

**STRENGTHS AND LIMITATIONS OF USING MOBILE TECHNOLOGY IN  
COMMUNITY BASED REHABILITATION IN A RESOURCE-POOR  
SETTING**

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KARI-PEKKA MURTONEN: STRENGTHS AND LIMITATIONS OF USING  
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**ABSTRACT**

Limited access to rehabilitation, especially in the world's poorest areas, is global health, development, and human rights challenge. Mobile technology and the increase of smartphones in Sub-Saharan Africa has created new opportunities to improve and scale rehabilitation in situations where rehabilitation professionals are few. Research on mobile technology and Community Based Rehabilitation in resource-poor setting is limited both in number and quality.

This research aims to increase knowledge on how mobile technology could improve and scale access to rehabilitation in resource-poor setting. The study has been done using qualitative content analysis. Altogether 28 caretakers from households with disabilities and rehabilitation personnel from Tanga, Tanzania were interviewed. Aim was to get views from present availability and quality of health, rehabilitation, and other relevant services including factors contributing towards self-management and motivation of households. Data was also collected relating to the role of mobile technology in households and in home-based rehabilitation. Participants tested the applicability of AI-powered mobile solution that could provide automated advice and support.

Inductive content analysis was used during the analysis phase. The analysis found external and internal contributors that impact home-based rehabilitation outcomes. Data also shows how mobiles are presently used in rehabilitation and what participants expect from mobile technology in future.

This research provides evidence that when households with disabilities have access to evidence-based information and learning, rehabilitation can be effective, even when rehabilitation professionals are few or not available. Community Based Rehabilitation provides an opportunity for tele-rehabilitation and especially for using AI-powered technologies to automate rehabilitation advise and support. More research is needed on cost effectiveness and how to ensure equal access.

Keywords: mobile technology, artificial intelligence, tele-rehabilitation, Community Based Rehabilitation, rights of children with disabilities, health equity, self-management, resource-poor setting

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## ABBREVIATIONS

AI	Artificial Intelligence
CBR	Community Based Rehabilitation
CP	Cerebral palsy
CRPD	Convention on rights of persons with disabilities
CRW	Community Rehabilitation Worker
CWD	Children with disabilities
IoT	Internet of Things
NLP	Natural language processing
NPHW	Non-physician health workers
OECD	Organisation for Economic Co-operation and Development
UN	United Nations
WHO	World Health Organisation
YDCP	Youth with Disabilities Community Programme

## 1. INTRODUCTION

Limited access to rehabilitation in resource-poor areas is global health, development, and human rights challenge.

Child mortality has been steadily decreasing globally, also in Sub-Saharan Africa. However, the number of children under 5 with epilepsy, intellectual disability, sensory impairments, autism spectrum disorder, and ADH rose by 71,3% from 8.6 million in 1990 to 14.7 million in 2016. Notably, these figures are underestimates since most children with motor dysfunctions and idiopathic disabilities have been excluded from the Global Burden Disease study in 2016. (Siega-Riz, 2018)

A limited number of rehabilitation professionals is one of the main reasons why children with disabilities are not getting access to rehabilitation services in resource-poor settings. As a result, millions of children will never reach their potential, and their human rights are not realized. Also, households with disabilities continue struggling in abject poverty making situation challenging for all family members. (WHO & WorldBank, 2011)

World report on disability states that “In lower-income countries, the focus should be on introducing and gradually expanding rehabilitation services, prioritizing cost-effective approaches” (WHO & WorldBank, 2011, p. 121). Tele-rehabilitation has been researched around the world and evidence is increasing on its applicability. Results vary depending on methods of tele-rehabilitation used or type of support provided. In some disciplinaries, tele-rehabilitation can be more effective than face-to-face therapy. Although, more research is needed, tele-rehabilitation seems to also a cost-effective approach. Tele-rehabilitation should be made an integral part of rehabilitation services also in resource-poor areas. (Salminen, Hiekkala, & Stenberg, 2016; Bright, Wallace, & Kuper, 2018; WHO & WorldBank, 2011)

Due to the high prevalence of mobile phones at a household level compared to any other technologies in sub-Saharan Africa (GSMA, 2018), tele-rehabilitation through mobile phones is most applicable technology to reach households with disabilities. Other tele-

rehabilitation or tele-medicine technologies could be effective as part of providing group therapy, online learning to rehabilitation personnel or ensuring access referral services. Automation of rehabilitation advise and support through use AI-powered solutions could have potential in situations where health and rehabilitation professionals are limited or not available. Further discussion is needed on the role of self-management and self-care in rehabilitation systems before these technologies can be used to scale access to rehabilitation. Tele-rehabilitation technologies are often designed from high income country perspective where the role of rehabilitation professionals is integral. In resource-poor settings tele-rehabilitation technologies and digital strategies should be designed support also informally trained persons or other health care personnel with no previous training in rehabilitation. (Dorsey, Glidden, Holloway, Birbeck, & Schwamm, 2018; Guo & Li, 2018; Wahl, Cossy-Gantner, Germann, & Schwalbe, 2018; WHO & WorldBank, 2011)

Using mobile technology in Community Based Rehabilitation has not been researched widely. Tele-rehabilitation and especially of AI-powered technologies in situations where rehabilitation professionals are few provide many opportunities but are limited in research and evidence. This thesis provides new information to this discussion and deepens knowledge about role of mobile technology in the lives of households with disabilities and rehabilitation personnel in Tanga, Tanzania. Needs of households with disabilities in resource-poor settings are often many and context to provide services is complex. Therefore, results of this study also provide information widely about these complexities that need to be understood before the role of disruptive technologies can be further discussed.



