper based on a metasynthesis of literature of lived experience of physical disability in East and South East Asia.

In Chapter Four, I present background to decisions regarding the framework of the research. I describe the links relating to the elements of the research, to ensure that my research is ‘research that attends to all three elements (epistemology, methodology, and method) and demonstrates internal consistency between them’ (Carter & Little, 2007, p. 1316). The chapter has three sections: firstly, the background to the research question, secondly, considering the philosophical framework behind the research methodology, and finally, a discussion of the research paradigm.
CHAPTER 4 RESEARCH METHODOLOGY

4.1 The Background to the Research Question

While considering a topic for research, related to my experiences in Timor Leste, I spoke to one of the facilitators during a course on Disability in Development, presented at the Nossal Institute, in Melbourne. This facilitator indicated that the lived experience of disability, was one of the aspects of disability which was under-reported in disability literature, especially coming from those living in non-Western countries, and this was confirmed when I carried out the metasynthesis described in the previous chapter. The importance of understanding the lived experience of disability in the planning and implementation of development programs has been noted in previous chapters. In summary:

- People with disabilities are generally omitted from the processes of consultation and planning and may subsequently miss out on the benefits from foreign aid and development planning (MacLachlan & Swartz, 2009). While people with disabilities make up a significant part of the population as described in preceding chapters, a development program cannot serve a local population if those with disabilities are not considered.

- Understanding lived experience will reveal whether unique cultural factors are significant in a development programme and this includes people with disabilities (Grech, 2012). For example, there may be difficulties with gender balance where assumptions are made about gender roles within a development programme.

- Where a development programme is directly targeting people with disabilities, a study of lived experience will reveal if there has been an oversimplified expectation that all people with disabilities have similar aspirations, as described by Grech (2012) and Miles (1995).
• Health and illness are viewed differently in different cultures (Iwama et al., 2009; Meekosha, 2008) and health programmes will be more effective if the experiences of those using health programmes are explored. People with disabilities are users of health services thus their experiences will help examine whether a health programme is effective or not.

• Information based on the lived experience of disability cannot be found in population-based data-sets (Singal, 2010) as data relating to disability is generally obtained from a medicalised perspective (Albert, 2004; Oliver, 1996).

Therefore, while population based data is needed to set up and deliver effective development programmes and services for people with disabilities, a depth of understanding of lived experience will provide a depth of understanding of what makes services and development programmes effective for all beneficiaries, whether disabled or not.

4.2 The Research Methodology

In selecting a research methodology, ethnography was first considered as it is frequently used in cross-cultural research. In ethnography, the researcher observes the day to day events, both the ordinary everyday events as well as the unusual events, which occur from time to time, with a view to examining the experience of a social or cultural phenomena (Schwandt, 2007). The ethnographer frequently develops cross-cultural theories which consider the groups under observations - examples could be groups such as families where family relationships are the object of the research, or people involved in parenting and all that it entails (Huberman & Miles, 2002). I elected not to use ethnography in this research project as the cross-cultural setting was the context rather than the primary phenomena under investigation.

Phenomenology was the approach of choice in this study, as a pathway to investigate the ‘lived experience’ of men and women in Timor Leste who live with disabilities.
Phenomenology has been used by Western academics with disabilities such as Kay Toombs (2001) and James Overboe (1999) to examine their own lived experience of disability within their cultural and academic environments. Phenomenology has also been extensively used by outsider researchers seeking in-depth understanding of lived experience of disability. Examples include a study of the lived experiences of early dementia (Harman & Clare, 2006), lived experience of chronic pain in women with fibromyalgia (Råheim & Håland, 2006) and a report on the experience of art and healing (Sin, 2007), to name but a few of the many phenomenological studies of experiences relating to disability.

Schwandt (2007) described phenomenology as complex and multifaceted, and that the concern of the phenomenologist is the life-world, or a description of ‘things’ (phenomena, or the essential structures of consciousness) as one experiences them (Schwandt, 2007, p. 374). In essence, phenomenology is a methodology to investigate and describe ‘being in the world’ (Csordas, 2002) and the ‘foundational question’ of phenomenology is ‘what is the meaning, structure, and essence of the lived experience of this phenomenon for this person or group of people?’ (Patton, 2001, p. 104). Phenomenology is both a philosophy and a research method, with differing schools within the philosophy and differing perspectives by which phenomenological research may be undertaken (Dowling, 2007; Schwandt, 2007).

Phenomenology has its beginnings in European philosophy prior to World War 1, based on challenges to the philosophical view at that time about the nature of Truth (Dowling, 2007). Edmund Husserl (1859 – 1938), a mathematician and philosopher, declared that knowledge can be subjective and can originate in human experience prior to explanation or interpretation; that is, ‘before we have applied ways of understanding of explaining it. It is experience as it is before we have thought about it’ (Crotty, 1996, p.95). Husserl’s insight was that individuals have personal bias (Moran, 2001) which can be overcome by abandoning one’s own subjectivity, through bracketing and suspending one’s viewpoints (Giorgi, 2000).
Husserl’s descriptive views of experience were challenged by those writers, including Martin Heidegger, who claimed that experience must be rooted in the world and cannot be separated from life. Furthermore, Heidegger insisted that lived experience is an interpretive process which must be explored with the use of hermeneutics (Racher & Robinson, 2003). Both stances, that is phenomenology as description, and phenomenology as an interpretive process, are two separate schools of phenomenology, with the interpretive approach being preferred by researchers in the caring professions such as nursing (Benner & Wrubel, 1989). This is the approach taken in this study.

Phenomenology places human experience at the centre of the task, based on a premise that human beings will be best understood by considering the experience of their ‘life-worlds’ (Manen, 1990, p. 67) and by exploring taken-for-granted assumptions. However, phenomenological research does not necessarily reveal the dramatic or new, as contended by Sokolowski:

Phenomenological statements, like philosophical statements, state the obvious and necessary. They tell us what we already know. They are not new information, but even if not new, they can still be important and illuminating, because we are often very confused about just such trivialities and necessities (Sokolowski, 2000, p. 57).

This outcome is congruent with an occupational therapist’s concerns where research on all the mundane activities of daily living, including simple daily experiences, were of interest. The participants were, in essence, ordinary Timorese and I wanted to know how their individual ordinariness was manifested.

4.2.1 The research paradigm.

The way in which the researcher undertakes the research topic depends on firstly, an ideological framework, or ontology. The ontology signifies secondly, how the world can be known, that is, the epistemology. Epistemology is the discussion about ‘how we know what
We know, thus each research project is framed by an epistemology or dominant way of knowing’ (Patton, 2001, p. 134). Crotty defined epistemology as ‘the theory of knowledge embedded in the theoretical perspective and thereby embedded in the methodology’ (Crotty, 1998, p.3). Accordingly, epistemology is the study of the nature of knowledge and provides justification for the choice of method with its accompanying aims, and assumptions (Schwandt, 2007). My research is grounded in my professional epistemology; that is, as a consequence of my experiences as an occupational therapist and the knowledge produced within the occupational therapy community (Kinsella & Whiteford, 2009). My understandings come from the science of occupation and my assumptions are that the dignity of engaging in purposeful occupation is a basic human need with accompanying experiences of well-being and quality of life (Kronenberg, Algado, & Pollard, 2005). (See the definition of occupation in Chapter One)

In this research project, my own ontological assumptions include, but are not confined to the social model of disability. The social model places most of the barriers for people with disabilities in the physical or social environment, however, as an occupational therapist, I have also engaged with people with disabilities within a medical model framework, for example when I have worked in inpatient rehabilitation settings and treated people with disabilities following trauma or illness.

As an occupational therapist, I could be expected to have a positivist perspective in this research project; that is, a philosophical stance which ‘offers assurance of unambiguous and accurate knowledge of the world’ (Crotty, 1998, p.18). Occupational therapy originates in the medical health system, based on the medical model of health care, where disability was traditionally construed as a part of the health agenda. Traditionally, the medical model was grounded in knowledge gained through experimental research from a basis of a positivist
paradigm, and occupational therapists, in line with medical practitioners, are keen to practice from a scientific evidence base (Blair & Robertson, 2005; Kinsella & Whiteford, 2009).

However, paramedical researchers, including occupational therapists, now question an approach which seems to exclude the life experience of the patient, while commenting on a condition or disease process from an expected outcome or ‘norm’ (Richardson, 1995). Qualitative research, by its very nature, is an investigation of experiences, followed by interpretation of experiences and this approach within the health sciences has been welcomed as a paradigmatic shift (Gitlow & Flecky, 2005). Patient’s beliefs, perceptions and opinions are noted ‘in a way that provides the humanistic dimension that is otherwise lacking when the research is only expert-driven’ (Ritchie, 1999, p. 255).

Therefore, instead of positivism, the paradigm used in this study was interpretivism, a theoretical perspective which explains human and social reality (Crotty, 1998). The interpretivist approach ‘looks for culturally derived and historically situated interpretations of the social life-world’ (Crotty, 1998. P.66-67), by seeking meaning of social action and events through the lens of those involved and by replacing the question why with the question how. The positivist view is deductive and seeks a single verifiable constant truth. In contrast, the interpretivist view is inductive, and the researcher is considered to be a part of the study. The subjective meanings established in the study are considered to be derived in part from the researcher’s interactions with the study participants (Miles & Huberman, 1994).

There are diverse scholarly traditions under the umbrella of interpretivism. All these traditions have the common emphasis on firstly, understanding meaning rather than causative factors; and secondly, on understanding the social dimensions of the construction of reality, which comes from understanding the shared or common interpretations (Prasad, 2005). Schwandt (2007) stated that while interpretivism can be a synonym for all forms of qualitative investigation, the term ‘denotes those approaches to studying social life that
accord a central place to Verstehen (deep understanding) as a method of the human sciences, that assume that the meaning of human action is inherent in that action, and that the task of the inquirer is to unearth that meaning’ (p.160). The interpretive tradition in phenomenology is also known as the hermeneutic tradition\(^5\) and hermeneutics is described as both a process and method, which can reveal aspects of the human condition which are normally hidden (Spiegelberg, 1975). Thus, this study can be considered as interpretive or hermeneutic phenomenology.

4.2.2 Occupational therapy as a ‘two-body’ practice

Despite the assertions above, occupational therapy can be considered as a practice which links two epistemological spaces, as the profession is considered to be a combination of art and science (Kielhofner, 1997; Bryant and McKay, 2005). The occupational therapist uses a positive approach with deductive reasoning based on fact, representing science. At the same time the art of occupational therapy can be seen where the therapist’s work is based on a humanist approach and guided by ethics and intuition (Turpin, 2007) and the occupational therapist understands that good occupational therapy practice and the ability to work with each individual in his/her unique life situation is based on the reported experiences of patients or clients (Clarke, 1993; Helfrich & Kielhofner, 1994).

Mattingly (1994) explains occupational therapy as a ‘two body’ practice (p 37) where the occupational therapist may be concerned with both the patient’s physical body and at the same time consults the patient about his/her experience of the disease or condition on injury. The occupational therapist may use clinical knowledge and clinical reasoning to address the world as it is experienced by the client, for example by modifying the clients environment, or takes the clients experience of the world, by attending to the stories put forward by the client to establish whether these experiences represent satisfaction, or health or other desirable

\(^5\) Named after Hermes, a Greek god who carried clear messages between the gods.
aspects of occupational performance (Turpin, 2007). An example here may be the patient who reports on her satisfaction or dissatisfaction with her performance as she learns to carry out daily activities such as cutting bread one-handed, using a modified bread-board, following a stroke. Thus occupational therapy can be seen as a profession with a pluralist approach with ‘both artistic and scientific values and perspectives, as well as acknowledging that multiple perspectives and experiences coexist’ (Turpin, 2007 p. 479). The focus of phenomenology accords with the practice of occupational therapy and, as will be seen below, accords with the intentions of photovoice.

4.3 Linking photovoice to the Research Framework

At the time I was considering an appropriate research method to learn about the lived experience of physical disability in Timor Leste, a training in photovoice as a research method was presented at the University of the Sunshine Coast. This approach had three appealing aspects, firstly, as a way of engaging people with disabilities to actively participate in the research process, secondly, as well as being a way to reduce the risk of misunderstandings inherent in cross-cultural research and photovoice is described in full in the following chapters and thirdly, as a way to obtain a truer picture of the participants lived experiences by inviting them to present material which was significant to them, rather than taking detailed directions from the researcher.

In summary, photovoice was developed for individuals or community members to record their experiences and express their views with the help of photographs, which they have taken expressly for the research process (Wang & Burris, 1997; Wang, 2006). The participants’ choice of photographic subject material accords with the intention of phenomenology, which is to describe and understand the meaning of a phenomena as it is experienced by one or several individuals (Creswell, 2012). Photovoice is a strategy within participatory research and is founded on a community-based use of photography, together
with feminist theory and critical consciousness. The research participants as photographers can:

- illustrate their everyday realities,
- can highlight community concerns and strengths
- can clearly illustrate their concerns to policy makers


Two potential challenges needed to be considered in the use of photovoice in this study. The first challenge appears when trying to match photovoice as a method with phenomenology as its overarching methodology. Photovoice originally sought to identify problems such as social injustice or oppressive social structures, whereas interpretive phenomenology does not engage in this way (Plunkett, Leipert, & Ray, 2012). Firstly, this challenge can be addressed by considering that participants are asked to take photographs focusing on themes which represent their lived experiences (Carlsson, 2001), and the nature of these experiences is clarified in the discussion within the ensuing interviews. Secondly, the original authors of photovoice were concerned primarily about the social justice aspect of their participants’ lives, and developed photovoice as a tool for empowerment (Wang & Burris 1997; Wang, Cash & Powers, 2000); and photovoice has been used successfully to this end (Brunsden & Goatcher, 2007; Castleden, Garvin, & First Nation, 2008; Kronk & Weideman, 2014; Morgan et al., 2010). On the other hand, researchers have used photovoice for different outcomes; examples include investigating the meaning of play for children in Zanzibar (Berinstein & Magalhaes, 2009) and investigating the realities of English language learners (Graziano, 2011).

Photovoice has also been used in cross-cultural research; examples include an Australian study with aboriginal women (Brooks, Poudrier, & Thomas-MacLean, 2008; Liamputtong, 2010), in Cameroon in a study of the experiences of people with epilepsy
(Allotey & Reidpath, 2007) and in a study of Asian international students living in Flemish Belgium (Wang & Hannes, 2014). These are examples of the ever broadening application of photovoice. While photovoice has become a successful strategy for academic research with a variety of goals and outcomes, it has also taken on a more accessible and popularist nature with the evolution of the PhotoVoice website with its vision statement: ‘PhotoVoice’s vision is for a world in which no one is denied the opportunity to speak out and be heard’ (PhotoVoice, n.d.).

The participatory aspects of photovoice, as well as the potential for participant empowerment, made this a suitable research method in this study of the lived experience of people with disabilities in Timor Leste, and further explanations of different outcomes from photovoice can be found in the studies presented in Chapters six, seven and eight. An overview of the components of the research framework is now outlined in the table below.

Table 3
An Overview of the Research Framework

<table>
<thead>
<tr>
<th>Epistemological Assumption</th>
<th>The dignity of engaging in purposeful occupation is a basic human need with accompanying experiences of well-being and quality of life</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ontological Assumption</td>
<td>That difficulties arise in the lives of people with disabilities from barriers within the physical or social environment. People should be able to make choices which will allow them to explore and realise their own capabilities</td>
</tr>
<tr>
<td>Theoretical Perspective</td>
<td>Interpretivism</td>
</tr>
<tr>
<td>Methodology</td>
<td>Hermeneutic phenomenology</td>
</tr>
</tbody>
</table>
Research Approach

Photovoice using participant photography, interviews, group discussions, stake-holder interviews and key informant interviews.

4.4 Summary and Conclusions

In this chapter the background to the decisions relating to the research question, the philosophical framework and the research paradigm have been outlined. The links between these three aspects of the study were demonstrated by explaining the research framework as hermeneutic phenomenology with an interpretivist theoretical perspective, and by describing the epistemological and ontological considerations behind the methodology and the place of occupational therapy within these considerations is explained. Finally, the suitability of photovoice in the research framework was presented. This framework will be considered further in the following Chapter Five, in which I detail the position of the researcher/occupational therapist within the research. Then further details of the research method, photovoice, are introduced, followed by discussion of some of the issues encountered in cross-cultural research.
Chapter Five: Methods

Key to the thesis

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<tr>
<th>Chapter</th>
<th>Description</th>
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<td>11. Implications for practice</td>
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<tr>
<td>Appendix P</td>
<td>Descriptive article</td>
<td>Published</td>
</tr>
</tbody>
</table>

In Chapter Four the research framework and the research paradigm were presented and the research was identified as hermeneutic phenomenology with an interpretivist theoretical perspective. The description of the epistemological and ontological considerations behind the methodology were explained, as based on my background and experiences as an occupational therapist, and I located the research method, photovoice, within the research framework.

Chapter Five provides some background to my position as researcher, from previous experiences in Timor Leste, and from the need to position myself within hermeneutic
phenomenology. A description of some issues relating to rigor in research is presented; and finally, details of data collection and coding are provided.

5.1 Putting the Researcher in the Picture

I now describe my position in the research by firstly, reflecting on some of the circumstances surrounding my visits to Timor Leste, as a young traveller then as a development worker, occupational therapist and researcher – see below:

1972 – First visit to Portuguese Timor where I stayed with a family
2000 – Volunteer work in Dili
2001 - Voluntary work, Klibur Domin, residential facility
2002 - ‘Improving the lives of disabled children’ teaching project
2004 - Voluntary work, Klibur Domin, residential facility
2006 - AVI volunteer - Community Based Rehabilitation and Tuberculosis project
2008 - Masters research project, Deakin University
2012 - Pilot study for the PhD
2013 – Main study for the PhD

My interest in Timor Leste has been described in some detail in Chapters One, Six, Seven and Eight. I am a white Australian female, older that most of the ex-patriate development workers in Timor Leste and older than most of the people in Timor Leste, which has an exceptionally young population (Neupert & Lopes, 2007). My first visit was in 1972 in Portuguese colonial times where I stayed with a family in a fishing community living near the beach on the edge of Dili. My host family had a child with apparent developmental delay although at the time of that early visit I was unaware of Timorese attitudes to disability as this child appeared to be accepted by his family and the surrounding community.

This period is now known as tempo Portugueses, (‘Portuguese times’ before 1975), when Dili was a much smaller, sleepy, and neglected colony of Portugal (Molnar, 2010) with
its own array of attitudes which I assumed were the mark of a colonial culture. For example I attempted to take my Timorese hosts out for dinner as a token of thanks for their kindness in allowing me to stay with them for several weeks. We walked to a restaurant in Dili; to my horror, my hosts were turned away because they were Timorese, even though, I was welcome to eat in the restaurant. Despite the ‘White Australia’ policy which prevailed in Australia at the time (Tavan, 2004), I personally, had never encountered attitudes such as these.

Since 2000 I have visited, volunteered and worked in Timor Leste. During those visits I encountered a range of responses to people with disabilities. I observed disabled adults or children living in very poor circumstances and I wondered how a poor family managed with a family member with high needs, in a country which has a hungry season each year between November and February (Lopes, Ximenes, Ferreira, Spyckerelle, Williams, Nesbitt, & Erskin, 2013). I noted beliefs that disability was contagious, that disability was the result of family members disturbing the ancestors (see Chapter Eight) and I spoke to a family who stated that sacrificing a chicken was a successful way to appease the ancestors. During the period of civil unrest in 2006 I was living in a rehabilitation facility outside of Dili and some of the residents, both disabled and able-bodied fled to the hills; I reflected on the difficulties which a family or individual must encounter when fleeing in fear.

More recently I have observed change in Timor Leste, especially in Dili. During recent visits to Timor Leste, I noted that people were embracing 21st century values, with an increasing number of shops and services appearing in Dili; although, in the post-conflict Timor Leste, internal change is not all towards Western ideals and values as was described in Chapter 1. Timor Leste has a long history of social and political change and upheaval, and the Timorese have the capacity to accommodate uninvited change while reinstating customary

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6 The White Australia policy was a policy associated with immigration where there was an expectation that Australia should remain populated by people of European descent. The policy was in place from 1901 until 1972.
practices. For example, even though the population of Dili is growing rapidly, some Timorese families are re-establishing sacred relationships with the land and ties with ancestral origins (McWilliam & Traube, 2011); and in rural areas, and even in Dili, sacred houses, *uma lulik*, associated with traditional community values and association with deceased family members, are being rebuilt (Hicks, 2008).

5.2 Language in Timor Leste

The language situation in Timor Leste is complex and had some bearing on the research project. Many of the research participants were not fluent in English and I am not fluent in any of the twenty languages used in Timor Leste. Consequently, I needed to carefully consider the complexities of translation in research. Portuguese is one of the official languages used by children in school. It is also understood by older Timorese educated during Portuguese colonial rule, as well as the Timorese political elite. Indonesian is the language of adults schooled during the Indonesian occupation from 1975-1999, and is considered a major utilitarian language with links to Timor Leste’s nearest neighbour, Indonesia.

Both Indonesian and English are considered ‘working languages’ under the constitution (Taylor-Leech, 2013). Tetum is widely spoken and is one of the official languages; however, not everyone understands Tetum, especially away from the capital, Dili. The language backgrounds of the Timorese are varied, some Timorese are monolingual and many are multilingual (Taylor-Leech, 2009). In this research, I used English when speaking to people who were comfortable speaking English; otherwise, the use of an interpreter with the appropriate language skills was necessary.

There are assumptions about languages in research which may not match with day to day realities of research in a developing country. For example, assumptions include expectation that there is conceptual equivalence across languages, where techniques such as forward-backward translation checks are expected to ensure rigor (Temple & Young, 2004).
Research also has its own meanings which are not necessarily found in target languages (Larkin, de Casterlé, & Schotsmans, 2007); and I found this to be true. For example, there is no word for research in Tetun so when explaining my project, the interpreter generally used the Portuguese word *pesquisa*, and this word was probably meaningless if the person in the conversation had no knowledge of Portuguese.

Occasionally a participant asked the meaning of *pesquisa*. I usually explained that I was collecting information about people with disabilities to help others understand how people with disabilities live. I explained that although there would probably be no immediate benefit to the participants, in the long term the participant was potentially helping others with disabilities, for example, with equipment, medical help or income earning opportunities.

Additional problems in translation may occur if the interpreter is considered a mere invisible conduit. The researcher needs to consider that the interpreter may feel aligned with either the interviewer or the interviewees, or may consider him or herself aligned with dominant groups within the culture (Angelelli, 2004). The interpreter may be influenced by his or her perception of the researcher’s own origins such as ethnicity, religion, gender, perception of wealth and age (McGoldrick and Hardy, 2008; Mullings, 1999). I managed these possibilities by trialling some of my research questions in a role play with the interpreter to see if there was potential for difficulties or misunderstandings and also to clarify the requirements when giving participants cameras for the first time. (See appendix I for the interpreter’s confidentiality agreement and appendix Q for notes about the camera training which were given to the interpreters).

I also was careful not to rush discussions and interviews, and to attempt to keep conversations at a conversational pace. I asked important questions in several different ways; I took note of body language; and I checked any complex details with the interpreter or cultural mentors later. I have a basic understanding of Tetun, the language most often used in
interviews, and I could engage in introductions and jokes in Tetun; however, an interpreter was always needed when the participant was not confident in English.

5.3 The Position of the Researcher in the Methodology

My research project was based on interpretive or hermeneutic phenomenology where the researcher is acknowledged as having a place within the research process. If, instead, I were to undertake descriptive phenomenology I would bracket, or lay aside personal knowledge and biases when interacting with the research participants (Lopez & Willis, 2004). However, bracketing is not a part of hermeneutic phenomenology. In hermeneutic phenomenology, the researcher has an acknowledged role in initiating, conducting and making meaning of the research. Firstly, the researcher is seen to have some expert knowledge which guides the enquiry, and from which the researcher has elected to undertake the particular research project in the first place (Koch, 1995). Secondly, the interpretivist researcher makes the preconceived ideas explicit, and clarifies how these ideas may interact or influence the ensuing study, (Lopez & Willis, 2004). Thirdly, meaning is made from the circumstances within the research which include both the researcher and the researched (Geanellos, 2000), for example my reflections are a part of the research data, as in the next section below. Hermeneutic phenomenology may be characterised by an absence of method although specific attitudes to the research are evident. Attitudes within hermeneutic phenomenology include the involvement of the researcher in the research, involvement of the hermeneutic circle which is described as firstly reviewing the whole text, then considering the individual parts, then again returning to the whole text (Giorgi, 1997). (In this research I frequently reflected on the circumstances and stories where the participants were located then I needed to reflect on the cultural context which surrounded that individual, against which I could also reflect on my own position), samples are frequently small, a further feature of hermeneutic phenomenology is noted as seeking characteristics of the phenomena in question.
rather than seeking descriptions of individuals (Armour, Rivaux, & Bell, 2009). In this research project the descriptions of the individuals were an important part of the presentation of participants in a cross-cultural research setting where assumptions of behaviours or attitudes are different to those of the researcher and to Western readers.

Barnes and Mercer (1997) articulated the importance of acknowledging the person with disabilities as the ‘expert knower’ in contrast to the ‘expert-researcher’ who place their ‘skills and knowledge at the disposal of those being researched’ (p.6). Barnes and Mercer ask that research into disability be empowering and enabling; my use of photovoice represents the importance placed on empowerment and enablement of participants in this research project.

Next, the strategies used to place the research in context, to understand my influence on the participants, and to ensure rigor in the research are outlined.

5.3.1 **Rigor in research – a trustworthy picture.**

The amount of data generated in a PhD research project amplifies the importance of rigor in the research, (Morse et.al., 2008). The research must be valuable and useful, honourable in its intentions, can be repeated if necessary, and must be completely honest, and the word ‘rigor’ is implied in this process (Krefting, 1991). This term appears to have ominous implications, reflected in the title of a paper by Margarete Sandelowski, namely, ‘Rigor or rigor mortis: The problem of rigor in qualitative research revisited’ (Sandelowski, 1986). However, these concerns regarding rigidity and lack of flexibility in qualitative research were contradicted by the well-established view that good research design and data analysis create the value of qualitative research (Barbour, 2001).

Thus, qualitative research needs to be worthwhile and believable (Cronin-Davis, Butler, & Mayers, 2009). Additionally, qualitative research needs to display validity in the form of ‘trustworthiness’, which ‘refers to the extent to which the findings are an authentic
reflection of the personal or lived experiences of the phenomenon under investigation’ (Barbour, 1998, p. 89); and trustworthiness in qualitative research can be established by ensuring that all strategies are transparent (Krefting, 1991). This transparency includes considering how criteria relating to quality were addressed; was the setting described, was member-checking undertaken, was triangulation established and is reflexivity a part of the research process (Curtin & Fossey, 2007). The following discussion is a summary of how transparency and trustworthiness were demonstrated in this research project.

Trustworthiness is used within the interpretivist paradigm as an indicator that findings can be generalised to new experiences or new situations (Bowen, 2008). Trustworthiness is an aspect of rigor in research which includes the methods used, and the skill of the researcher using them (Michael, 2002). As a researcher with a long association with Timor Leste, I intended to do everything possible to ensure that my research was trustworthy for all associated with it. Firstly, the rights of the participants were respected (Brooks, Poudrier, & Thomas-MacLean, 2008; Wang & Redwood-Jones, 2001) by initial verbal explanation that involvement in the research was completely voluntary, by explanation that participants could withdraw from the research at any time without fear of reprisal, that photographs taken by participants were the property of the participants and participants signed an agreement regarding which photographs could be used in the research, and that participants’ identity would be protected by use of pseudonyms; where necessary, circumstances were changed if a controversial or difficult situation was being described and stories were omitted at a participants’ request.

This aspect of the research is dealt with in each of the chapters relating to findings and especially in Chapter Seven, where the ethics approval process is also explained in detail, in relation to both Australia and Timor Leste. I also undertook the four aspects of
trustworthiness suggested by Curtin and Fossey (2007), which are (a) thick description, (b) triangulation, (c) reflexivity and (d) member checking, which are outlined below.

5.3.1.1 Thick description.

Photovoice was chosen, firstly, for its visual and verbal data sources and secondly, because I expected that by being active in the research as photographers, the participants would better understand and benefit from their engagement in the project. Thirdly, the method provided an extra link with the participants by basing discussions on something concrete in the form of the photographs, while at the same time reducing the power imbalance inherent in the interviewer/interviewee situation (Carlsson, 2001).

Photovoice is a research method involving participants taking photographs, then providing explanations based on the photographs relating to their life-worlds. I hoped that the photographs would provide me, in my status as cross-cultural researcher, with visual clues from which to ask further questions about relevant details visible in the photographs, but not described by the participant in the first instance. This was, in fact, what happened, and I benefited from rich description of the everyday aspects of the phenomena of interest (Geertz, 1973); that is, the lived experience of physical disability in Timor Leste. This aspect of the use of photovoice was noted by others such as Guell and Ogilvie (2013), whose participants provided rich narratives based on their photographs, in a study of the nature of well-being.

5.3.1.2 Triangulation.

Triangulation traditionally involves looking for convergence of the findings in a study, as a method to increase validity and credibility. However, in qualitative research there is the expectation that findings will not entirely converge when searching for understanding of lived experience (Curtin & Fossey, 2007). Instead of attempting to use triangulation to achieve congruent views from all sources, the researcher should also investigate the differences, to better understand patterns within the overall picture, coming from different
data sources (Patton, 1990). Patton suggests three different forms of triangulation which were used in this research:

*Data triangulation* was undertaken by noting data saturation in participant interviews; when the same view emerged frequently, this indicated a broad finding which could be generalisable to new situations (Bowen, 2008). An example here is that the participants who were high achievers, had a mentor, not necessarily a family member, who offered encouragement at important times during their lives.

*Methodological triangulation* was undertaken by interviewing key informants and stakeholders as a part of the research to investigate the match between their views and the views of the people who had taken cameras and participated in the photovoice projects. The stakeholders and some of the key informants did not have disabilities themselves; some were Timorese and some were Europeans. They provided either outsider or insider expressions of their experiences and of the societal or cultural aspects of life in Timor Leste for people with disabilities.

*Researcher triangulation* was undertaken by the processes of supervision which is a part of the PhD process, as well as by discussion of relevant aspects of the data with cultural mentors. Triangulation also was used by having two sample manuscripts independently coded by a colleague, to compare the coding results, prior to the data analysis. Finally, the data from the field-work in Timor Leste was compared and contrasted to the data which was obtained in the metasynthesis of lived experience of physical disability in East and Southeast Asia, reported in Chapter Three of this thesis.

5.3.1.3 Reflexivity.

Reflexivity in research involves the researcher taking a self-aware stance, to examine and record how the research might be influenced, and even transformed, by the presence of the researcher (Finlay, 2002). As the researcher in this qualitative enquiry, I acknowledged an
active role in the research process (Krefting, 1991), keeping a record of my observations and reflexive notes of the impact on the participants. An example of my impact could be seen at almost every visit to a participant’s home, where I was always offered a plastic chair to sit on, the participant usually sat on a chair, family and community members usually sat or stood, and the interpreters usually sat at the same level as the participant. I could see that while I considered the participant views were of prime importance I also acknowledged that my personal biases, my values and my assumptions, my personal appearance and my gender all probably influenced the participants’ responses (Curtin & Fossey, 2007).

I reflected on my individualistic Western world-view, when I hoped to be able to interview people in private; however, my participants were primarily members of their family and community units. Family and community members frequently attended interviews; they usually sat in silence, although interjections during discussions were not uncommon.

I also reflected on my concerns about acquiescence. Examples of acquiescence in other settings include Finlay’s (2002) explanation of acquiescence as an element in psychometric research surveys, where there is a tendency for the client to say ‘yes’ regardless of the question. Acquiescence was also noted in a phenomenological study of South Asian patients in an English hospital who felt unable to criticise their therapy. The researcher in this instance, believed that the participants may have been unaccustomed to the free English service, or that they felt that their complaints would reduce their possibilities for treatment in the future (Yeowell, 2010). In Chapter Nine I discuss possible participant responses to the research including acquiescence.

I was particularly concerned that photovoice in this research not be the cause of any distress to any individual due to acquiescence. I saw Timorese society as hierarchical, with people with disabilities at the lower ends of the social hierarchy, and my personal opinion was that participants with cameras may be tempted to exercise their new-found power as
photographers, in order to take photographs of reluctant subjects. To that end, I included in the participants’ camera training, discussion about respecting the wishes of those who did not wish to be photographed (see appendix Q for the outline of the camera training).

When viewing the participants’ photographs later, I had continuing concerns regarding power and recorded these in my research journal, realising that some participants took photographs of other people with disabilities. One participant described the subjects of the photograph as members of his disability support group. He said that he was proud to be a member of this group; and I acknowledged that ‘one premise of photovoice is that everyone has the right to portray his or her life in a creative way regardless of age or station in life ’ (Wang, 1999, p. 191). I remained, however, concerned that the people who were the subjects of the photograph may not have been happy to be photographed; yet, conversely, I was also aware that Timorese seldom smile when they are being photographed.

Although the cultural mentors assured me that people were happy to be photographed, the dilemma remained unresolved for me. (There are further reflections of this dilemma in Chapter Nine). I addressed this ambiguity by making my explanations as clear as possible and checking with participants that they understood the instructions relating to the cameras. The journal of events, observations and reflexive notes such as these enriched the findings (Finlay, 2003) and also contributed to trustworthiness by providing an audit trail (Smith, 1999).

