Activity and Participation in individuals who have received lower limb prostheses from Exceed

A qualitative study conducted in Cambodia

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FIELD WITHIN: Prosthetics & Orthotics

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SUMMARY

**Background:** Cambodia has one of the highest percentages of persons living with disability in the world. Disabled people often encounter stigma in the community, and they do not have the same access to a range of services as the rest of the population. A prosthetic device can enable a disabled person and help them to become more active and participating.

**Aim:** The aim of this study was to investigate the perception of individuals who have received lower limb prosthesis from Exceed regarding factors that affect their level of activity and participation.

**Method:** The study is based on recorded qualitative interviews with semi-structured questions. 10 participants between the age of 22-68 who had a prosthesis were included in the study. An inductive content analysis was performed on the data.

**Results:** The study yielded two main categories which affected the participants activity and participation; Prosthetic limb and a Psychosocial environment.

**Conclusion:** This study gives a deeper understanding of facilitators and barriers affecting activity and participation for individuals with a prosthesis. The results of this study highlight the complexity of the issue and the importance of both the prosthetic device and psychosocial environment. The study gives an insight into factor contributing to different levels of activity and participation and it can help to improve the outcome for prosthetic users.

Keywords: Developing countries, Cambodia, prostheses, activity, participation
SAMMANFATTNING

Aktivitet och delaktighet hos individer som mottagit en protes från Exceed - En kvalitativ studie genomförd i Kambodja

Bakgrund: Kambodja är ett av de länder i världen med störst andel personer med funktionshinder. De stöter ofta på stigma och har inte samma tillgång till en del av de tjänster som resten av befolkningen. En protes kan göra det möjligt för en person med funktionsnedsättning att övervinna svårigheter och bli mer aktiv och deltagande.

Syfte: Syftet med denna studie var att undersöka hur protesanvändare som mottagit sin protes från Exceed uppfattar sin aktivitet och delaktighet och vilka faktorer de anser påverkar detta.


Resultat: Studien resulterade i två huvudkategorier; Protes och Psykosocial miljö, som enligt deltagarna påverkade deras aktivitet och delaktighet


Nyckelord: Developing countries, Cambodia, prostheses, activity, participation
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## ABBREVIATIONS

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Full Form</th>
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<tbody>
<tr>
<td>WHO</td>
<td>World Health Organization</td>
</tr>
<tr>
<td>ICF</td>
<td>International Classification of Functioning, Disability and Health</td>
</tr>
<tr>
<td>WHODAS 2.0</td>
<td>World Health Organization Disability Assessment Schedule 2.0</td>
</tr>
<tr>
<td>NGO</td>
<td>Non-Governmental Organization</td>
</tr>
<tr>
<td>ISPO</td>
<td>International Standards of Prosthetic and Orthotic devices</td>
</tr>
<tr>
<td>P&amp;O</td>
<td>Prosthetist and Orthotist</td>
</tr>
<tr>
<td>EVA</td>
<td>Ethylene Vinyl Acetate</td>
</tr>
</tbody>
</table>
1 INTRODUCTION

Cambodia has the highest percentage of persons living with disabilities in the world, with at least 650,000 individuals classified as having a disability. The exact number is not known but may be as high as 1.4 million (Buschbacher Connelly, 2009). Most of the rehabilitation services provided in Cambodia come from the non-governmental sector (Powell, Mercer, & Harte, 2002). One organization who supports people with disabilities in Cambodia is Exceed. The aim of Exceed is to equip, enable and empower people with disabilities through provision of assistive devices and by supporting them in gaining education and employment (Exceed).

People with disabilities are one of the most vulnerable groups since they often lack access to services and opportunities that are offered to the rest of the population. With help from an assistive device, a disabled person can overcome impairments and barriers to be a more active, participating and productive member of society (Tebbutt et al., 2016).

This study was conducted to increase knowledge about the environmental barriers and challenges, activity limitations and participation restrictions that individuals with lower limb prostheses experience in their daily life. This is important in order to provide evidence-based prosthetic services that improve outcomes for the individuals who have undergone an amputation.

The aim of this study was to investigate the perception of individuals who use prostheses regarding factors that affect their level of activity and participation.

2 BACKGROUND

2.1 Disability

Concepts of disability have confused social scientists for many years. Researchers have struggled to find operational definitions of disability that are complete, global or stable over time (Grønvik, 2009). It is difficult to specify and measure disability, because it is related to many areas of life and involves interactions between the person and his or her environment. Disability is defined by the World Health Organization (WHO) as "An umbrella term, covering impairments, activity limitations, and participation restrictions. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations. Thus, disability is a complex phenomenon, reflecting an interaction between features of a person’s body and features of the society in which he or she lives" (World Health Organization).

In order to address this issue, the World Health Organization (WHO) (World Health Organization, 2001) brought together representatives of more than 100 countries, to produce the International Classification of Functioning (ICF) which is a framework for conceptualizing disability. The ICF takes
each function of an individual – at body, person or society level – and provides a definition for its operational assessment. It defines disability as “a decrement in each functioning domain”. While the ICF encourages a holistic view of disability and provides a common language to discuss aspects of disability, is not a tool for assessing and measuring disability in daily practice.

The ICF is an important framework through which our understanding of the interactions between people and their environment, participation and activities can be enhanced, see Figure 1. It has the potential to be an excellent international development tool that can be used to ensure the inclusion of people with disabilities in health, educational and economic development projects and programs in developing countries (Gallagher, Donovan, Doyle, & Desmond, 2011; Vanleit, 2008).

![Figure 1. Interactions between components of ICF (World Health Organization, 2001).](image)

In order to operationalize the ICF, the World Health Organization Disability Assessment Schedule 2.0 (WHODAS 2.0) questionnaire was developed. This is a universal assessment instrument which provides a standardized method for measuring health and disability across cultures. It was developed from a comprehensive set of ICF items that are sufficiently reliable and sensitive to measure the difference made by a given intervention (World Health Organization, 2001).

WHODAS 2.0 covers 6 domains of function:

- Cognition – understanding & communicating
- Mobility – moving & getting around
- Self-care – hygiene, dressing, eating & staying alone
- Getting along – interacting with other people
- Life activities – domestic responsibilities, leisure, work & school
- Participation – joining in community activities
2.2 Disability and poverty

Disability and poverty are believed to operate in a cycle, with each reinforcing the other (Banks, Kuper, & Polack, 2017). Growing evidence suggests that easily preventable illnesses are a common cause of disability, their impact is exacerbated by a lack of basic healthcare facilities (Allotey, Reidpath, Kouamé, & Cummins, 2003). When there is a lack of basic healthcare together with poverty, the risk of being born with an impairment also increases (Singal, 2011). The reverse is also true, and it is commonly accepted that people living in poverty have limited access to basic healthcare, insufficient and/or unhealthy food, poor sanitation facilities, and an increased risk and likelihood of living and working in hazardous conditions (Singal, 2011).

According to Singal (2011) people living in chronic poverty have two important exit routes, namely high dependency on their own labor and formal education, which improves the quality of their labor. When examining these routes in relation to people with disabilities, neither are particularly viable. Establishing small businesses requires capital resources which many lack. Moneylenders do not trust the capacity of disabled people to repay loans, making access to financial credit extremely difficult (Gartrell, 2010).