5.3.1.4 Member checking.

Member checking can be used to ensure trustworthiness in qualitative research (Krefting, 1991; Punch, 2005). This may occur at different levels and at different stages during the research, although most commonly in the early stages (Carlson, 2010). In this research project, participants were asked to check the recordings of their interviews or groups. The
participants all declined to check the complete recording of their interviews or groups, although some participants listened to a part of their interview and expressed satisfaction with an incomplete check. The recording, rather than the transcripts were offered to the participants as many of the interviews were undertaken with the help of an interpreter and few participants were able to read a full interview transcript written in English. Those who were proficient in English checked the transcripts of their interviews written in English, with the exception of one key informant with visual impairment who listened to excerpts of his recorded interview instead.

5.4 Data Collection

In this section, a description of how data was collected in the photovoice research projects is presented. The research was designed to understand the lived experience of physical disability in Timor Leste, based on photovoice projects, with three groups of people with disabilities in Timor Leste.

The first project was a pilot study, reported in Chapter Six; Chapter Seven describes a photovoice project undertaken with a group of young men who attended a clinic in a rural district near Dili, and Chapter Eight examines a photovoice project undertaken with a group of people in Dili who worked in the disability sector. The group members who worked in Dili reflected on their own lives, as well as providing shadow data, where shadow data is data about the phenomena of interest gathered second-hand (Morse, 2000).
Table 4. Summary of the three studies

<table>
<thead>
<tr>
<th>Study no.</th>
<th>Participant description</th>
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</thead>
<tbody>
<tr>
<td>Study no. 1.</td>
<td>A group of four participants in a remote district in Timor Leste. All had mobility impairments (see Chapter Six. Table 5). These participants were selected by convenience sampling. They lived in a remote district in Timor Leste, they lived near an accessible road and were not afraid to speak to a foreign researcher.</td>
</tr>
<tr>
<td>Study no. 2.</td>
<td>A group of five male participants who attended a small clinic in a rural district near Dili, all had mobility impairments and four had intellectual disabilities (See Chapter Seven. Table 6). These participants were invited by the staff of a new health clinic set up in a rural area near Dili. They were accessible for the clinic’s bus and were not afraid to spend time with a foreign researcher.</td>
</tr>
<tr>
<td>Study no. 3</td>
<td>A group of eight participants employed in the disability sector in Timor Leste, all had mobility impairments (See Table One in Chapter Eight). These participants responded to an invitation to participate in the research, all those invited participated in the research and some were known to the researcher from prior project work. Also eleven key informants, some of whom had mobility impairments participated in the research as well as an interpreter (see Chapter Eight, Table 2).</td>
</tr>
</tbody>
</table>

5.4.1 Local ethical considerations

As the community of people with disabilities and those who work with them is small and centralised in Timor Leste, extra care needed to be taken to de-identify participants. All participant names were changed to pseudonyms and occasionally gender was changed to protect identity. Specific information regarding the location of the studies was also not provided. The whole project was undertaken following ethics approvals from both the University of the Sunshine Coast and following discussions with the vice-rector of the University of Timor Leste and a presentation to the Disability Working Group in Dili (see Chapter Six for details of the ethics approval processes).

5.4.2 The interviews.

The participants in these studies were identified by convenience sampling (Patton, 2002). The participants were mostly people already identified by disability NGOs, that is,
either my sponsoring organisation, the Leprosy Mission of Timor Leste, or another service, the Health and Hope Clinic (pseudonym). Also, from previous visits and work in Timor Leste I knew people with disabilities employed in the disability sector in Dili and these people were invited to participate in the research and were asked if they know of others in employment who would like to be research participants. Participants living in rural districts needed to live near a road and needed to be willing to share their stories with a foreign researcher. All these aspects were needed to be able to study the phenomena of interest, the lived experience of physical disability.

The participants who consented to undertake the research (See the consent form, appendix F) engaged in interviews and a group discussion. The first interview was semi-structured with some focus on basic data collection, such as the make-up of the family, and the first interview was also designed to form an initial relationship with the participant (Plunkett et al., 2012). (See appendix B for the outline of the first interview). Later interviews were convenience, semi-structured interviews, undertaken in a conversational manner and in a manner congruent with a phenomenological approach; that is, with the participants explaining the importance of the photographs which they had taken to describe their lived experiences (Patton, 2002).

The participants in this study were people who potentially had experienced difficulties in their lives - from their own personal history, from their disability or from the events such as periods of violence which occurred in Timor Leste during recent years. If these circumstances proved to be difficult to discuss, then the enquiry moved away from difficult topics, to an area where the participant was able to speak more freely. The group discussion was designed to elicit discussion which would build on the themes visible in the participants’ photographs. During the group discussions, the selected photographs were placed on the floor or on a table and conversation (with as little prompting as possible) was allowed to develop.
This photovoice project was different to many photovoice projects which make use of the acronym SHOWeD, in the group setting (Wang, 1999). SHOWeD consists of the following components: ‘What do you See here: What’s really Happening here: How does this relate to Our Lives? Why does this problem or strength exist? What can we Do about this?’ (Wang et al., 1998 p. 80). My photovoice project was based on a phenomenological approach where my intention was to understand the ‘life-world’ of the participants (Manen, 1990, p. 67) rather than to primarily ask the participants to take a stand against social injustices. For the aforementioned reason, I did not use SHOWeD, making use instead of the acronym PHOTO in relation to each photograph (Graziano, 2011; Hussey, 2006) although ultimately some of the participants elected to show their photographs on public display. The components of PHOTO are:

- Describe your picture.
- What is happening in your picture?
- Why did you take a picture of this?
- What does this picture tell us about your life?
- Does this photo have a message for others (some photographs were of a personal nature and this question was not asked – for example a photograph of a person bathing, however at times the photographers indicated pride in a photograph and in this case I asked the photographer to elaborate on any message – for example those in employment were keen to show that people with disabilities were capable of paid employment).
<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Figure 1. Photovoice in action modified from Wang (1999)</strong></td>
<td></td>
</tr>
<tr>
<td>1.</td>
<td>Selected a group of participants</td>
</tr>
<tr>
<td>2.</td>
<td>Introduced the method to potential individuals including the reason for the research and the proposed benefits. These included long term benefits which may result in more accurate information derived from people with disabilities themselves to inform program designers and policy planners.</td>
</tr>
<tr>
<td>3.</td>
<td>Clarified the research question and how that can be addressed in photography. The participants were asked to take photographs so as to be able to explain to the researcher ‘what is it like to be me’. This included what is important and what is difficult in daily life as a person with disabilities.</td>
</tr>
<tr>
<td>4.</td>
<td>Discussed ethical photography including the importance of consent of photographic subjects</td>
</tr>
<tr>
<td>5.</td>
<td>Obtained informed consent for the research from the participants</td>
</tr>
<tr>
<td>6.</td>
<td>Participants took an agreed time to collect photographs to address the research question</td>
</tr>
<tr>
<td>7.</td>
<td>Met with each individual after the agreed period of time to discuss each individual’s photographs. Three most significant photographs were selected for use in a group discussion.</td>
</tr>
<tr>
<td>8.</td>
<td>Met for further discussion of the selected photographs</td>
</tr>
<tr>
<td>9.</td>
<td>The group decided to display a selection of photographs in Timor Plaza for the International Day of Disability to show what people with disabilities in Timor Leste can do.</td>
</tr>
</tbody>
</table>

All interviews were recorded, and all interviews were transcribed. When each conversation was transcribed, the acronym, SPEAKING was used to provide prompts regarding the background details, such as location of the interview and who was present, at each interview (Hymes, 1974) (see appendix C for an example of the acronym in use) The transcript was written up using a pseudonym, and if necessary, change of other personal details, for each participant. After each session, I began the iterative process of analysis of the content of the session by writing up a discussion summary sheet to provide reminders of the
main features of the contact, plus any memos regarding what I could might need to ask about, or change or improve in future sessions (Miles & Huberman, 1994). (See Appendix D for an example of the discussion summary sheet.)

5.4.3 **The photographs.**
In this study, the participants’ photographs were secondary data; that is, the photographs were used as prompts for the discussions with the participants, and this is most commonly how photographs in photovoice projects are utilised (Catalani & Minkler, 2010). Because of the large numbers of photographs provided by the participants, it was not possible to have a complete story about each photograph. To manage the numbers of photographs, the participant provided a title or caption for each photograph (Denzin & Lincoln; Plunkett et al 2013), which was recorded in the interview notes; detailed stories were collected from a small selection of significant photographs chosen by the participant and the participant also chose three photographs to be used for discussion in the group setting.

However, the photographs provided another component to the research. I offered to print three of each participant’s most significant photographs, and these were not necessarily the photographs chosen for the in-depth discussions. The printed photographs were sent back to the participant as a keepsake and token of thanks for their time and efforts in the research project. I also asked each group of participants what they wanted to do with the photographs. One group elected to simply keep their selected photographs, one group elected to have carefully chosen photographs mounted on the walls of the local clinic to show others what people with disabilities can do. The third group elected to exhibit photographs in a public exhibition at my university in Australia for the International Day of People with Disabilities, and simultaneously held an exhibition in Timor Plaza in Dili. Both these exhibitions were intended to give messages which showed what people with disabilities in Timor Leste can do. The participants who contributed photographs for public display signed documents
consenting to having their chosen photographs exhibited in public (see appendix H for copies of the consent forms).

5.4.4 Stakeholders.

Stakeholders were interviewed in this research project. Some were Timorese who did not engage in the study as photographers and others were ex-patriates working in the disability sector. Some stakeholders had disabilities; and all worked with people with disabilities; or were engaged in policy-making which had the potential to affect the lives of people with disabilities. The stakeholder interviews were initially planned to provide simple background to the stories being gathered by the participants however it soon became apparent that the legislative climate of Timor Leste was rapidly changing with activities relating to the proposed signing of the UNCRPD. (See pages 55-57 of the thesis for details). Therefore stakeholders were asked about:

- Their own roles in the disability sector and about how they felt about their roles
- About changes that they had seen in Timor Leste regarding (a) legislative changes and (b) changes in the lives of people with disabilities and (c) if there were discrepancies between (a) and (b)
- About how they believed the culture of Timor Leste impacted on the lives of people with disabilities.

5.4.5 Field-notes and research journal.

Field-notes can provide contextual data when in the field. These were written after interviews or after conversations with participants. Field-notes were also written after events such as a car trip, and notes were made after discussions and debriefing with the interpreters (Bryman, 2012). Additionally, there was time to make brief notes while undertaking
interviews, and during intervals when the interpreters were active and responding to the participants.

The research journal was usually written at the end of the day. It was firstly, a record of daily events and secondly, a reflexive activity where thoughts and experiences were evaluated and considerations for the future were identified. The research journal has several functions; for example it can help keep a record which helps the researcher understand her own behaviour during the research process (Krefting, 1991). It may also provide a platform for the researcher to reflect on events during interviews, with the potential of developing a better understanding of the participants’ experiences, such as the reflections recorded by Smith in his research of the suffering of people who engage in problem drinking (Smith, 1999). The field-notes and research journal contributed to triangulation and added to the range of sources from which to understand the experience of lived experience of disability (Denzin & Lincoln, 2005; Smith, 1999).

5.5 The approach to data analysis

The approach to data analysis needed to be consistent with a phenomenological research study aimed to capture the essence of living with physical disability, as described by individuals who explain their views and examples of that particular phenomena (Holloway & Todres, 2003). Thematic analysis was chosen to analyse the research data because it is a detailed and nuanced strategy which at the same time is flexible enough to be used ‘across a range of epistemologies and research questions’ (Braun & Clark, 2006 p. 27) and can identify common threads from a single interview or from an entire cluster of interviews (DeSantis & Ugarriza, 2000). Thematic analysis is described as ‘clarifying meaning by moving back and forth between whole meanings and part meanings’ (Holloway & Todres, 2003, p 348) as is consistent with hermeneutic phenomenology. The details of the data analysis are now described next.
5.5.1 **Data analysis: Pieces of a montage**

This section describes the first steps of data reduction and data analysis which included developing initial codes, and which eventually became the building blocks in the montage which was the ‘lived experience of physical disability in Timor Leste’. Data reduction starts at the beginnings of the research planning until the final report is completed (Miles & Huberman, 1994); however, there is a significant period of data reduction which is associated with ‘writing summaries, coding, teasing out themes, making clusters, making partitions, writing memos’ (Miles & Huberman, 1994. P10). The data used for analysis in this research were located in documents generated from interviews, field-notes, the research journal and memos, as well as the participants’ comments or stories related to their photographs. I recorded initial ideas as memos about codes or categories and the analysis continued throughout the field-work as an iterative process (Richards, 2009).

I attempted to complete transcribing the interviews from the recordings as soon as possible after each interview or group session; and this meant that, as I listened to the recordings, I could transcribe and also make further memos (Swanson & Holton, 2005). Furthermore, I became familiar with the data through the transcription process of writing down the English sections of the recorded interviews, as well as beginning the basic iterative processes of summarising and memo-ing on a daily basis (Richards, 2009), making notes as recurring themes were identified. This gave me a ‘start-list’ of codes (Miles & Huberman, 1994) from which to begin my initial coding. Thus, I began to create a code book with descriptions and exclusions for the meaning of each code. (See examples from the code book in appendices M and N).

I had followed the discussions which abound, regarding the relative value and limitations of computer-assisted qualitative data analysis software (CAQDAS) in qualitative research (Weitzman, 2000). For this research I chose to remain close to the data by using the
relative simple tools available in Microsoft Word (La Pelle, 2004; Saldana, 2012; Swanson & Holton, 2005).

My interviews and group sessions did not generate the large bulk of transcripts which are found where only one language is used; and, in any case, software does not provide an alternative to the researcher’s skills, such as making meaning, or identifying similarities and differences (García-Horta & Guerra-Ramos, 2009). My phenomenological enquiry was based on a three-staged process described by Sullivan (2003) which involved (a) collecting descriptions from participants of their lived experience of physical disability (b) reviewing data in the form of transcripts of the participant interviews, my field-notes and memos and stakeholder or key-informant interviews to begin to generate themes, then (c) reviewing the themes, and noting their inter-relatedness and how they contribute to the understanding of the phenomena in question, that is, the lived experience of physical disability in Timor Leste.

5.5.2 Coding using Microsoft Word.

A description of coding a document using Microsoft Word follows. When preparing a transcript, I re-arranged the document so that there were no long paragraphs, ensuring that each speaker’s text started on a separate line. I then saved the original document and placed another version of the document in a table by using the ‘convert text to table’ function in Microsoft Word. Extra columns were added, based on the addition of a header row (see figure 2 below), similar to Swanson and Holton (2005), ensuring that each column was the same size across all documents being coded.
Figure 2. The heading of the coding table

<table>
<thead>
<tr>
<th>Code</th>
<th>ID</th>
<th>Turn #</th>
<th>Question</th>
<th>Data</th>
<th>Notes</th>
</tr>
</thead>
</table>

**Code:** the code finally attached to the piece of data.

**ID:** participant identifier.

**Turn#:** equivalent to ‘line number’. This column allows the researcher to return to the original shape of the document being coded if necessary.

**Question:** the question being asked.

**Data:** the chunk of text being coded.

**Notes:** notes or memos relating to the chunk of data.

The steps using this method involve firstly, using the data in the data column and making notes on each chunk of data. (Note that my questions were at times in the second person and the interpreter gave the participants’ answer in third person). Consequently, at the end of this process, I had an entire document with data and notes. I could add codes from the pre-determined start-list or I could insert a new code, which would then be added into the ‘Code’ list. I then selected the Code column and used the ‘sort text’ function in Word, so that all the codes were clustered in their groups and I could see different iterations of each code. The Turn# column meant that I could track my changes back to the original if I needed to identify the place of the selected piece of text in the main document. The first step for each document was to code, using initial or holistic codes (Saldana, 2012), as shown in the example below in Table 5.
Table 5
Example of a section of coding prior to sorting the Codes column

<table>
<thead>
<tr>
<th>Initial codes</th>
<th>ID</th>
<th>Turn #</th>
<th>Question</th>
<th>Data</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Childhood friends</td>
<td>ArD</td>
<td>11</td>
<td>Did you have some good friends at school?</td>
<td>yes he have a lot of friends</td>
<td>Friends</td>
</tr>
<tr>
<td>Community attitudes</td>
<td>ArD</td>
<td>22</td>
<td>And what about in your community, did you feel that people understood you and supported you when you were in the community?</td>
<td>Some community and families in the areas is good and some make discrimination and say why you have disability, why you go to the school, because you have bad hand and bad leg so why you go to the school</td>
<td>Variety of responses to his disability.</td>
</tr>
<tr>
<td>Personal goals</td>
<td>ArD</td>
<td></td>
<td>And what did you do after you left school?</td>
<td>When he finish school, he say he want to work with the DPO, the disability organisation to help people with disability in their life, he want to help them</td>
<td>Personal goal to help people with disabilities</td>
</tr>
</tbody>
</table>

Each document was coded and saved (see appendix M for notes on the initial, holistic coding) and, if I then wanted to explore further themes or use a different focus, I could code again. For example, I examined all the participant interviews using ‘emotion coding’ (Saldana, 2012, p. 105) (see appendix N, emotion coding) to investigate participants’ emotional responses within the interviews, in this instance, what they liked, didn’t like, were afraid of. I defined the terms relating to emotion coding in my code-book; for example, I included words such as sadness, loneliness, joy, happiness amongst other terms commonly associated with emotions, as well as the terms strong, positive, success, as well as phrases such as ‘get what I want’.
5.5.3 Making the montage.

The coded data in the interviews and other documents then needed to be manipulated further, in the search for abstraction and meaning. The researcher at this point takes the details acquired by the manipulation of the codes and comes up from the data to reconstruct meaning (Richards, 2005); however, Microsoft Word does not have the capacity to provide creative exploration of themes (Swanson & Holton, 2005). The researcher then needs to become an interpretive ‘bricoleur’ (maker of quilts), assembling the pieces of the research in the quest for understanding (Denzin & Lincoln, 2011).

Bricolage ‘involves taking research strategies from a variety of scholarly disciplines and traditions as they are needed in the unfolding context of the research situation’ (Steinberg, 2006, p. 119). Where visual data is featured, Denzin and Lincoln note that the metaphor of a montage could be used instead of considering the researcher as bricoleur; in either case, the metaphors involve the researcher who ‘stitches, edits, and puts slices of reality together. This process creates and brings physiological and emotional unity to an interpretive experience.’ (Denzin & Lincoln, 2011, p. 5). In this process, the bricoleur understands that there is a complex overlaying of the experiences, histories, and views of the researcher and the researched, which produces a ‘quilt-like bricolage, a reflexive collage or montage; a set of fluid, interconnected images and representation. This interpretive structure is like a quilt, a performance text, or a sequence of representations, connecting the parts to the whole’ (Denzin & Lincoln, 2011, p. 6).

Different methods were used in creating the montage; for example the codes and themes were visualised by noting interconnections between themes, overarching themes, and patterns. Next, by considering metaphors or chains of events with the help of diagrams and mind-maps, the principles of thematic net-works were then used to reconstruct the montage (Attride-Stirling, 2001). I assembled the participants photographs in coded groups to match
the codes derived from the written transcripts to help illustrate a theme for myself. This also at times suggested a further theme which I had not initially observed in the coded text.

Further examples of the results of these can be seen in the articles following in Chapters Six, Seven and Eight and a poster based on a montage can be seen as Appendix S. In brief, the data analysis moved from coding and categorising, to description, and finally to understanding the themes which were established from the data. The research questions relating to ‘what is the lived experience of people with disability in Timor Leste?’ were addressed with a range of answers from the participants, analysis dismantled the data, and the data was reassembled into explanation and presentation of the whole (Richards, 2009). The discussion chapter, Chapter Nine is a presentation of the discussion regarding the overall picture of the lived experience of disability in Timor Leste as revealed in the three articles in Chapters Six, Seven and Eight.

5.6 Summary

In this chapter, I presented some of the background to my position as researcher, from both previous experiences in Timor Leste, and from consideration of how I positioned myself as a researcher using hermeneutic phenomenology. I then discussed issues relating to rigor in the form of trustworthiness in the research. I addressed data analysis with a detailed description of the use of Microsoft Word as a tool for data analysis, followed by considerations regarding managing the disassembled coded data.

Chapter Six follows, as the thesis goes to press it is an article under review. The article reports on how the research method, photovoice, was undertaken in the pilot study. The article provides details of the remote setting in which the first photovoice project was carried out and the learnings from the pilot study. One significant feature of this study was that it was not possible to undertake the group process which is generally used in the second phase of a photovoice project, because of the logistical problems of transporting people with
significant disabilities to a common venue, from remote locations, on poor roads. The data and learning from the pilot study were therefore significant in planning the studies which followed and are reported in Chapters Seven and Eight.
Chapter Six: First Study Findings

A study of disability and occupation in a resource-poor setting: Photovoice in research

Key to the thesis

<table>
<thead>
<tr>
<th>Chapter</th>
<th>Description</th>
<th>Article</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Introduction</td>
<td>Background</td>
<td></td>
</tr>
<tr>
<td>2. Literature review</td>
<td>Relevant literature</td>
<td></td>
</tr>
<tr>
<td>3. Literature review</td>
<td>Article, metasynthesis</td>
<td>Published</td>
</tr>
<tr>
<td>4. Methodology</td>
<td>Methodology, research framework</td>
<td></td>
</tr>
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<td>5. Methods</td>
<td>Research method, research details</td>
<td></td>
</tr>
<tr>
<td>6. Methods</td>
<td>Study #1. Pilot study</td>
<td>Under review</td>
</tr>
<tr>
<td>7. Findings</td>
<td>Study #2. Research project</td>
<td>Under review</td>
</tr>
<tr>
<td>8. Findings</td>
<td>Study #3. Research project</td>
<td>Published</td>
</tr>
<tr>
<td>9. Discussion</td>
<td>Discussion, limitations and learnings</td>
<td></td>
</tr>
<tr>
<td>10. Implications for practice</td>
<td>Book chapter</td>
<td>In press</td>
</tr>
<tr>
<td>11. Implications for practice</td>
<td>Implications for practice</td>
<td></td>
</tr>
<tr>
<td>Appendix</td>
<td>Descriptive article</td>
<td>Published</td>
</tr>
</tbody>
</table>

The previous chapter explained the details in the research including the position of the researcher in the overall research picture, some relevant background to Timor Leste as the research site, some relevant background to photovoice as the research method, how to ensure rigor in the research and the strategies for data collection and analysis.

Chapter Six begins the Findings section of the thesis with a presentation of the pilot study which was undertaken in a remote district in Timor Leste. This study was written up as an article for the Hong Kong Journal of Occupational Therapy which has an impact factor
of .704 in 2014, and at the time of writing the article was ‘under review’ with this journal.

The Hong Kong Journal of Occupational Therapy was selected because of its Asian location together with a world-wide readership and because it publishes both qualitative and quantitative research.
Chapter Six. Findings

A study of disability and occupation in a resource-poor setting: Photovoice in research

Short title: Photovoice and disability in a resource-poor setting

6.1 Abstract

Background: There is little research on the lives of people in resource-poor settings and even less on experiences of living with disabilities in societies where little practical help or services are available. There are challenges for occupational therapists in cross-cultural research such as language differences, perceptions of power and ethical considerations in relationship to data-collection. Methods: In this article the benefits and challenges of photovoice, a method using participant photography, were explored to understand the lived experience of physical disability in Timor Leste. Thematic analysis was used to analyse transcribed interviews in combination with participant photographs and field-notes. Results: Data consisted of participant photographs, interview notes, field-notes and stakeholder interviews. The five participants took 464 photographs over approximately five days. Four core themes were identified (1) the person within the family, (2) The person within the community and (3) Poverty as a part of the total experience Conclusions: Photovoice provided relevant and rich data about participants’ occupational roles and activities which may not be available using other approaches and participants were able to direct data collection by photographing material of their choice. Researchers must be vigilant with ethical considerations such as considering power differentials between researchers and participants. The visual data in photovoice helps validate other methods of data collection, thus reducing risk of misunderstandings in cross-cultural research. An occupational therapist
using photovoice can generate a rich source of information about issues, and problems identified by the population under investigation.

Keywords: Photovoice, disability, cross-cultural research, Timor Leste.

6.2 Background

Timor Leste is a small developing Asian country an hour’s flight north-west of Darwin, Australia’s northern-most city. Timor Leste has a past which includes colonial administration by Portugal followed by 26 years of oppressive occupation by Indonesia. The country’s infrastructure was mostly destroyed in 1999 following a national referendum which ended the Indonesian occupation and subsequently United Nations (UN) peacekeepers administered the country from 1999 until independence in 2002. Approximately 80 per cent of the population is still engaged in subsistence lifestyle and 40–56 per cent of the population are unemployed despite the revenue from the country’s oil reserves (Richmond, 2011) and despite the foreign aid which has flowed into the country since the arrival of the peacekeepers. This was the setting for a photovoice pilot project aimed at understanding the lived experience of people with disabilities in a resource-poor setting.

The census of 2010 in Timor Leste noted that there was a population of 48,243 people with disabilities, i.e. 4.6% of the population of 1,066,409 (Census of East Timor, 2010). These figures are in contrast to the 15.6% of people with disabilities in the global population as determined by the World Health Survey and reported in the World Report on Disability (WHO, 2011). This relatively low percentage of people with disabilities in Timor Leste could be due to the presence of stigma in Timorese communities which results in such people being unrecorded in the census (The Leprosy Mission 2011), or to a limited number of impairments being included in the census; for example the functional losses of aging may be considered normal and subsequently not reported (WHO, 2011).
Timor Leste as a resource-poor country receives foreign aid from Western countries including Australia and there has been extensive research providing health data as background for foreign aid, however, the big data sets provide little understanding of the day to day experiences of vulnerable people (Singal, 2010). Unless there is an understanding of the needs of people with disabilities there is a risk that, ‘inclusion’ may simply be a tokenistic exercise (Bone, 2012; Donnelly, 2012). This study was the pilot project for a larger study aiming to investigate the ‘lived experience of physical disability in Timor Leste’ as a step towards filling the gap in knowledge about the daily lives of this population.

6.3 Use of Photography in Low-Resource Settings

Wang and Burris (1997) developed photovoice as a participatory research tool for health promotion and research in rural China. The method combined documentary photography, Freire’s (1970) theory of ‘education for critical consciousness’ and feminist theory, with the participants themselves as photographers (Carlson, Engebretson, and Chamberlain, 2006; Graziano, 2011; Plunkett, Leipert and Ray, 2012) The method was designed to ‘… affirm the ingenuity and perspective of society’s most vulnerable populations’ (Wang & Burris, 1997, p. 372); no academic literature based on the use of photovoice was found relating to Timor Leste.

6.4 Method

In Timor Leste difficulties with informed consent in research arise from low levels of literacy and lack of educational opportunities in first languages (Taylor-Leech, 2013; Yeo and Moore, 2003). However, creative strategies have been developed by others where written consent is difficult, for example: Liamputtong (2013) recorded verbal consent being given by her participants and Flory and Emanuel (2004) captured visual records of their participants expressing their consent to the research processes. University of the Sunshine Coast ethics committee approved the research project (see appendix E) however, approval was also
needed in Timor Leste where there were no protocols to provide ethical research approval. The University of Timor Leste’s (UNTL) Vice-Rector, proposed a consultation with the Disability Working Group of Timor Leste (DWG) to request (1) approval for the photovoice project and (2) advice about use of verbal consent where people have low levels of literacy; the DWG discussed the proposed research and supported the use of verbal consent where participants were illiterate.

Research on ‘lived experience’ invites a phenomenological approach to investigate the life-worlds of individuals participating in the research. An interpretive framework was used to tease out individuals’ experiences based on cultural, contextual and historical interpretations of their experiences (Crotty, 1998; Schwandt, 2007). The research process at the ‘cultural interface’ was directed by the guidelines set out by Thomas, Gray and McGinty (2011). These authors state that the occupational therapist needs: (1) Flexibility and responsiveness, (2) supervision and mentoring (3) cultural advisors and (4) relationships with Indigenous (in this case Timorese) people and effective professionals in cross-cultural research and these steps were broadly adhered to in this study.

Data collection came from translated interviews; an initial introductory interview, followed by a data collecting interview and then a third interview based on the participants’ photographs. Field-notes and transcripts from debriefing with the interpreters were also a part of the data. Interviews were carried out with the help of two interpreters who also acted as cultural mentors and gate-keepers, as they were employees of the sponsoring organisation, The Leprosy Mission of Timor Leste (TLMTL)

6.4.1 The participants.

The interpreters in this research project made contact with potential participants prior to the arrival of the Australian researcher/occupational therapist, simply referred to as ‘the researcher’ from now on. The participants were chosen by convenience sampling (Patton,
2002) and the criteria for participation in the study were (a) the individual was interested in the research project, (b) was accessible by motor-bike (as there is little public transport in the district, (c) had a significant physical disability and (d) was willing to tell his/her story to a visiting foreigner. Initially six potential participants expressed interest and four of these people subsequently became a part of the study. Details of the participants can be seen in Table 6

Participants in the Pilot Study (all names provided are pseudonyms) Of the two who did not participate, one lived in a community accessed by exceptionally poor roads and the other was not confident with camera use.

6.4.2 Photovoice in action.

The researcher travelled by motor-bike with the two interpreters to each of the six participants homes for an initial introductory visit. If the proposed participant expressed interest, a second visit was arranged for the participant to formally agree to the project and to provide initial data. At this stage the participant learnt how to use the camera and precautions and safety issues were discussed. Each participant was asked to ‘take photographs which will help explain how you live your life, what you do every day and what is important to you’ and at the end of each trip a debriefing session was held with the interpreters.

The interpreters carried out a camera check after two days, then three to four days later the researcher visited each participant again with the interpreters to review the photographs on a laptop computer; the participant explained each photograph and provided a caption for each (Denzin & Lincoln, 2011, p480). Participants were asked to select their six most important photographs and to give a more detailed story about these. All interviews and field-notes were recorded with the participant’s verbal permission; participants were invited to listen to their interview recordings however, only one participant accepted the offer and
listened to a part of one of the interviews. All data were analysed using thematic analysis (Braun & Clarke, 2006).

Table 6
Participants in the Pilot Study (all names provided are pseudonyms)

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Marcelina</th>
<th>Donato</th>
<th>Annalisa</th>
<th>Jeremiah</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>29</td>
<td>27</td>
<td>39</td>
<td>40</td>
</tr>
<tr>
<td>Others in the household</td>
<td>Mother and two siblings</td>
<td>Parents and five siblings</td>
<td>Husband and three children</td>
<td>Wife and three children</td>
</tr>
<tr>
<td>Community</td>
<td>Poor beachfront community near ferry landing. Sandy ground and a sealed road to the market</td>
<td>Remote hill-top community, poor farming. Rocky undulating environment, dusty road</td>
<td>Poor lowland farming community. Environment includes a steep small gully where weaving group meets</td>
<td>Lowland village, sealed main roads dirt local road. Level environment although extended family are visited via a road in the river-bed when it is dry.</td>
</tr>
<tr>
<td>Impairment</td>
<td>Paraplegia and sensory loss</td>
<td>Hemiplegia and contractures on affected side</td>
<td>Paraplegia</td>
<td>Paraplegia</td>
</tr>
<tr>
<td>Mobility</td>
<td>Wheelchair when outdoors or when working in the home, such as cooking. Crawls short distances indoors.</td>
<td>Single crutch, crawls at times</td>
<td>Crawls around the home, borrows a wheelchair at times,</td>
<td>Wheelchair. Crawls at times</td>
</tr>
<tr>
<td>Cause of physical disability</td>
<td>Fall from palm tree</td>
<td>Early childhood fever</td>
<td>Early childhood fever</td>
<td>Fall from palm tree</td>
</tr>
<tr>
<td>Year of physical disability</td>
<td>2006</td>
<td>Early childhood</td>
<td>Early childhood</td>
<td>2000</td>
</tr>
<tr>
<td>Education</td>
<td>Primary school</td>
<td>None, can use money</td>
<td>None, can use money</td>
<td>None, can use money</td>
</tr>
<tr>
<td>Income source</td>
<td>Sells food to ferry passengers. Handiwork</td>
<td>Pension, helps in kiosk</td>
<td>Weaving traditional cloth, sells vegetables</td>
<td>Family fields, small family kiosk</td>
</tr>
<tr>
<td>Language</td>
<td>Primarily Tetun</td>
<td>Bikeno</td>
<td>Bikeno</td>
<td>Tetun with Bikeno for detailed explanations</td>
</tr>
</tbody>
</table>
6.4.3 Data analysis

The interview transcripts from the total of twelve interviews were analysed using a hybrid approach to analysis similar to that described by Fereday & Muir-Cochrane (2006). This method of analysis involves using both an inductive and a deductive approach to coding; inductive coding was undertaken by identifying sections of text from the interview transcripts, from the participants caption for each photograph as well as from the transcripts of the debriefing sessions with the interpreters which were given a brief descriptive title.

The brief descriptive title identified rich aspects of the phenomena in question, and could be thus considered a code. (Boyatzis, 1998). A template approach was also used (Crabtree & Miller, 1999) and the template was based on previous research undertaken by the author in the form of a meta-synthesis of literature reporting on the lived experience of people with physical disabilities in East and Southeast Asia (Shamrock, 2016). This research, undertaken in the geographical region in which Timor Leste is located, provided six themes found in articles investigating the lived experience of physical disability. The six themes found in the meta-synthesis together with codes identified in the inductive search were supported by a code book to ensure consistency in identifying the codes (see Chapter Five for description of the code book).

The codes used in the analysis of the transcripts are listed below:

(1) Family life
(2) Personal attributes
(3) Physical health
(4) Education
(5) Poverty
(6) Traditions - values and beliefs
(7) Community
(8) Environment - Positioning oneself and moving around

(9) Work

(10) Disability services

(11) Community development

The overarching themes relating to the lived experience of physical disability in Timor Leste derived from the codes were thus:

(1) The person within the family

(2) The community and the environment

(3) Poverty and outside assistance.

Figure 3. Steep ramp to Marcelina’s house

6.5 Results

The experience of undertaking research in remote communities in Timor Leste was an experience of a significant cultural gap between the researcher and the participants. For example, the
researcher and sometimes the interpreter were always offered blue plastic chairs to sit on, as an indication of respect:

We pulled up beside a cement house where a group of about 10 people waited. More came to join in as we greeted everyone. Donato [pseudonym] was perched on the low wall around the porch. [the interpreter] sat beside Donato in his usual exquisite positioning so that he was level with Donato and ... I was offered a blue plastic chair … (Field-notes 21st August 2012)

None of the participants had used cameras before and the field-notes record Annalisa’s first experience:

She giggled like crazy when asked if she would like to use a camera. The families around all craned forward to listen to the story about the camera, in disbelief perhaps ... I squat next to her to show her how to use my camera. She tries it out, a slender finger reaches into the twenty first century and presses the knob and takes her first photo! She giggles in disbelief. She tries several photographs and continues smiling and seems to enjoy the process (Field-notes 20th August 2012)

The participants found the cameras easy to use despite having no prior experience and they took photographs themselves or asked other family members to take photographs to help them in their quest:

‘He have no problems with the camera, he practice and he take a lot of photos, it’s easy and he has family member with a camera, there are no problems for him’ (Interview Jeremiah [pseudonym] with interpreter, 27th August 2012).

Photovoice provided the researcher with explicit naïve views of the participants in their homes and environments, where they move around and the activities in which they engaged. Twelve interviews were conducted with participants and extensive field-notes were taken at the time of the interviews, and again, following reflection at the end of each day
together with the interpreter. The interviews and the 464 photographs taken by the four participants provided rich insights into their daily lives with 20 photographs too blurry for use. The participants took an average of 111 photographs each over five days.

The photographs offered opportunity to discuss a range of matters with each participant, with the photograph being a prompt. As there were a large number of photographs, some photos were simply described by a caption, for example ‘she is going to the bathroom’, and some photographs elicited further details or a story. None of the interviews were undertaken in private. In all the interviews there were family members and at times neighbours or community members present and thus it was not generally appropriate to ask for detailed personal information such as questions about bathing and hygiene, or questions about personal family relationships.

The interview transcripts, data from the photographs and the field-notes provided important insights into experiences of (1) the person within the family, (2) the person within the community and (3) poverty as a part of the total experience of living with disabilities. These themes reflected the participants’ expressions of their lived experience of physical disability in Timor Leste and these three themes found in the data are closely interwoven.

6.5.1 The person with disabilities within the family

This section highlights a combination of attributes of the participant in question interwoven with the individuals family, as almost every task and role undertaken by the participant was associated with the tight-knit Timorese family; all participants presented a large percentage of their photographs which included a family member in the photograph. The photographs showed the participants in their daily roles and activities and how each was influenced by the disability. The sub-headings from the interview transcripts supported by the photographs are associated with the participants’ experiences of (a) work and skill (b) a limited education (c) maintaining health (d) mobility and access (e) family roles and support (f) cultural activities and these sub-themes are interlinked.
6.5.1.1 The family as a source of love and support

Three of the four participants commented on the importance of the support provided by their families and the importance of families could be seen by the number of photographs showing family members as have been described in the sections above. Families were a source of strength and support, for example, Annalisa’s husband can be seen in many of her photographs, attending her wound, making coffee and helping her to sort the piles of completed weaving in the evening.

![Marcelina with family](image)

*Figure 4. Marcelina with family*

Marcelina told a story relating to a photograph where she was sitting in a wheelchair surrounded by two little boys and an older woman and baby (see figure 6 above):

She say this is her mother and her little brothers. Even though she is disabled she is surrounded by love and support and people to teach her to trust herself. This is her
family is very important (interview Marcelina [pseudonym] with interpreter, 27th August 2012). (See figure 4 below)

Donato expressed appreciation of the love and support of the family, however Donato’s father expressed frustration that his son could not do the activities that a son should do. He stated that Donato ‘… can’t go very far and he can’t do much and he can’t work in the garden’ (Interview Donato [pseudonym] with interpreter, 28th August 2012).

The photographs showed the participants carrying out their family roles, Annalisa had photographs of herself cooking at her fire on the floor with her children around her. She explained that she does most of the work caring for her family and that her husband helps a little.

He’s helping her a bit,

Do Timorese husbands usually help like that?

This is his work he help her and here you can see he makes the coffee

Do husbands in other families sweep and make the coffee?

Sometimes they do this in the family (Interview Annalisa [pseudonym] with interpreter, 27/8/2012)

Jeremiah commented that his family is the most important aspect of his life as they can help him fulfil his own family roles, as home-maker in the garden or as shop-keeper:

Why is the family so important?

Family is important for him because sometimes anything is hard to do he called the family will come. Children help with the shop and the wife in the garden. (Interview Jeremiah [pseudonym] with interpreter, 27/8/2012)
6.5.1.2 Participants’ approaches to health

The environments in which the participants moved in their daily life offered challenges to maintaining optimal health for example cooking and food preparation was done on the floor. This was difficult for Marcelina who had sensory loss in her legs as a result of her paraplegia and had a weeping open sore on her leg, clearly visible on the first visit. The field-notes describe:

‘Her left leg is infected and has weeping sores from a burn where she was cooking because she has no sensation in her legs … She uses traditional balm on the wound but it looks raw and infected. Marcelina believes that the traditional medicine that she uses is good.’ (Interview Marcelina with interpreter. 28/8/2012)

Annalisa had photographs of a wound on her leg which she acquired crawling from her outdoor community weaving area. Photographs showed the wound being dressed by her husband who used warm water and a piece of cloth, and at the time of the research visit the injured area looked healthy. Jeremiah reported that after his spinal injury he used traditional methods of massage to try to recover from his accident. All participants stated that they generally used traditional treatments for injuries at home and traditional treatments mentioned included balm or massage together with an understanding that wounds need to be cleaned with water. The main town had a small hospital however Marcelina stated that the hospital was too far away and thus too difficult for her to visit, even though she was the closest of the four, to the hospital.

6.5.1.3 Experiences of mobility and access

All participants had a significant number of photographs demonstrating difficulties with positioning oneself and moving around, such as in a photograph of Annalisa crawling to her outdoor bathroom with her toiletries balanced on her head (see figure 4 below). She reported that during the rainy season crawling was much more difficult outdoors and she
tried to keep herself clean by wiping herself with a towel, or at times her husband or a child helped her. The subsequent photograph showed her sitting on the ground reaching up with difficulty into the traditional concrete water tank commonly used in Timorese bathrooms and used by three of the four participants.

Jeremiah explained a photograph where he is turned uncomfortably sideways in his wheelchair to cut a piece of palm branch to build a fence:

‘J: It must be difficult to do this work, I can see he is turning sideways to hold the piece of palm tree, ask him if it’s hard to work like that?’

‘He say yes, but he can do, before he can do and now it is not so good to do, not easy for him’

J: ‘Yes, I can see that, did he get some help?’

‘Yeah, this boy come after school help him’ (Interview Jeremiah [pseudonym] with interpreter, 27/8/2012)
Donato had a photograph of himself climbing a stone wall which surrounded the garden where his family grew vegetables. The photograph shows his determination to climb the wall, managing his contractures and carefully positioning his walking crutch to keep it in reach.

6.5.1.4 Importance of work and skill

Whilst poverty meant that work opportunities for all Timorese were limited, and the participants treasured their work or work-like roles, however they frequently needed the help of their families to undertake their work roles. For example two participants had fifty six (33%) and ten (55%) of photographs respectively, showing themselves at work. Annalisa had photographs of her loom indoors where she worked at night. She commented that she needed to work at night as well as in the daytime because of her commitment to the aid-funded weaving project of which she was a member. Annalisa’s photographs of her weaving also show her in the context of her family; the weaving group consist of other female members of her extended family as well as a neighbour; and another photographs showed her daughter carrying the folded loom to the home at the end of the day as Annalisa needed to crawl up the hill to her home.

Jeremiah was a fisherman prior to his accident and he explained his frustration at his inability to work. He could no longer go out to fish and his skill at repairing fishing nets was of little value as most men in his community could do the same thing. The main value to him was to fill in time as he sat in the family roadside kiosk where basic items such as cigarettes, beer, washing powder and cakes were sold:

Yeah … when he waiting in the kiosk … You know before he is a fisherman and he can make this one and repair this one but now he is just waiting … this is not his special skill, many people in his community know this one, many people are fisherman in his community but now he cannot go (cannot go out to fish) (interview with Jeremiah [pseudonym] with interpreter, 27th August 2012).
Instead of fishing as he did prior to his accident, Jeremiah devoted some of his time to home repairs. Photographs also show him building a fence out of palm fronds as well as working with his uncle, a carpenter, who was helping him to rebuild his home. Jeremiah described his photos as working with his uncle although in many of the photos he appeared to be actually watching his uncle working as he himself could not reach most aspects of the work from his wheelchair. For example he was unable to reach up to position timber in the door-frames or windows which his uncle was building. While Jeremiah could build the fences around his home to keep animals out of his family’s garden, his wife tended the garden and his children helped him in the kiosk. Jeremiah expressed frustration that he could no longer fish or actively earn an income.

*Figure 6. Jeremiah repairing fishing nets*

6.5.1.5 Participants with limited education

While the participants photographs did not explicitly show educational activities, nor was there extensive discussion about education, the interviews noted that only one participant had basic literacy although all could ‘use money’, meaning that they were confident making
purchases or selling produce in the market (see table 6.) In contrast, the participants with children commented on the fact that their children attended school and Jeremiah commented that education would help his son to get a job in the future.

6.5.2 The person with disabilities within the community

The second theme, the person with disabilities within the community demonstrated the importance of the community for the participants together with difficulties accessing the community due to their mobility impairments. This theme had sub-themes, namely: (1) Experiences of cultural and community activities (2) experiences of disability and health services.

6.5.2.1 Experiences of cultural and community activities

The participants and their families were embedded within the culture of their remote Timorese communities and activities such as Annalisa’s weaving, Jeremiahs fishing net repairs and church-based activities took a significant amount of the participants’ time. Annalisa was engaged in a traditional weaving project, from which she hoped to be able to earn an income. In this activity Annalisa and her weaving group, consisting of female extended family and neighbours sat for long hours in the shade of a cluster of palm trees in a dried creek bed weaving on traditional backstrap looms. Donato had a series of photographs of himself attending church and receiving communion, an important activity for most Timorese (see figure 7. below). He offered another series of photographs and extensive commentary about another community activity which involved community members meeting to discuss community work projects.
Marcelina reported that she receives communion from a visiting priest each week as well as visiting the statue of the Virgin Mary to pray each Sunday with her mother and Jeremiah reported that after his accident he trusted in God for help with his injury.

Both Marcelina and Jeremiah reported negative community attitudes to disability following their accidents and they believed these attitudes initially. They both reported that they were able to overcome their responses to community attitudes with the help of the visiting field-staff from the sponsoring organisation. For example Marcelina explained:

Before TLMI visited she was told that people say like you can’t do anything. Here you wait for other people to do things for you. She was dependent. After CBR (people from the Community Based Rehabilitation service) and DPO (people from the Disabled Persons Organisation) came to visit she is happy because they explain and advise her. (Interview Marcelina [pseudonym] with interpreter, 27th August 2012).

Community access was limited for the participants because of difficulty managing distances with mobility impairments. Donato could move around independently in his home area using his axillary crutch however he needed to travel by ojet (motorbike-taxi) to travel
longer distances, such as to the church. Jeremiah had a series of photographs of himself with a young son to help him as he wheeled himself to visit extended family along the dried gravel river-bed; Annalisa had a series of photos of a trip to the main town showing firstly the family passing her wheelchair over the fence, then her husband wheeling her down the road towards the main bus stop. Annalisa reported that the wheelchair was hidden in bushes and they travelled together in the bus to visit government offices. They needed to repeat the process to return home at the end of the day.

6.5.2.2 Experiences of disability and health services

The disability and health services in Timor Leste provide some help for people with disabilities, with some success and with some frustrating experiences.

Timorese are often reluctant to attend hospitals as the hospital system at times imposes unhappy experiences. For example Marcelina reported that when she was in hospital following her accident she was treated roughly by a nurse who was from a different part of the country:

While in Dili hospital a Lorosa’e (eastern part of the country) nurse from Viqueque moved her arm around very vigorously and painfully, telling her that she had to learn to be strong. Marcelina [pseudonym] is Loro mono (western part of the country), being from Oecussi so this was an aggressive act on the part of the Lorosa’e nurse. (interview Marcelina [pseudonym] with interpreter, 27th August 2012).

Jeremiah reported that he did not go to hospital following the accident which resulted in his paraplegia. ‘He did not want because he does not trust the hospital. Hospital is not always good experience for Timorese’

The participants were all clients of the sponsoring organisation and as such had benefited from the disability services available in Timor Leste. Two of the four participants had received detached bathrooms designed by their supporting NGO, and these had concrete
floors, corrugated iron walls, a squat toilet and a traditional tank where water is taken with a dipper and poured out for bathing. However the process of qualifying for this assistance was slow. The participants needed to undergo a process of consultation through their local DPO to ensure that aid to people with disabilities was apportioned fairly and with full knowledge of others with disabilities in the communities, thus aid was apportioned according to need.

Donato explained that he was proud to be a member of his DPO group and he provided a range of photographs of group members including a small boy with a large swelling over his spine:

   Donato: The boy has a problem, he can stand up but he can’t walk.

   Interviewer: Why did Donato take the photo?

   Donato: Because they are his friends and he wants to see another people (he wants to show other people) that they are have a program for disable people.

   Interviewer: Who does he want to show?

   Donato: He wants other people, malai (foreigners) to know that he is not alone?

   Interviewer: Did Donato go to visit these people especially to take the photos?

   Donato: He just went to take the photos? Yes. (Interview Donato [pseudonym] with interpreter, 28th August 2012)

   The health and disability services are stretched and have their problems thus the participants experienced confusion and disappointment from the health and disability services. For example the DPO appeared to have difficulties such as members’ mismanagement of money:

   The grant that ... (was given) ... before, the members ... decided to do business but they did not repay the loan. This is not right that they benefit, they should be excluded but they want to join with the group. Donato [pseudonym] is afraid that the same thing will happen again. (Field-notes. August 2012)
6.5.3 Poverty as a part of the total experience of living with physical disabilities

The sections above all displayed elements of poverty and these could be easily seen in the participants’ photographs; the need for help to build accessible bathrooms, the reluctance to use the health services, minimal education levels and problems obtaining work. The descriptions provided by the participants of their lives and the detail visible in the photographs clearly demonstrated poverty as a pervasive factor in a life with physical disabilities in a remote part of Timor Leste. The influences of poverty were categorised under the following sub-headings: (a) Poverty influences home life, (b) poverty influences mobility (c) poverty reduces opportunities and (d) poverty influences health.

6.5.3.1 Poverty influences home life

The field-notes and photographs show poor communities with the participants homes made of cheap building materials set in dusty environments with sparse food gardens nearby. Only one home had a dirt floor, the other three had floors of concrete slabs and the participants houses were made of palm material with timber frames and iron roofs.
The participants’ homes had little furniture, cooking was done on the floor and families ate on the floor indoors, all this reflecting the poverty of this particular remote district.

The participants’ gardens also reflected poverty. Participants obtained most of their food from their gardens and the gardens at Jeremiah’s and Annalisa’s homes contained cassava, beans, bananas, corn and green vegetables which are basic foods common in the poor districts of Timor Leste (see figure 5 above).

The photograph below taken by Annalisa’s eldest daughter shows a family meal consisting of rice, chili, green vegetables and corn. The meal shown in this photograph had no meat, another indication of poverty.

Figure 9. Annalisa family meal

6.5.3.2 Poverty influence health

Section 6.5.1.3 above note some of the influences of poverty on health, such as the participants preference for simple home treatment for health problems rather than attending a hospital, the need to crawl in the home environment and the reluctance to attend the local
hospital for treatment to injuries because of the cost of transport. Poor people in Timor Leste also have poor diets as could be seen in section 6.5.3.1 above.

6.5.3.3 Poverty influences mobility

Section 6.5.1.4 above describes the experiences of mobility which are based on poverty. This is compounded by the difficulties with the health and disability services which are unable to replace damaged mobility aids. Jeremiah explained.

He has had his wheelchair since 2008 (four years) … He showed us that his wheelchair has chunks out of the wheels and that the front wheel is wobbly. There are other problems with the big wheels as well. (Interview Jeremiah [pseudonym] with interpreter, 27/8/2012).

Figure 10 Jeremiah visiting extended family

The reason for the damage to the wheelchair could be seen in relation to the photographs Jeremiah took as he traversed the dry stony river-bed in his wheelchair.

6.5.3.4 Poverty reduces opportunities
The participants expressed frustrations and disappointments regarding basic needs which can be attributed to poverty. Jeremiah longed to be able to earn a sufficient income again.

Before he was a farmer, he had – still has two rice fields. He also made wine. After his accident he didn’t know what to do ... He was sad because he couldn’t do what he did before... he made money before. Now there is no money for food. (Interview Jeremiah [pseudonym] with interpreter, 27/8/2012).

Opportunities for other interests were also denied because of poverty. Marcelina described her enjoyment of basketball and she had heard of the wheelchair basketball games being played in Dili by people with disabilities. However she lived in a remote district and did not have enough money or support to go to Dili to develop her interest:

Marcelina … used to be a basketball player. She has heard about wheelchair basketball and she would like to do this but there is no money. (Interview Marcelina [pseudonym] with interpreter, 27th August 2012).

6.6 Discussion

The significant findings from this research project pointed to the absolute importance of the family for a person with disabilities in a remote setting, and the overall effect of poverty. Family members helped with transport and mobility, with daily tasks such as cooking, gardening and bathing, the support of families was acknowledged by the participants together with frustrations as expressed by one participant’s father whose son was unable to engage in activities normal for other family members. The unique aspects of life in Timor Leste could be seen in the photographs, such as the importance of the church and the traditional approach to medical matters with accompanying risks to health. The overarching effect of poverty was evident in all aspects of living with disabilities in Timor Leste, in the
environment, problems maintaining health, the availability and types of food, the difficulties of travel and the effects of these difficulties and overall, the lack of opportunities.

6.6.1 Cross-cultural research.

The participants led the direction of the interviews by taking photographs of material which was important to them and providing descriptions of the most important photographs. In this study, as in others (Castleden, Garvin, & First Nation, 2008; Hergenrather, Rhodes, Cowan, Bardhoshi, & Pula, 2009; Jurkowski & Paul-Ward, 2007), photography was a tool for empowerment and three of the participants specifically expressed pride that they could use the cameras without prior experience.

There was a ‘cultural interface’ where Timorese from poor rural villages met the researcher from a Western culture, each bringing their own history, experiences, social practices and world view; and each party possibly had assumptions which were invisible either to themselves or to the other party (Nakata, 2007). Despite the success of photovoice as a data collection method, there will always be imbalance of power where a Western researcher enters a community in a developing country and great care must be taken not to abuse this power (Smith, 1999).

For example, disappointment at the cultural interface may come from very poor people hoping that there will be some benefit from their outlay of time in the form of material gain for themselves or their families. This situation was noted in Sierra Leone, a country with a long history of charitable organisations providing support for people with disabilities prior to eleven years of atrocities and conflict during the second half of the 1990’s. Here people with disabilities reported expectation of food, shelter and other basic services as a result of visits from government and international NGOs (dos Santos-Zingale & McColl, 2006).
Photovoice was an approach to empowering participants however, the researcher also wanted to promote a sense of mutual commitment, by presenting the research not as a one way process, and instead introduced a component of ‘giving back’ (Swartz, 2011). In this research project the time and effort of the participants were acknowledged and participants were asked to select photographs which were later printed and sent back to them as a keepsake.

6.6.2 Interpreters.

The interpreter should be considered as more than an invisible conduit as he or she may feel aligned with either the interviewer or the interviewees or may be aligned with dominant groups within the culture (Angelelli, 2004). There may also be influence from the perception of the researcher’s own origins such as ethnicity, religion, gender, perception of wealth and age (McGoldrick & Hardy, 2008). In this study the researchers’ cultural mentors who were staff in the sponsoring organisation believed that these influences would not be limiting factors in the research as the researcher was familiar with Timorese culture and had visited many times in recent years.

Despite their reassurances, the researcher was an able-bodied outsider, a foreigner needing the help of interpreters and needing well-positioned gate-keepers to access the four participants in a remote district of Timor Leste. The researcher carried out trial interviews with the interpreters prior to the research to see if there were any interview questions which would pose problems in a cultural context, for example when communicating with a woman with a male interpreter. While the interpreter did not identify any difficulties, the researcher remained conscious of the cultural gap.

The cultural divide between the researcher and the researched was significantly reduced in the later stages of the overall research project of which this pilot study is a small part. In the main study the researcher used Photovoice to investigate the lived experience of a
group of Timorese employed in the disability sector in Timor Leste. These participants took cameras on their field-trips and were able to collect photographs of people with disabilities in remote districts without the imposing the cultural divide when a foreign researcher is directly involved (Shamrock, Gray, Cameron & Oprescu, 2016).

6.6.3 Poverty.

Poverty was a core category (Draucker et al., 2007) in this research influencing most aspects of the participants’ life experiences. People with disabilities in developing countries have been described as ‘the poorest of the poor’ (Beresford, 1996; Yeo, 2005) and poverty limited participants options for participation and travel in public transport, influenced the availability of food and access to health care. Malnutrition has been associated with poor educational achievements and limited economic progress (Victora et al., 2008) and is represented by stunting and wasting in children, for example in 2011 half of the children in Timor Leste demonstrated moderate to severe stunting (Stevens, et al., 2012). Other chronic health conditions are common in Timor Leste for example malaria is considered to be one of the major public health problems despite attempts by the Ministry of Health to implement malaria control strategies (Martins, Zwi, Martins & Kelly, 2009).

Further difficulties associated with poor health in a cohort of people already compromised can be seen in the under usage of medical services by the participants. It is common for many developing countries to have a shortage of medical expertise and doctors and/or an uneven distribution of health services. In Timor Leste this problem is partially being addressed by a large group of Timorese doctors being trained in Cuba (Palagyi, Brian & Ramke, 2010) together with a large groups of Cuban doctors working in Timor Leste (Anderson, 2008).

Training for nurses is gradually improving in Timor Leste in areas such as community health (Higuchi, Okumura, Aoyama, Suryawati & Porter 2015) and in healthy practices
relating to childbirth (Lane, 2014). However, overall Timor Leste still features poor health outcomes which can be seen through indicators such as lack of quality services, and services which are poorly utilised, there are poor responses to immunisation campaigns, high infant mortality and a high percentage of births occur at home (Saikia & Hosgelen, 2010). The participants in the research project were all disadvantaged in access to health care and health services and thus were more vulnerable as a result poverty and mobility restrictions.

6.6.4 Considerations for change

Poverty is associated with lack of income, and ironically there is a proposal for an extensive ‘fantastical development scheme for the geographically and politically peripheral enclave district of Oecusse-Ambeno’ (Yoder 2015, p.300). This project is considered ‘fantastical’ as Oecussi has long been considered a neglected isolated corner of Timor Leste with poverty much greater than the rest of the country (Yoder 2015). This project is vast and ambitious, but if it goes ahead, the opportunities for people with disabilities to participate and benefit from activities associated with the project are limited. Lives of poverty and reduced ability to participate in community or education have resulted in illiteracy, poor mobility options, poor health, lack of experience with contemporary activities, including the use of simple digital cameras as well as reliance on others, especially family members.

Development in Timor Leste is commonly undertaken by donor governments or International Organisations (INGOs). The small funded programs which make use of small grants are considered by McGregor (2007) to be an appropriate and less invasive strategy for distributing aid to communities. Such programs are considered to be more flexible that larger institutional programs and are not focused on pre-determined outputs (McGregor, 2007). Whatever style of development occurs in Oecussi enclave in the future there is still the problem of inclusive consultation and inclusive practice, as most commonly, people with disabilities are excluded from development planning processes with resulting failures in the
practical aspects of aid. (Cramm & Finkenflügel, 2008; Mitra, 2006; Toribio et al., 2014; Yeo & Moore, 2003). For these reasons, the practice of extensive appropriate community consultation is needed as the platform on which community development occurs.

The findings also point to the importance of establishing culturally appropriate health and medical services for people with disabilities and indeed for culturally appropriate services to the people of Oecussi enclave. As families are an integral part of the experiences of living with physical disabilities, families need to be a part of services for people with disabilities in Timor Leste. Yan, Accordina, Boutin and Wilson (2014) note the importance of respecting and engaging with Asian families in relation to beliefs, hierarchical family structures, and family roles, as well as considering the importance of education as a method of changing discriminatory beliefs and attitudes within families.

6.7 Limitations

This pilot study informed the larger study on the lived experience of physical disability in Timor Leste; to reduce the complexities related to transport the main study was undertaken in a district where transport and access were simpler.

This study of four participants is a small sample from a remote district in Timor Leste. However, the approach of phenomenology is to look at the range of experience of the phenomena; the experiences of the four participants are a part of the range of lived experience of physical disability in Timor Leste, and are not expected to represent all people with disabilities, rather, their experiences are a part of the spectrum of experiences of living with disability.

6.8 Conclusions

Photovoice provided a rich picture of the participant’s worlds and was an effective way to engage vulnerable people. The participants reported that they were able to take up the unfamiliar technology and make day to day life with physical disabilities visible to the
researcher. The research points to further unknowns in the life of people with disabilities such as (1) what happens to children with disabilities in remote communities and (2) how successful was the weaving project, especially considering that weaving is a slow process requiring an outlay of funds and a vast amount of time for a person whose day to day life is already considerably hampered because of mobility impairments and (3) to explore effective occupational therapy interventions for people who come from remote and impoverished environments. Implications of the research includes the importance of understanding barriers experienced by vulnerable populations and provides impetus to minimise the risk of repeating these barriers. For example, how should families be successfully included in culturally appropriate service planning and health interventions.

6.9 Notes

All names are pseudonyms

All interviews make use of interpreters and are therefore in the third person

6.10 Acknowledgements

I would like to thank Natalie Smith and the Leprosy Mission of East Timor (TLMTL) for their generous support of my recent work and research in East Timor.

6.11 References


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The original paper ends here

6.12 Chapter Six. Key points

- This group of participants lived in different parts of a remote rural district with few services and limited transport options.
  - They were all beneficiaries in a small way of aid support
  - Poverty was a significant feature of their lives affecting health-care, education, transport and availability of food.
  - Three of the four had never attended school
  - The three who were illiterate were able to ‘use money’, that, is they could purchase and sell items if necessary.

- The difficulties encountered in daily life were significant and included:
  - Transport
  - Moving around in the home, in the surrounding spaces and to other places because of mobility difficulties
  - Poverty influenced all aspects of life and participation
- Maintaining good health was a difficult
- Home life was important as the participant spent most of his/her time at home. Food was generally grown at home and cooking was undertaken on fires on the floor by the females in the household. The homes reflected poverty
- The participants’ life roles were important especially family roles, work roles and community roles.
- Poverty was the overarching theme evident in the photographs, and in the barriers reported by all the participants. Poverty was a source of frustration where hopes were raised by visiting foreigners and were no material assistance resulted from a foreigners visit.
- The interpreters had big roles in this study, acting as gatekeepers providing access to the participants and helped with follow-up visits. Working with interpreters may result in ambiguities in cross-cultural research and in this instance the interpreters also acted as cultural mentors, providing advice and guidance where a situation was not easy for the researcher to understand.
- Photovoice proved to be a suitable approach to cross-cultural research, providing stimulus for discussion and visual clues about the participants’ lives. Participants were able to influence the direction of the research by taking photographs about topics that they wanted to discuss.

6.13 Conclusions

Chapter Six was based on the pilot study to the research using photovoice in a remote district in Timor Leste. The pilot project was an exploration of the lived experience of disability and participants provided photographs from which rich discussions ensued. The barriers experienced by people with disabilities could clearly be seen as well as the factors in their lives which were valuable and important. Poverty could be seen as an impairment which
was frequently greater than the physical impairments of these four participants. This highlighted the importance of considering poverty when working as a health care professional in a majority world setting.

The following chapter, Chapter Seven, is based on a study of the lived experience of physical disability undertaken in a poor rural district closer to Dili involving a small group of young men. Four of the men had intellectual disabilities, which provided challenges in the research but also provided data about a disadvantaged group, those with intellectual disabilities, which is usually difficult to obtain.
Chapter Seven: Findings Second Study

Health and Hope Clinic: Living with disabilities in Timor Leste, the results of a Photovoice pilot project

Key to the thesis

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Chapter Seven is based on a study of the lived experience of physical disability undertaken in a poor rural district closer to Dili involving a small group of young men. Four of the men had intellectual disabilities, and the study considers the challenges when researching with a group of participants such as these. There were also benefits to researching those with intellectual disabilities as there is little research undertaken with this disadvantaged group of people and no record of similar research in Timor Leste.
The study was written as a research paper for Disability and Rehabilitation, a journal selected for its broad research base on all matters relating to disability and rehabilitation from both qualitative and quantitative research. The journal has an impact factor of 1.085 and at the time of writing the thesis, the article was ‘under review’.
Health and Hope Clinic: Living with disabilities in Timor Leste, the results of a Photovoice project

7.1 Abstract
Purpose: Little is published about the lives of people with disabilities in developing countries, including in Timor Leste. This research presents a study of the lived experience of people with disabilities in a rural area in the vicinity of Dili, the capital. Method: Participants were drawn from a small clinic newly built in a rural area. Photovoice was the method of data collection and data included interviews, participants’ photographs and field-notes, data were analysed using thematic analysis. Results: Five men participated in the study, four of them with intellectual disabilities as well as physical disabilities. Three themes were identified; (1) the men’s enjoyment of simple activities could be seen against (2) a backdrop of isolated lives and (3) the vulnerability of living with intellectual disabilities in a post-conflict, fragile state. Conclusions: Barriers to participation experienced by people with disabilities, especially intellectual disabilities are extensive in Timor Leste and understanding these barriers will help inform research and health service planning for this group of people. Processes which include families and communities will help improve the lives of people with intellectual disabilities. A degree of momentum is already visible in Timor Leste and this can be supported by continuing communication with stakeholders at all levels.

Keywords: Participation, intellectual disability, Timor Leste, qualitative research, vulnerable people.

7.2 Introduction
This paper presents the results of a study to understand the lived experience of physical disability in Timor Leste. Timor Leste is a small, recently independent, country at the eastern end of the Indonesian archipelago, to the north-west of Australia. It has a history
of 400 years of colonial influence from Portugal then a 25 year period of harsh occupation by Indonesia. Indonesian occupation came to an end in 1999 following a referendum, monitored by the United Nations (UN) however, militia-led reprisals had severe repercussions in the population: Over one thousand people died, over 200,000 people fled to Indonesian West Timor and most of Timor Leste’s infrastructure was destroyed. United Nations (UN) peacekeepers administered the territory until the Democratic Republic of Timor Leste was declared in May 2002 [1] This complex recent history of occupation, violence and deprivation of civil liberties in the general population has contributed to Timor Leste’s status as a post-colonial, post-conflict fragile state [2,3] and the experiences of the difficult times still influence East Timorese, including people with disabilities.

As a newly emerging developing country, Timor Leste receives foreign aid, despite being rich in oil reserves [4,5]. Aid and development programs generally attempt to be inclusive to ensure that aid benefits all members of target populations. However, theory and study of disability is centred in Western countries and derived from a Western perspective. Little is written about the experience of living with disabilities in non-Western countries [6-8] and little is written about the impact of rehabilitation services to the lives of people with disabilities in developing countries [9]. There is a gap in communication between development work and how development includes people with disabilities, described here:

‘..the disability community is not schooled in the language and logic of development work, and the development community is unfamiliar with the tenets and priorities of the disability community.’[10]

An AusAID (Australian foreign aid) report of 2013 noted that ‘people with disability (in Timor Leste) do not face exclusion and discrimination only because of impairment, but also because of physical, attitudinal, institutional, communication or other socially created barriers.’ [11]. Research on vulnerable people in developing countries, especially those
living in remote regions is especially difficult [12] but without an understanding of the needs of vulnerable members of communities there is risk that the inclusion built into foreign aid may be tokenistic rather than practical [13,14].