2.3 Activity and participation

As described by the ICF framework (2001), there are environmental and personal factors that affects activity and participation with an ongoing dynamic interaction between them. The ICF defines activity as “the execution of a task and action by an individual” and participation as “involvement in a life situation” (World Health Organization, 2001). Everything that influences how the individual experiences disability, such as age, gender, social background, behavior and education are the internal personal factors. The environmental factors include all aspects of the external world that affect an individual's ability to function in different areas of life, like attitudes, products and technologies, services, relationships and support from the surroundings.

The world Health Organization (2001) describes the environmental factors that significantly affect participation. An assistive device is a factor that is classified as environmental, and it can assist or be an obstruction. A clinical evaluation of an intervention should not only be from a biomechanical point of view but should also assess improvements in how a person lives their life (Jaini & Lee, 2015). Assistive devices can greatly reduce inequalities experienced by all people living with impairments, children and adults with disabilities, by enabling them to be active, productive and participate in all areas of life (Tebbutt et al., 2016).

Amputation is a major cause of disability affecting not only body structure and function but also activity and participation. The loss of a portion of, or an entire limb can, according to Kelly & Dowling (2008) cause a loss of sensation and reduced balance confidence which is associated with reduced participation in certain social activities. The emotional impact of the disability on self-esteem and
confidence is also an important aspect and emotional distress plays an important role when describing participation restriction (Gallagher et al., 2011).

The main areas affected by an amputation are physical and cultural activities, like sports or going to the temple, employment and job seeking. Walking long distance and standing for long periods are the activities where individuals with a prosthesis experience most difficulties (Gallagher et al., 2011).

### 2.4 Cambodia

Many nations have experienced armed conflicts in the last decades and 80% of those who need Prosthetic & Orthotic services in the world do not have access to them (Exceed, 2015-2016). Cambodia has suffered both civil and international wars where landmines have had devastating consequences on many people’s lives, leaving them disabled (Kang, Sawada, & Chung, 2017). Cambodia has the highest percentage of the population living with disabilities in the world, at least 650,000 but the exact count may be as high as 1.4 million (Buscbacher Connelly, 2009).

In Cambodia there are about 40,000 amputees and over 50,000 victims of polio and other disabling diseases such as clubfoot and cerebral palsy. The only individuals in Cambodia who receive financial assistance are war veterans, others with more complex disability’s or mental impairments do not qualify for social services from the government (Vanleit, 2008). Most of the rehabilitation services provided come from the non-governmental sector, their primary focus however is on the physical functioning, but not on other important aspects of life (Powell et al., 2002; Vanleit, 2008).

### 2.5 Prosthetic services in Cambodia

Non-Governmental Organizations (NGO) are very important for the disabled population in Cambodia. Organizations like Veterans International Cambodia, Humanity Inclusion and Exceed Worldwide all work to help those who are marginalized and in poverty. They provide free prosthetic and orthotic devices for those least able to pay for services, so they can be an active member of the community and contribute to the family (Exceed; HI; VIC).

Exceed is working to address the need for prosthetic and orthotic services in a number of southeast Asian countries. The organization has established five schools across Southeast Asia, each accredited by the International Standards of Prosthetic and Orthotic devices (ISPO). Exceed has also established rehabilitation clinics linked to their schools, in these clinics Prosthetists and Orthotists (P&Os) make and fit artificial limbs and provide support for those who need it the most. A review in 2016 reports that Exceed had provided 50,182 custom made prosthetic and orthotic devices in Cambodia (Exceed, 2015-2016).

Exceed also offer community-based rehabilitation with projects that directly address poverty and the exclusion of persons with disabilities. Initiatives include projects to facilitate access to education.
and provision of small business grants which assist persons with disability in gaining a stable income. Between 2014-2015 Exceed supported 52 new businesses in Cambodia and the project is still going (Exceed, 2014-2015). According to the disability poverty theory (Singal, 2011) this initiative should reduce the likelihood that individuals end up in the poverty cycle, or even to help them out of poverty. A way to help them get back into participating in daily activities and to provide for their families.

2.6 Barriers for disabled people in Cambodia

Environmental factors can work as a facilitator to increase an individual’s level of activity and participation or become barriers which lead to activity limitations and participation restriction (World Health Organization, 2001).

Almost everybody faces hardships and troubles sometime in life, but for individuals with disabilities the impact of these barriers can be much greater. The WHO’s (2010) definition of barriers is “Factors in a person’s environment that, through their absence or presence, limit functioning and create disability”. Barriers can be classified as physical and accessibility barriers, attitudinal barriers and social barriers.

2.6.1 Physical and accessibility barriers

In Cambodia many households, especially in the rural provinces, are built high on stilts to avoid flooding in the rainy season and can only be reached by climbing steep flights of stairs. This poses a major accessibility problem for persons with disabilities affecting their mobility. Some households have toilets or outhouses down on the ground, creating barriers to adequate hygiene (Vanleit, 2008). Most of the houses have hard beds made of wood where the socializing and eating takes place instead of tables and chairs. This requires people to sit down directly on a flat surface, something that can be difficult while wearing a prosthesis (de Laat, Dijkstra, Rommers, Geertzen, & Roorda, 2014).

Inaccessibility is also a problem in the cities where doorways are narrow, there are multiple floors and stairs, and very often several steps up to the bathrooms (Vanleit, 2008).

The intersection between health, disability and transport has significant practical challenges for people with a disability living in low- and middle-income countries (King et al., 2018). Cambodia is a highly rural and agrarian society and 77% of the population reside in rural areas year 2018 (ESCAP, 2018), where the roads are rudimentary, the road infrastructure is poor and unsafe to travel (King et al., 2018).

The public transportation system is not yet well-developed and not designed with accessibility in mind, which makes it more difficult for a disabled person travel and access care such as prosthetic services. Private transportation such as taxi or rental cars is viewed as prohibitively expensive for most people, partly because of the long distances (King et al., 2018; Vanleit, 2008).
The few footpaths that are present in the cities are often in poor condition, blocked by vehicles, trash, vendors or roadside furniture, and they are lacking in ramps and other features that would assist people with a disability (King et al., 2018).

In the rural areas of Cambodia people with physical disabilities also have difficulties working, because in the rural areas employment usually depends on physical labor like rice farming, which is the most common form of employment (Vanleit, 2008). But families have identified strategies to include the disabled family member for example taking care of chickens (Vanleit, 2008).

According to Gallagher (2011) climate is another environmental barrier for people with a disability. A hot and humid climate, as is the case in Cambodia, causes perspiration which can lead to poor suspension and physical discomfort of the stump and ultimately less usage of the device. During raining season, wet leaves and mud on the ground can also have an effect on mobility and participation in activities.

2.6.2 Attitudinal barriers

Public awareness and knowledge of disability in the society of Cambodia is very limited and no education is provided on how to include individuals with a disability in society, school, workplace or general activities of daily life (JICAPED, 2002).

The practices, attitudes and perceptions of society has a major impact on restricting opportunities for equal participation for persons with disabilities. Individuals with a visible disability tends to be exposed to more negative attitudes from the public, for example the assumption that they are beggars. With a “less disabled” appearance they are less likely to experience discrimination from society (JICAPED, 2002).