Recommended strategies to ensure the effectiveness of aid in development include thorough research into the context of aid, broad consultation, building trusting relationships, a two-way capacity building approach, participatory programme management and the inclusion and empowerment of vulnerable people including people with disabilities [15]. Research into the lived experience of disability can provide information which is not available in large data-sets [7] and this information could enhance the effectiveness of aid and could help develop realistic, inclusive policies in research, health services or health promotion. Despite these recommendations there is little research on the lived experience of disability in developing countries.

The experience of disability is influenced by cultural explanations of illness and disability [16] including understandings based on religion and philosophy [17] and historical attitudes embedded within religions [18-20]. In both Western and non-Western countries people with disabilities and their families frequently experience stigmatisation and exclusion derived from cultural-based understandings. Examples from Asian countries include believing that a child with disabilities was born into the family because of misdeeds in the past, including in past lives of individuals in the family.

There may be a belief that more subtle misdeeds such as negative thoughts cause disability or disability may be seen as resulting from the actions of a malevolent entity or spirit [21]. Such beliefs may be accompanied by shame where people with disabilities are hidden from the community, and not encouraged to gain an education or to participate in community activities [22]. The World Health survey of 2002-2004 estimated that the average prevalence of disability in adults over 18 years of age in 59 countries worldwide was 15.6%
and 80% of people with disabilities were estimated to live in isolated rural areas in developing countries. Definitions of disability vary, based on cultural expectations and differing thresholds of disability; for example where the functional losses associated with aging are be seen as normal, aged people are not recorded in the national census as having disabilities [23].

Disability is considered to be a development issue closely linked to poverty where one is considered to be a direct cause of the other [24]. This cycle of poverty is linked to public health factors linked to disability; such as clean water and sanitation, unsafe living or work conditions and low birthweight and malnutrition. These factors influence the lives of people with disabilities who are more more likely to be poor and have less opportunity to escape poverty [23].

The non-government organisations (NGOs) providing services to people with disabilities in Timorese communities reported the effect of shame in families when they discovered adults or children with disabilities who had lived all their lives in isolation within their families, at times unknown in the surrounding community; one such person was a participant in the research project described below.

While the stigma and social barriers from old traditional ideas about disability and illness are widespread, in recent years active efforts are being made to embed inclusive legislation within the relatively new government of Timor Leste. At the time of the study a group of five members from the Disability Working Group of Timor Leste (DWG) travelled to Geneva and New York to attend a series of United Nations meetings on disability rights. This was specifically to begin to understand what will be expected of the Government of Timor Leste and of local and international NGOs (non-governmental organisations) after Timor Leste ratifies the United Nations Convention on the Rights of Persons with Disabilities

The relatively rapid change occurring within the legislation of Timor Leste is a part of a process of change in attitudes to disability and small increments of change are evident. Examples include installation of traffic lights with auditory warnings in two sites in Dili. People with disabilities, at least in Dili, are becoming more visible; and are at times seen in public places, or relaxing on the waterfront. However, attitudinal change is slow and the majority of people with disabilities are excluded and many are neglected, especially in remote communities.

7.3 Photovoice

This cross-cultural research project aimed to help better understand the lives of people with disabilities and required careful consideration in regards to its approach. The researcher was neither a person with disabilities nor Timorese, nor the researcher wanted the participants to understand the project and to be able to guide this research to a significant understanding of their lived experience. Photovoice was considered suitable because of its collaborative approach where the participants directed the research by choosing and describing the material, people or events which were significant to them [25].

Photography has evolved as a research tool starting with the first extensive usage of photography undertaken by Margaret Mead and Gregory Bateson in their ethnographic studies of Balinese culture in the 1930s; in these early studies the subjects generally did not know they were being photographed [26]. Engaging participants in the actual processes of photography was first used and named Photo Elicitation (PE) in the 1950’s by researchers at Cornell University. Here the researchers investigating the environmental bases of psychological stress presented their subjects with photographs and elicited their responses. For comparison the researchers also undertook non-photographic interviews with the same
participants and noted that the photographs helped increased accuracy and reduce misunderstandings in interviews [27].

Wang and Burris developed photovoice for use in the field of health promotion to allow research participants to (1) demonstrate the strengths and concerns of their communities, (2) expand participants understanding of their communities concerns and strengths and to (3) to be able to pass their concerns on the relevant policy-makers describe [28,29]). The method has three central influences: firstly, feminist theory which emphasises the value of subjective experience and the importance of participatory methods; secondly, Freire’s (1972) concern for seeking out community knowledge as a basis for community action; and thirdly, the power of photography as a documentary tool.

Photovoice ‘can affirm the ingenuity and perspective of society’s most vulnerable populations’ [28] and was, therefore, considered a suitable approach for understanding lived experience of disability in a cross-cultural environment such as Timor Leste. Photovoice has been used in a range of fields such as ‘AIDS education, public health, nursing, community psychology, disability, health education, adolescent mental health, inter-professional care, human services, special needs, dementia and various aspects of education and management’ [31]. Photovoice has also been used in cross-cultural research for example in Canada with First Nation peoples [32], and with Australian indigenous people [33-35], with participants with epilepsy in Cameroon [36] and in a comparative study of people with paraplegia based in either Australia or Cameroon [37].

Photovoice has also been used with populations with intellectual disabilities in a range of inquiries such as the experiences of mothers with intellectual disability [38], the health beliefs of Latinos relating to the social and physical environment [39], and the perceptions of barriers to participation by children with Autistic Spectrum Disorder (ASD). Booth and Booth (2003) commented on the revealing and powerful nature of the photographs despite
difficulties experienced during the course of the research with people with intellectual disabilities. At the time of writing there is no record of photovoice being used with any population in Timor Leste.

7.4 Method

7.4.1 The setting.

This research project was undertaken in Health and Hope Clinic (pseudonym), in village L (the name and initial are pseudonyms), which is a small community within easy access from Dili, the capital of Timor Leste. Health and Hope Clinic was established as a centre for people with disabilities in Feb 2013. Health and Hope Clinic was a part of the vision of Brazilian-born Maria (pseudonym) who has been working in Timor Leste since 2002 and whose work has been strongly supported by faith-based volunteers and donation sources. The Catholic Church has a long history of involvement in Timorese life, dating from the arrival of the Portuguese in 1515 [4]. In more recent times the Catholic Church has supported ordinary Timorese against the excesses of the occupying powers and provided sanctuary at times of civil unrest and civil collapse [4].

The clinic itself had only just been completed at the time of the study. The concrete building was similar to a family home with a concrete foyer, a large living area, smaller bedrooms and a kitchen, and the whole was located on a level block beside the main road. An exception to the layout of a normal family home was two bathrooms side by side, one with disability access. The building was secured by four meter high concrete walls and a steel barred three meter high gate. At the time the clinic was being built, volunteer staff was already getting to know people with disabilities in the local area. At times this was a slow process where families were reluctant to admit to having a person with disabilities in their midst. As soon as possible the clinic staff began to use the clinic facilities to help people with disabilities who were unable to bathe or appeared malnourished, and these individuals were
showered or fed in the centre. On completion of the clinic, the staff organised a group of people with disabilities and their carers to meet each other for the first time. The first meeting of the study was therefore the second meeting held at the clinic.

7.4.2 The participants.

The five participants in the study were recruited by convenience sampling. This implies that participants were easily accessible and willing to participate in the research project although convenience sampling is ‘probably the most common sampling strategy—and the least desirable’ [40]. The researcher spent time with Maria, the director of the clinic listening to the stories relating to finding people with disabilities concealed in their homes as well as stories relating to the periods of civil unrest in Timor Leste when Maria protected families in her own home.

The researcher provided Maria with a description of the research project explaining the need for adults over the age of 18 years with physical disabilities; Maria proposed to ask her staff to identify potential participants who would like to meet the researcher and decide if he or she would like to participate in the study. In this study, with Maria acting in the role of gate-keeper to these vulnerable potential participants, convenience sampling was the only option open to the researcher.

7.4.3 Translation.

Translation in this study was undertaken by a female staff member, Augustina (pseudonym) from the sponsoring organisation who also acted as key informant and at times as cultural mentor. (See Thomas, Gray and McGinty [45] for description of cultural mentorship). Augustina had a disability herself, and walked with the aid of a stick. At times the researcher spoke directly to the participants, making use of a basic understanding of the local lingua franca, Tetun, and checking the meaning of participants’ replies with a nearby
volunteer if necessary. Many of the interactions with the participants were of a playful nature which was a part of the process of building rapport.

Table 7
Participants in the Study.

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Age</th>
<th>Lives with</th>
<th>Photos</th>
<th>Mobility</th>
<th>Enjoys</th>
</tr>
</thead>
<tbody>
<tr>
<td>Marcos N.</td>
<td>25</td>
<td>Family: father (employed), mother and two younger siblings</td>
<td>Eighteen photos taken by sister and self</td>
<td>Crawls when the environment is unsuitable for his wheelchair</td>
<td>Watching television, cleaning his wheelchair, playing piano at the clinic, listening to music in his house, making picture frames.</td>
</tr>
<tr>
<td>Domingos C.</td>
<td>22</td>
<td>Mother</td>
<td>Fourteen photos taken by neighbour</td>
<td>Crawls</td>
<td>Playing with CDs, eating, playing (Tetun ‘tuur halimar’ lit. play sitting)</td>
</tr>
<tr>
<td>Abilio M.</td>
<td>25</td>
<td>Aunt and 4 cousins</td>
<td>Twelve photos taken by cousin</td>
<td>Crawls, wheelchair is broken</td>
<td>Washing, resting, and playing near his home Tetun ‘tuur halimar’ lit. play sitting. Talking with his family,</td>
</tr>
<tr>
<td>Mateus M.</td>
<td>24</td>
<td>A carer</td>
<td>Eleven photos taken by Carer</td>
<td>Crawls</td>
<td>Sweeping, and helping at home, playing (Tetun ‘tuur halimar’ lit. play sitting)</td>
</tr>
<tr>
<td>Joaquim N.</td>
<td>28</td>
<td>Uncle (a self-employed fisherman)</td>
<td>Six photos taken by Clinic volunteer</td>
<td>Walks with crutches, travels on roads in his purpose-built hand propelled fish-cart</td>
<td>Wheelchair basketball, selling fish.</td>
</tr>
</tbody>
</table>

*Tuur halimar* which means literally play sitting or, in colloquial English, sitting around.
7.4.4 Ethics and consent.

Written consent can be a barrier in cross-cultural research, particularly with vulnerable or illiterate groups [41,42]. The University of the Sunshine Coast ethics committee approved the research however, in-country reciprocal ethics approval is ideally required for research in another country. Timor Leste did not have an established protocol in local universities for ethical guidance in research so advice was sought from the Vice-Rector of the University of Timor Leste (UNTL). He advised presenting the research proposal to a meeting of the Disability Working Group (DWG) to seek approval and advice regarding research with people with disabilities in Timor Leste. The Disability Working Group consisted of members of many of the non-government organisations (NGOs) active in Dili and its surrounds, representatives from the two government ministries associated with disability: the Ministry of Health and the Ministry of Social Solidarity, as well as representatives from the East Timorese Disabled Peoples Organisation (DPO). The DWG approved the research proposal and approved the use of verbal consent where research participants were illiterate.

Developing ethics protocols for people with intellectual disabilities is a complex process where the value of and the reason for the research may not be clearly understood [43]. Attempts to make research and consent easier for participants to understand involve alternate methods of gaining informed consent. These include audio recordings of verbal consent [42] or audio-visual recordings of participants giving verbal consent [44]. This study in Timor Leste made use of verbal consent with consent being recorded with the participants’ permission. Photographs were treated separately and a simple consent form was developed and approved by the University of the Sunshine Coast Ethics Committee. Each participant sat with a scribe, and described each photograph that he permitted others to see (see Appendix J). The verbal description was written down by the scribe and the forms were signed or marked by the participant and counter-signed by a witness.
Photovoice in action.

Photovoice is frequently undertaken as a six stage process consisting of:

1. Finding potential participants and explaining the research
2. Introducing digital cameras and camera training
3. Participants taking pictures
4. Reviewing pictures with each participant who then selects three significant pictures
5. Group discussion where participants tell stories based on the pictures
6. Targeting an audience beyond the group.

[38,46,47]

The staff of Health and Hope Clinic initially approached potential participants and asked each one, as well as his/her carers if he/she would be interested to meet the researcher and to find out more about the research. Those who expressed interest were brought to Health and Hope Clinic for the first meeting in the clinic’s mini-bus. Following the advice of the clinic staff, the activities relating to the project were combined with games, activities and a refreshment break, facilitated by a clinic volunteer so that participants and staff could relax and meet the researcher. Following the games, the participants sat in a circle to hear about the research project.

To facilitate an understanding of photography the participants and volunteers were invited to try out the digital cameras; these were enjoyable and easy to use as they provided instant feed-back. Following familiarisation with the cameras the participants were invited to participate in the research. All of the participants, the mother of a participant who was also present, and the clinic volunteers expressed interest in the research, the participants with disabilities and their carers agreed to take the cameras home to take photographs which would help describe their lives. Further instructions were given and participants practiced...
using the cameras, for example asking permission to photograph others, with explanation that photography must never cause distress or discomfort to another person.

A second meeting was held a week later. The participants were again brought to the clinic in the mini-bus, this time with their cameras. The formula of combining games and a snack break was used again and the researcher was able to spend time with each participant and the interpreter, looking at and learning about the participant’s photographs which were viewed on a lap-top. Each participant was asked to select three favourite photographs to be enlarged and used in a group process in the following session. The interviews were recorded with the participants’ permission, each interview consisting of collecting preliminary information about the participant as well as the explanations of the photographs. Later the researcher had the selected photographs enlarged and printed in Dili in readiness for the third meeting.

In the third meeting, the session began with drinks and games, then all the photographs were placed on the floor with the intention of having a facilitated discussion based on the photographs. The participants were all asked individually what they would like to do with the photographs; they were also asked individually for permission to use selected photographs in research and their responses were recorded. A fourth meeting was held for a further discussion about the use of the photographs and to clarify that the participants and their carers understood the process and agreed to have their photos displayed either at the researchers university or on the walls of Health and Hope Clinic.

7.4.6 Analysis.

At the beginning of the project, the interview questions were trialled with the interpreter to see if there were any potential problems with the planned questions or if there were potential problems where a female interpreter interviewed a male participant and vice versa. Interviews were semi-structured and participants were asked about themselves and
their families, about their homes and about what they did each day. Data used in this study consisted of transcripts of the recorded interviews and field-notes taken at times during the meeting, after the sessions and on reflecting with the interpreters or the clinic staff at a later time. The photographs were intended as prompts to be used in discussion with the participants, rather than as primary data in themselves; later some of the photographs were used with permission, in public displays. Data was gathered by asking the participant to describe what could be seen in the photographs, the transcripts of the discussions were read and re-read and sub-themes were assigned to significant words or blocks of text and then clustered into themes.

7.5 Results

The five participants in this group were not of a single diagnostic category, as the clinic staff provided service to anyone who was disabled. The principal researcher, an occupational therapist, considered that four of the five participants had intellectual disabilities together with their physical disabilities and a brief description of the participants in the study can be seen in table 7. Three of the men were unable to stand as they had fixed contractures of their knees indicating that they had never been encouraged to stand and weight-bear. One participant had stiff legs and walked with the aid of crutches. One man did not have developmental delay although he also had contracted legs.

The men engaged in four group meetings in Health and Hope Clinic. Two participants missed one session each, and in the second session the participants provided a total of 61 photographs. To help build confidence and rapport the researcher responded to the abilities of the participants, for example whether the participant was shy or reluctant, or eager to speak to the researcher. Although the sessions were considered to be group sessions, the conversations were carried out one-to-one while the rest of the group engaged in the group activities, or while the other group members sat on the floor or in chairs and listened. The group activities
were facilitated by the clinic volunteers and the researcher joined these activities at times, either playing ball games, joining in paper and pencil activities, sitting with each individual reviewing the operation of the camera, or spending time in simple conversation, within the researchers’ abilities in the local language, Tetun.

The recording proved difficult as the open meeting room was very hot, ceiling fans made a constant background noise, and the environment outside the clinic was even hotter. The recordings were mostly difficult to hear especially as participants often spoke softly. This difficulty was offset by the researcher having time to make extra field-notes during translation. Transcriptions of the interviews where possible, were supplemented by field-notes and by the reflective discussions with clinic staff and the interpreter.

During the second visit the photographs were reviewed with each individual participant. At that stage it became apparent that only one participant had used the camera himself. This participant had three photographs of his sleeping area in his house, and of some of the tools he used when making photograph frames, which was one of his hobbies. The remainder of his photographs were taken by his sister as he engaged in activities at his home. The photographs presented by the other participants were all taken by other people, one participants’ mother stated that she could not use the camera and she asked a neighbour to take photographs of her son as he engaged in some of his daily activities. The participants usually responded with simple descriptions of their activities when asked about the photographs, for example ‘sweeping my house’ (16th October 2013). Joaquim’s response was similarly brief when asked about a photograph of a man standing beside a bicycle:

Researcher: who is that man in the photo? (a man in the background of one of the photos holding a bicycle)

M: My cousin

Researcher: what is your cousin doing?
M: He has a bicycle (Interview Joaquim [pseudonym] with interpreter, 16th Oct 2013)

Another finding in the study was the surprise expressed by the volunteers and staff that people with disabilities and their families or carers could operate digital cameras with very little prior experience, and take expressive photographs:

That was the one thing that I was scared about, that ‘oh no, they could break it (the camera)’ but no, I think that was really good, keeping it simple. And I was really surprised at the really good quality photos that they took. (Debrief with the volunteers 15th October 2013)

The themes found from the data analysis were: (1) small pleasures, (2) an isolated life and (3) vulnerable people.

7.5.1 Small pleasures.

The pleasure experienced by the participants in their activities could be seen in their descriptions, photographs and in comments by others and this theme is built on two aspects of the participants’ pleasure: (a) firstly engaging in activities which are enjoyable for their own sake and (b) activities which involve the expression of a particular skill.

7.5.1.1 Activities which are enjoyable for their own sake:

The participants’ photographs show their pleasure in simple activities which included the trip in the bus, the games and social interactions at the clinic and the novelty of the cameras. Participants also could be seen in the photos at home engaging in tasks which they found enjoyable such as being shaved and having a hair-cut.
Abilio provided a selection of photographs demonstrating his enjoyment of bathing, shaving and getting a hair-cut. He described why he liked getting his hair cut:

Researcher: what does Abilio think of the photos? Which one does he like?

Interpreter: Oh, he says that he likes this one (the photo of the hair cutting). He used to have long hair, here it is (the photo of Abilio with long frizzy hair)

Researcher: why did he get his hair cut?

Interpreter: he says he wanted short. I think his aunt got it cut for him to come to the clinic. He says he liked the haircut, he says he feels clean and nice, you can see here. (Interview Abilio [Pseudonym] with interpreter, 16th October 2013)
Abilio’s appreciation of the pleasure of being shaved by a family member can be seen in figure 10 above.

7.5.1.2 Activities which involve the expression of a particular skill.

Figure 12. Mateus engaged in the cutting and colouring activity.

One participant had photographs of himself squatting on the ground as he swept around his home with a local-style broom. A photograph selected by Mateus showed his engagement in an activity involving cutting out and colouring in designs on paper. The four participants with intellectual disabilities deeply engaged in this activity and the clinic
 volunteer explained that she had used this activity with people with intellectual disabilities at clients who also found the activity deeply engaging.

Marcos was the only member of the group who appeared not to have an intellectual disability and he was able to articulate stories related to his photographs. He had briefly been to one of the two basic residential centres in Dili for people with disabilities where he had learnt to make picture frames and he had photographs of the frames that he had made. He expressed pride in his work and he described how he had presented a framed picture to an important friend, who was one of a group of American marines whom he met on the local beach. He was proud of his skill and spoke of a ‘circle of friendship’ in which he could contribute to the friendship with the marines by offering an object which reflected his own skill. Marcus was also learning to play the electric piano at the centre and he sat at the keyboard for as long as possible at each of the visits to the clinic. He enjoyed learning the piano as it was an activity that he could do despite his disabilities and he hoped to be able to play like a significant musician who could be heard at times on the local radio.

Manuel: I am playing the piano, I am learning the piano

Jane: What does it mean to learn to play the piano?

Manuel: I like to play piano, I want to play like ……. (I can’t understand the answer),

Jane: I know it sounds silly, but why does he want to do this, like, what does it mean to him?

Manuel: I like to play like something special for me, the music this I can do

(Interview Marcos [with interpreter] 15th October 2013)
Figure 13 Marcos learning to play piano

Joaquim owned a purpose built hand-operated bicycle with a box-like cart attached to the front. He could travel on level roads transporting fish caught by his uncle, a professional fisherman, to sell in the surrounding neighbourhood, and he brought his bicycle to the centre on two occasions, on the other two occasions he arrived in the centre’s bus.

7.5.2 An isolated life.

The five participants in the study had significant mobility restrictions and only two of them had their own mobility aids: Joaquim used crutches provided by a rehabilitation service, as well as his purpose-built, fish-cart. While Joaquim was independently mobile and able to negotiate the sale of fish in the local community he was very reluctant to sit with people in the group or speak with others, he preferred to walk around the room with the aid of crutches and observe activities from a distance. Marcos had attended a residential facility in Dili where he was given an overly large wheelchair which allowed him to propel himself, provided the surfaces were level and easily negotiable. The other three participants were
unable to walk and although Abilio had a wheelchair, it was broken. Abilio, Domingos and Mateus all had similarly contracted legs, which may have been the result of untreated polio.

![Joaquim with his fish-cart](image)

**Figure 14. Joaquim with his fish-cart.**

Without mobility aids and with limited communication skills, these three had very restricted access to the world beyond their home environment, especially if, as explained by the clinic staff and volunteers, families were ashamed and reluctant to allow their disabled family member move in the community.

The Timorese clinic volunteer explained her work at the clinic, the shame of disability and the isolation of people with disabilities in many Timorese families:

I help with the disability people, I give the bath or the food, like Mateus, I help them ... I think it’s very hard for them. Some people hide in the home and we don’t see and the shame for them. Mana Maria (term of respect for a colleague, similar to sister) works and helps them but she is very busy …
Mateus … is like family, like relative for me and I care for him … I don’t do for him (I don’t have to do things for him), he can do anything but he stay in the house … just help a little bit and tuur halimar (play sitting). He just sit and he help a little bit when I ask, but he is most just sitting. (Interview with clinic volunteer, 16th October 2013)

Two of the participants had photographs of themselves eating however, in both photographs the participant was sitting alone on the floor, one of them in the company of a thin dog. In both instances the explanations were that this was the preferred place to eat. The carers at the Health and Hope Clinic reported finding the men in the local community during the previous year, three of the men were found in dependent or neglected circumstances in their homes, being cared for by parents; one man lived alone, barely able to care for himself as his parents had recently died. One member of the clinic staff told a story of the first meeting of people with disabilities at the clinic, about a month previously:

They brought the people with disabilities to the centre, they had a picnic and they put all the PWDs (people with disabilities) on a tarp on the ground, There were people who appeared amazed that there were others with disabilities like them and G. described the scene as very moving. (Discussion with clinic volunteer 8th September 2013).

7.5.3 Vulnerable people.

Overall the participants in the study had received little support from other organisations until very recently: Marcos had lived in a residential facility for four months and was using a donated wheelchair which was too large for him to manage comfortably, Abilio had a broken wheelchair and two other men had no mobility aids at all. Joaquim was the exception with both the fish-cart and his crutches provided by the therapy centre in Dili.
The community of village L. was at sea-level and relatively flat, however, except for the main road, roads and paths were not sealed and the annual heavy rains mean that there were deep drains beside and across roadways and paths, and during the rainy season all roads and paths except the sealed main road became deep with mud. The environmental barriers to the world outside the home were extensive, even with mobility aids, for all the participants.

People with mobility problems have limited options at times of civil unrest and violence such as during the period of militia–led violence in 1999 and during other periods of danger such as 2006, 2007 and 2008. The field-notes taken following discussion with Maria suggest the extent of the difficulties:

I asked Maria how people with mobility problems manage when people flee in times of civil unrest. Maria replied that … she only had families and old people in her house at that time, no people with disabilities … she heard that people get abandoned by their families and she had heard of someone who was carried in a blanket by his family into the hills (Interview Maria [pseudonym] 25th September 2013)

The staff of Health and Hope Clinic spoke of the adults and children with disabilities that they met prior to Health and Hope Clinic being built and who were initially the motivators for Maria to build the clinic. A young man with very frail elderly parents had been found and when the frail parents of the young man died he was taken to live with one of the volunteers from the Health and Hope Clinic, and he subsequently became one of the participants in the research project.

Apart from the commentary above, the structure of the Health and Hope clinic itself reflected a sense of vulnerability and a need for extra measures. The photograph shown in figure 15 below shows the clinic built with heavy iron gates, painted in rainbow colours to
provide a sense of security for all who attended the clinic.

Figure 15. The protective front gates of the Health and Hope clinic

All the photographs clearly demonstrated the endemic poverty which is a feature of life for most of the population of Timor Leste, including the people with disabilities. The participants did not speak of poverty however the volunteers at the clinic commented on the poverty of the local area and in particular their efforts to provide food and shelter to people with disabilities prior to setting up the clinic. The photographs showed features of poverty such as walls of houses made of branches of palm trees or beaten iron sheeting, roofs were frequently made of grass and bathing places can be seen outdoors with a dipper and bucket and no drainage (see figure 10 above). An exception to these photographs were those taken in Marcos’s home. Here in one photograph he could be seen sitting on a floral covered mattress on the floor, and in another photographs could be seen sitting on a concrete floor with speakers and equipment for playing music.
7.6 Discussion

The most striking features of the data in this research was the isolation and subsequent lack of opportunities for participation for the men with disabilities in this study. While this was not explicitly expressed by the participants, the photographs, the discussions with stakeholders and transcripts point to a life with limited opportunities for participation. This isolation was compounded by social isolation and inability to move freely in the community together with the men’s inability to engage in roles and responsibilities expected from Timorese by the community at large.

The International Classification of Functioning, Disability and Health (ICF) (World Health Organisation 2001) places participation as an essential aspect of human functioning. Participation can be described as ‘the performance of people in actual activities in social life domains through interaction with others in the context in which they live …’ [48] and includes relationships with others including friends and family, learning, employment, social and civic life as well as leisure [48,49]. Barriers to participation may come from firstly, the environment [48,50] – including the attitudes of families and others in the social environment, the legislative environment including social supports and services and the built environment. Secondly, limitations to participation may come from the attributes of the individual himself - including skills, physical limitations and motivation [50,51]. However, the social model of disability aims to clarify the difference between the individuals’ impairment and disability; impairment being the aspect of the individual which may be addressed by health and rehabilitation services and disability being that which is imposed by disabling elements of society such as attitudes, the physical environment and the built environment [52]. Occupational therapists consider participation as the core of everyday life through which the individual can ‘acquire skills and competencies, connect to others and … communities and find purpose and meaning in life’ [50].
In a developing country such as Timor Leste, there are extensive barriers to participation coming from lack of knowledge about disability, and attitudes drawn from cultural and religious understandings [53-55]. Barriers also include underdeveloped infrastructure such as roads, footpaths, public transport, poor access to public spaces such as markets and buildings including schools, together with poverty [56]. In Timor Leste there are few services and support for people with disabilities and those available are based in the population centres; the poor roads and basic public transport of the rural districts making access to services a considerable barrier.

There are other barriers and risks for people with disabilities in developing countries. Timor Leste is a post-conflict society [3] which has experienced a long history of occupation and trauma. Violence is seen as a part of culture, and while not explicitly sanctioned within families, is common and accepted, with vulnerable family members, including women and children, recipients of family violence [3,57]. Sexual and gender-based violence (SGBV) is known to be a common phenomenon in societies which have experienced conflict and violence [58] and explosive anger has been noted as a phenomena amongst those who have experienced or been exposed to extreme human rights abuses [59,60] however, family violence in many cultures is accepted as normal, even by those who are the recipients of violent behaviour [58,61]. As violence is underreported yet common in post-conflict societies, people with disabilities are at risk and have few possibilities of redress where personal mobility is severely compromised and communication skills are not well developed.

A discussion point arises in this project about whether the data collection can be considered to be photovoice. Photovoice was initially developed to give voice to marginalised people who were able to identify important aspects of their lives which researchers might otherwise overlook [62]. These issues could then be brought to the attention of policy-makers [28]. However, four of the five participants in this group had
intellectual disabilities and were unable to reflect or identify complex issues when discussing their photographs. Since the inception of photovoice the method has been used in different forms and with different populations, including people with intellectual disabilities and a study by Booth and Booth also found that group discussion was too difficult for their participants with intellectual disabilities [38].

There is debate too about the legitimacy of research with participants who have impaired communication skills, however, the inability to communicate complex ideas or views should not be a reason to exclude people from research [41]. Supported decision making is accepted practice where individuals are unable to make decisions or take actions for themselves [63] and proxy consent procedures are in place in both Australia and North America, with accompanying risk of proxies basing their communication on a self-serving basis. But, ‘if research involves only those people who are able to speak for themselves, the views and perspectives of an already marginalised sector of the population … will continue to be missing’ [41]. The onus is therefore on the researcher to draw out the threads of lived experience with the material at hand.

7.7 Conclusion

The research highlighted the isolation and vulnerability of people with disabilities, especially people with intellectual disabilities in Timor Leste and the absence of women participants in the research emphasised the greater exclusion and vulnerability of women with disabilities.

Therefore services for people with intellectual disabilities need to include a component of education where families and communities can learn their potential and how to maximise that potential. Services should include family members by providing culturally relevant support, education and practical guidance on how to make home environments accessible and how to maximise the participation of their disabled family member.
The major barrier to participation comes from societal attitudes based on lack of knowledge together with traditional understandings of disability. However, Timor Leste is unique in the progress being made to legislation and this must be supported on the ground by continuing conversation between policy developers, service planners, community awareness, disability advocates and rehabilitation services. In this way those living with disabilities will have more options for participation in Timorese society. Further research is needed to establish the best culturally relevant ways to include families and communities in services for people with disabilities in Timor Leste.

This was an exploratory study based on cultural differences when a female researcher from a Western country researched the lived experience of men with intellectual disabilities in a developing country, with the accompanying language and cultural differences. Firstly, the group was very small, secondly, there were no women involved in the project. Thirdly, the type of disabilities limited the amount of discussion and the depth of views from the participants. For that reason other forms of data such as discussions with the staff and volunteers in the clinic and the field-notes were given more significance.

Despite these differences photovoice proved to be a successful participatory method of qualitative data collection. The method elicited pride in the participants and those involved in their care. The participants enjoyed showcasing their skills, the clinic staff learnt more about those in their care. And the researcher had access to data which was not available from verbal discussion alone.

7.8 Declaration of Interest

The authors declare that they have no conflict of interest.
7.9 Acknowledgements

This research project would not have been possible without the generous support of Natalie Smith and the staff of The Leprosy Mission of Timor Leste (TLMTL). As well as TLMTL, the Director and staff of Health and Hope Clinic generously introduced me to the potential participants for the research project and provided the venue and their time and enthusiasm in support of the research. Dr Edmundo Viegas from the University of Timor Leste (UNTL) provided direction and support and members of the Disability Working Group (DWG) graciously sat through the presentation and provided discussion and support as well. Finally, I would thank the participants who joined in a series of activities which were unfamilliar yet productive, for both the research and for others with disabilities in Timor Leste.

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The original paper ends here

7.11 Key points

- Participant photography again proved to be an effective way to work with participants even though four of the five participants had intellectual disabilities.

- While the verbal data was limited because of the nature of the disabilities and the protective approach of the clinic manager, a picture of the participants lives could be seen in the available data, especially:
  - The vulnerability of the participants as four of the five men could not walk or express complex ideas.
  - The pleasure taken in small daily activities and the novelty of the research
- The isolation experienced by some of the participants
- Poverty was a constant feature of the lives of these participants

- The limited data available from these participants should not exclude research with people with intellectual disabilities as data can be found from other sources such as stakeholders, cares or families.

### 7.12 Summary and Conclusions

The paper above is based on the first of the main studies and was undertaken in the Health and Hope Clinic, located in a coastal area nearby to Dili. In this study the participants were five young men, four of whom had intellectual disabilities. The photographs taken by the five men or their family members showed their pleasure in simple activities, their vulnerability and isolation associated with their impairments and overarching poverty.

The following paper, presented in Chapter Eight, is based on data from a group of people with disabilities who were working in the disability sector in and around Dili. They were educated, they were mobile with the help of mobility aids and they were not affected by poverty as they were in employment. The findings from the following study showed the extremes of the experience of physical disability in Timor Leste and highlighted the value of people with disabilities acting as advocates for people with disabilities.
Chapter Eight: Third Study Findings

People with disabilities working in the disability sector in Timor Leste: a study of ‘lived experience’ using Photovoice

Key to the thesis

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The previous chapter was based on a photovoice study with a group of five men, four of whom had intellectual disabilities. The challenges relating to this group of men were examined and the value of the findings when researching with people with intellectual disabilities was discussed.

The next chapter is based on a larger group of participants, all of whom were employed in the disability sector; they were based in Dili and some were based in rural districts where the circumstances in which people with disabilities were living was at times,
quite different to the urban life. These participants reflected on their own lives as well as providing shadow data regarding the people with disabilities encountered during the course of their work.