Buddhism is the biggest religion in Cambodia and a common perception in the Buddhist society is the belief that people are born with or develop disabilities because of karma and that actions from past lives are linked to bodily status and well-being in this life (Gartrell, 2010; Vanleit, 2008).

2.6.3 Social barriers

One common societal belief is that disabled people have impaired brain and nervous function, that they are emotionally erratic and unaware of the social norms of behavior (Gartrell, 2010). Their abilities are not being recognized and that is one reason for unemployment among disabled people. Banks et al (2017) showed a significant relationship between disability and unemployment, if they have a job, they are more likely than their able-bodied counterparts to have low status occupations and earn less (Gartrell, 2010).

During the Khmer Rouge regime 1975-1979, schools were shut down and replaced with ideology camps and reeducation centers. Approximately 96% of students with higher education and 75% of all teachers were killed during this time (Clayton, 1998).
During the Khmer regime children were prevented from going to school or had to drop out from school. This led to a lack of knowledge and inability to read and write among almost an entire generation. This lack of basic education can also limit the possibilities to get a job. Disability is also a factor that can affect whether a child can go to school. If a child is born with a disability, some parents do not even think to send a disabled child to school and instead keep their children hidden at home (Gartrell, 2010).

3 AIM

The aim of this study was to investigate the perception of individuals who have received lower limb prostheses from Exceed regarding factors that affect their level of activity and participation.

4 MATERIAL AND METHODS

4.1 Study design

A qualitative cross-sectional study using semi-structured interview approach was conducted. This means that all participants were asked the same questions, but every participant had the opportunity to talk freely around the questions. Depending on the answer and the situation, the order of the questions was varied. To ensure that all questions were covered, the interviewer had an interview guide as support. To address the range of factors that may affect activity and participation questions were developed using the WHODAS 2.0 questionnaire as inspiration. The study used a qualitative phenomenological approach. This approach aims to offer insights into how different individuals and groups experience different phenomena (Henricson & Billhult, 2017).

The interview guide was well described and used during the interviews to give consistency to the study. The qualitative approach was chosen to allow the researchers to obtain a deeper level of understanding related to the phenomena and to access more profound information. By using filter questions to acknowledge which aspect was the most important and relevant for each participant, the authors were able to focus on specific areas with follow-up questions.

To the authors knowledge, no validated translation of the WHODAS 2.0 questions to Khmer and the authors felt that a qualitative methodology based upon the WHODAS 2.0 was more appropriate than attempted to use a translated and not yet validated version of the questionnaire. The qualitative method also made the subject matter easier to understand for participants in the Cambodian context where illiteracy is high.

4.2 Sampling

In this study a purposive sampling was used since the researchers were interested in recruiting participants with varied experiences (Elo et al., 2014). In this case the participants of interest
were people living in Cambodia who used a lower limb prosthesis.

4.3 Participants

Ten eligible participants were identified from patient records at Exceed, with help from a community worker employed at the facility. The subjects recruited for this study were adults, between the ages of 22-68, who had received a prosthetic device from Exceed. The study included both men and women and they were recruited on the basis that they understood the aims of the study and what was expected of them and that they could communicate in Khmer or English. Individuals recruited for the study included people from both urban and rural communities. The individuals were not subjected to mental or physical injury or violation. Individuals with additional health complication were excluded from the study.

4.4 Data collection

To implement this study in Cambodia, approval from the Ethical Committee at Jönköping University and National Ethics Committee for Health Research at the Ministry of Health in Cambodia was obtained, see appendix 1 and 2.

The interviews were conducted in either Exceed’s clinical facility, in the participant’s home or their workplace. To collect the data, an interpreter was used to translated between English and Khmer. To reduce the risk of misunderstanding in terms of culture and lifestyle, semi-structured open questions were asked (Polit & Beck, 2017). Both authors carried out the data collection in all the interviews, one author lead the interview while the other took notes and made sure nothing was missed. Flexible follow-up questions were used to explore unanticipated issues and to make sure there were no misunderstandings or misinterpretations.

Before beginning to collect data for the research, two pilot interviews were conducted together with the researchers and the interpreter. This was done in order to investigate the validity of the questions, potential language barriers, if the focus of the questions were correct, to identify unnecessary questions and the need for additional questions. Some questions required further explanation, which the researchers took into consideration and prepared for.

At the beginning of every interview the participant received a consent form, see appendix 3, describing the study’s aim, and that participation was completely voluntary. They received the information in written and oral form in Khmer. The personal consent form was developed with consideration of different ethical aspects. All individuals were informed that their participation in the study would not affect their healthcare or the services they receive from Exceed. Both the interview guide and the information and consent forms were reviewed before the start of the study by a professional in the field with knowledge of the Cambodian culture and ethical principles in order to avoid unnecessary stress on the participants and misunderstanding.
With consent from the participants all the interviews were recorded with a Dictaphone to make sure all the data and information was collected.

4.5 Data processing

The authors transcribed all the data separately and the transcribed material was controlled by both authors to detect possible mistakes. All data were coded into numbers, so it would not be possible to identify any individuals.

The transcribed material was analyzed using inductive content analysis. The material was read though and meaning bearing units were identified. This was first done separately by the two authors and then together to correct for differences between the author’s units. The sentences were shortened into condensed meaning units, with the core meaning of the data still intact. The next step was to formulate codes which are descriptive labels that briefly described the content of the condensed meaning units, to help find associations between them. The five first interviews were coded by both authors together and the last five separately to establish dependability. This step was carried out with very limited interpretation from the authors. The codes were then sorted into sub-categories by comparing them and group the codes who appeared to belong together and dealt with the same area together in a sub-category. To reach higher level of abstraction and bring out the underlying meaning of the data the sub-categories were grouped in main categories, see Table 1 (Erlingsson & Brysiewicz, 2017; Graneheim & Lundman, 2004).

Table 1. Examples of the data analysis process.

<table>
<thead>
<tr>
<th>Meaning unit</th>
<th>Condensed meaning units</th>
<th>Code</th>
<th>Sub-categories</th>
<th>Main categories</th>
</tr>
</thead>
<tbody>
<tr>
<td>The prosthesis is very important, and meaningful to me.</td>
<td>The prosthesis is very important and meaningful to me...with the prosthesis I'm able to walk...</td>
<td>Need the prosthesis to walk</td>
<td>Ability to move around</td>
<td>A well-functioning prosthetic limb</td>
</tr>
</tbody>
</table>
4.5 Trustworthiness

While every attempt was made to ensure authenticity and trustworthiness of the data in the proposed research, the authors collecting data for this project are from Sweden with different culture and backgrounds, which was something the authors had in mind throughout the whole process.

For achieving trustworthiness in a qualitative study, you must fulfil the four criteria: **confirmability**, **credibility**, **transferability** and **dependability** (Lincoln & Guba, 1985). These criteria symbolize objectivity, internal validity, external validity and reliability. Even though it can be divided in four aspects, trustworthiness should be viewed as one variable (Graneheim & Lundman, 2004).

**Confirmability** means that the findings represent the participant’s voice without interpretations from the inquirer. In order to establish this, the authors made sure that both the conduct, findings and evaluation were based on participants’ responses and not any potential bias or personal motivations of the researchers to fit a certain narrative (Lincoln & Guba, 1985; Polit & Beck, 2017). They were also based with respect to the wider political, cultural and social implications of research.