This study was written as an article for the Third World Quarterly which has an impact factor of 0.750, and at the time of writing the article was ‘under review’ with this journal. The Third World Quarterly was selected because of its broad view of issues relating to disability in developing countries and because of its broad readership.
Chapter 8. People with disabilities working in the disability sector in Timor Leste: a study of ‘lived experience’ using Photovoice

8.1 Abstract

Perspectives on disability in developing countries are beginning to appear in disability literature. However, discussions may become lost in rhetoric if they are not grounded in contact with those who are the objects of discussion. This article reports on a qualitative study using photovoice to examine the lived experience of employed people with disabilities in Timor Leste. The participants recounted their experiences of disability and they described the lives of people with disabilities encountered during their field-work. People with disabilities have powerful messages of disability advocacy for Timorese communities, the development sector and the Timorese community at large.

Keywords: Photovoice, Timor Leste, disability, advocacy, development practice, lived experience.

8.2 Introduction

At last, disability in non-Western context is beginning to be acknowledged as different to the Western context. Discussions are occurring within disciplines in the West such as in post-colonial studies (Connell 2011), and non-Western forms of knowledge are also being acknowledged (Hoppers 2002), such as from the perspective of indigenous New Zealanders, known as Kaupapa Maori (Henry and Pene 2001). However, much of the discussion about disability remains at a conceptual level; without tapping into the experiences of those being discussed, that is the people with disabilities in non-Western cultures; the discussions may become lost in theory.

There is little literature written in English on the lived experience of disability in non-Western countries (Meekosha 2008) and no literature on the lived experience of disability in
Timor Leste at the time of writing. In this article we explored the lived experience of physical disability in Timor Leste, to begin to bring a sense of living with disabilities into the overall picture and discussions relating to disability in developing countries.

8.2.1 Recent history.

Timor Leste is a unique society in that it is dissimilar to large countries with deeply embedded attitudes to disability. Timor Leste is a small country, which declared independence in 2002, located on the eastern half of the island of Timor. The capital city, Dili can be reached by a one hour flight from the nearest Australian airport, Darwin. Timor Leste is not on the popular tourist routes in South East Asia. Infrastructure to support tourism is embryonic and prices are higher than in Indonesia, the country's large neighbour. Only a small number of adventurers can be found mingling with the development workers in the new hotels, dive shops and the new Timor Plaza shopping complex, all of which are indicators of recent rapid change in the country.

The rapid changes visible in the capital, Dili, barely mask the influences of a complex past which profoundly affects all aspects of Timorese life, including those with disabilities. The complex history of Timor Leste comes from a lengthy period of Portuguese colonisation followed by twenty six years of Indonesian occupation which ended in violence in 1999 (Leach 2006; Molnar 2010). A period of administration by United Nations’ peacekeeping forces preceded the declaration of the Democratic Republic of Timor Leste in May 2002.

8.2.2 Donors’ invasion.

However, since the withdrawal of Indonesian rule in 1999, the country has experienced another ‘invasion’ (Brunnstrom 2003). This has been labelled the malae (foreigner) period characterised by foreign non-government organisations (NGOs) moving into many sectors of East Timorese administration and service delivery in both Dili, and in
the rural areas. While new planning processes and services grew from these interventions, development processes occurred frequently without full discussion with the proposed beneficiaries, including Timorese impacted by disability (McGregor 2007).

Estimation from the World Health Survey by the World Health Organisation (WHO) places 650 million people with disabilities world-wide with 80% of those people living in developing countries (WHO 2011). The census of 2010 in Timor Leste noted that 48,243 Timorese were disabled, representing 4.6% of the population (Gardner May 2012).

Data is readily available on prevalence and incidence of disability in Timor Leste, however, ‘… concepts, definitions and classifications of disability are based on a medical and impairment model, thus underestimating the prevalence of disability’ (Takamine 2004) and there is limited research on lived experience of disability in Asian countries written in English (Meekosha 2008), and this includes Timor Leste.

Most research on disability highlights the enormous range of difficulties and disadvantage relating to people with disabilities. An AusAID (Australian foreign aid) report of 2013 notes that ‘people with disability (in Timor Leste) do not face exclusion and discrimination only because of impairment, but also because of physical, attitudinal, institutional, communication or other socially created barriers’ (McCoy et al. 2013, p. 5). However, this data does not show lived experience and little can be heard from the voices of people with disabilities themselves (Kett et al., p.658). No research was found where the successes of people with disabilities were noted, or about the lived experience of disability in Timor Leste.

This research presents the voices of people with disabilities including some of the successes where people with disabilities have been employed within the disability and rehabilitation sector in Timor Leste and act as advisors, therapists or advocates in workplaces, communities or at the national policy level. During the course of their work
these people found others with disabilities living in remote districts in Timor Leste whose lives were usually characterised by isolation and at times extreme disadvantage.

Since independence, services for people with disabilities in Timor Leste have gradually begun operation, such as residential care for those recovering from accidents or orthopaedic surgery, small services for those with vision impairment, a small faith-based service for those with hearing impairment, a rehabilitation and prosthetic service which also is a centre for Community Based Rehabilitation (CBR). There is a limited mental health service and a special school for children whose disabilities make mainstream school too difficult, and these services are mostly in Dili. Services in Timor Leste are considered to be underutilised as people with disabilities remain within their families and family attitudes are frequently based on misunderstanding and exclusion. However, the experience of living with disability is not defined by services or therapies; people with disabilities, in Western countries at least, do not define themselves by their disability (Giangreco 2010).

8.3 Method

Data collection for this study on the lived experience of disability was undertaken using photovoice, a participatory method of data collection (Wang & Burris 1997). Photovoice as a new research method of ‘lived experience of disability’ in Timor Leste has been described at length by Shamrock (2015, in review). In this study photovoice proved to be a suitable method for gathering rich detail in a cross-cultural setting for an Australian occupational therapist not fluent in the local languages.

8.3.1 The research project.

The research project into the lived experience of people with disabilities is a part of a larger project on the lived experience of physical disability in Timor Leste which began in 2012 and prior to this, the first author had a long association with Timor Leste as an occupational therapist involved with services for people with disabilities. The project which
is the topic of this paper is based on one of the participant groups who were people with disabilities employed in the disability sector who lived relatively privileged lives because of their employment. Some of them travelled to remote districts during the course of their employment, spreading the messages of disability rights and offering help to access services and education to individuals and families. Consequently they had access to isolated disabled people who were almost out of reach to a foreign researcher.

8.3.2 The participants in the study.

The purpose of this qualitative study was to examine the lived experience of physical disability in Timor Leste. The participants were selected by convenience sampling (Patton 2002) by inviting people with disabilities who were employed in the disability sector to participate in the study. All ten people who were invited to participate joined the study. The participants gave rich descriptions of their own lives, including their early life and schooling experiences, some described their experiences of the civil crisis and violence which followed the vote for independence in 1999, others described their studies and their work life, all readily described their personal achievements and their family circumstances. As well as their personal details, these respondents described their encounters during the course of their work with people with disabilities living in remote rural communities. Some details of the participants are presented next in Table 8.
Key informants were also interviewed in the study to provide context or background to the worlds in which the participants moved. Key informants were either ex-patriates or Timorese, all were working in some way with people with disabilities and some had disabilities themselves. Some key informants worked at high level policy development and some visited rural communities and noted the circumstances under which people with

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disabilities were living. The key informants were important in this study as they gave their perception of some of the unique circumstances within Timor Leste which contributed to the participants gaining employment and the legislative changes underway during the period of the research.

8.3.3  The research.

Ten people with disabilities participated in the research. They each engaged in firstly, an initial discussion with the researcher regarding the research project, to confirm that they wanted to join the research. Secondly, they engaged in an interview to gather basic data and to receive the digital cameras which were the basis for data collection. Thirdly, there was an individual meeting to discuss the photographs taken by the participant within the predetermined time-frame, between seven to ten days, and each participant was asked to select three especially significant photographs to subsequently be the basis of a group discussion. Finally, the participants engaged in a group session, for the group to reflect on the selected photographs.

During the second individual interview with the participant and in the group sessions, the participants’ photographs were an integral part of the interview, providing a focus for discussion, as a prompt for memories from the past, and as a basis from which the interviewer could ask further questions. Where the participant was not fluent in English an interpreter was used in the interviews and an interpreter was used in the group sessions. All discussions were recorded with the participants’ permission and all participants were invited to check the recordings. One participant asked that a section of information regarding complex problems relating to one of his clients not be included as final data and this request was honoured, four of the participants declined the invitation to check the recordings and five listened to brief excerpts of the recordings and stated that they were confident that their stories had been told correctly.
An environmental audit or Go-Along drive, similar to a Go-Along walk (Carpiano 2009) was carried out with Sujana (pseudonym), one of the participants. Sujana responded to a general request to undertake the Go-Along trip because (a) she was fluent in English and (b) her work commitments were flexible. The Go-along drive consisted of a drive around Dili to various places where Sujana habitually engaged in various activities; these included her home, her church, a sporting facility and a local market. She described the activities undertaken at each venue including why she visited these sites, what she did and the value of these visits to her as well as how she accessed footpaths, and buildings during the rainy season when the streets of Dili can become deep in water and mud for periods of time. She also described other details of her life prompted by memories in the conversation during the drive. Another participant with a disability was involved in the research project as interpreter. During trips to rural areas his strategies for managing the constant environmental barriers could clearly be seen. With his permission his work was included in the observations made during field-trips together with his commentaries which all became part of the research.

All recordings were transcribed and underwent thematic analysis as this process, while not restricted to a pre-existing theoretical framework, is an approach to analysis which can extract rich and complex meaning from data (Braun & Clarke, 2006). The approach involved identifying recurrent phrases or meaning units by reading and re-reading the data then undergoing a process of sorting and clustering the themes using Microsoft Word (Saldana 2012, La Pelle 2004, Swanson and Holton 2005).

8.3.4 Ethical considerations.

It was important to ensure a transparent ethical approach to the research process, that is by considering the ‘rightness and wrongness’ of all aspects of the research (Miles & Huberman 1994 p 288). This was done firstly, by obtaining ethical approval from both the University of the Sunshine Coast in Australia and obtaining advice from the Disability
Working Group in Timor Leste to undertake research which involved the use of participant photography (Shamrock 2015 under review). Secondly, potential participants were either approached individually, or if appropriate, a group invitation was issued. In both instances the invitation included emphasis that the research entailed safeguards such as confidentiality, the right to withdraw from the study and the right to set limits on the use of participants’ photographs. Thirdly, ‘trustworthiness and authenticity’ are important in qualitative research in the processes of data collection and data analysis (Miles & Hubermann 1994; Punch 2009). Butin (2009) suggests that trustworthiness and authenticity means ‘being clear about what you did, why you did it, and the limits and value of your methods’ (p. 103).

In this photovoice project the stages of the project were discussed with the participants initially, and as needed, as the project progressed. Fourthly, dependability and reliability are needed in qualitative research to ensure the long term stability of the research data (Bloomberg & Volpe 2008; Miles & Hubermann 1994). The main checks in this research project were firstly, by asking the participants to check the interview recordings. Secondly, a cultural mentor was consulted if situations arose which were not easy to understand, (see Thomas, Gray & McGinty [2011] for explanation of the cultural mentor). For example there was a discussion about the few women who participated in the research and this was explained as women’s reluctance to have opinions in Timor Leste. If there was any material which, during the first reading of the interviews was unclear, this was checked with the participant him or herself, or with a cultural mentor. Checking details with key informants was another way to verify details from the interviews. For example: reasons for families hiding people with disabilities in their homes was discussed at length. This led to a final understanding that families may be (a) protecting their family member or (b) that they were ashamed because of abuse of the family member or (c) they were ashamed because of cultural stigma relating to disability. Finally, the group process in the photovoice project
allowed the researcher to explore ideas presented in individual interviews and allowed the development of ‘data and insights that would be less accessible without the interaction found in a group’ (Punch 2009 147).

8.4 Findings from the Study

Analysis of the data revealed four themes with associated sub-themes relating to the lived experience of physical disability which were (1) barriers and enablers for people with disabilities in Timor Leste, (2) people with disabilities working in the disability sector (3) people with disabilities and personal resilience (4) the context of Timor Leste.

8.4.1 Barriers and enablers in Timor Leste.

Barriers and enablers were clustered under sub-themes of (a) traditional views of disability (b) early life and education and (c) gaining employment.

(a) The traditional view of disability in Timor Leste is that a person with disabilities cannot be independent, work, marry and have a family or travel. There is also a deep-rooted fear of being disabled or having a disabled family member, as disability may represent a misdeed in the past. Nico (pseudonym) was educated at tertiary level and he understood the deep rooted nature of beliefs about disability in his culture and he explained the depth of this belief about disability:

… because only cultural belief, people who have disability have a punishment … they think that in the past the father did something bad to other people, or the mother, that’s why the son or daughter has disability … So there is the belief and it’s not just in rural area. It’s also in Dili … It’s not only from the god, some of the things are from the culture ... this cultural belief still stick in our brain. (Interview Nico [pseudonym] 2nd October 2013)
(b) Early life and education: These common attitudes to disability resulted in participants experiencing exclusion in many families or from individual family members within a broadly accepting family. Negative experiences included being teased because of physical differences or because of wearing an orthosis or using a mobility device such as crutches or a wheelchair. Some participants moved to live with extended family who were nearer to a school to overcome mobility limitations. One participant lived with his aunt adjacent to the school and he could haul himself across the school ground to his classes. Most participants lost school time during the Indonesian occupation if there was civil instability in the area, or if there were no teachers in attendance. Some participants were unable to get to school during the annual rains. One participant was sent away to live with extended family in another remote district. She fared little better with this family as she was expected to care for animals rather than attend school. She subsequently ran away and lived for a time with a religious order in Dili.

Some participants in this study described harsh childhood experiences relating to traditional treatments for their disability initiated by their families in their childhood years. Some found the traditional treatments beneficial while others did not:

Yes he was ill for many months and his legs and arms started contracting … there is a type of traditional balm that they put on the arms and then they splinted it and the both arms were straight … Yes, they (the splints) hurt and he didn’t sleep. He used the splints for about 5 months, the splints with the balm. His legs contracted however, due to the splinting his arms were fine. (Edmundo [pseudonym] with interpreter, 7th October 2013).

Attending university was a common goal for most participants, however, most university buildings, even those on level terrain, traditionally have two or three steps for access. There were no elevators to upper classrooms, (in fact there were no elevators at all in
Dili until 2011), toilets were often approached with similar steps and cubicles were small. Despite these difficulties, all the participants in this study who wanted to go to university were given time for study by their employers. Agostinho explained how he fitted university into his work schedule:

   I have the schedule from the university and from September I have classes and I can coordinate with my boss, with our organisation … and when I have the class one or two weeks I can take annual leave and go to school and then after that I can go back to the work. University is very important for me for my life, to get the good job and the recognition that people say yes, this man can work and study. This is good for me. (Agostinho [pseudonym] with interpreter, 2nd October 2013).

Apart from the physical barriers, university was not easy when people had low levels of literacy from previously interrupted schooling together with mobility limitations.

(c) Gaining employment: Gaining employment was difficult for people with disabilities in Timor Leste and some institutions had active policies of exclusion:

   … after I graduated I just tried to seek opportunity to work as a public employee, I tried many times but I could not pass. Every year the government announced the new enrolment for the new public servant and I tried to apply but I did not pass … I tried to apply to technical school but they have the criteria that they will not allow people with physical disability to apply so I applied to another school. (Mauricio [Pseudonym] 2nd October 2013).

Some found ways to earn a living by first volunteering then being offered work. Others worked independently, examples include selling phone-cards on the streets or offering to clean offices or homes for a small fee. One participant offered to mind a workplace during the period of civil unrest in 2006. When Dili became dangerous due to violence and random
burning of buildings and homes, the office staff fled and he remained hidden at his work site as caretaker.

Five of the participants gained their present employment as a result of responding to an advertisement which specifically invited people with disabilities to apply to be field-staff in a disability organisation. All reported feeling ‘shy’ and all were determined to obtain work when they realised that their limitations could be a resource enabling them to be employed and to develop skills and experience.

8.4.2 **Personal resilience.**

In this section personal resilience had three significant components: (a) an ability to attract mentors, (b) ability to creatively solve problems and (c) re-inventing the story of disability.

The participants had attributes which contributed to resilience and the ability to make the most of their circumstances. These attributes included (a) an ability to attract mentors: all participants in the study spoke of having a mentor in their early years to support or inspire them to move beyond the stigmatising attitudes prevalent in their communities, and the participants were able to build on this support. Mentors included teachers, family members, enlightened employers or a nun or priest.

… his parents didn’t want him to go to school but one teacher really support him and say he should go to school. But his parents never support or encourage him to go to school. But they didn’t stop him yes, they just didn’t really help him.

(Interview Francesco [Pseudonym] with interpreter, 14th October 2013).
(b) Participants had to creatively solve problems for themselves for example, two participants paid other students to carry their books to school. Another participant was actively encouraged by the family and was given a large stick as a mobility aid by her father.

![Figure 6. Jose at work visiting a client at home.](image)

One participant whose disability was acquired in adult life remained at home for two years after his accident in the belief that his active life had ended. When he was eventually invited to attend the new local rehabilitation facility to learn how to live an active life despite his spinal injury, he rapidly absorbed the new information and was soon teaching others with disabilities to use a wheelchair; he subsequently was offered work in the disability organisation. One participant, now a Paralympic power-lifter, discovered the value of power-lifting as a sport that he could engage in and excel at, without the ability to walk.
Re-inventing the story of disability: All the participants reported pride in their achievements which included getting married and having or intending to have children as well as obtaining employment and developing new skills. Those who used the three wheeled motor-bikes especially designed for people with physical disabilities, were proud to be seen travelling freely around Dili. Women riding the three wheelers were especially proud of overcoming the barriers of being disabled as well as overcoming the general limitations common to women in Timor Leste.

Some people expressed pride and satisfaction at being able to help others with disabilities while others expressed pride at being a role model for those wanting to overcome their particular barriers to inclusion. One participant stated that he had everything that he wanted and expected to continue his life in the manner that he had achieved. Another participant explained that he was proud to be a disabled Timorese working in a Timorese organisation and had refused offers of employment with an international NGO, he felt that he
could be a more effective role-model for others with disabilities, by working with a local organisation. Another participant, Sujana described her approach to her achievements:

I have a job and I work for the disabled people and I don’t depend on my family. I don’t stay at home in my house. I want to share with the people in my community that people with disability can be independent like other people.

And also I want to show that the people with disabilities, especially women, have the right as the other people to get married. (Interview Sujana [Pseudonym] 3rd Sept 2013)

Figure 8. Mauricio training at the gym

8.4.3 Working in the disability sector.

The participants all worked in the disability sector in one of two main services for people with disabilities based in Dili.

Six participants visited rural areas in the course of their work, taking messages of disability rights while offering help or support to people with disabilities encountered during
their visits. This section highlights: (a) Difficult practicalities, (b) Finding hidden people and (c) Disability rights and advocacy.

(a) Difficult practicalities: The visits to remote areas were not easy. The participants’ employer usually provided a vehicle for the major part of the journey. However, rural roads in Timor Leste are generally rough and when roads end, people have to find another way to get to more distant destinations. When the participants travelled to the most remote districts they at times hired an *ojet*, a motorbike/taxi, which was able to traverse footpaths and horse tracks and go into places that a four-wheeled vehicle could not go. These journeys were physically demanding and the reception with remote communities ranged from welcoming to cordial to, at times, suspicious. When the response was suspicious the field-workers believed that the communities had probably been involved in projects in the past with unfulfilled promises being made to induce villagers’ engagement in the projects:

... like the rural area people just think that we are working for an organisation that has a lot of money and they just think I will bring the money, so the people just ask for the money. Or they think we will give them something. That attitude is very difficult … We explain that we are from the disability organisation and we come
here not with the money to give you but we want to help the people with disability, first not to get the money or material but help with the group [of people with disabilities] and get the same [get the same benefits] as the other people. We explain how our organisation work, and that we want to help them. (Interview Agostihno [pseudonym] with interpreter, 14th October 2013).

The field-staff reported difficulties at times with accommodation for overnight trips. Timorese often have wide networks of family and friends whom they can call on when necessary, however, accommodation posed problems if there were no personal contacts in the remote communities, and, if the field-staffer needed to find and pay for accessible accommodation with accessible facilities, or more commonly, manage without.

(b) Finding hidden people: At times field-staff came in contact with people with disabilities whose lives were quite different to the relative freedom of their own lives. On entering a community the field-staff usually asked if there were community members with functional limitations. Sometimes people with disabilities in the communities came forward to listen to a public talk based on disability rights and to see for him/herself a person with disabilities providing this information. However, sometimes a person for whom the advice was targeted was unable to attend the community discussion. At times the field-staffer needed to gradually form a relationship with a family in order to access a person who was being extremely protected or extremely excluded:

… so he does some investigation with the neighbours and then he meets with the family members putting up barriers. It’s a consultation process with neighbours that there is really a person with disabilities living in the house and he uses that information to talk to the family and explain, there is no need to be scared, I’m here for these reasons …. On Saturday he found a new person with disabilities ... this particular person with disabilities has quite a lot of capacity; he’s an artist and
paints. He explained the opportunities that are available for people with disabilities, like the scholarships and the benefit (the small allowance paid to qualifying people with disabilities). He found that the person has got the skill and his parents in this case, have been hiding him behind that house, they were protecting him. They were really surprised at the opportunities that are available. (Interview Edmundo [Pseudonym] with interpreter, 7th October 2013).

The field-staff commonly met people with disabilities who had never attended school or who had seldom been out of their homes and occasionally met people who were so excluded that the community at large were unaware of their existence. On very rare occasions they came across people who were physically restrained in their homes. On very rare occasions the communication pathway between the participant and a potential client or family failed. An example occurred where a field-worker attempted to protect a person with disabilities from sexual abuse. The abuser’s powerful family connections made reporting the abuse dangerous for both the abused person and the field-worker and, for the safety of both, the field-worker had to withdraw and take up work in another district.

(c) Disability rights and advocacy: The field-staff were involved in advocacy work which included preparing presentations to advocate for disability rights in communities, both rural and local, and preparing presentations for local and international non-government organisations (NGOs) to illustrate the barriers faced by people with disabilities. An example included giving workers blind-folds and a mobility cane or tying someone’s leg so that crutches were needed for mobility. The intention was to provide direct experience of some of the barriers for people with disabilities, such as understanding why basic daily activities take longer for a person with disabilities. These trainings conducted by a person with disabilities were reported to have a powerful impact on the trainees.
Eight of the ten participants were members of the Disabled Peoples Organisation (DPO) involved in a range of activities which had disability rights as the main message. These included a community theatre group which developed plays promoting equality for people with disabilities. One participant was a Para-Olympic athlete who spoke of the importance of his prowess as a role-model for those who wish to excel despite their barriers.

At the time of the research, a group representing Timor Leste and including a person with disabilities went to Geneva to participate in meetings in the United Nations (UN) to understand the obligations which Timor Leste would face on becoming a signatory to the United Nations Convention for the Rights of People with Disabilities (UNCRPD).

8.4.4 **Context, findings from the key informants.**

There were three sub-themes in this section: (a) Change is evident but slow, (b) the place of the ‘active youth’ and (c) the benefits of being a new small country.

(a) Change is evident but slow: Some of the key informants were working in advisory roles directly with national policy development as Timor Leste is a relatively new country with national legislature still being fine-tuned. Key informants who were ex-patriate foreign consultants or volunteers located within the disability sector, were enthusiastic about some of the potential for significant change in Timor Leste. At the policy level at least, change could be seen in Dili, although the key informants were at pains to point out that while major changes were being written into the policies of the still-evolving legislation in Timor Leste, implementation and change, especially in rural areas was very slow.

Both participants and key informants commented on the power and influence of the community leaders in more remote areas:

If you get some chefe de sucu (village leader) or some strong leader who believes in including people with disabilities then I think the rest will follow. Because if families are discriminating, I really don’t think they know why they are
discriminating. If one strong person stops discriminating ... then others fall into line (Interview with KI 3. 29th March 2013).

People seemed to have an unquestioning agreement with the attitudes of community leaders.

Key informants and participants agreed that rural families were less inclined to include a disabled family member in community events or to consider work, school or family responsibilities for their family member. KI 5 spent time in a rural centre and noted:

Much discrimination like children with disability are not going to school because parents say that my son is disabled and he stay home. And then you know women with disability are getting abused, sexual abuse, violence, then there is loneliness, stress, parents acknowledge some (children) are not considered like people [are not thought to be real people], like when they are getting sick … (Interview with KI 5. 18th October 2013).

(b) Active youth. A key informant noted the characteristics of the active youth or young adult generation in Timor Leste. Young adults were children during the resistance years and do not have the scars of the older Timorese, from the period of the Indonesian occupation. Young people of working age based in Dili want to prosper, some attended university, and all wanted better lives. The adults with disabilities interviewed in this study were within this age-group and espoused similar attitudes.

(c) The benefits of being a new small country. Legislation is still evolving and inclusive policies are still being designed. This is unlike countries with large populations where stigmatising attitudes in society are supported by long standing stigmatising attitudes in government legislation, with accompanying lack of understanding or the will to understand why this should be any different:
(Timor Leste) is small, it’s a small country. Yes it’s bureaucratic but it’s a small population and you can meet a minister in the street and people are related to ministers. In (country X) it’s a country of 120,000,000 (people and) you would never get that link ... and from having a DPO (in Timor Leste) that was voluntary staff in 2009 to a DPO with almost 20 paid staff in 2012, and (from) having no disability policies to having policies in just a few years. (Interview with KI 2. 1st October 2013).

A visit to Geneva which included people with disabilities, was funded in part by Australian donors at the time of the research, to study the obligations for Timor Leste when the United Nations Convention for the Rights of People with Disabilities (UNCRPD) is signed. This was also a unique period as Timor Leste rolled out the National Disability Policy starting in 2012, which identified strategic areas of intervention such as health, education, employment and vocational training, sport and cultural life. For each of these areas, the relevant laws of Timor were identified and specific strategies to progress the rights of people with disability were developed within each.

8.5 Discussion

The participants were living within the rapid changes in Timor Leste. Changes ranged from the planned ratification of the UNCRPD and all that is implied by this step (Meekosha & Soldatic 2011), such as the potential for making disability a significant part of the struggle for recognition within legislation in Timor Leste. Meanwhile change was occurring at the street level such as the installation of audible traffic lights during the period of data collection in 2013. Other changes in Timor Leste included changes where traditional family cohesion was being challenged by urbanisation, the increasing birth-rate and population, and on-going gender violence (Niner 2011). At the same time negative attitudes such as deprivation of opportunities for participation and access for people with disabilities
were being exposed and hopefully lessened when visitors such as members of the DPO began to make their mark in rural communities.

The participants in this study spoke of the people with disabilities found in rural communities, describing their exclusion and lack of opportunities as based on either fear or ignorance or lack of knowledge of the potential of people with disabilities and lack of knowledge of services available, albeit in Dili. Three of the participants described the surprise with which they were greeted when they visited new districts; people were surprised to see a person with significant disabilities who was employed, speaking from a position of informed experience about disability rights and the potential for others with disabilities.

Figure 10. Edmundo’s wedding day.

The poignancy and impact from this research came from the intimate details revealed by the participants. It was possible to understand details in the participants’ life such as how a field-worker is pushed in a wheelchair over rough ground to interview a family, or how a participant does the washing at home. The participants in this study were proud of their
achievements and this was the characteristic of most of the conversations; this was because they had overcome a range of significant barriers and were in employment in Dili. This is exceptional for people with disabilities in Timor Leste because most do not have jobs, or the combination of circumstances or background or education or contacts to acquire work. The participants were able to take up the enablers within their grasp, they were within the age-group of the ‘active youth’ who remember the harsh periods of occupation but are young, educated and ambitious, they intend to succeed in acquiring coveted office jobs and the potential to pursue consumer goals (Wigglesworth 2010).

While all participants did not have all these advantageous conditions, the research showed that the research participants were flexible and able to make the most of the circumstances in which they found themselves. The participants’ impairments did not exclude them from the workforce, and this is despite the generally held attitudes that people with disabilities are unable to work (Connell 2011). The participants overcame these attitudes by taking up many of the values of Western foreign aid which were brought to the country during the malae or aid period (Brunnstrom 2003). A significant example here is the Western ideal that the needs of the individual are paramount while Asian societies are more concerned with the place of the individual in the community (Mira 2012, Iwama 2007). The individuals in this study were balancing between an old culture which did not readily accept their impairments or their individuality, and the malae or foreign culture which came with Western concepts and individualistic Western ideals which are, inaccurately, promoted as ideal for all cultures (McGregor 2007, 156).

Timor Leste has made significant progress in embedding inclusive legislation within most of the government sectors. However, there are sobering messages from other countries where the pressing problems for people with disabilities are being considered. In Uganda the Disabled Peoples Organisation (DPO) was involved in consultation and planning of the
Poverty Eradication Action Plan (PEAP) and subsequently was given a role to make sure policy and governance decisions were inclusive. Despite this relatively active role, a respondent in a study by Mwendwa et al. (2009) noted that the DPO members themselves with their salaries and allowances were the main beneficiaries of this process. This same study noted further difficulties associated with poverty reduction strategies where people with disabilities were involved. In Uganda these difficulties included problems obtaining robust data, lack of a strong advocacy movement in Uganda and a preference of people with disabilities themselves for short term projects with clear results such as income generating projects. While these circumstances were not in evidence in Timor Leste, they are examples of change taking an unintended direction without the expected benefits to the relevant people. There may be risks of unexpected outcomes in Timor Leste, as inclusive policies continue to be developed and interpreted amidst the other pressures of contemporary governance in Timor Leste.

8.6 Limitations in this Research

Some questions emerged which were beyond the scope of this study. Firstly more needs to be known about the participants’ visits to people with disabilities in remote communities; what elements of those visits had the most impact and what else can be done at those points of contact? Secondly, research is needed into the relevance of Western style messages of disability rights in East Timorese communities; are there more culturally relevant messages to be delivered by disability advocates to improve the lives of people with disabilities? Finally the lived experience of physical disability for women in Timor Leste needs to be studied further as there were only two female participants in the total group of ten in this study. Further research to clarify these questions will add to the knowledge from which relevant services, policies and research can be based.
8.7 Conclusions

Photovoice proved to be an effective way to gather rich data for the research on the ‘lived experience of physical disability in Timor Leste’. A wide range of experiences of disability was described by the participants within the context of contemporary Timor Leste. Descriptions ranged from the relative freedom and access to the homes and families, workplaces and communities of the research participants, in comparison with the people with disabilities visited in the course of their work. Here photographs and the participants’ descriptions showed endemic poverty and participants reported people with severe and untreated disabilities living with social stigma and exclusion. The snapshot of Timor Leste provided by the key informants showed inclusive legislation and services being developed centrally in Dili, while change in the rural and remote districts happened more slowly.

The conversations with the participants revealed their resilience and their pride in their achievements as they managed their daily lives despite their impairments. The participants in this study were located at cross-cultural cross-roads, i.e. between their Timorese background as people with disabilities and the changes influenced by foreign aid and rapid globalisation within their country. The position of the participants was very different from the stories of the people that they visited during the course of their work in remote communities where people with disabilities lived in poverty, often with restrictions imposed by physical impairments, geographic barriers or social attitudes. These two positions provided a picture of not one, but two extremes of the lived experience of physical disability in Timor Leste. Understanding the experiences of those living with disabilities can provide background information to help with further research, policy or service development where people with disabilities are involved.
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8.9 Key points

- This group of participants were people with disabilities with some education who were all in employment and working in the disability sector in and around Dili. Stakeholders interviewed for the research were also involved in the disability sector; some worked at the policy level and some had disabilities themselves.

- Culturally based stigma prevails in Timor Leste, even amongst educated people and relates to culturally located ideas of blame from past misdeeds of individuals or families.
• Participants in this group found creative ways to overcome their barriers. They demonstrated personal resilience and usually had at least one mentor to support them to achieve their goals.

• The participants were proud of their achievements such as being employed, getting married and having a family and they freely used their own lives in their role as disability advocates, to inspire others when they visited remote districts to speak to communities about disability rights.

• The participants reported experiences during their work such as: at times finding people with disabilities concealed within their families as well as the difficulties associated accessing remote communities and finding suitable accessible accommodation.

• Cultural context was explored and findings included; the slow pace of change of attitudes towards people with disabilities and even less change outside of Dili. There were benefits to be seen from the relative newness of Timor Leste as an independent republic, still writing legislation and at times inviting consultation regarding how to make legislation inclusive.

8.10 Conclusions

This chapter investigated the lived experience of physical disability with a group of people with disabilities, working in the disability sector in Timor Leste. They provided a broad view of the experiences of living with disabilities, from their own lives and from those they encountered during the course of their work. In this chapter the contribution that people with disabilities can make to promotion of disability rights and advocacy could also be seen.

The following chapter, Chapter Nine is the discussion chapter which has two sections. Firstly, there is a discussion of the occupational therapist as a researcher, then there is a review and discussion of some of the details of the research methods. This is followed by
examination of a proposed model of lived experience of physical disability to draw the findings together in a way that may be useful for policy development or occupational therapy practice. Finally, limitations to the research are noted and suggestions are made for further research.
The previous chapter, Chapter Eight was an article written about the findings from the group of participants mostly based in Dili who provided their own stories as well as shadow data about people they encountered during the course of their work.

Chapter Nine is an examination and discussion of the overall research, of both the method and the findings. The first section considers the research itself including the experience of an occupational therapist as a researcher. The second section considers the applicability of the research. The third section draws the findings and discussions of the research together to propose a model of the lived experience of physical disability. Finally,
the limitations of the research project are discussed, and future research possibilities are considered.

This research is the result of my interest and association with people with disabilities in Timor Leste, extending back to 1972. I wanted to investigate the lived experience of people with physical disabilities in Timor Leste, to develop a body of knowledge which may inform scholars, policy makers and practitioners, especially occupational therapists and to engage people with disabilities in the research process as active participants. The following aims were framed to achieve this:

- to examine the barriers to and facilitators of satisfying engagement in family and community life for people with disabilities
- to identify and examine contextual and cultural factors which influence the daily lives of people with disabilities in Timor Leste
- to build on these findings and identify implications for cross-cultural occupational therapy practice which will enable people with disabilities to develop capacity and agency and to realise their potential.

These questions, which provided the basis of the participant interviews in the research were devised from my understanding, as an occupational therapist, of the importance of occupation in human life and how occupations reflect engagement in family and community roles (Duncan, 2011)

To answer the research questions, I firstly carried out a pilot project in a remote district in Timor Leste. There were two main lessons from the pilot project. Firstly participant photography was a successful way to undertake cross-cultural research in a developing country; and, secondly, that work in a remote setting resulted in logistical difficulties, such as travel for myself and for participants, which stretched the resources of my sponsoring organisation. I decided that one set of data from a remote setting would suffice and that the
next projects could be closer to the capital, Dili. Therefore on a second visit to Timor Leste I carried out two more studies thus a total of three studies were carried out: and, subsequently the three studies were written up as academic papers and are inserted in the thesis as Chapters Six, Seven and Eight. The pilot study, the two main studies, together with the metasynthesis reported in Chapter Three, were undertaken with the intention of answering the research question which was ‘What is the lived experience of people with disabilities in Timor Leste?’

9.1 The Occupational Therapist as Researcher

Occupational therapy as a profession considers the occupations and roles which are important to the individual, where occupations are considered to be all the activities that an individual engages in during the course of the day (Christiansen & Townsend, 2010). Definitions of occupational therapy differ due to the vibrant nature of the profession (Creek, 2006) however, the occupational therapist typically views health as intertwined with the ability to participate in these chosen roles and occupations. Thus occupational therapy practice involves promoting health through influencing the capacity for satisfactory engagement in occupation, in life roles (for example work or family roles) and subsequently, to experience a good quality of life. An extension of occupational therapy practice is the view that individuals have a right to express the basic physical, social and emotional needs through occupation; this is considered occupational justice (Wilcock, 2006).

As an occupational therapist I am interested in what people can and cannot do, how they do what they do, and what they say about their daily lives. I wanted to have an active partnership with the participants in my research, with the understanding that an active partnership generally ensures a successful engagement (Creek, Ilott, Cook, & Munday, 2005). There is a potential challenge from those who considered that although photography adds a visual dimension to phenomenological investigation, visual data could be construed as limiting the research to seeing ‘modes that are visual’ (Dicks, Soyinka, & Coffey, 2006, p.
In contrast to this perspective, I experienced photography as a source of richness rather than a constraint.

The participants’ stories, and photographs informed my occupational therapists interests. I learned about the occupations of daily life which are so ordinary as to be almost invisible, occupations include preparing meals, bathing or relaxing at home, in the unique way that the individual does these activities, in his or her own environment and culture (Hasselkus, 2006). More could also be learnt about the meaning of the activities and the associated roles during group discussions with the participants. I was researching from my occupational therapists’ understanding of the ‘lived body’, locating the participants in their real-life situations and understanding them from within both the physical and social environment (Mattingly & Fleming, 1994). The occupational therapists’ concern about the minutiae of life (Sokolowski, 2000) parallels the focus of phenomenology which investigates the ‘obvious and necessary’ details of life (Sokolowski, 2000, p. 57) to arrive at important and illuminating understanding of these details.

9.2 Reviewing the Research

9.2.1 Review of the themes from the studies.

Each photovoice study had a significant theme together with the constant theme of poverty. The pilot study demonstrated poverty as a major influence together with the importance of the small daily activities in the home, and how these activities are carried out, often with great difficulty. The study in the Health and Hope Clinic highlighted the poverty and vulnerability of the participants as well as the simple activities which gave them pleasure. The participants in the Dili group, (Chapter Eight) also noted poverty as well as highlighting their experiences of their work and its importance to others when they act as role models and advocates for people with disabilities; their passion for their work was one of the surprising findings in the study. Table 9
Summary of the Findings from the Three Studies is a summary of the findings from the three studies.

Table 9
*Summary of the Findings from the Three Studies*

<table>
<thead>
<tr>
<th>Chapter</th>
<th>Chapter 6</th>
<th>Chapter 7</th>
<th>Chapter 8</th>
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</thead>
<tbody>
<tr>
<td><strong>Name of the associated paper</strong></td>
<td>‘The benefits, challenges and ethics of Photovoice as an approach to cross-cultural research in a resource-poor setting: a pilot study’</td>
<td>‘Health and Hope Clinic: living with disabilities in Timor Leste, the results of a Photovoice pilot project’</td>
<td>‘People with disabilities working in the disability sector in Timor Leste: a study of ‘lived experience’ using Photovoice’</td>
</tr>
<tr>
<td><strong>Location</strong></td>
<td>Remote rural community</td>
<td>Rural community near Dili</td>
<td>In Dili with shadow data from remote rural locations</td>
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<td><strong>Features of the project</strong></td>
<td>Difficulties with transport and access. Ethical considerations with illiterate people in cross-cultural research. Rich details of lived experience of disability</td>
<td>Vulnerable and isolated participants recently identified by the clinic staff, now joining clinic activities.</td>
<td>Reported and photographed their own lives plus the lives of people living in remote districts encountered during their work.</td>
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9.2.2 **Photovoice and phenomenology.**

A further discussion is now presented with the examination of the use of photovoice in phenomenology, as the two could be seen as incompatible; phenomenology investigates the life-world of the participants and it ‘is a matter of studying everyday experience from the point of view of the subject, and it shuns critical evaluation’ (Schwandt, 2007, p. 226). In contrast, photovoice was originally intended to have a social justice approach and was developed to give participants tools to ‘identify, represent and enhance their communities’ (Wang, 1990, p. 185). Photovoice has evolved since those original studies, and participant photography has proved to be a powerful and empowering strategy for research, even without the emphasis on social justice. This was also the case in my studies:

(a) The participants’ photographs provided rich stimuli for interviews and conversations about lived experience, as described in the photovoice projects reported in Chapters Six, Seven and Eight.

(b) Participant photography resulted in building trust with the participants by giving them a more active role in the research process than a traditional interview.

(c) The participants held some of the power in the research as they chose the material to be photographed and finally

(d) The emphasis in the interviews was on the photographs themselves rather than on the unfamiliarity of the interview setting. (Brunsden & Goatcher, 2007; Plunkett et al., 2012). While social action was not taken up in the study, some of the participants placed their photographs in public view as a positive statement of the capacity of people with disabilities in Timor Leste.
9.2.3 Use of the photographs.

Although social action was not the primary purpose for using photovoice in this research, in the spirit of the original photovoice, I wanted to keep an option open for the participants if they identified an issue and if there was a consensus that some form of action was needed. I had, for example, imagined a possible scenario where the access to the local church was a problem for people with mobility problems, and I determined to support any reasonable and do-able suggestion made by the participants, towards addressing such a situation as a part of the research. Despite having the potential for action in the research agenda, a detail made known to the participants at the beginning of each study, no social or environmental issues were identified by the participants and this option was not taken up.

As there was no request by the participants for any form of social action to address identified problems, complexity of the project was not increased. On the other hand, it seemed that this option could have been attractive to someone with an issue which they believed needed to be addressed; and I was not convinced that the participants were unaware of any social injustice in their world. It appeared to me that they were unwilling to state a negative opinion. People with disabilities are often represented by others such as family members, as they are disempowered as decision-makers themselves (Coleridge, 1993; Sneeuw, Sprangers & Aaronson, 2002); and may be unused to having opinions of value which could be discussed with others. Further discussion of acquiescence is presented in Chapter Five.

There are some further reflections regarding the participants’ choice of photographic material. They were asked to take photographs of activities in their daily lives, to answer the questions such as, ‘What do you do each day?’ ‘What is easy and what is difficult?’ On the one hand the participants were responding to the request to show what they could do; that is, the request was not to show what they could not do. Subsequently, the photographs showed
the participant undertaking activities, despite obvious difficulties. Examples include a participant crawling to the bathroom with toiletries balanced on her head; another photograph showed Francesco crawling up the steps of the Palacio, (the government offices) to attend a public ceremony and to meet the President. Explanations of these photographs were always matter-of-fact: ‘she says she is going to the bathroom, she takes these things with her’ and, ‘He is going up the stairs for the ceremony at the Palacio to meet the President’. With further questioning, first participant simply responded ‘this is the way she goes in her home’. In the case of Francesco, he explained that he did not want to be carried up the stairs, which was the only other option in this instance, as there were no ramps or lift. (Note that these two participants are speaking with the help of an interpreter, hence the use of third person).

The lack of access for Francesco is a significant inequity of access when viewed with a lens of occupational justice (Hammell, 2008); those who designed the building, built in the Indonesian architectural style, had not considered the needs of different people who might be attending functions at the Palacio; and this inequity of access also potentially excluded anyone with mobility impairments from becoming a parliamentarian. While Francesco had a significant impairment resulting in his inability to walk, his other personal attributes, determination and pride,
enabled him to ascend a flight of stairs to a public function unaided; and this to him was the significance of the photograph.

9.2.4 Research looks like foreign aid.

Photography in research has the potential for misunderstandings. Research and foreign aid may appear similar to people who have had little experience with either process, as each process involves interviews, often with foreigners. In foreign aid, interviews often result in projects or activities which have some tangible and significant results for the benefit of the participants or their communities. Indeed, one participant asked if I planned to show her photographs to the NGO which sponsored her income generation project, despite my explanations at the beginning of the photovoice project that the photographs would be used for my research alone, unless individuals chose differently. I wondered whether participants who were illiterate and who were not familiar with research processes, may believe that if they appeared to complain, they may suffer recrimination by removal of their benefits or their support from foreign aid.

9.2.5 Self-reflection in photovoice.

A benefit for some participants was the opportunity for both self-reflection and increased understanding of others. This included people assisting in the study, such as a Timorese interpreter had not thought about how illiterate people could buy and sell produce in the market; and during the photovoice project he learnt that illiterate people can ‘use money’:

… she didn’t go to school … because of the disability, she is far from the school and she is shy. For her it is very hard to go to school and the family don’t want so for her she works in the home … Oh yes, she can use money. (the interpreter is surprised). She can’t write or read but she can use the money. When she buy something in the market she use the money and she sell the vegetables … she just
learn to do that by herself. (Interview Albertina [pseudonym] with interpreter, 26th August 2012).

The interpreter was an educated Timorese, with disabilities acquired in adulthood and his experience as interpreter provided him with an insight into the experiences of people with disabilities living in remote districts. He lived a relatively privileged life despite his impairment, while the participant we were interviewing lived with an aging parent on the outskirts of a rural centre. These two individuals displayed different positions within the spectrum of the lived experience of physical disability in Timor Leste.

Telling personal stories and self-reflection were challenging and tiring for the participants, especially where conversations needed to be translated. Despite that, participants saw value in telling their stories. The participants’ comment, below is followed by a comment in the field-notes:

It’s a bit difficult for him to tell about his life, but it’s good for him to tell his story, he learns about himself and it’s like advocacy. He is happy for people in Australia to see his photos and to have the story because it’s like advocacy for him.

(Interview Francesco [pseudonym] with interpreter, 14th October 2013).

The interview concluded and the following comment was from the field-notes:

We conclude with thanks and further discussion about showing his photos in Australia. We talk about the [consent] form and the importance of him being very sure about showing his photos in Australia ... I’m aware that I haven’t been through all the questions but Francesco is showing signs of fatigue, his eyes are drooping and it’s just before lunch-time. And the process is quite long with the interpreter and trying to hear above the noise of the fans. (Field-notes 14th October 2013).
I understood that self-reflection was satisfying yet challenging; at the end of one of the groups, the value of the process was explained to me by Sujana (pseudonym), one of the participants:

I just have to say to you I am very happy to give you the information and to give information about my experience and my life and you can make the story and you can show to them in Australia. It’s good for me and thank you very much for your kindness to help us and to show our picture and out story to the university, and you make the advocacy for us ... You can show the people about Timor Leste (Interview Sujana [pseudonym] 3rd October 2013).

This provided information that this participant was happy with the outcome of her investment of time, and this satisfied one of my concerns in this research project, that the research be of value to those who were engaged in it.

9.2.6 Traditional pictures.

Different cultures have different responses to photography; Guillemin and Drew (2010) noted in a participatory photography project that some participants approached photography with the idea of taking ‘happy snaps’ (Guillemin and Drew, 2010, p180). This approach was supposed to demonstrate that the subject was apparently happy and active, and only subsequent discussion revealed problems associated with the activities seen in the photographs.

Those being photographed in Timor Leste had their own cultural response and most people seen in the photographs taken for the photovoice research did not smile. Traditionally, people in Timor Leste do not smile when being photographed and their preference is to stand or sit in a formal pose and the severity of their expressions could be mis-construed as suffering, or as discomfort about being photographed, or as this traditional formality at work. Some of the participants’ photographs displayed stilted traditional postures while others were
able to move beyond their cultural norms and take photographs of people, either the participant him or herself, or another person, carrying out daily tasks.

The researcher in Timor Leste using participant photography needs to be aware of the meaning of the expressions of photographic subjects in research. The exceptions to a formal face in photography were the more globalised responses by urban young people, who were familiar with digital technology and social media and who were happy to pose, smiling, and making V signs with their fingers.

In conclusion, the preceding discussion outlined details associated with the research method: the occupational therapist as a researcher, the blend of photovoice and phenomenology, as possible confusion regarding the research and the way the participants responded to, and viewed both photography, and the photographs. The second part of this chapter is a discussion of a proposed model of lived experience of physical disability. A model is simply a heuristic device or a device to aid understanding (Barnes, 2001); and I propose this model as a way to understand the lived experience of physical disability in Timor Leste. A model of lived experience of disability can assist the policy maker or health practitioner, such as an occupational therapist, understand more about disability when devising policies or treatment strategies for Timorese with disabilities.

9.2.7 Disability rights and misunderstandings.

At first glance, the idea of disability rights and the rights to participation in all aspects of Timorese society may seem incontestable. However, misunderstandings are possible where disability rights are being expressed. An example is the Israeli Disability Strike of 1999 which was intended to highlight that people with disabilities had identical human rights to those without disabilities. In the resulting publicity, people with disabilities were seen as objects of pity rather than people entitled to the same rights as others (Rimmerman & Herr,
Another source of misunderstanding was presented by Friedner and Osborne (2013), who reported on possible outcomes of disability activism, such as demands for changes in the built environment. These authors suggest that demands for accessible environments may lead to changes in the nature and the function of the non-accessible elements of an environment: ‘Does a curb with a ramp to facilitate wheelchair access function the same as a traditional curb? In other words, does it control storm water run-off or demarcate the pedestrian and automobile environments as effectively as before?’ (Friedner & Osborne, 2013. P.45). This may appear to have merit, although in the bigger picture both aspects of curbing need to be considered.

Limited access is one of the core barriers to equality. This issue includes access in the built environment, opportunities for travel, access to community spaces, as well as circumstances such as armed conflict or natural disasters, where there is increased personal danger for people with disabilities, and even greater danger and risk to women and children with disabilities (Mitchell & Karr, 2014). When people with disabilities themselves are consulted on the experience of moving within a particular environment, either a physical or social environment, the information about barriers in the environment will be more accurate and useful for all people with mobility impairments.

9.3 Towards a Model of Lived Experience of Physical Disability in Timor Leste

In this section the findings from the three studies (as described in table 4 above) suggest a model by which to understand the lived experience of physical disability in Timor Leste, as a developing country. There are already tools for assessing the experiences of people with disabilities such as the Perceived Impact of Problem Profile (PIPP), a tool based on the biopsychosocial model of health and functioning. This tool was developed to compare
data across countries for use in both research and to measure clinical functioning in people with mobility problems in Thailand, Malaysia and Australia (Misajon et al., 2008). This tool is being developed to include other contexts and cultures; but does not address the variety of factors which act as barriers or enablers to participation for people with disabilities. A model of lived experience of disability considers the barriers and enablers of the individual, it considers the effect of poverty as well as the context and culture in which individuals are located. Such a model can therefore can serve to remind both practitioners and policy makers that details of potential barriers, or enablers, need to be considered in practice.

The capabilities perspective as developed by Sen (Sen 1985, 1999, 2005), as explained in Chapter 2.2.3 has been considered in some depth by occupational therapists in relation to a range of circumstances such as spinal cord injury (Hammell, 2015) in relation to occupational justice (Hammell, 2016), study of employment rights of people with mental illness (Reberio Gruhl, 2010), in relation to global health (Ruger, 2009), in relation to CBR and poverty reduction (Mousavi, 2015) and in the study of social skills for people with learning impairment (Burton, Kagan, & Clements, 2013) amongst others.

The formative framework or model from which to consider the lived experience of physical disability has three broad sections, or filters by which the participants experienced their lives:

(a) a core of experiences within daily life which are positioned between barriers or enablers to participation.

(b) the cultural and contextual factors on which the barriers or enablers are based.

(c) an overlay of poverty which is a characteristic of the experience of disability, and which penetrates the barriers, which modifies the enablers and is a part of the culture and
context of the majority of people with physical disabilities in developing countries, as has been discussed in Chapter One.

The model of lived experience of physical disability in Timor Leste can be seen in figure 18 below.

![Diagram](image)

**Figure 12. Proposed model of the lived experience of physical disability in Timor Leste.**

A discussion of each of the components of the model follows and the relationships between each component, starting with the culture and context, will be explored. However, it is important to note that the various aspects are not discussed in order of importance. A diagram demonstrating the attributes of each sector of the model can be found as appendix R.

9.3.1 **Context and culture**

This component represents all the cultural and contextual influences which underlie the experiences of the individual with disabilities and there are four main findings under this section. The findings can be summarised as follows:
(a) rapid changes such as the development of new policies and infrastructure, of rapid urbanisation, of services for people with disabilities being developed and from the engagement of members of the DPO in these processes. The increased visibility of people with disabilities moving around in the streets of Dili represents the changes which have occurred in recent years - changes include the development of an active DPO which is involved in training others about disability rights as described by one of the stakeholders. People with disabilities need to be visible, to be seen engaging in the communities and expressing and enacting the same roles and achievements as the rest of Timorese society. This has a snowballing effect as difference becomes acceptable in the public eye.

(b) The natural and built environments dictate experiences of access and have been discussed in Chapters Six, Seven and Eight. The changes occurring in Dili, described above, mean that Dili is rapidly changing into a typical Asian city similar to those described in a study of ‘walkability’ in 13 Asian cities in 2010. This study demonstrated that pedestrians are ‘transport disadvantaged’ as a result of poor pedestrian crossings, lack of pavement forcing pedestrian to walk beside chaotic roads or creating pedestrian traffic jams, as well as steps and heavy traffic (Fabian, Gota, Mejia, Leather, & Center, 2010, p. 44). Meanwhile people in remote districts are disadvantaged by the natural environment, as described in Chapter One.

(c) Language can reflect how a society views people with disabilities as language is an indicator beyond communication, reflecting approaches to control and domination and public perceptions of disability (Harpur, 2012). Those working in the disability sector in Timor Leste were involved in a move to change discriminatory language, as described in Chapter Eight. This is a complex task in a country with four main languages and approximately 20 minority languages; and until all languages reflect changes in thinking and understanding of disability in the population, discrimination, reflected in language usage will probably continue. Together with the attempts to change language usage, is an active
approach to publicising activities involving people with disabilities such as wheelchair basketball, or where a person with disabilities makes a noteworthy achievement. The inclusion of people with disabilities in media goes parallel with changes in public attitudes and may even be instrumental in initiating those changes (Kolucki, 2001).

**Figure 19. Members of the wheelchair basketball team training.**

(d) A post-conflict, fragile state poses risks for people with disabilities. Timor Leste is a complex country with significant internal pressures and considered by many to be a post-conflict, fragile state (Browne, 2007). Some of the features of the fragile-state status which influence Timor Leste, and subsequently the lives of those with disabilities, include risk of return of conflict if deeply embedded grievances are not satisfied or resolved (Fitzpatrick & Fishman, 2014). In Timor Leste, this risk is exacerbated by high levels of unemployment, rapid urbanisation and loss of traditional community structures as Dili grows rapidly (Moxham, 2008). Timor Leste has a tradition of strong energetic membership of various groups such as martial arts; and these may be benign and supportive or may be based on violent protection of urban spaces (Richmond, 2011; Scambary, 2009). There also risks based on a government, which is conducted along Western lines, but which is also attempting to
reconcile with the traditional forms of governance which hold considerable power in rural communities (Brown & Gusmao, 2009; Cummins, 2010). One implication of uncertain governance and associated rule of law is that people with disabilities need strategies to manage localised violence or large-scale civil unrest.

Koca-Atabey (2011) is an academic with cerebral palsy who noted the differences in her experiences of disability between Turkey, England and the USA: ‘As a person with cerebral palsy, my impairment is necessarily stable; but when the environment that I live in changes, the experience of disability changes enormously. Here ‘environment’ is used in the physical, social and psychological sense’ (Koca-Atabey, 2011, p. 1028). Koka-Atabey’s comment describes the disabling nature of environmental factors and she clearly illustrates how people living in remote rural areas experience their disabling environments.

A diagram illustrating the culture and context found in this study is presented in Figure 13, where each of the sections overlaps and influences the others.

![Figure 13. The six interlinking components of culture and context in Timor Leste.](image)

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9.3.2 Poverty

Poverty is represented in the model (see figure 18) as the arch over the other components of the model, as it is an overarching aspect of living with disability in a developing country such as Timor Leste. The lives of people with disabilities in these studies were affected by the interlinking and interdependent influences of poverty, health and education which can be seen in many reports and in other research. For example, lack of formal education for children has been linked to poverty in adulthood (Groce, 2011) and both are linked to disability and low birth-weight (Hartman, Mandich, Magalhães, & Orchard, 2011). Poverty increases the likelihood that a person with an existing health condition will become disabled, for example, poverty may make access to appropriate health and rehabilitation services more difficult (Peters et.al, 2008).

The most common method used by people in Asian countries to pay for health care is out-of-pocket (OOP) payment (Somkotra & Lagrada, 2009; van Doorslaer et al., 2007), where there is lack of provision of a national health service, thus leading to further poverty. The Multidimensional Poverty Index (MPI) showed that a person with disabilities and his/her family were likely to be poor, and earning less than US$2 per day. These families were also at greater risk of facing a demand for ‘catastrophic payments’, as a result of events such as illness or injury, resulting in the need to reduce food consumption or to sell possessions such as animals. Inevitably, these costs pushed already poor households deeper into poverty (O’Donnell et al., 2008; van Doorslaer et al., 2005). These factors interlink; conversely, reducing one of the negative influences helps mitigate against the effects of the others - for example better education improves work opportunities and the ability to meet health-care needs. Poverty is a vast influence infiltrating all aspects of life for people, especially those with disabilities in a developing country.
9.3.3 Barriers

Shame within families has been described in Chapters Six, Seven and Eight. The staff of the Health and Hope Clinic and the staff of TLMTL reported stories of finding people with disabilities hidden in the family home. Hiding people with disabilities has been reported where people have leprosy (Heijnders, 2004; Peters et al., 2014), although leprosy has unique stigma, associated with fear of the infective and deforming nature of the disease (Jacob & Franco-Paredes, 2008; Kazeem & Adegun, 2011; Nations, Lira, & Catrib, 2009). The metasynthesis, Chapter Three, was the only study in this thesis which did not identify people with disabilities being hidden from sight, as such people would generally not be available for interview. There are reports of families hiding disabled children in Cambodia, Indonesia and Thailand to either keep them safe or because of shame from belief that the family is being punished for family misconduct (Takamine, 2004). The comments of Takamine (2004) apply to Timor Leste as well as other Asian countries: people with disabilities may be excluded from education, may be denied normal roles in their societies, may have little self-esteem (Van Brakel et al., 2012), and these attitudes, when internalised, make it very difficult for a person with disabilities to be able to be involved in awareness raising. This was expressed by Jacinto, one of the participants:

... so at the start I’m very shy, I’m a little ashamed ... working with this organisation, when I look at myself it seems like shame. I am disabled and it feels like that I am going to talk about myself” (Interview Jacinto [pseudonym] October 2013)

Most people with these life experiences find it difficult to take on leadership or advocacy roles and are reluctant to have opinions or make requests for assistance, especially if their own family has never been supportive of their needs.

9.3.3.1 Barriers for women in Timor Leste
A second significant barrier to participation for women in Timor Leste was highlighted by the use of convenience sampling (Patton, 2002) in the research. This led to a predominance of male participants and reinforced a previous finding by Niner: ‘women are invisible in much analysis on East Timor, particularly in academic and political commentary’ (Niner, 2011, p.415). Invisibility of women matches absence in other aspects of Timorese life. Women are less well educated and there are low levels of literacy where two thirds of women over fifteen years are illiterate, in contrast to half the adult Timorese men (UNDP, 2006). There are also relevant health indicators, for example the maternal mortality rate of Timor Leste is 929/100,000 and this is greater than the average in Southeast Asia, setting Timor Leste in seventh highest position in the world regarding maternal mortality (Hogan et al., 2010). Only 19% of births are attended by a skilled health practitioner (Niner, 2012).

There are difficulties for those who wish to change the status of women to a more equal and empowered position in Timorese society. Reasons for this may include a longing for a return of traditional culture which comes with a traditionally subordinate role for women. Many women feel that it is wrong to participate actively in society, such as in politics. Some argue that women should return to their traditional home-making and maternal roles and insist that male leadership and pride requires women to be subordinate. The role of the woman is considered to be within the family, thus education is not a priority for girls, especially in poor families (Wild, Barclay, Kelly, & Martins, 2010). In support of these arguments, there are reports of hostility to Western feminism in other post-conflict Asian countries such as Cambodia and Vietnam (Niner, 2011).

Conversely, there are changes occurring towards new cultural gender roles for women in Timor Leste. Gender differences are being discussed within the overarching theme of nation-building as well as at operational levels such as health-care, education and support services, including help and support for gender-based violence (Trembath & Grenfell, 2007).
Despite deeply the entrenched ideas described above, the status of women is gradually improving with the development of organisations such as Fokupers, a women’s NGO focussing specifically focussed on violence, Rede Feto, a women’s advocacy network, and even a men’s network, Assosiasaun Mane Kontra Violensia (AMKV), the Association of Men Against Violence, all of which are trying to change the disadvantages faced by women in Timorese society (Hall, 2009).

The women who participated in this research study were atypical, and their self-confidence allowed them to tell their story. In more traditional parts of Timor Leste, women do not readily come forward to speak, especially to a foreign visitor. In Western cultures, women and feminists are increasingly adding their voices to disability studies; however, women in non-Western cultures are generally disempowered without the confidence to hold opinions (Addlakha, 2007), thus the stories unique to women with disabilities are not so readily heard.

9.3.4 **Enablers**

Many of the participants in the third study, the Dili group, were members of the DPO (Disabled Peoples Organisation) and they spoke of the importance of advocacy in their work roles and they freely used their own lives as examples to others with the intention of enabling others to follow their example:

I think [about] how can we communicate with them [the people with disabilities in remote districts] ... I can explain to the family with the example of me. Look! I can go; I can ride the motorbike, everything I can do. How about your child? Did you do everything? You can see about his condition and you can see me, you can think about me and think about your child. Sometimes we just take the information like this with the example. (Interview Vitoria [pseudonym] 7th October).
This comment from a participant based in Dili, reflected her thinking as she worked with people in remote districts in her role as advocate. She described how she used her own life as an example of a disabled person, going out to work and travelling freely.

People with disabilities working as disability advocates can address stigma at three levels: at a micro level where the individual faces his or her own sense of stigmatisation, as was seen in the quotation by Jacinto above. Then, at a meso level where stigmatisation is experienced when it is expressed by others; and here the DPO members demonstrated by example that this can be overcome. Finally, at a macro level where it can be seen as institutional or structural stigmatisation (Weiss, 2008). The experience of an observer below explains how the DPO members can influence at this level. Some DPO members focussed on presenting notions of disability rights to community groups and to national government; that is, they acted as the macro level and they presented powerful and empowering views of disability. The following story was reported by a stakeholder who was involved in a training led by a member of the DPO and saw this dynamic in action:

[Members of the disabled people’s organisation (DPO)] came to do a sensitisation session and they brought a whole lot of gear like white canes and wheelchairs … and gave everybody a go [an opportunity] at using a mobility aid … then they asked for comments on people’s experiences and one man stood up and took the microphone and thanked everyone for their time and immediately started crying … and all of a sudden everybody sat up in their chairs and you could hear a pin drop and the man turned back around and explained that he was [in a significant position in his work] so he worked with disability issues every day and his son was born blind … and he said ‘you know I get [understand] disability but I don’t think I ever really understood before what my son’s life is going to be like. In a couple of years I’m going to have
to teach him how to use a white cane and I just wanted to say thanks for giving me this experience.’ (Stakeholder interview St 4. 11th October 2013).

This scenario demonstrates the impact of the experience of using a white cane on the father of a vision-impaired child. The comment also illustrates that the father, who worked in the disability sector, did not know that there was already a rudimentary service in Dili for people with vision impairments, indicating a lack of effective communication between various service providers in Dili.

People with disabilities in the role of disability advocates can send strong and effective messengers of empowerment by being role models for others with disabilities, by pressing home the human side of disability and making clear the barriers to participation, by actively lobbying for equity of access and the means to achieve this. Discussion of the influence of DPOs has been noted in other countries such as Indonesia (Strachan, 2014), in Korea (Kim, 2010), in Africa (Mirza, 2011), in Turkey (Bezmez & Yardımcı, 2010) and Israel (Rimmerman & Herr, 2004) amongst others.

9.3.5 **Using a model of lived experience of physical disability.**

I will now briefly sketch the potential place of the model of lived experience of physical disability and its place beside the medical model and the social models of disability. The medical model is the basis on which to collect data regarding people with disabilities, the resulting actions available from this data would relate to disease or impairment, perhaps followed by individual treatments and therapies or broad scale health promotion activities. This is being undertaken in Timor Leste and is an important part of improving health outcomes, for example, in tuberculosis treatment and in the improvement of child and maternal health. However, this individualist focus does not include social factors such as the readiness of support by families for people with disabilities. If the social model were the basis of changing the lives of people with disabilities, the focus would be on investigating the
social constructions of disability and the barriers imposed by social constructions. Examples would include the built environment, public transport and societal attitudes to people with disabilities. The built environment, transport systems and societal attitudes pose significant barriers, as could be seen in the research; however, all disabilities are different and individual personal or cultural variations in experiences do not inform this model.

By comparison, investigation into barriers to participation using the model of lived experience of disability would start with experiences of those concerned, specifically the barriers and enablers, the effects of poverty and other cultural and contextual factors.

Take for example, a hypothetical investigation into the transport options for adults with mobility limitations living in the remote district of Oecusse enclave. This is a very poor district and transport is relatively inexpensive however, the hypothetical individual has unique barriers, for example, physical access to the bus-stop from the individual’s home needs to be managed. Frequently an ojet (taxi motor-bike) has to be used for destinations outside the mini-bus routes, although this requires extra payment. A cultural factor may be that people in the mini-bus may be unhelpful to a struggling individual, causing embarrassment and distress; so a family member needs to travel together with the person to provide reassurance and to help manage transfers in and out of the mini-bus and subsequently, a person with disabilities from a poor family will be exhausted by such a complex journey.

Barriers and enablers such as these together with the influences of poverty and cultural and contextual details will be revealed when using the model of lived experience. The consequences of difficulties may also be revealed, for example transport difficulties and expense may be the reason that the individual chooses not to travel by public transport more than absolutely necessary and as a result, needs to use home remedies which are not always effective and which could result in harmful side-effects and co morbidities.
Quality of life is all-important when considering lived experience. Research on quality of life provides insights, based on data from Western countries, showing evidence that the severity of impairment does not match with the degree that quality of life is reduced (Hammell, 2004). Research shows that there are other causes for reduced quality of life: physical aspects of disability such as pain, fatigue, accompanying illness or infections; social aspects such as lack of contact with others; environmental barriers and discrimination and lack of agency (Hammell, 2015). Quality of life may be enhanced by family relationships, which can be seen as enablers in the model of lived experience. Barriers to a satisfying quality of life will be found if people are unable to get medical help, if they are unable to move around in their own environment, if there are few or no transport options, and if their needs, wants or opinions are unsought or disregarded. Investigation based on the model of lived experience of disability linking barriers, enablers, the contextual factors and poverty can reveal insights into quality of life which would be found with further research.

The model can also indicate how changing one aspect of the model can influence the other aspects. For example the participants with disabilities living in Dili had attained a level of mobility which was physically impossible in the past. The three-wheeled motorbikes provided by their work-place meant that a major barrier to participation was had been removed and thus the effects of having capacity to earn an income and remove poverty, dramatically improved mobility. These participants had full employment, they had education, they had intrinsic factors such as personal drive and they had many more opportunities than those living in remote districts such as Oecusse enclave.