Use of an interpreter is a limitation in this study because the authors could not understand the exact words of participants. To limit bias due to translation, clear instructions and education were given to the interpreters prior to the study. The interpreters were informed in both written and oral form about the aim of the study and the interview guide, how the questions were to be asked and that they were to translate exactly what the participants answered. Information about the consent letter was also introduced to the interpreters before conducting the interviews.

To show the connection between the results and the data, suitable quotes from the transcribed text are presented together with the results which links the categories and themes to the data (Graneheim & Lundman, 2004).

**Credibility** deals with the focus of the research and the trust in the truth of the data. To address this aspect all interviews were conducted with both authors present, one leading the interview while the other followed the conversation carefully and taking notes. With this method, two interviewers will obtain more important and deep information (Skärvad & Lundahl, 2016).

Another step towards credibility was using a population with a wide demographic spread and conducting the interviews in different situations, both at clinic and private settings.

**Transferability** refers to the potential for extrapolation and to which extent the results could be repeated in other settings or groups and result in similar findings (Elo et al., 2014; Graneheim & Lundman, 2004). In order to promote transferability, information about cultural aspects, the selection and demographics of the participants, data collection and how the data was analyzed are provided in the report.

**Dependability** refers to the stability over time and that the results could be repeated and result in similar findings (Elo et al., 2014). A well described interview guide was used and principles and criteria
of the selection of participants and clearly stated in order to achieve this. To increase the reliability the material was transcribed separately by the two authors to detect mistakes and interpretations. The first five interviews were coded together by the two authors and the following five separately in order to detect and confirm all possible codes.

4.6 Ethical considerations

Information about the participants was treated with confidentiality in mind and used for research purposes only. All information was kept in a secure place and no individual participant could be identified from the data. Individuals involved in this research were not subjected to mental or physical injury or violation.

Before the interviews began, the participants were asked permission that the interview could be recorded. If participants were not comfortable with recorded interviews, permission would have been requested to take notes instead. The authors also made sure that the participant knew that they could chose to stop the interview at any time if they did not want to continue or answer a question.

Questions in this study did not address any issues that may have caused mental harm to the individual. They were related to the individual’s current situation and participants were not asked to recall or describe any part traumatic experiences. If a question seemed to bring back traumatic memories, the participants would have been reminded that they always had the choice to not answer a question, take a break or withdraw from the study.

This research was responsive to the health needs or priorities of this minority group and the research could not be carried out in a nonvulnerable group since it was the self-perceived view of activity and participation that were being investigated. In addition, this minority group could stand to benefit from the result from this research since it will be used to help Exceed increase the level of activity and participation for people with an assistive device.

Results will not be shared directly with participants but will be presented to Exceed in order to facilitate quality improvements of their services.
5 RESULTS

Ten individuals who had been provided with a prosthesis from Exceed Worldwide participated in the study, including three females and seven males. Participants had a mean age of 46.8 years, ranging between 22-68 years. The sample included individuals who lived in urban (6) and rural (4) areas of Cambodia. Three participants were amputated at the transfemoral level and seven at the trans-tibial level. Reasons for amputation were diabetes (1), congenital limb deficiency (2) and trauma (7). The causes of the traumatic amputations were landmines/bomb explosions (5), traffic (1) and workplace accidents (1). Participants with congenital dysmelia could not recollect when they were fitted with their first prosthesis, only that it was early in their life. For the remaining eight participants, the mean waiting time to receive their first prosthesis was 9.9 months and when the interviews took place, they had used a prosthesis on average 19.8 years, range 5-29.

The sample of people interviewed in this study had quite high levels of activity and participation within their community and at home. Visiting the local temple, attending weddings and ceremonies were activities that were common among all participants. The majority also reported that they were active in providing for family and doing domestic work.

“When I’m free I like to spend time with my daughter...go to the supermarket, swimming, go to the beach, Siem Reap and Angkor Wat...” (P7)

“...if the government is making a new road...they call me, and I join the meetings with the village boss...” (P5)

When analyzing the data and looking at what affects activity and participation, ten sub-categories emerged which gave rise to 2 main categories, presented in Table 2 below. Quotes from the participants are presented to show the connection between the categories and the data.

<table>
<thead>
<tr>
<th>Main-category</th>
<th>Prosthetic limb</th>
<th>Psychosocial environment</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sub-category</strong></td>
<td>Ability to move around</td>
<td>Physical discomfort</td>
</tr>
<tr>
<td></td>
<td>Poor education and poverty</td>
<td>Support from others</td>
</tr>
<tr>
<td></td>
<td>Personal attitudes</td>
<td>Need to provide for family</td>
</tr>
</tbody>
</table>
5.1 Prosthetic limb

5.1.1 Ability to move around

It was apparent from the responses that access to a prosthesis was a key enabler allowing people to move around their house and community independently. Great emphasis was put on the ability to walk since the participants experienced walking as the basic prerequisite for all other activities. The ability to walk was also the first and most important function that would be limited if the participants were not allowed to use their prosthesis.

“My house has ten stairs...I can walk the stairs...but not without the prosthesis, then I must crawl...” (P5)

“The prosthesis is very important and meaningful to me...with the prosthesis I’m able to walk...” (P7)

Although the participants described positive effects of the prosthesis on their mobility, they also indicated that there were limits to what they were able to achieve with their prosthesis. This was typically related to endurance or performing complex tasks such as climbing or walking and carry heavy items.

“I cannot walk so much...not so long...just walk around the house...or where I work...when I need to go to work, I take motorbike.” (P2)

“I can’t do anything like climb up the roof and other things for repairing...” (P6)

The alternative to using a prosthesis was, in most cases, crutches. Participants indicated that crutches were impractical, making it generally more difficult to do their job and move around the house.

“...I can work with crutches but is much slower...I wouldn’t be able to clean around the shop because when I walk, I need two crutches...it’s difficult...” (P8)

The prosthesis enabled independent transportation when participants needed to travel far. It was very important and gave a feeling of freedom and independence. One participant explained the feeling of something missing while driving without the prosthesis and others expressed a need for the prosthesis while transporting heavy thing on a motorbike. Difficulties to keep balance was also mentioned by the participants which increased the risk of falling.

“...I feel happy, free and independent...I can drive wherever I want to go with my prosthesis...” (P4)

Access to a prosthesis was also suggested to facilitate access to education. One of the two individuals who was born with a disability, did not have a prosthesis growing up and was unable to go to school because of the lack of other transportation.
“...it was very hard because long distance to school...and no transportation...I didn’t have a prosthesis, so it was very hard for me to walk...” (P7)

5.1.2 Physical environment

According to ICF a prosthesis is classified as an environmental factor and can work both as a barrier of facilitator for activity and participation. Something that all the participants had in common was the feeling that the prosthesis was very important for them by enabling them to join activities and participate in the society. They also expressed the feeling of having no life without it.