9.4 Limitations of the Research

There are limitations when undertaking a new approach to research in a new setting. Firstly, the use of convenience sampling meant that the participants were all beneficiaries of aid, as they were known to the two NGOs who provided contacts for the research. This meant
that there was no-one who was *not* a beneficiary of aid; and this omission probably excluded some responses to living with disabilities. There are difficulties approaching people with disabilities in cross-cultural research, especially where disability includes intellectual and cognitive disabilities. The researcher’s influence may be considerable and a skilled and trusted gatekeeper and interpreter is needed. For this reason, the data from the participants reported in Chapter Eight is especially significant, as the influence from direct contact with the foreign researcher was minimised. Convenience sampling also resulted in the predominance of male participants, and has been discussed above, and this reflected the culturally embedded lack of opportunities of engagement with women.

The number of participants, 29 people in total, including stakeholders, appears small, however, phenomenology seeks data which is generalisable. In this research, data saturation was reached as described in Chapter Five, producing themes from which to construct the proposed model of lived experience of physical disability. A researcher with a different background, visiting different participants with different disabilities in Timor Leste may obtain different, but associated and generalisable themes when analysing the data and this would provide a further set of lived experiences of physical disability. The task of the researcher would be to link the different sets of data and broaden the understandings of lived experience, rather than negating it.

This research did not include people whose impairments came primarily from mental illness or from epilepsy. In Timor Leste people with epilepsy come under the umbrella of the mental health services and little research has been done on the experiences of people with mental illness or epilepsy in Timor Leste. Thus mental illness and epilepsy as well as children under the age of eighteen were all outside the scope of this research.
9.5 Future Research Possibilities

This study of the lived experience of physical disability in Timor Leste was the first of its kind undertaken in Timor Leste and the study presents an array of possibilities for further research for the occupational therapist.

Investigation of the lived experience of physical disability can be deepened by further investigation into whether a person is actually ‘able to do the things she or he would value doing, and whether their circumstances actually allow them to do what they would like to do’ (Hammell, 2015 p 82) based on the capabilities approach put forward by Amartya Sen (see section 2.2.3). The importance of deeper investigation can be seen when noting that the ICF does not consider subjective experience of disability when addressing the individuals potential for participation (Hemmingsson & Jonsson, 2005; Perenboom & Chorus, 2003) (see Section 2.3.1) and it overlooks any consideration of the impact of an individual’s family (Trani et al., 2009). In contrast, the capabilities approach considers whether the individual has the freedoms and opportunities to choose what she or he wishes to do or be (Sen, 1999). Moreover the capabilities approach offers a framework by which to understand the impact of poverty beyond a basic understandings simply linking poverty with income, by considering poverty as ‘capability deprivation’ (Sen, 1992 p 15). The capability approach can provide a framework for thinking about well-being and quality of life in the context of bodily impairments to inform the occupational therapist or occupational therapy researcher seeking a deeper understanding of disability in the context of a developing country.

Other areas for consideration include:

- Within an occupational therapy setting, research is needed to learn how best to promote the capabilities of an individual, to allow him or her to capitalise on his or her strengths and to manage impairments within the local culture and context.
A deeper investigation into explanatory models of health, illness and disability would provide valuable information for disability, chronic disease management and health promotion within Timor Leste.

Further research is also needed to understand the experiences of women with disabilities in Timor Leste, to identify what partnerships are needed to achieve gender balance in services for women with disabilities.

In-depth discussion of discrepancies in power and control within Timorese society is an important part of discussion of the lives of people with disabilities however this focus is beyond the scope of this thesis.

Research is needed on how to assess violence in the home and how to safely help people with disabilities, especially women, to avoid violence.

Inclusion of people with disabilities in disaster relief has only just begun to be addressed in Timor Leste. Better understanding of inclusivity and disaster relief is needed together with how best to give the DPO effective tools to participate in disaster planning.

Participatory research has the potential to add value for both the researcher and the participants. The research using photovoice demonstrated the power of the method as a participatory tool. Photovoice has the potential for transformational change (Nolas, 2011) making participatory research a method of choice, where relevant, where qualitative data is sought.

Finally the model of the lived experience of physical disability will provide a framework from which to investigate the lived experience of physical disability in other contexts.
9.6 Summary

This chapter looked at some of the details of the research: the value of photovoice in phenomenology, some considerations regarding display of the photographs and some complications regarding expectations from research. This was followed by an examination of a model of lived experience of physical disability in Timor. Limitations of this research project were discussed and recommendations for further research were put forward.

The following chapter, Chapter Ten is the first part of the final section of the thesis, where I outline implications for policy and practice. This is a book chapter in press, to be published in 2016. The chapter describes some aspects of my work in Timor Leste and makes use of vignettes to explain specific practical approaches to working in Timor Leste and other cultures in developing countries. Chapter Eleven is the conclusion of the thesis with more detail about implications for policy and practice.
Chapter Ten: Implications for Policy and Practice

People with disabilities in East Timor: some considerations for occupational therapy practice in developing countries

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This chapter is a book chapter, Chapter 49, in Occupational Therapy without Borders which will be published in 2016. The book chapter describes vignettes of cross-cultural practice to illustrate particular skills which an occupational therapist needs in a cross-cultural practice setting in a developing country such as Timor Leste.
Chapter Ten

People with disabilities in East Timor: Some considerations for occupational therapy practice in developing countries

10.1 Introduction

Globalization and ease of travel inspire an increasing number of occupational therapists (Humbert et al., 2011) and occupational therapy students (Humbert et al., 2012) to work or volunteer in other countries, including developing countries. Occupational therapists are learning that activities of daily living may vary from culture to culture and even from household to household, depending on levels of poverty, resources available, and in the instance of disability, the capabilities of the individual and family. However, occupational therapists almost exclusively absorb their professional knowledge from models which arose within Western societies (Whiteford & Wilcock, 2000, Iwama, 2007). Theories of disability and occupation are generally developed in Western settings (Grech, 2009, Barnes and Sheldon, 2010) while the remaining 83% of the world’s population, live in environments where beliefs and constructs, and connection with occupation and the practice of daily life may be significantly different from people in Western societies (Hammell, 2011).

In this chapter I describe some of my experiences as an Australian occupational therapist working and researching in the cross-cultural setting of East Timor. I worked in East Timor intermittently as an occupational therapist between 2000 and 2008 and since that time I have been undertaking doctoral research on the ‘lived experience of physical disability in East Timor’. In this chapter I describe some of the challenges of cross-cultural practice, using the voices of East Timorese people with disabilities to illustrate some of the points. The aim of this chapter is to discuss:

- The importance of a community centred approach.
- The role of the occupational therapist in Community Based Rehabilitation (CBR).
- The importance of taking time to begin to understand the new culture.
- Considerations with translation and language.
- Some considerations regarding personal safety.

10.2 Background

East Timor is a small and recently independent Asian country accessible from Australia by plane on a one-hour flight from Australia’s main northern city, Darwin. Here the dilemmas of cross-cultural practice are experienced by the occasional occupational therapist and by aid workers on a daily basis.

East Timor was a colony of Portugal for approximately 400 years. However, in 1975 the colonial period ended with a few months of independence, followed by annexation and a 26-year occupation by Indonesia. During that time reports filtered through of the suppression of local resistance organisations (Molnar, 2010) including the deaths of five Australian journalists attempting to report on these and other human rights violations (O’Shaughnessy, 2000).

In August 1999 a referendum was held by the Indonesian administration in East Timor in which 78% of the population chose independence from Indonesia. In the lead up to the vote and within hours after the announcement of the results, paramilitary forces began attacking civilians in and around the capital city, Dili. United Nations (UN) observers fled and many Timorese families escaped to the mountains. A systematic destruction of property and infrastructure was carried out until the arrival of UN forces in September 1999. The militia activity reduced over the next few months under the administration of the International Force for East Timor (INTERFET). However, by the time peace returned, most of the country’s infrastructure and many public and private buildings were destroyed.
I first visited the country as a young traveller in 1972. At that time it was a colony of Portugal and I stayed with a Timorese family who had a child with multiple disabilities. My interest in East Timor remained during the Indonesian occupation and I returned as an occupational therapist and humanitarian volunteer in early 2000. Since 2000 I have been involved in several projects, staying up to four months at a time and working with people with disabilities.

**10.2.1 East Timor since 2000.**

There is a hint of the complexity of the small country of East Timor in the following speech by Xanana Gusmão, Prime Minister of East Timor 2002 – 2007.

‘Both the catholic faith and the Portuguese language took up roots in our existence, assuming more visible presence during the period of the Indonesian occupation and becoming an important instrument for the Timorese resistance.

It was from this meeting of cultures and civilisations that our small half-island, with an enclave inside the other half, within an archipelago composed of over 14 thousand small and large islands of Indonesia that our Country, Timor-Leste, affirmed itself as a People.’ (Gusmão 2014. P 3)

I wanted to know what happened to the family who had hosted me in earlier years. I returned to Dili in 2000 to find a town unlit at night, with the burnt out shells of shops and businesses and the streets full of rubble. As an occupational therapist and humanitarian volunteer I felt almost out of my depth in the small medical clinic where I was volunteering. With the help of interpreters I listened for hours to family members describing how they lived their lives and managed at home with whatever barriers they were experiencing while trying to regain a normal life.
Alita’s (pseudonyms are used throughout the chapter) story was an example from that time.

**Text box #1 story of Alita**

Alita was a young woman determined to go to her newly restored school despite her diagnosis of tuberculosis. Her difficulties arose firstly, from fatigue and secondly, from lack of furniture in the classroom. All the girls in Alita’s class carried a stool from home each day as the school chairs had all disappeared, and any new chairs brought into the classroom also disappeared overnight. Alita was not strong enough to carry a stool to and from the school. My occupational therapy intervention with Alita and her mother was simply to explore strategies to manage fatigue together with options for getting a stool to and from the school; I was surprised that this simple discussion seemed to be helpful. I concluded that the recent trauma made lateral thinking and problem-solving difficult for Alita and her mother.

10.2.2 **Disability in East Timor.**

Forty-one percent of people in East Timor live below the poverty line and there is a ‘hungry season’ each year as a result of traditional cropping practices worsened by erratic rainfall (Barnett, Dessai, & Jones, 2007). Services for people with disabilities have gradually developed in recent years but are mostly limited to the capital city. Families generally love and care for a disabled family member but that is the limit of everyone’s’ expectations. During 2012 and 2013 a research project entitled ‘the lived experience of physical disability in East Timor’ was an opportunity to investigate the barriers faced by people with disabilities. For example there is a common assumption in East Timor that the disabled person will never get married, work or contribute to society, and thus normal occupations are out of reach.
Sylviana was ambitious but frequently experienced a lack of support in her quest for an education:

‘The people said to me, you have no life, you are disabled, why do you go to school, why do you want that, when you finish school what can you become?’

(Sylviana, September 2013)

For those who managed to get an education there were problems with employment:

‘After school graduated I just tried to seek opportunity to work … I tried many times but I could not pass … I tried to apply to technical school but they have the criteria that they will not allow people with physical disability to apply’ (Mauricio, September 2013).

Disability is a strong predictor for the presence of physical or sexual abuse throughout the world, in resource-poor and resource-rich settings. At times during my work in East Timor I sought advice from a local non-government organisation (NGO) which specialised in trauma and abuse. If I suspected abuse, the NGO staff were helpful, offering reassurance that my concerns were valid and promising to visit the family and attempt to understand if the person about whom I had concerns was at risk.

10.3 Cross-cultural Considerations for Occupational Therapy Practice

Occupational therapists have at times insisted that patients and clients fit to Western cultural norms rather than occupational therapists seeking to understand how clients and patients live and experience their own worlds (Iwama, 2007). The ‘cultural safety’ approach to cross-cultural work has been developed to help occupational therapists understand how power relationships may affect client and patient outcomes (Thomas et al., 2011, Nelson, 2007). When planning a new occupational therapy service in the United Arab Emirates (UAE) Awaad identified a range of influences on cross-cultural practice; for example that
Culture is dynamic and may be different in different family contexts, that the practitioner needs to consider details such as modes of address and conversational etiquette, body language, personal space, the amount of information that individuals are willing to divulge and the effects of family members as interpreters (Awaad, 2003). For those planning to practice occupational therapy in communities with a colonial past, a questioning of power relating to Western ethnocentric assumptions is needed (Smith, 1999). Together with these considerations, occupational therapists need to consider their own beliefs stemming from their own ethnic background, religion, class, gender, relative or perceived wealth and age (McGoldrick and Hardy, 2008; Mullings, 1999).

In isolated communities the arrival of a foreigner can be an interesting and public spectacle. When visiting remote communities, I often met with people with disabilities together with family and neighbours present, making privacy impossible and putting pressure on those being interviewed. East Timor has a hierarchical society and people with disabilities are placed towards the lower end of the ladder. When I met people with disabilities together with their family, especially in a remote setting, the discussion at times appeared difficult and uncomfortable. I assumed that someone with disabilities might be unused to being the focus of attention in a meeting with a foreigner like myself, or perhaps people were wary in front of an outsider, like myself.

10.3.1 Language.

Over twenty languages are used in East Timor including many local languages. Tetum (an indigenous language) and Portuguese are the national languages while English and Indonesian are classed in the constitution as working languages. School children now learn Portuguese, together with their Timorese teachers. Most people in and around Dili and in most of the districts of Timor can speak Tetum and around Dili Tetum is sprinkled with
Portuguese words. English is used in foreign aid workplaces in Dili but is little understood away from the capital.

Translation and understanding in cross-cultural practice is also much more than simply word-for-word transmission of language (Temple and Young, 2004). Although Tetum is the most commonly used language, words from English, Indonesian and Portuguese are often used to manage communication about contemporary matters such as computers, the processes in planning health projects or in trade and business. Skilled interpreters need time to gain familiarity with specific professional terminology. When using interpreters, I found that the concerns of the occupational therapist such as the details of daily life appeared so insignificant that at times the interpreters felt that they could save time and answer such basic questions for the person being interviewed. I had to explain that as a foreigner I did not know these details. For example, I needed to know how the person gets to the bathroom, is it near the house and is it necessary to crawl in the dirt, and I really wanted to hear directly from people how they managed at home.

Temple and Young (2004) extend their concerns regarding power in cross-cultural communication to those who do not speak the dominant language in a country. Interpreting is also much more than transmission of information through an interpreter. The interpreter has agency, may feel aligned with either the therapist or the interviewee, is embedded in a particular culture and is a member of a more, or less dominant social group (Angelelli, 2004). When working with interpreters I made use of some or all of the following strategies:

- I consulted with a cultural mentor prior to visiting a remote district to check if I could safely ask my planned questions.
- At times I engaged my interpreter in a role play to ensure that he/she understood my questions and to get any other relevant feed-back.
• As I seldom had a female interpreter I first asked advice of a female cultural mentor about how I could approach a woman or women with a male interpreter.

• I found that laughter, at times related to cultural differences, was a way to develop relationships and keep a fresh focus on the work at hand.

10.4 The CBR Training in East Timor 2006 – 2007

I was involved in planning the first CBR training programme funded by Australian foreign aid in East Timor (2006 – 2007) together with two Australian physiotherapists. There were no locally trained allied health professionals in East Timor at the time and we felt that Timorese trained in CBR would be able to start to provide basic services in local communities with a CBR grass-roots approach. Twenty-five people started the training and most were either school-leavers or local health workers wanting to add to their skill-base.

‘Community-based rehabilitation (CBR) focuses on enhancing the quality of life for people with disabilities and their families; meeting basic needs; and ensuring inclusion and participation. It is a multi-sectoral strategy that empowers persons with disabilities to access and benefit from education, employment, health and social services. CBR is implemented through the combined efforts of people with disabilities, their families and communities, and relevant government and non-government health, education, vocational, social and other services’. (WHO Introduction. Date unknown, no page)

CBR is a term covering a range of programmes based on principles of health promotion which include enablement, social justice, importance of a meaningful lifestyle and respect for cultural difference (Fransen, 2005). In East Timor we used the CAHD tool-kit (Community Approaches to Handicap in Development) described in Disability in Development (2006) as the basis for the training programme. We made changes to ensure
that the training was culturally specific to East Timor, for example by describing typical Timorese life and families when discussing a case study. The tool-kit provided outlines of teaching modules such as basic anatomy, basic communication skills, and safe feeding techniques for people with severe disabilities, interviewing skills and assessment skills, among many other topics. The training program was designed to run for a year based on one week of classroom activity per month followed by a period of supervised practical work. The story of Fatima illustrates some of the difficulties in the life of a person with disabilities as well as some dilemmas of cross-cultural practice.

| Text box #2 Story of Fatima |

Amando was a trainee CBR worker and I was Amando’s supervisor. Amando was expected to undertake home visits and carry out simple interventions as a part of his field-work between modules of the CBR training program.

We visited Fatima and her mother about two weeks after they were discharged from the residential facility. Fatima was a very small, eight year old child with a large head and stick-thin arms and legs who had previously arrived in the residential facility with her mother. She demonstrated developmental delay, general weakness, contractures and malnutrition. They both lived in a hut at the edge of her community as her mother was ostracised by the community for having a disabled child. Fatima was so malnourished that her mother could easily carry her inside the home although she was too heavy to carry to the distant garden where her mother worked, growing a few vegetables to eat or to sell; for much of her day Fatima was at home, alone and immobile. They stayed together at the rehabilitation centre for three weeks and during that time Fatima’s smile broadened every day as she and her mother ate plenty of nutritious food and for the first time Fatima played with toys. She listened to music and had others around her to communicate with.
Fatima and her mother eventually returned to their hut at the edge of the village. At the time of our home visit Fatima’s mother reported that initially she could no longer carry Fatima around because of her weight gain however, Fatima had since lost that weight. Both were further ostracised by the community for having received help and extra food. They returned to the rehabilitation centre for further problem-solving within the CBR programme, this time by finding ways for Fatima’s mother to better connect to her community and by starting a process of increasing community understanding of disability and community advocacy. The importance of community engagement could clearly be seen in this instance.

An evaluation of the training programme carried out during 2008 revealed positive results together with some difficulties. While the CBR workers were contributing to the general welfare and occupational engagement of their clients, the role of the CBR worker was not easy. For example, many felt isolated after the training ended due to the departure of the expatriate trainers (Shamrock, 2009).

10.4.1 Personal safety.

Towards the middle of 2006, during the first three months of the CBR training, tension began to develop in Dili as a faction of the army representing mostly personnel from the west of the country complained of discriminatory practices relating to salaries. Many of this group deserted the army taking with them a quantity of weapons and gathered in a remote rural centre. On their return to Dili there were armed clashes which resulted in at least five deaths. Unemployed youth joined the fighting around the centre of the town and markets and at times houses of those suspected of hiding the opposition or opposition sympathisers were set on fire. By the end of May homes were frequently burnt and shooting in the main marketplaces became commonplace. Trainees and trainers were fearful and preoccupied and the CBR training temporarily closed. By early June many Timorese had fled and many were housed in Internally Displaced Persons (IDP) camps and most expatriates were evacuated.
For a few weeks fighting was commonplace in and around Dili and near to the rehabilitation facility where I lived together with two other foreigners and some of the CBR trainees. Timorese who had been traumatised in the past during the Indonesian occupation were quickly fearful again. As foreigners we were unsure whether we would be targets in the general atmosphere of fear and distrust, or would we simply be ignored in an internal conflict. Timorese either stayed indoors or fled into the neighbouring hills.

The rehabilitation facility had an intermittent phone service. This was the only phone in the local district and people came into the facility hoping to be able to make phone calls to trace missing family members. The phone was located in a central community room and some people remained in the room gathering comfort from the presence of others. I saw the fear and general distress of the people who came to the community room and found a large jigsaw puzzle to spread on the dining table. The puzzle provided a simple distracting leisure activity, and invited communication between people without requiring concentration or complex problem solving. I also observed the power of play for the children who lived in the facility. They were frightened by the gunfire and a small group of children were gathered together by one of the volunteers. She and the children found that fear was easier to manage with activity which reflected the source of their fear. While the guns sounded in the distance, the children marched around the compound with imaginary guns, shouting words of songs or nonsense words, or counting out loud, anything to make a noise and to be active.

Specialised training programmes conducted by NGOs are available in Australia for people going to work in dangerous environments. Participants can learn strategies for managing personal safety such as making preparations for emergency departure, strategies for survival as a hostage or when threatened physically. An occupational therapist planning to work in a dangerous developing country may be offered training in personal security. Even when specific training is not necessary, an awareness of personal security is advisable for
those working in a new culture. For example, both men and women may find that dress considered suitable by the locals will help reduce cultural gaps and promote a collegiate relationship. Details of what constitutes suitable dress can be discussed with a cultural mentor.

10.5 Occupational Therapy and the DPO (Disabled Peoples Organisation)

Disabled Peoples Organisations (DPO) are those where 51% of the board members are people with disabilities. DPOs are involved in activities such as self-help and self-advocacy groups and provide advice at local and national levels as well as in the United Nations (Hurst, 2003). The DPO in East Timor has been involved in practical projects such water, health and sanitation (WASH) projects (See INCLUSIVEWASH 2011) and I found that my relationship with DPO members enriched my understanding of disability in East Timor. DPO members were usually people with disabilities who were articulate; for example they could describe the experiences of stigma, exclusion, and problems with mobility common to most disabled East Timorese. They also considered themselves as role models for people with disabilities in rural areas where traditional attitudes and stigma were more common.

In East Timor the movement had a very modest beginning in 2006 with a sole representative sitting in committee meetings when the CBR training was being discussed. By 2013 the DPO had representatives in all the districts of East Timor and consisted of approximately fourteen staff, most of whom had disabilities themselves. It was a difficult transition for some members who experienced stigma in the past to actively advocate for others, and themselves:

‘... so at the start I’m very shy, I’m a little ashamed ... working with this organisation, when I look at myself it seems like shame. I am disabled and it feels like that I am going to talk about myself’ (Jacinto, October 2013)
Some of the DPO members were trained in group facilitation techniques to train staff in government and non-government organisations about disability rights and barriers, in line with the National Disability Policy. Augustina’s story illustrates some of the common experiences of members of the DPO in East Timor including interrupted education, stigma and exclusion which she manages in her work while rapidly learning new ideas from her expatriate mentors.

Text box #3 Story of Augustina

Augustina is a small attractive woman who walks confidently supporting her shortened leg with one hand while holding a stick in the other. She is unusual as she was always encouraged and supported by her family. She is now a powerful member of the DPO in Timor and uses a three-wheeled motorbike to move around Dili:

‘Sometime they say that the people with the disability can’t do anything. And they can just stay at and home and they can just … eat and sleep. I just say it’s true, but you can see my condition and you can make an example from me … I can teach you and I can drive the motorbike. You can look at me’. (Augustina, September 2013.

Augustina completed her high-school education although she missed a lot of school time during the Indonesian occupation of Timor when schools were closed or barely functioning, and she now works with a disability organisation. She is attending university part time and she plans to get married eventually and have children. She is a trainer and leader in disability rights and a change agent within her community yet people at times still question her right to these universal roles and occupations.
Augustina has made a powerful difference in her work as an advocate for people with disabilities; she has conducted training sessions with staff from government ministries, giving them blindfolds and canes or crutches to get first-hand experience of mobility problems.

However, Augustina is relatively inexperienced. She left school one year prior to getting her job with the disability NGO so she had to rapidly learn the concepts and processes which are embedded in foreign NGO projects such as needs assessments, consultation with beneficiaries and stakeholders, monitoring and evaluation and report writing. Augustina is still learning all of this on the job. In her consultations with foreign NGOs she needs to explain her culture while having these concepts at her finger-tips. Augustina is courageous and confident, however, women with her level of confidence are uncommon in the conservative society of East Timor. When I worked beside Augustina I had unique insights from the viewpoint of a woman, a person with disabilities and a Timorese.

The occupational therapist can provide professional knowledge to community health workers on issues such as childhood milestones, and facilitate development of specific skills such as how to do a home assessment. When learning is linked to the local context by a person with a disability the message is much more potent. Augustina manages many barriers and she can explain to others, such as visiting occupational therapists, what these barriers are and how they affect her life.

**Conclusion**

In this chapter I described some of the challenges in cross-cultural practice in East Timor and some of the strategies used to address these challenges. Occupational therapists are well positioned to work with these challenges especially when including:

- A community centred approach.
• Taking time to understand the new culture and in particular the origins of barriers to participation.
• A relationship with one or more people as cultural mentors.
• Time to develop a good working relationship with interpreters.
• Being thoughtful regarding personal safety and personal presentation.

Working in a context one is not familiar with is a complex process and the occupational therapist must take time to meet people, listen to stories, ask naïve questions, study the local language, understand the place of humour and consider the acceptable speed of change. In this way occupational therapists can make positive contributions to that change.

10.6 Acknowledgements

I would like to thank Natalie Smith and the Leprosy Mission of East Timor (TLMTL) for their wholehearted and generous support of my recent work and research in East Timor.

10.7 References


DISABILITY IN DEVELOPMENT, 2006. viewed 26th February 2015.


INCLUSIVEWASH, 2011.


10.8 Key Points

- The occupational therapist needs to have a community centred approach and to engage relevant community members when working with people with disabilities.
- The occupational therapist needs to take time to understand the new culture and in particular the origins of barriers to participation.
- A relationship with one or more people as cultural mentors to ask advice to help understand circumstances which initially appear to be complex.
- The occupational therapist needs to take time to develop a good working relationship with interpreters.
- Being thoughtful regarding personal safety and personal presentation.

10.9 Summary and Conclusions

This chapter is chapter 49 in the book, Occupational Therapy without Borders and it is the first part of the section in the thesis entitled Implications for Policy and Practice.
The following chapter, Chapter Eleven is the final section of the Implications for Policy and Practice section, and is therefore the final chapter of the thesis. In this section I summarise the work and put forward the implications for policy and practice which are the result of the study.
Chapter Eleven: Implications for Policy and Practice and Significance of the Research

Key to the thesis

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<thead>
<tr>
<th>Chapter</th>
<th>Description</th>
<th>Article</th>
</tr>
</thead>
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<tr>
<td>1. Introduction</td>
<td>Background</td>
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<td>Relevant literature</td>
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<td>3. Literature review</td>
<td>Article, metasynthesis</td>
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<td>4. Methodology</td>
<td>Methodology, research framework</td>
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<td>5. Methods</td>
<td>Research method, research details</td>
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<td>Study #1. Pilot study</td>
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<td>11. Implications for practice</td>
<td>Implications for practice</td>
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<tr>
<td>Appendix</td>
<td>Descriptive article</td>
<td>Published</td>
</tr>
</tbody>
</table>

The previous chapter, Chapter Ten, was the first part of the final section, Implications for Policy and Practice. Chapter Eleven constitutes the second part of this section. In this chapter I examine the practical value of the research as it relates developing policy and occupational therapy practice where people with disabilities are involved in Timor Leste.

**11.1 Summary of the Research**

This research evolved from my long term association with people with disabilities in Timor Leste and my overall aim was to understand disability with more depth and detail than
the data provided by population-based research. It is anticipated that the research will (a) clarify guidelines for therapy and practice and (b) will help inform policy development and its implementation where people with disabilities are concerned.

In Chapter Nine, a model was put forward on the lived experience of physical disability, based on the research findings. The model acknowledges that people with disabilities constantly experience barriers and enablers to participation; barriers and enablers are positioned within local culture and context, and poverty is seen as the overarching factor penetrating the other sections of the model.

![Proposed model of the lived experience of physical disability in Timor Leste](image)

*Figure 14. Proposed model of the lived experience of physical disability in Timor Leste.*

The four sectors of the model of lived experience of disability have been described in Chapter Nine and the diagram representing the proposed model can be seen above.

11.2 Implications for Policy.

There is already a national policy for inclusion and promotion of the rights of people with disabilities in Timor Leste. The constitution of the Democratic Republic of Timor-Leste states that ‘the disabled citizen have the same rights and are subject to the duties of other citizens, and that no citizen can be discriminated against on the grounds of physical or mental condition, as provided in paragraph. 1 of article 21 and paragraph 2 of Article 16’ (‘Constitution of the Democratic Republic of Timor-Leste,’ 2002). Implementation of the
rights of people with disabilities under the constitution is being undertaken in some parts of the National agenda and in some NGOs in Timor Leste. The CBM-Nossal Institute Partnership for Disability Inclusive Development reported on the Disability Advocacy Project which was being led by the Timorese Disabled Persons Organisation or DPO, (RHTO National Disability Awareness Project, 2014) and noted that the DPO was making an impact on shaping government policy as well as directing the government to ratify the UN Convention on the Rights of Persons with Disabilities (UNCRPD).

The findings from my research on the lived experience of physical disability in Timor Leste supported the findings in the report from the Nossal Institute on the effectiveness of people with disabilities working at the level of policy implementation. I saw the results of the activities of the Timorese DPO, (Ra’es Hadomi Timor Oan), from the point of view of those in the DPO, as well as beneficiaries. Based on these findings, key principles for developing and implementing policy are outlined below:

11.2.1 **Key principles for policy development and implementation.**

*People with disabilities continue to work at the level of policy planning and implementation.* People with disabilities are needed to continue to work at the level of developing inclusive policies and policy implementation. The DPO members have successfully undertaken projects such as the Disability Advocacy Project and their continued engagement in similar work will allow inclusive practice to continue to evolve in Timor Leste. Engagement at the level of policy planning and implementation requires skill and confidence and DPO members need on-going support to develop sufficient skills and capacity to progress with this approach to continue to deliver strong messages to policy-makers.

*Public visibility of people with disabilities.* Policies which promote visibility of people with disabilities engaging in public events such as sports or recognition of achievements in fields such as the arts, education or business will help demonstrate to the population at large
that people with disabilities have the same human attributes and needs as other East Timorese, and some can excel at their chosen field of endeavour.

_Poverty mitigation programmes need to have strong inclusive focus._ As poverty is the overarching factor which results in barriers for people with disabilities in developing country, such as Timor Leste, all programmes designed to address poverty must ensure that people with disabilities can participate in such programmes at the planning and implementation levels, by ensuring equity of physical access and information.

_Disaster-preparedness needs to cater for both permanent and short-term impairment._ The constitution of Timor Leste identifies the importance of acknowledging people with ‘special needs’. However, all people experience periods of impairment, such as periods of injury, pregnancy, aging, or cognitive impairment from alcohol consumption, amongst others (Fjord & Manderson, 2009). Disaster preparedness along the lines of equity, participation, capability and resilience (Rushford & Thomas, 2015), developed to accommodate people with impairments as well as the ‘able-bodied’ will ensure that more people are able to successfully participate in disaster preparation, disaster management, recovery and evaluation.

### 11.3 Implications for Practice

Those whose professional practice involves people with disabilities, such as occupational therapists, will be able to practice more effectively and in a culturally appropriate manner, if they consider the following aspects of the lives of those they encounter in their practice:

_Poverty:_ The diagram above (figure 21), representing the research findings, demonstrates the barriers imposed on people with disabilities by poverty in developing countries including Timor Leste. Many possible scenarios may be the result of coming from impoverished circumstances, for example, a person with disabilities attending a rehabilitation program...
centre or receiving therapy in the home may be seen to be in touch with a different and apparently wealthier world and this may cause difficulties when the individual returns home. Others in a community may become resentful that a person with disabilities is receiving attention and benefits that are not available to the able-bodied in the community such as assistance with transport or different food. Sensitivity to the effects of poverty are needed and can be discussed with the person concerned or with a cultural mentor.

Potential for violence: Family violence is a feature of family life for many families in Timor Leste, although it is not readily spoken about. People with disabilities are generally the lowest ranking in families and communities and may be the recipients of family violence, and the practitioner will need to ask the advice of a cultural mentor if this occurs. There are NGOs in Timor Leste which provide services for those encountering violence, especially gendered violence, as described above, however, violence needs to be addressed with care so that the person with disabilities in not put at further risk by an intervention.

Key relationships: Another consideration in practice is acknowledging significant others in the life of a person with disabilities. Especially in rural areas, families are strong units and other family members contribute to the well-being of a person with disabilities. The practitioner may need to initially contact the head of the family, as well as the community leader. By contacting these people the practitioner can introduce messages of disability rights where necessary. Contact with the extended family may also help with investigation of cultural explanations of health, illness and disability.

Cultural explanations: Cultural explanations of health, illness and disability are important, and may be difficult to identify. However, cultural explanations can be included as tools for health promotion messages and can be incorporated into interventions with people with disabilities. For example, people living with disabilities at home may be living with a
co-morbidity which is not being managed effectively, such as pressure sores being treated by an ineffectual traditional treatment, where a person has a spinal injury. Understanding the cultural explanations may help the individual seek more effective help and thus improve participation by improving general health.

*Mentoring:* Carefully mentoring and supporting people as they overcome deeply entrenched barriers in their culture can be a powerful intervention. Mentoring should involve connecting people with disabilities with the DPO where members have disabilities themselves, to help overcome ‘shyness’ and reluctance to participate. DPO members can encourage engagement in networks such as the DPO itself, as well as appropriate inclusive networks such as income generation programmes. Where possible, others with disabilities can be involved in helping people with disabilities undertake new learning, such as learning to use mobility aids, applying for the small disability benefit to which people with significant disabilities are entitled, and problem solving and making the home more accessible.