“My prosthesis is very important for me to do anything and to go anywhere...without it I can’t do anything...I can’t live my life...” (P4)

“...but with the prosthesis...I can involve in the society...join weddings...it makes me feel happy...” (P6)

Other situations discussed were related to sitting. In Cambodian society it is common to sit on the floor or a wooden bed when eating and socializing, and chairs are usually not available. Being able to sit down with a prosthesis is also for crucial for joining religious activities. Some participants experienced no troubles sitting with their prosthesis which made it possible for them to join these activities. Other considered it to be a barrier which subsequently led to unwillingness to join people on the ground or simply leaving sooner. Since the knee joint they use in Cambodia is a single axis knee, it is hard to bend without having to rotate the leg, this results in having to keep the knee straight when sitting or simply taking the prosthesis off.

“...it’s difficult to sit down on the floor...so I don’t want to join the people who sits on the ground...” (P2)

“...in the temple...sitting is very difficult... cannot sit for a long time...pain in the leg...I just go home...” (P8)

The physical environment in which participants live had major effects on their ability to participate in desired activities. Stairs and inaccessible sanitary facilities were issues that were repeatably raised by participants as barriers to their participation.

“My house has seven stairs...I don’t go up, just stay at ground floor... “(P2)

“but when I go to sell in the province it’s difficult because we have no toilets, sometimes no water...and sometimes we have no place to sleep.” (P3)

5.1.3 Physical discomfort

Pain and fatigue were frequently mentioned as barriers to activity and participation, as the resulting discomfort impeded the use of their prosthesis and ultimately the level of mobility. Situations when
Participants experienced pain in their stump included carrying heavy things for example vegetables to the market, gas tanks or a sewing machine. The solution to this problem was to ask for help or adapt to the limitation and carry in a different way, on the shoulder or with help from a motorbike. A poor fitted prosthesis, standing for longer periods and walking a long distance were also reported to cause pain.

“Sometimes I feel tired when I have a lot of work to do...so when I take a step it difficult to control the knee...unstable during walking...” (P6)

“...when I walk and carry the heavy vegetables it hurts in my stump.” (P5)

The hot climate made the stump very hot when being physically active, which also gave rise to discomfort of the stump. The majority of the participants in this study used pellite or Ethylene Vinyl Acetate (EVA) liners, vacuum formed over plaster model of the stump together with a sock. Friction between the stump, the sock and the liner cause shear forces and perspiration and this discomfort affects the daily use of the prosthesis.

“When I walk I get tired and sweaty...in my stump...I don’t feel good when I walk a long way or long time...” (P2)

5.2 Psychosocial environment

5.2.1 Support from others

One sub-category that arose in almost all the interviews was the importance of support from others, both emotionally and financially, which was demonstrated to affect activity and participation.

Many of the participants described a need for help, both at work and in daily life. They considered it to be more difficult for a disabled person to get a job and most of the participants subsequently ran their own small businesses, repairing or selling things at home or at a market. There was a general agreement that without some external support, money or supplies, it would have been difficult to start up or develop the business. Some of the participants got support from their own families while other received support from an NGO. This support proved to be very meaningful for the participants, and helped them to start up the business, improve it and thereby earn more money.

“...when I come home from the market...neighbors come to help me...help to hold the moto and I can carry the stuff to my house...” (P8)

“I got support from Exceed...to buy oil and wheels for use or selling...service is much faster it helped to improve my business...can earn more money by that...expand the business more.” (P8)

If the family lacked financial resources and there was no access to support from an NGO, it was considered to be challenging to get any other form of support. Modes that were available for most
people, such as a loan from the bank, were not an option for people with a disability. Since the banks do not trust in their abilities to repay the money.

“...if I don’t have a house, I can’t loan money from the bank...” (P7)

5.2.2 Need to provide for family

The ability to provide for family was considered of high importance among the participant. Many indicated that they worked most days of the week and rarely had any days off. Participants could not afford to lose customers as they needed money and considered themselves responsible for providing for their family. There was a general agreement among that family was the most essential part of life and participants wanted to be a participating member working hard for their family.

“I have no days off...we need to be open 7 days a week...or customers will go to another place...” (P9)

“...even though I get tired I need to try, because of money...” (P6)

Some participants grew up in poverty and with families who could not support them with material items such as school material because it was too expensive. Many had to leave school and start working to help provide for their family. This could be considered as limiting one sort of participation but gaining another. Some also had to change jobs to be able to earn enough money.

“Before I worked as a police man, but the salary was not good so I could not support my family...I quit and started helping my wife instead...at the market and at the house...now I can support my family...find the money so my children can go to school...” (P5)

5.2.3 Societal attitudes

Another commonly mentioned sub-category which affected activity and participation was the many different attitudes existing in the Cambodian society, both positive and negative. Negative attitudes generally were thought to occur because of lack of knowledge. Something that was often mentioned was verbal discrimination at work because of their disability and not having their abilities being recognized. The feeling of not having the same opportunities as everyone else created a feeling of sadness. Furthermore, some of the participants described difficulties getting another job because of their disability. They expressed that the job they had wasn’t their dream job, but suitable for their situation.

“Before the amputation I worked at a clothing factory and after the accident my boss said that I would get my job back...but after the treatment he didn’t want to hire a disabled person to work at his factory, the policy can’t accept it...” (P3)

Several participants expressed that before they received their prosthesis, strangers could easily identify that they had a disability. Because they did not know these people, they could be exposed to their
negative attitudes and assumptions, which subsequently lead to reduced activity and participation. But most of the participants described that they seldom felt discriminated in their own community, among family and friends.

“When I got amputated…and went to the market people thought I was a beggar…” (P9)

“...when I join other events also no problems, in my community the others know that I am a disabled person, but no one looks down on me.” (P1)

5.2.4 Personal attitudes

Being comfortable in social situations, self-determined and believing in their own ability was a major facilitator towards living an active life and participating in society. A common reason for being socially active mentioned by the participants was their own personal satisfaction. Feeling happiness, a sense of purpose and affinity with other people took the focus away from their disability and was a reason to join different events.

“Now I feel confident and normal wearing my prosthesis...” (P4)

“I never feel embarrassed with my friends and other people in the community...mostly I wear shorts...I don’t worry...” (P5)

Social discomfort deals with how comfortable a person is to engage in a social activity. A high level of social discomfort lead to reduced activity and participation as a result of feeling shy or ashamed of showing the disability. It was also affected by the beliefs of others.

“I always hide my prosthesis...rarely show my legs...because I’m different from other people, I’m disabled...it’s hard to show others...I feel so ashamed...just at the Exceed clinic...but I still mind.” (P7)

Many of the participants explained how their self-confidence had increased and their social discomfort had decreased with time wearing the prosthesis. It was also indicated from the result that the time between amputation and first prosthesis could have affected how comfortable they were wearing the prosthesis.

“...before when I woke and put on the prosthesis...it felt complicated...I felt stressed...nowadays no problem, it has become a habit...” (P1)

“I have worn it maybe 30 years...so I am not shy or embarrassed with my friends. My friends always support me...not talk about the prosthesis...no one discriminates me for my amputation...” (P4)
5.2.5 Poor education and poverty

Among some generations in Cambodia the education levels are low. During the Khmer Rouge regime, most children did not go to school because they had to work. The result of this affected many people, especially those with a disability. The inability to read and write was often linked to other problems, such as difficulties finding employment and being excluded from opportunities to fully participate in the society.

“Because I didn’t go to school, I don’t know so much...it difficult for me to find work at another company...difficult with communication.” (P2)

Another effect created from the lack of education was poverty. If you live in poor conditions, buying food is sometimes not possible. Making sure you have something to eat then becomes one of the main activities for the day.

“...when I don’t have food...almost every day...I need to walk in muddy places...the river to catch fish...” (P10)

A lack of money can also be a problem when wanting to practice sports or participate in other activities. Since it often cost money to join a club, get access to a training facility, go to the movies or visit a restaurant.

“...before I played sports but after the amputation I never play. Because I think it’s difficult...I like to watch sport but never play myself...because here in Phnom Penh you need to pay to play sports...I don’t know a place where I can play...” (P2)

“I don’t join the activities in the community often because of my business. I just go to relatives’ weddings....” (P3)

6 DISCUSSION

It is suggested that the knowledge about how strong the link is between loss of a limb, the perception of one’s physical appearance and activity and participation has been underrated (Deans, Burns, McGarry, Murray, & Mutrie, 2012). The present research has attempted to address this issue by providing a deeper understanding of what people with a lower limb prosthesis experience as affecting their levels of activity and participation. The qualitative approach allowed participants to express their subjective perspective on the subject, since they are the only ones that can truly give an answer to the questions posed. This leads to a richer understanding of the phenomenon, (Deans, Burns, McGarry, Murray, & Mutrie, 2012). The present research has attempted to address this issue by provided a deeper understanding of what people with a lower limb prosthesis experience as affecting their level of activity and participation.
The following section will include a discussion about the method and results of this study, including limitations and trustworthiness.

6.1 Method discussion

6.1.1 Study design
A cross-sectional design was used in this study as the time and budget was restricted. The challenge with this type of study is that it does not provide a certain explanation to the findings and it can be hard to distinguish cause and effect from a simple association (Mann, 2003).

One limitation in the present study is that the questions used in the interviews were not validated. The questions were based on WHODAS 2.0 and developed to fit the contextual implementations of the research. To increase the validity of the questions they were controlled by people with knowledge in Cambodian culture, within the prosthetic and orthotic field and with previous research experience.

6.1.2 Recruitment and Sample
Recruitment for this study was done with help from Exceed and patient records. Because of geographic limitation, time restrictions and the desire to do the interviews face to face, the study became limited to Phnom Penh and nearby provinces. This and the fact that participants were only collected from Exceed, can limit generalizability of the results.

6.1.3 Data collection
To conduct the study an interpreter was necessary because none of the participants understood or spoke English.

The first four interviews were completed with one interpreter, the optimal choice would have been to use the same interpreter in all the interviews to increase the dependability and credibility (Wallin & Ahlström, 2006). But due to external circumstances the first interpreter was unable to attend any more interviews which forced the authors to use a second one for the remaining six interviews. On the other hand, only using one interpreter would increase the risk of boredom and fatigue, and risk that the interpreter would use abbreviations and summaries instead of giving the exact translation, which subsequently could affect the validity of the research (Kapborga & Berterö, 2002). The two interpreters spoke both fluent English and Khmer and shared the same the culture as the participants. There were also a community worker present in all the interviews, this community worker was the link between the patients and the Exceed clinic. This connection between the participants and the community worker was important to make them feel safer and more comfortable in the interview situation, not only for ethical reasons but also to make a more reliable and validated data collection (Kapborga & Berterö, 2002).
The two interpreters were both working at the clinic and were familiar with the Prosthetic and Orthotic field which enabled a deeper understanding and better translation process.

Since neither of the authors spoke or understood Khmer, they could not have full control over the data collection and the reliability was therefore reduced. But as previously mentioned it was unavoidable as interpreters were necessary to conduct the study.

The authors had considered that their presence might affect how the participant would answer the questions. This because the answer could affect their treatment from the clinic, which could lead their answer in an undesirable direction. And that would subsequently decrease the reliability of the collected data. To avoid or minimize this error, every interview started with the authors declaring that they were students and that nothing the participants said in the interview would affect their treatment in any way.

The possible power relationship that may occur between the interviewers and the participants needs to be considered when conducting interviews. This can be caused inequality in socioeconomic status between the countries, but can also be rooted in gender, ethnicity and other social differentiations (Elwood & Martin, 2000). In this case two women from Sweden being students with higher education can possibly create a sort of power hierarchy.

The location of the interviews was chosen to be as convenient and comfortable as possible for each participant. Interview subsequently took place after an appointment at the clinic, at their home or workplace. Conducting the interviews in the participants’ homes could help break down the uneven power relationship between the researchers and participants, making them feel in control (Elwood & Martin, 2000). The location where the interview is conducted gives the researcher an opportunity to make observations that creates richer information than what could be concluded with only the content of the data. Observations from the home environment of a participant, accessibility and neighbors gives a deeper understanding about the participants life situation, as do observations from work or clinical settings.

It is important to consider different relationships and interactions at the site of the interview. Participants could feel uneasy to speak freely and spontaneously in the presence of others and with risk of them overhearing what is being said. During the interviews, friends and family members tended to speak in the participants place but also explicate the answers.

6.1.4 Data analysis

The recorded material was divided between the two authors who separately transcribed the data verbatim. The authors then listened and read through each other’s transcripts to detect errors and misunderstandings. All transcripts were of high accuracy and only few minor alterations had to be made, which indicates that the truth of the data is represented in the transcripts.

The aim of content analysis is to create latent meanings from manifest and literal material, which is challenging and time-consuming. It starts with reading and re-reading the interviews to gain
understanding of the content. The next step is, with the research aim in mind, find meaning bearing
units and condense these, keeping the core meaning intact. It’s a fine line between keeping
unnecessary things and taking away something of importance. Graneheim & Lundman (2004) speaks,
however of the risks making too short meaning units since this can generate fragmentation while
Erlingsson & Brysiewicz (2017) consider having long meanings as a bigger problem. Dividing the
condensed meaning units into codes is the next step. The first five interview were coded by both
authors together in order to get used to the method. The last five were coded separately, with a high
level of conformity which indicates dependability of the coding process. Finally, the codes were divided
up in categories. A problem that appeared while formulating categories was that they overlapped, and
codes fit into more than one category. This can imply a too big of a jump from code to category
(Erlingsson & Brysiewicz, 2017). The codes where therefor divided up into more confined categories
and later composed into sub-categories and two main-categories.

6.1.5 Saturation

Saturation of a data is indicated by replication or redundancy and increases the quality and validity of
the research (Bowen, 2008). Saturation was achieved when the ten interviews were collected. No
additional information emerged from the material that added to the understanding of the research
topic. The researchers were reasonably assured that additional data collection would result in similar
conclusions and confirming the previous emerging categories.

6.2 Result discussion

The goal of ICF is to establish a patient centered healthcare, when implementing the ICF in the
provision of a prosthesis the clinicians should not only look at the results from a pure biomechanical
perspective. The intervention should give improvements in the patient’s life and allow the patient to
live their life as it satisfies them (Jaini & Lee, 2015; Jarl & Ramstrand, 2018). The results in the present
study showed that there are several factors affecting activity and participation, not only the physical
factors showed great importance but also the psychosocial factor, as the ICF implies (World Health
Organization, 2001).