*Disability networks:* The practitioner needs to be aware of the existence of appropriate networks for people with disabilities and encourage engagement in such networks. The practitioner in Timor Leste should actively support the DPO because of the DPO’s key part in engaging other sectors of society by promoting equality and reducing stigma at many levels.

### 11.4 Conclusions and the Significance of this Research

The aim of the research was to explore the lived experience of people with physical disabilities in Timor Leste. I wanted to develop a body of knowledge to inform scholars, policy makers and practitioners, especially occupational therapists and I wanted to do this by engaging people with disabilities in the research process as active participants.

The research was undertaken using participant photography in the form of photovoice which resulted in rich detail of the lives of a range of people with disabilities living in Timor
Leste. The research is significant in that it is the only research to date on lived experience of physical disability in Timor Leste and is a part of a very small body of knowledge, as identified in the meta-synthesis in Chapter Three, of lived experience of disability in any country in East or Southeast Asia. The research therefore provides an understanding of the experiences of living with physical disabilities in the region and identifies some or the factors, cultural and otherwise, which are enmeshed in those experiences.

The research highlighted the importance of family and community and the importance of people with disabilities engaging in valued roles. The method of data collection provided vignettes showing how individuals with disabilities undertake their daily routines despite their impairments, it notes the range of experiences of people with disabilities, from extreme isolation and vulnerability to members of the work-force, and it notes the importance of people with disabilities becoming empowered and working with others with disabilities.

The research also suggests that in recent times (2009 to 2014), policies were developed and changes were made to begin to improve the place for people with disabilities in East Timorese society. The corollary is that a positive climate may be difficult to replicate as the priorities of foreign aid change, with a shift to a more business-driven focus, as can be seen in the Sustainable Development Goals discussed in Chapter Two. Nevertheless, the momentum has begun and steps are continuing towards inclusive policies and practices within Timor Leste. The studies which make up this research helped emphasise the importance of people with disabilities being able to have the freedoms to enjoy their lives, to live in a culturally satisfying environment and to realise their potential within Timorese society in an atmosphere of occupational justice. The knowledge from this research has been distilled into a set of implications for policy and implications for practice as can be seen above.
On a more personal note, it has been very satisfying to engage in this research and to hear first-hand, from participants and from those working in the disability sector, of the changes which are under way, especially in Dili. It has been satisfying to see services which were set up by foreign-led NGOs being transferred to Timorese management and it has been satisfying to see the activities of the DPO members, as they learn new skills by which to continue working as advocates to bring more Timorese with disabilities out of the shadows. Timor Leste is a complex society which is changing rapidly and there is still a long way to go before all people with disabilities are free of stigma and disadvantage. However, Timor Leste, despite a difficult recent history, is making progress.

The majority of people with disabilities, in fact 80%, live in countries of the majority world. Despite that, most of the research on lived experience of disability has been undertaken in the minority world, such as in the industrialised countries of Australia, the USA and the UK. There is therefore a lack of information at the personal level, which reflects social and cultural influences on people with disabilities, from developing countries such as Timor Leste. Timor Leste is one of many developing countries in the Asian region, and the value of this research is that the findings and insights into lived experience of physical disability in Timor Leste may be generalisable to other similar cultures, and have the potential to inform policy-makers and practitioners, including occupational therapists, beyond Timor Leste.
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http://dx.doi.org/10.1177/1468794103033004


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### APPENDIX A List of abbreviations

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<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
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<tbody>
<tr>
<td>ADTL</td>
<td>Asosiasaun Defisiensia Timor-Leste (formerly the Disability Working Group until 2013)</td>
</tr>
<tr>
<td>AusAID</td>
<td>Australian Agency for International Development</td>
</tr>
<tr>
<td>CA</td>
<td>Capabilities Approach</td>
</tr>
<tr>
<td>CBPR</td>
<td>Community-based participatory research</td>
</tr>
<tr>
<td>CBR</td>
<td>Community based rehabilitation</td>
</tr>
<tr>
<td>CHCF</td>
<td>Central Human Capabilities Framework</td>
</tr>
<tr>
<td>DALYs</td>
<td>Disability Adjusted Life Years</td>
</tr>
<tr>
<td>DDOP</td>
<td>Disaster and Development Occupational Perspective</td>
</tr>
<tr>
<td>DFAT</td>
<td>Department of Foreign Affairs</td>
</tr>
<tr>
<td>DPO</td>
<td>Disabled Peoples Organisation or Disabled Persons Organisation</td>
</tr>
<tr>
<td>FDTL</td>
<td>Forcas Armadas de Defesa de Timor-Leste (the East Timorese military)</td>
</tr>
<tr>
<td>ICD</td>
<td>International Classification of Diseases</td>
</tr>
<tr>
<td>ICIDH</td>
<td>International Classification of Impairments, Disabilities and Handicaps</td>
</tr>
<tr>
<td>IMF</td>
<td>International Monetary Fund</td>
</tr>
<tr>
<td>INGO</td>
<td>International non-government aid agencies</td>
</tr>
<tr>
<td>ISF</td>
<td>United Nations International Stabilisation Force</td>
</tr>
<tr>
<td>MDG</td>
<td>Millennium Development goals</td>
</tr>
<tr>
<td>NGO</td>
<td>Non-government organisation</td>
</tr>
<tr>
<td>OECD</td>
<td>Organisation for Economic Co-operation and Development</td>
</tr>
<tr>
<td>OFM</td>
<td>Occupational Functioning Model</td>
</tr>
<tr>
<td>PIPP</td>
<td>Perceived Impact of Problem Profile</td>
</tr>
<tr>
<td>Acronym</td>
<td>Full Form</td>
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<tr>
<td>PNTL</td>
<td>Policia Nacional de Timor-Leste (National Police of Timor Leste)</td>
</tr>
<tr>
<td>SDG</td>
<td>Sustainable Development Goals</td>
</tr>
<tr>
<td>RHTO</td>
<td>Ra’es Hadomi Timor Oan (Timorese name for the DPO)</td>
</tr>
<tr>
<td>UN</td>
<td>United Nations</td>
</tr>
<tr>
<td>UNCRPD</td>
<td>United Nations Convention for the Rights of People with Disabilities</td>
</tr>
<tr>
<td>UNDP</td>
<td>United Nations Development Program</td>
</tr>
<tr>
<td>UNTAET</td>
<td>United Nations Transitional Authority of East Timor</td>
</tr>
<tr>
<td>UPIAS</td>
<td>Union of the Physically Impaired Against Segregation</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organisation</td>
</tr>
</tbody>
</table>
APPENDIX B The first interview

(Structure for the first interview)

<table>
<thead>
<tr>
<th>APPENDIX  B</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interview #1. Semi-structured interview for PV participants</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Insert S.P.E.A.K.I.N.G.</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Insert: date time place present</th>
</tr>
</thead>
</table>

**Note:** watch for interjections from family or neighbours, watch interpreter. Interview may need to be adjusted depending on who else is present and participants’ responses to the interview.

**Explanation of the project – questions?**

**Notes about the explanation:**

**Introduction to the interview**

Thank you for making time to speak to me today and for being a part of the study. In this interview I would like to get to know you a little bit and to hear about your family and your life-story. I understand Tetun a little bit but not enough to really understand a conversation and that is why I have the help of an interpreter today. If you do not want to answer a question that is not a problem, please just tell us that you don’t want to answer to the question.

**General background**

I would like to know some background to your story.

This is your home?

How many family members live with you? (which family members?)

What do the family members do each day? (Go to school, work, anyone sick, anyone working away?)

Who lives nearby?

(Ask about any features in the landscape where the interview is being held eg this is your kitchen? Bathroom? Drying corn? Animals, motor-bike etc)

Where is the nearest market:? Do you go to the market?

Where is the church? Do you go to the church?

Do you go to festas? How do you go to festas?

Have you ever been to Dili? How did you get to Dili?

What do you do in a typical day?
<table>
<thead>
<tr>
<th>Question</th>
<th>Answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Where were you born?</td>
<td></td>
</tr>
<tr>
<td>How many siblings?</td>
<td></td>
</tr>
<tr>
<td>What did you like to do as a child?</td>
<td></td>
</tr>
<tr>
<td>Did you go to school? How did you feel about going to (not going to) school</td>
<td></td>
</tr>
<tr>
<td>What did you do in your childhood?</td>
<td></td>
</tr>
<tr>
<td>How did you get to school?</td>
<td></td>
</tr>
<tr>
<td>Can you read/write/use money?</td>
<td></td>
</tr>
<tr>
<td>(If appropriate) ask 1999, 2006, 2008 where did you go? How did you get there?</td>
<td></td>
</tr>
<tr>
<td>What is important to you now in your life?</td>
<td></td>
</tr>
<tr>
<td>What gives you pleasure?</td>
<td></td>
</tr>
<tr>
<td>What is difficult for you?</td>
<td></td>
</tr>
<tr>
<td>What makes you angry?</td>
<td></td>
</tr>
<tr>
<td>As you know I want to learn about how people with disabilities live in Timor Leste? What else about you should I know?</td>
<td></td>
</tr>
<tr>
<td>Is there anything you want to know about me?</td>
<td></td>
</tr>
<tr>
<td>Is there anything else you need to know about the camera project</td>
<td></td>
</tr>
</tbody>
</table>

**Conclusion**

Thank you so much for taking time to talk with me today, I really appreciate hearing your story and learning about your life. I’m sorry I can’t speak Tetun.

*Describe the next stage of the project, and when we will meet again.*

**Expand by asking:**

Please tell me more about that

I don’t understand, that is new for me, please tell me more?

Can you give me another example of that?

Can you please explain further?

Can you tell me another example of when you felt like that?
<table>
<thead>
<tr>
<th>Question</th>
</tr>
</thead>
<tbody>
<tr>
<td>Is that something that you have experienced?</td>
</tr>
<tr>
<td>Is that something that others in your family might think/say?</td>
</tr>
<tr>
<td>Checks with the interpreters:</td>
</tr>
<tr>
<td>Please ask her if she is she/he saying … ?</td>
</tr>
<tr>
<td>Does this mean … ?</td>
</tr>
<tr>
<td>Does she/he agree …?</td>
</tr>
<tr>
<td>Is that all she/he said?</td>
</tr>
<tr>
<td>That was a long response, is that all she/he said?</td>
</tr>
<tr>
<td>What does (an interjector) say?</td>
</tr>
<tr>
<td>Does (the participant) agree (with the interjector)?</td>
</tr>
</tbody>
</table>

Notes:
APPENDIX C The acronym SPEAKING (Hymes, 1974)

Example: Photovoice group 3rd October

SETTING: the group is in the X offices in Dili. We have managed to find a time when most of the staff are out so that it is not too noisy, although the air conditioner and the loud chatter next door make the recording a bit tricky. The room is cramped, full of desks and chairs and the wheelchairs fill up the space. We roughly sit around a central table.

PARTICIPANTS: N… is translating for M… and S… is the main interpreter for the others. S … is field-staff from X office. Also N, V, A, F, E, present as participants.

END – (PURPOSE AND GOALS): Participants to look at each other’s photos and to draw some understanding of the lived experience of disability in Timor Leste during the course of the discussion, to draw some general features of lived experience in Timor Leste, and generally to see where the discussion takes us.

ACT SEQUENCE – (COMMENTS ON THE COURSE OF THE INTERVIEW) everyone arrives and we arrange the furniture. I have copies of all the photographs and put them out on the table. Participants shuffle the photos, then we have the discussion. The meeting closed on time. The participants seemed to find it fatiguing, possibly the concentration involved was unfamiliar.

I found that the participants primarily wanted to talk about their own stories and were not so interested in the others stories. I worked hard to facilitate and to link things up

KEY – (THE OVERALL TONE OR MANNER OF THE EVENT): the event was surprisingly semi-formal, the group was taken quite seriously.

INSTRUMENTALITIES – (FORM AND STYLE, AUDIORECORDING, NOTES TAKEN ETC): N … and S… translated, recorders were running and I also took field-notes.

NORMS – (WHAT IS EXPECTED, CULTURE): this was not a normal meeting, it was special to my research. I expected that we would look at the collection of photographs and that a discussion would follow, to gain more insight into the lived experience of the participants and this is what occurred.

GENRE – (INTERVIEW, FORMAL MEETING, WALK THROUGH ETC): a semi-formal meeting with interpreters.
APPENDIX D Discussion summary form

<table>
<thead>
<tr>
<th>District:</th>
<th>Present:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date:</td>
<td></td>
</tr>
<tr>
<td>Interpreter:</td>
<td></td>
</tr>
<tr>
<td>Driver:</td>
<td></td>
</tr>
</tbody>
</table>

What were the main themes apparent about this contact? (people, environment, circumstances?)

Summary of the info gained during the session.

Anything else important about this session?

Are there new questions as a result of this session?

Is there anything that was left out and that needs to be asked next time?
APPENDIX E Original ethics approval

1 August 2012

Barbara Palmer
Manager, Office of Research
Tel: +61 7 5459 4574
Fax: +61 7 5459 4727
Email: humanethics@usc.edu.au
F19220

Mrs Jane Shamrock
Prof Marlon Gray
Dr Michael Lyons
Faculty of Science, Health, Education and Engineering

Dear Jane, Marlon and Michael

**Expedited ethics approval for amended research project: The lived experience of disability in East Timor (S/12/426)**

This letter is to confirm that on 31 July 2012, the Chairperson of the Human Research Ethics Committee of the University of the Sunshine Coast granted expedited ethics approval for an amendment to the project, *The lived experience of disability in East Timor* (S/12/426).

The amendment of the project refers to consulting members of a Disabled People’s Organisation prior to commencing the research project, to ensure that the approaches and planned interview questions will be culturally appropriate for people with disabilities in a village community.

The conditions for ethics approval for this project as outlined in our letter of 27 June 2012 continue to apply.

If you have any queries in relation to this matter or if you require further information please contact me by email at humanethics@usc.edu.au or by telephone on +61 7 5459 4574.

Yours sincerely

Barbara Palmer
Manager, Office of Research
APPENDIX F Consent to participate in the research project

Research project: ‘The lived experience of disability in East Timor’

Researcher: Jane Shamrock

I……………………………………………………………………………………(print name)

agree to participate in the research project as described by Jane Shamrock in the Research Project Information Sheet.

I understand that I am participating in the research entirely voluntarily. I understand that I may withdraw from the research at any time and there will be no problems for me if I decide to withdraw from the project.

I understand that I am not obliged to participate in all parts of the research, I may be invited to participate in interviews, a focus group and/or I may be invited to learn to use a digital camera and take photographs.

Signature…………………………………………………………………………………..(date)……………………

The principal researcher, Jane Shamrock and the University of the Sunshine Coast thank you for your support and interest in the research project.

Jane Shamrock (principal researcher)
APPENDIX G Email regarding change to the consent forms

Hi Greg,

I would like your advice about participants’ consent (1) to be interviewed and (2) to use their photographs in the research project.

You may recall that I asked for consent last year for illiterate participants to give verbal consent for the above and this was granted.

I have started interviews here in Dili with people who are literate and I find that the consent forms are too long and confusing. I would like to propose a new format:

- I verbally explain my research project:
  - ie, that it is about the participants experience of living with disability
  - that there is no immediate benefit however, in the longer term people with disabilities will benefit as those who read the published papers begin to understand the realities of living with disabilities, eg, donors or administrators
  - that participation is entirely voluntary and the person may step aside at any time.

Once the person says that they understand I would like them simply to sign a form saying that they understand and are happy to participate.

If the person continues and decides to take a camera to take photographs, I would like to use the following format, whether the person is literate or not:

- I verbally explain that the photographs are (1) firstly for my research and (2) only and if they choose, they can use some of the photographs for advocacy.
- That the person can step aside from the project at any time.
- If the person chooses to use the photographs we will discuss further what form this might take.
- If the person is happy to use the photographs for advocacy purposes they sign a form listing the photographs that they have selected and saying what the particular use might be. (The possibilities that people have suggested in discussion so far include a local photo exhibition, an exhibition at USC, a photo album or a slide show)

This simpler approach with verbal explanation is more culturally appropriate. Many Timorese may be literate however, their education and familiarity with written language has been influenced by occupation and change of regimens. Up until 1999 education was in Indonesian. The country’s infrastructure was damaged during 1999 and since then a different approach to education has been developed and is still developing. The local language, Tetun, is a basic language and Indonesian is still commonly used to explain contemporary issues.

It should be noted that many Timorese have mobile phones and readily share photos and use social media and photograph sharing.
I look forward to your advice in this matter,

Best wishes,

Jane
APPENDIX H Interpreters confidentiality agreement

Research project ‘The lived experience of disability in East Timor’

Jane Shamrock

I, ___________________________________________________________ undertake to respect the following conditions of confidentiality concerning all documents or translation tasks that may be supplied to me by Jane Shamrock

- To keep strictly confidential all information that may be communicated to me verbally or in written or any other form for purposes of translation by Jane Shamrock.

- I will not use any information, documents or other material given to me by Jane Shamrock for any other purpose than to provide the translations for Jane’s project.

- I undertake not to keep any copies after the project has finished. All summaries, transcripts and all other materials will be returned to Jane Shamrock at the end of the project.

- I undertake not to put at risk any documents that are in my care. I will always keep documents, materials and storage systems such as computers or hard drives in a secure, locked place at all times. I will securely lock my work area and secure all documents and materials when I am not working on them.

- I undertake not to take work away from the office designated for my work

Signature:...................................................................................... (date   /   /   )

Signature of witness........................................................................... (date   /   /   )
Photographic Consent & Release Form for photographs to be used in the photographic exhibition.

Research project: ‘The lived experience of disability in East Timor’

Researcher: Jane Shamrock

I agree that the following photograph/s may be used by the researcher for his/her project.


I understand that this means that a copy of the may be used in any way that is consistent with presenting a photographic exhibition. I understand that I will also have a copy of the photograph.

Signature: ......................... ......................... (date / / )

Signature of a witness: ...............................(date / / )
APPENDIX J Tetun Photographic consent and release for participants

(Tetun version of appendix I)

Akordo atu fo fotografia hirak ne’e no formulariu akordu atu uza ba projetu peskiza ne’e.

Projetu peskiza: ‘The lived experience of disability in East Timor’

Peskizadora: Jane Shamrock

Hau konkorda katak fotografia hirak ne’e sei uza ba projetu peskiza ne’e.

Hau komprende katak fotografia hirak ne’e atu uza ba objetivu peskiza ne’e.

Hau mos komprende katak hau hetan kopia husi fotografia hirak ne’e.

Asinatura: …………………………………………………. (data / / )

Asinatura husi sasin : …………………………………… (data / / )
APPENDIX K Tetun words used in the thesis

<table>
<thead>
<tr>
<th>Tetun</th>
<th>English</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chefe suco</td>
<td>Village leader</td>
</tr>
<tr>
<td>Chefe aldeia</td>
<td>Hamlet leader</td>
</tr>
<tr>
<td>Cristo Rei</td>
<td>Christ the King – the name of the statue in Dili harbour</td>
</tr>
<tr>
<td>Malae</td>
<td>Foreigners</td>
</tr>
<tr>
<td>Ojet</td>
<td>A motor-bike used as a taxi</td>
</tr>
<tr>
<td>Pesquisa / peskisa</td>
<td>The Portuguese word used in Tetun for research</td>
</tr>
<tr>
<td>Tais</td>
<td>Traditional fabric woven on a back-strap loom</td>
</tr>
<tr>
<td>Tasi Feto</td>
<td>The female sea or Banda Sea</td>
</tr>
<tr>
<td>Tasi Mane</td>
<td>The male sea or Timor Sea</td>
</tr>
<tr>
<td>Ra’es Hadomi Timor Oan (RHTO)</td>
<td>Name of the Disabled Peoples Organisation (DPO)</td>
</tr>
<tr>
<td>Palacio do Governo, or Palacio</td>
<td>Government buildings</td>
</tr>
<tr>
<td>Uma lulik</td>
<td>Traditional sacred houses</td>
</tr>
</tbody>
</table>
APPENDIX L More samples of participant photographs

Samples of participant photographs (All names are pseudonyms).

Sujana cooking at home

![Sujana cooking at home]

Jeremiah travelling up the river-bed to visit family

![Jeremiah travelling up the river-bed to visit family]
Fernando going on a home visit, being helped by his driver over rough ground.

Edmundo and his baby.
Annalesa weaving

Marcelina making sate to sell
Abilio being shaved by his cousin

The people in the rural areas are very poor; 2 photographs by Francesco which show poverty
APPENDIX M Code book – holistic coding and notes

Holistic coding (Saldana p142)

Community – anything pertaining to the participants, community, attitudes, engagement

Family – anything about the people’s early life in the family, attitudes of immediate family, anything related to the immediate family of spouse or partner, anything about a significant family substitute

NGO – any association with NGOs which have influenced the participant

Personal – any personal attributes, story of the disability, attitudes, personal plans, ideas

Study – anything pertaining to school, attitudes, levels of schooling, support or otherwise from school, university or other studies

Work – anything pertaining to work, attitudes to work, process involved in getting a job, what the person does at work, enjoys work or otherwise this includes paid and unpaid work

Interpreter – anything about the interpreter

Environment – anything to do with the physical environment

Poverty – anything that indicates actions or results of poverty

Attitudes – anything relating to attitudes of others

This worked well as the first round of coding.
APPENDIX N Code book - emotion coding and notes

Code book

Emotion coding (Saldana p105)

- Usual emotive words, sad, happy, confused, unhappy, miserable, joy, etc
- Like and dislike
- Discrimination – as it may imply loneliness or exclusion
- Security - Desire for a good place – seeking security,
- Wondering – thinking about the future
- Care – anything pertaining to physical or emotional care or the lack of care
- Alone – implying loneliness (ie not when it does NOT imply loneliness)
- Strong, positive, success
- Phrases such as ‘get what I want’

This generally worked well, added a few words later that I originally missed.
APPENDIX O PRISMA

Figure 1. Flow chart based on PRISMA. Search strategies for the meta-synthesis. Mohar et al., (2009)

The PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines for building reviews were followed during the preparation of the metasynthesis.
APPENDIX P Published article

This article was published in the Development Bulletin

The power of pictures: Using Photovoice to investigate the ‘lived experience of people with disability in East Timor’


Introduction

This report describes the processes of using Photovoice within the researcher’s broader study of ‘the lived experience of disability in Timor Leste’. Some background to the study is provided and Photovoice is explained as a method within qualitative research. The participants are briefly described and the complex roles of the interpreters are outlined. The experiences of the interviews and camera training are presented and observations and comments are provided to help inform those interested in making use of a visual method of data collection, such as Photovoice.

Photovoice in this pilot study proved to be relatively easy and effective as a data gathering tool and this report describes the experiences of the researcher while using the method.

The experience of disability in Timor Leste (East Timor)

Timor Leste has made progress in the provision of support and services for people with disability. However in practice, life for people with disability continues to be difficult. Most people with disability are poor in Timor Leste where family and community ties are strong and attitudes are based on long standing hierarchical values.

Popular belief is that people with disability are dependent; for example a person with a spinal cord injury may return home from hospital or rehabilitation as a wheelchair. Her family will probably expect that she is now unable to contribute in any way to home-making or income-earning activities. If she is fortunate, a local disability support field-worker may encourage her to take a more independent approach and may reassure her family. If she lives in Dili she may, for example, hear about and want to join the wheelchair basketball group, and she may eventually be able to get a loan to start a small kiosk. If she lives in a remote district she may have fewer options.

In practice the influences on the quality of life of people with disability in Timor Leste may come from:
• Traditional explanations, for example the belief that a deceased family member has been displeased. This may be put forward as the explanation for a child born with a disability or becoming disabled in early childhood. Families may consult a local healer and be advised to carry out traditional practices such as sacrificing an animal, and/or families may develop a fatalistic approach to the limitations of a disabled family member.

• The charity model of disability can still influence some organisations providing support to people with disability in Timor Leste. In this approach people with disability are seen as helpless recipients of ‘charity’ from a ‘caring’ society, rather than individuals with rights and interest in directing their own lives.

• Infrastructure is still being put in place in Timor Leste. Roads are often in poor condition and may be closed during the rainy season making travel difficult for all Timorese and especially difficult for people with disability.

• Poverty is one of the burdens of disability world-wide and Timor Leste is still one of the poorest countries in the world.

The site of the pilot study - Oecusse enclave

Oecusse is one of the thirteen districts of Timor Leste. It is unique in that it is situated on the northern coast of the island of Timor, surrounded by Indonesian West Timor. Because of this isolation, Oecusse experienced extended violence after peace was restored in the rest of the country following the referendum of 1999.

Oecusse is lagging behind the rest of Timor Leste in the development of infrastructure: Roads are mostly in a very bad state, and many of the thatched-roofed houses are also in poor condition. Oecusse can be reached most cheaply by the twice weekly ferry from Dili, although there is no jetty. There is a light aircraft owned by MAF (Mission Aviation Fellowship) which is frequently chartered for medical missions, land access is also possible by road through West Timor, although immigration requirements make this 80 km overland trip quite difficult.

The isolation, recent history, poorly developed infrastructure and poverty affect people’s daily lives and subsequently affected the results of the research project.

Researching ‘the lived experience of people with disability’ in Timor Leste: the pilot study.

A pilot study for ‘lived experience of people with disability in Timor Leste’ was carried out in Oecusse enclave in Timor Leste in August/September 2012 and the researcher was sponsored by the Leprosy Mission Timor Leste (TLMTL) based in Dili. Oecusse enclave was chosen as it was well serviced by experienced TLMTL field-workers.

The visual data from Photovoice was triangulated with key informant interviews and a community audit. A meta-synthesis of academic articles written about the lived experiences
of disability in countries in East and South-East Asia was carried out prior to the pilot project which helped inform the pilot study.

An overview of Photovoice

Photovoice is a form of qualitative research that combines documentary photography with storytelling. Individuals often excluded from decision-making process are able to present their views and give voice about their lives, their concerns and their communities, (Wang, Burris and Xiang 1996).

The Photovoice approach combines two particular theories: (1) feminist theory which describes power imbalances and gender inequality in particular, and (2) participatory methods of research, which call for action which has been identified by the participants i.e. the Photovoice participants. Photovoice was developed in rural China by researchers from North America working in the field of public health, carrying out asset mapping and needs assessments with women farmers (Wang & Burris 1997). Since that time Photovoice has been used widely in the fields of education, public health, mental health, understanding racism, in Latin America, Australia, Asia, Europe and North America.

Benefits of Photovoice include:

- The ease in which photographs can be taken and viewed
- Literacy is not a requirement for photography
- The photographs are excellent prompts on which the researcher can base her enquiries.

Some difficulties have been noted when using Photovoice:

- There may be pressure by friends and family to be in the photographs or to influence the photographer in some other ways. Wang and Burris (1997) noted this risk in their initial description of Photovoice.
- The photographers should be aware of the need for informed consent when taking photographs of others.

Photovoice: Method

The researcher worked with two TLMTL field-workers who acted as cultural mentors and interpreters. The field-workers selected possible participants for the research based on whether these people had the potential to enjoy interacting with a foreigner. This personal attribute was important as people with disability in remote Timor Leste are reportedly ‘shy’ and reluctant, or their families are reluctant for them to interact with outsiders.

Three visits were planned for each participant. Both interpreters attended each interview and at the end of each visit there was time for debriefing. Because of difficulty finding a printer in
Oecusse all photographs were viewed on the screen of a laptop computer and each photograph was discussed with the photographer.

The participants

The pilot study consisted firstly of interviews with six people with disability and their families in Oecusse district. Four of these people subsequently took digital cameras for four to five days and took photographs.

Of the four people who finally took cameras and participated in the pilot study, two of these individuals had relatively recently acquired their disability; both had fallen from coconut trees and were wheelchair users with paraplegia. The other two participants had longer term disabilities probably resulting from polio, both had severe mobility problems. There were two male and two female participants, their ages ranged from twenty nine to approximately fifty years of age. All the participants were members of poor families and had little or no education.

The interview process

The interviews were carried out with the help of the two TLMTL field staff. The conversations frequently appeared to be sprinkled with Indonesian words mixed with the combination of Tetun and Bikeno. Some participants seemed to need longer explanations in Bikeno when concepts were new or difficult to grasp. Notes were taken at each of the initial visits and were later transcribed. During the third and final visit, small recorders were used and notes were taken, as the participants reviewed and explained their photographs.

The study consisted of three interviews: firstly an initial interview where the project and the research were explained, the participants decided whether to participate in the study and initial data was gathered. This interview lasted about an hour. Three of the four interviews involved the subject together with a group of family and neighbours watching and joining in the discussion.

A second interview was carried out one or two days later, where the digital camera was explained and trialled. Initially there was an expectation that the participants would learn about the cameras in a group setting, however, this turned out to be too difficult as transport was limited and distances were great. The participants appeared excited and interested in the cameras and enjoyed taking practice shots of the people around them. An explanation was given about the need to be careful to only take pictures of people who wanted to be photographed, and basic instructions were given on care of the camera. Each photographer was given a small lanyard so that the camera could safely hang around his/her neck.

The third interview was held five or six days later. All the photographs taken by the participants were displayed on the researcher’s laptop computer and reviewed and explained to the researcher, with the help of the interpreters. Some of the photographs were clearly taken by the person with disability and other photographs were taken by another person to
highlight a particular activity, such as cooking, or weaving. During the interview the photographers were asked if they would like to display their photographs in an exhibition in Dili. All declined this option.

At the end of the final interview the participants were invited to select particular photographs that they would like printed. These were eventually printed in Dili and returned to the participants by the interpreters.

**Observations from the study**

The use of photography with this group of people was surprisingly successful and informative. There were also some ambiguities and limitations described below.

The method was successful in that:

- The little digital cameras were easy to use and sparked initial excitement. There were no problems, no cameras were damaged and there were very few unclear shots. Three of the participants took more than one hundred and fifty photographs over five days; the fourth subject took nineteen photos.

- Some of the photographs were surprisingly candid, for example, shots of two individuals bathing – these were taken by a family member.

- It was subsequently possible to have an understanding of rich detail of each individual’s life during the course of a day, As well as at night, which is not usually available to a visiting interviewer.

The complications and ambiguities include:

- It was not clear why the photographers were not interested in having their photographs exhibited. In the past the researcher has encountered people from Oecusse who were afraid that their personal information would be sold to a third party (Shamrock 2009), a similar fear may have led to this response during this pilot study.

- When taking photographs, others may have insisted on being photographed, for example there are three photographs of a subject being embraced by two young women. The participants’ explanation, via two interpreters, was that the girls wanted the researcher to see that they were his friends.

- There appeared to be expectations from participating in the study that the researcher had not foreseen. For example one woman thought that the researcher would report back to the Alola Foundation about the weaving project that the subject had photographed at length. (The Alola Foundation had supplied materials for a small income generation project where a group of women were weaving traditional cloth for sale).

**In conclusion**
Photovoice provided insights into the lives of four individuals in Timor Leste, the cameras were easy to use and the photographers appeared to enjoy the process.

Some problems arose due to the remoteness of the research site and the distances needed to travel to visit the participants. There were difficulties related to cultural differences. The researcher was also constrained by lack of time and resources limiting the way that Photovoice was eventually used.

The researcher found that Photovoice has significant potential to clarify the realities of the lives of people with disability. Learnings from the pilot study will inform changes to the next stage of the research.

References


Wang, CC, MA Burris and YP Xiang 1996, ‘Chinese village women as visual anthropologists: A participatory approach to reaching policymakers’, Social Science and Medicine, 42, 1391-1400.

APPENDIX Q Camera training - notes for the interpreters

The camera training for the project for the project ‘lived experience of people with disabilities in Timor Leste’

Version 6th September

Participants will learn to:

- Use digital cameras
- Keep the cameras clean
- Charge the cameras if necessary
- Take photos respectfully
- Take photos to represent their lives.

The camera training

Each participant will take a digital camera home so that he/she can take photos which can explain to Jane the story of his/her daily life.

- What makes him/her happy in his/her life
- What makes him/her unhappy in his/her life
- How does he/she do activities in his/her daily life

Precautions

- Do not take photographs of anyone without their consent
- Do not take photographs of anyone who does not know that he or she is being photographed
- Take care of the cameras
- Please return the cameras at the end of the project.

After the training each participant will borrow a camera to participate in the research they will be asked to take photographs describing their lives.

This will be followed by:

- A check-up to see that the cameras are in good working order (interpreters or Jane)
- Select the three most significant photographs for further discussion with Jane
- A group discussion with the three selected photographs with Jane

Note that there will be no direct benefit to participating in the research. Participants will be helping others such as TLMTL or other agencies to understand what it’s like to have disabilities in Timor Leste so in the long term others will benefit from the research.
APPENDIX R The model of lived experience of physical disability expanded to show the aspects of each component.

Poverty

Affects health, travel, education, isolation, information, nutrition, safety

Enablers

Active DPO engaged in changing attitudes and policies
Public visibility
Families or mentors
Personal attributes
Ability and opportunity to work

Barriers

Traditional attitudes to disability: isolation, exclusion or protection
Poor services: health, education, transport
Individual impairment
Physical and built environment

Culture and context

Post-conflict fragile state
Poor health determinants
Stigma and exclusion especially in rural areas
Families may be supportive or protective
Societal change
APPENDIX S The Lived Experience of Disability in Timor Leste poster