6.2.1 Demographic information

This study included both male and female participants, with a rage of 46 years of age (22-68), living in
different living conditions and with different levels and causes of amputations. All these different
demographics means that this study can provide a generalization to a big part of lower limb prosthesis
users in Cambodia. The result could be affected by the level of amputation. A higher amputation level
is related to lower levels of social participation and can subsequently lead to lower satisfaction with
participation (Roepke et al., 2017).
6.2.2 Prosthetic limb

The prosthesis is as mentioned before an environmental factor and can work as either a facilitator for activity and participation or as a barrier according to (World Health Organization, 2001). This was confirmed by the result of the study where the participants described both positive and negative aspects about the prosthesis. As a P&O it is easy to focus only on how much the prosthesis will help the patient and the negative aspects are often being neglected or overlooked. The possible limitations in activity and participation restrictions need to be recognized and it is important to make the patient aware of the possible outcomes and problems and how to deal and adapt to them.

A perquisite for joining activities and participating in the community is the ability move around and the prosthesis was a key enabler for increasing the individual’s level of physical mobility. The most valuable function of the prosthesis was considered by participants as being the ability to walk. This is consistent with results from Legro et al., (1999) who also reported the ability to walk as the most important factor. Schaffalitzky, Gallagher, MacLachlan and Wegener (2012) described “comfort while walking”, “walking with safety” and “balance when walking” as effects of prosthetic use and one important factor facilitating prosthetic use was “confidence in walking ability”. This put emphasis on the importance of gait training early after amputation.

The respondents chose to see the prosthesis as facilitator to mobility rather than a barrier. Despite the predominantly positive aspects of having access to a prosthetic limb, the participants also experienced limits to what they were able to do with the prosthesis. Stair climbing is an important activity in order to maintain mobility and independence (Ali et al., 2013). The ability to climb stairs can be affected when using a prosthesis and some of the participants expressed difficulties to climb stairs in their home. This is consistent with the results from the study conducted in the Netherlands by de Laat et al. (2013) who concluded that 32% of the participants in their study were not able to climb stairs at all and 62 % was required to use handrails. This is a problem in Cambodia since public buildings, like schools and hospitals and houses are not adapted to people walking with prostheses. The lack elevators or handrails are barriers for both activity and participation for these individuals.

Prerequisites to regain walking mobility with a lower limb prosthesis after an amputation is the ability to rise and sit down (de Laat et al., 2014). So, in order to increase the mobility, this aspect needs to be dealt with. The result from this study indicated a need for other components with different features, like the possibility to unlock the knee joint and rotate it while sitting down.

The common presence of physical discomfort in the residual limb fatigue occurred no matter how well the prosthesis was fitted because of the constant changes to the residual limb. It can swell, get ulcerations and calluses and this is often compounded by sensitive skin and scar tissue. The participants had different experiences of pain in the stump and how it influenced their life. Some perceived only minor problems, while the pain would impede the usage of the prosthesis and ultimately restricting the ability to perform daily activities for others. Standing a long period and the ability to work a lot were common activities affected but the main function limited by stump pain among the participants was long distance walking.
There are different opinions regarding if and how walking potential is affected by stump pain. Results from a study by Geertzen, Bosmans, van der Schans & Dijkstra (2005) showed a reduced ability to walk long distance if stump pain is present, along with Magnusson, Ahlström, Ramstrand & Fransson (2013) who also considered pain to be an issue when walking longer distance. However, Desmond, Gallagher, Henderson-Slater & Chatfield (2008) found no association between pain occurrence and activity restriction, including ability to walk 100 yards, activities involving physical effort and limitation of social activities. This study suggests that pain does affect walking ability and that it is an important issue to address.

According to Davis (1993) the most common reason for stump pain is prosthogenic, improper fitting of the prosthetic device, and choice of components. The EVA or pelite liner the participants in this study used is quite firm and shaped after the present status of the limb and does not respond well or adjust to changes in volume of the stump during the day which increases the risk of discomfort. It also requires the user to wear a sock between the skin and the liner where friction and shear force can lead to pain and discomfort. It is also important that the liner helps absorb the shock from the impact. According to Klute, Kallfelz and Czerniecki (2001) high-impact forces on the stump contributes to a higher prevalence of pain. Together with the warm climate, perspiration leads to elevated discomfort and activity restriction when the prosthesis needs to be taken off to dry or be cleaned. Liners made out of materials with good thermal conductivity have been studied (Klute, Rowe, Mamishev, & Ledoux, 2007; Williams, Washington, Miodownik, & Holloway, 2018) but more work needs to be done if they are going to be available in developing countries like Cambodia.

The feet used by the participants were stiff with little range of motion, which decreases the range of motion in the knee. The knee’s ability to absorb shock is there for limited. A rigid foot also leads to elevated pressure on the stump in the socket, with consequences resulting in pain and discomfort (Klute et al., 2001). Therefore, it would be interesting to try different, more flexible feet to see if that would result in less pain and discomfort. This is a challenge since Cambodia is a developing country where the price and availability play a key role while choosing components, and the supply is not the same as in for example Sweden.

Stump pain can also affect the psychological well-being of an individual when using a prosthetic limb (Horgan & MacLachlan, 2004). Research has shown that pain and depression tend to co-occur (Geerlings, Twisk, Beekman, Deeg, & van Tilburg, 2002; Haythornthwaite, Sieber, & Kerns, 1991). Chou (2007) found that mobility disability is a predictor for and increases the risk of developing pain as well as depression. The study also showed that pain and depression share the same predictors and developing one of the two entails greater risk of developing the other. Horgan & MacLachlan (2004) also describes another mechanism where pain in the stump influence personal well-being of the individual, namely via activity levels. The negative impact of stump pain on mobility and rehabilitation outcomes lead to limitations in activity levels and the individual can experience frustration and anxiety. Activity restriction relates to depression, a relationship that was found by Williamson and Schulz (1995). Therefore, the psychological well-being and pain is very important aspects that needs to be dealt with at an early stage before they may affect one another.
The participants mostly used a motorbike when they needed to travel longer distances. The few individuals included in the present study who did not know how to drive lived in the city and were usually driven by a family member or travelled by tuk-tuk. The participant living in the rural areas described how important it was to be able drive and expressed that it gave them a feeling of being independent and free. Individuals from rural areas also explained that public transport was rare and expensive. The same results were indicated by Magnusson et al., (2013), who indicated that public transport were inaccessible for disabled people and that they were often unable to pay.

6.2.3 Psychosocial environment

The amount of time that had passed since a person had been provided with a prosthesis have been found to affect the level of activity and participation, but it also influences psychosocial factors such as confidence and self-esteem (Horgan & MacLachlan, 2004).

In the present study the average time since receiving a prosthesis was 19,8 years. The fact that they had had it for such a long time meant that they had gone through most difficulties and problems and had found their way of dealing with their disability. Many of the participants expressed that in the beginning they experienced negative attitudes from their community because of lack of knowledge. This is consistent with results from Magnusson et al., (2013). The participants also expressed feeling ashamed over their disability, but with time their community learned about disability and nowadays they seldom experienced this feeling. Most had accepted their disability and adapted to the situation. This was also seen in the study by Horgan and MacLachlan (2004), who indicated that people who had undergone an amputation felt depressed and anxious for up to two years after their amputation, but with time this feeling reduced. Horgan and MacLachlan (2004) also stated that acceptance of a different body-image following an amputation increases with time.

According to Sinha, van den Heuvel and Arokiasamy (2014), a long-term prosthesis user shows greater abilities within the social and physical areas in life compared to people who had not used their prosthesis for a long time. Participants with shorter experience of wearing a prosthesis would likely have a different view on what factors affect activity and participation. Because they are in an earlier stage of the rehab process. In the present study all the participants had had their prosthetic device for an average of 19,8 years and it is possible the participants with more recent amputation would have reported different results.

The rehabilitation process is another factor that affects activity and participation, the environment which the rehab process is conducted in can help a disabled person overcome anxieties and have the confidence to participate in an activity (Deans et al., 2012). According to Marinelli and Dell Orto (1984) it is a widely held belief that a disabled person has a greater chance of getting a better and more successful rehabilitation if they accept their disability and are willing to adapt to it. The rehabilitation process affects activity and participation, and throughout the process patients have different thoughts, questions and goals. Gallagher and MacLachlan (2001) describe that early in rehabilitation questions
around mobility, function and appearance are some of the most common categories that patients ask about, these categories can in many ways affect activity and participation.

According to Deans et al., (2012) patients with an amputation seldom return to their pre-amputation activity level and there are more barriers than motivations to remain active. The present study showed that a big motivation for activity and participation is providing for their family and being able to earn money.

As mentioned earlier a factor that eases the adaption to wearing a prosthesis is time, another factor proved to help is high levels of social support (Horgan & MacLachlan, 2004). Many studies have shown the importance of social support in many different ways that agreed with the present study. It increases the psychological wellbeing, reduces stress levels, increases self-esteem and promotes social participation (Gallagher & MacLachlan, 2001; Horgan & MacLachlan, 2004; Thoits, 2011).

Another type of support that showed importance in the present was financial support to start or develop their own small business. In Cambodia generations from the same family often live together, the oldest active man in the family is responsible to provide for the whole family, often more than one generation, children, parents and grandparents. For a disabled person who has difficulties finding a job, a business of their own can enable them to be able to provide and be a participating member of the family.

6.3 Further research

For implementation of the results from this study, further research needs to be made on how to use this information in the clinical setting and increase the level of activity among these patients. The results from the present study gives us information about the factors these participants experience affects whether they are active and participating or not. How to apply the knowledge with best possible outcome needs to be investigated further.

The role different components and rehabilitation process have on the activity- and participation levels are also interesting subjects to study. This is not being considered or investigated in the present study, but the result indicates that they may influence these outcomes.
7 CONCLUSION

This research gives a deeper knowledge about the barriers and facilitators for activity and participation that individuals with lower limb prostheses experience in their daily life. The categories that emerged showed the complexity of the subject and the importance of not only the prosthetic device but also the psychosocial environment. The result of the research is valuable to be able to understand the underlying causes for different levels of activity and participation and is an important step towards providing evidence-based prosthetic care and improve the outcome for the individuals who use lower limb prostheses.

8 SPECIAL THANKS TO

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9 CONFLICTS OF INTEREST

The authors declare no conflict of interest.
10 REFERENCES


Appendix 1

Uttåtande
Forskningsetiska kommittén

Diarienummer
2018/3059–333

Uttåtande gällande ansökan nr. 18.09

<table>
<thead>
<tr>
<th>Titel på projekt</th>
<th>Activity and participation in people who have received and assistive device from Exceed in Cambodia</th>
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<td>Lisa Felixon och Malin Johansson, Ortopedingenjörsprogrammet</td>
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Uttåtande

Ansökan har behandlats som ett studentprojekt vilket gör att en ansökan till etikprövningsnämnd (EPN) i Linköping inte är aktuellt.

Kommittén har inga forskningsetiska invändningar men föreslår att följande beaktas:
- Rekrytering av deltagare behöver beskrivas mer utförligt både i projektplan och i informationsbrevet till deltagare.
- Utveckla i informationsbrevet om begreppen aktivitet och delaktighet kopplat till hjälpmedel, ange också hur långa intervjuerna förvånas vara, plats för intervju, att intervjuerna spelas in, möjlighet till tolk och att materialet raderas efter studien är avslutad. Vi rekommenderar att ni använder er av "stödmall för forskningspersoninformation" som finns att hämta på EPN:s hemsida.

Med vänlig hälsning Forskningsetiska kommittén, genom
Malin Stensson, ordförande

Jönköping, den 10 september 2018
Appendix 2

Ms. Malin Johannsson and Ms. Lisa Felixon

Project: Activity and participation in people who have received a prostatic or catheter device in Cambodia. Version No. 1, Dated 30 November 2018.

Reference: Year later on 99th January 2019
- Summary report of NICCHR's secretaries on 16th January 2019

Dear Ms. Malin Johannsson and Ms. Lisa Felixon,

I am pleased to notify you that your study protocol entitled “Activity and participation in people who have received a prostatic or catheter device in Cambodia. Version No. 1, Dated 30 November 2018” has been approved by National Ethics Committee for Health Research (NICCHR). This approval is valid for twelve months after the approval date.

The Principal Investigator of the project shall submit following documents to the committee’s secretariat at the National Institute of Public Health at #80 Sambath Penn South Blvd, Sangkat Bocangkot, Khan Touk Kork, Phnom Penh. (Tel: 012 842 442, 012 528 789, 012 205 383; Email: sayy@yahoo.com, no_chai_hai@gmail.com):
- Annual progress report
- Final scientific report
- Patient/participant feedback (if any)
- Analyzing serious adverse events report (if applicable)

The Principal Investigator should be aware that there might be site monitoring visits at any time from NICCHR team during the project implementation and should provide full cooperation in the team.

Regards,

Chairman

Prof. ENG HUOT
Appendix 3

Request for participation in the research study

**ACTIVITY AND PARTICIPATION IN PEOPLE WHO HAVE RECEIVED AN ASSISTIVE DEVICE FROM EXCEED IN CAMBODIA**

**Background and aim**
A prosthetic or orthotic device can enable a person with a disability to be more active and to participate to a greater extent in everyday activities. There are however limitations in both activity and participation that still need to be overcome and, as researchers, we need your help to identify what these are.

We are requesting your help to identify things that help you and things that limit you, from doing activities that are important to you. Our hope is that results from the study will be used to improve services for people who need prosthetic or orthotic devices.

**Voluntary participation**
Participation in this study is entirely voluntary and you can withdraw from the study at any time. If you choose to participate you will be interviewed about your daily life and activities. If you choose not to participate or choose to drop out of the study your treatment will not be affected in any way.

**Method**
The interview will take approximately one hour and if you feel comfortable, we would like to record it for our own records. If you are not comfortable with recording the interview, we take notes instead. The interview will be held at a location convenient for you. An interpreter will be present if needed.

Your name will not be included on any of the data collected. Results of the study will be presented as a report.

**Researchers:**
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**Supervisors:**
*Nerrolyn Ramstrand*, PhD, School of Health and Welfare, Jönköping

Sisary Kheng, MSc

**Consent**
I have understood the information above and give my consent to participate in the study as described. I am aware that my participation is completely voluntary and that at any time I can cancel my participation in the study. I agree that data from the study is published and distributed provided my identity is not disclosed.

Name of the participant: __________________________
Address of the participant: __________________________
___________________________
___________________________

Signature: ______________________________________
Place and date: __________________________________