## 2. LITERATURE REVIEW

This research aims to understand how mobile technology could improve and scale access to rehabilitation services in the world's poorest areas.

Literature review begins defining disability and giving a global picture of the present situation. It discusses the rights-based approach to disability following with short introduction to global access to rehabilitation, introducing approaches recommended by the World Health Organization (WHO). The second part of the literature reviews gives an overview of the mobile revolution in developing countries. Thirdly, literature review defines different aspects of tele-rehabilitation with a focus to understanding how mobile phones are used to provide rehabilitation services. Lastly, literature review explains self-management and self-care in rehabilitation mainly from the context of developing countries.

### 2.1 Definitions of disability

There are several different definitions of disability. Definitions have been changing over time.

Commonly agreed, definitions of disability are following:

- The International Classification of Functioning, *states that disability is an “umbrella term for impairments, activity limitations or participation restrictions,” which result from the interaction between the person with a health condition and environmental factors (e.g., the physical environment, attitudes), and personal factors (e.g., age or gender).* (WHO, 2010, p. 17)
- Convention on the Rights of Persons with Disabilities (CRPD) states that disability is an evolving concept and *“results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others”* (WHO, 2010, p. 17)

People's experiences from a disability vary and people are affected of impairments different ways. Some people have one impairment while others have multiple; some are born with an impairment, while others may acquire impairment later. (WHO, 2010).

Generalizations regarding disability should not made as persons with disabilities have diverse personal factors. Each has their personal preferences and responses to disability. Disability often correlates with disadvantage, however not all people with disabilities are equally disadvantaged. For example, women with disabilities can experience additional disadvantages associated with gender. (WHO & WorldBank, 2011)

## **2.2 Disability, human rights, and development**

Globally disability is not only a human rights issue, but it is also a development issue. Convention on rights of persons with disabilities (CRPD) is the most extensive global statement towards equalization of rights of people with disabilities. It outlines the civil, cultural, political, social, and economic rights of persons with disabilities with purpose to “promote, protect, and ensure the full and equal enjoyment of all human rights and fundamental freedoms by people with disabilities and to promote respect for their inherent dignity”. (UN, 2006, p. 4)

The CRPD applies human rights to disability including clarifying existing international law regarding disability. Thus, even when states do not ratify the convention, it helps to interpret other human right conventions to which the state is a party. (UN, 2006)

Article 3 of the CRPD outlines the following general principles:

1. respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;
2. non-discrimination;
3. full and effective participation and inclusion in society;

4. respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;
  5. equality of opportunity;
  6. accessibility;
  7. equality between men and women;
  8. respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.
- (UN, 2006, p. 5)

Disability is also a development issue as disability and poverty are closely linked. Living in abject poverty might lead to a risk of disability or household to have a child with a disability, might end up in poverty. There is increasing evidence that people with disabilities and families are more likely to experience economic and social disadvantages compared to others. Poverty among households with disabilities can increase due to many ways such as its impact on education, employment, earnings, and increased expenditures related to disability-specific needs. (WHO & WorldBank, 2011)

### **2.3 Global access to rehabilitation services**

This study defines rehabilitation based on world report on disability. Rehabilitation is “a set of measures that assist individuals who experience, or are likely to experience, disability to achieve and maintain optimal functioning in interaction with their environments” (WHO & WorldBank, 2011, p. 96). Rehabilitation term covers efforts to support those who have acquired disability congenitally or early in life as well as those who experienced loss of function later. Sometimes word habitation rather than rehabilitation is used when disability has been acquired congenitally or early in life. (WHO & WorldBank, 2011).

According to WHO over a billion people globally have some form of disability and a between 110 to 190 million adults have significant difficulties in functioning. UN

estimates that 80% of persons with disabilities live in developing countries. Evidence shows that rehabilitation can greatly help people whose health conditions lead to a limitation in functions. The global challenge is equal access to rehabilitation. However reliable data on exact need do not exist or is often incomplete and fragmented. Research available concludes however that coverage appears to be low for medical rehabilitation, assistive devices, therapy, and adherence. Also, lack of standard indicators measuring coverage would be needed. (WHO & WorldBank, World report on disability, 2011; Bright, Wallace, & Kuper, 2018)

### 2.3.1 Rehabilitation approaches by WHO

There is an increasing unmet need for rehabilitation globally. The situation is particularly challenging in low- and middle-income countries. “The availability of accessible and affordable rehabilitation is necessary for many people with health conditions to remain as independent as possible, to participate in education, to be economically productive, and fulfill meaningful life roles” (WHO, 2017, p. 3)

WHO has adapted two main strategies to promote rehabilitation services in developing countries. WHO aims encourages countries to improve rehabilitation through health their systems and Community Based Rehabilitation (CBR) followed the declaration of Alma-Ata in 1978. Since CBR has been further developed to become a more comprehensive approach to support disability rights. Affordable assistive technology is an integral part of all these efforts. (WHO, 2015)

#### 2.1.1.1 *Community Based Rehabilitation*

Over 90 countries continue to develop and strengthen their CBR programmes globally. CBR is often implemented as joint of effort on different stakeholders. People with disabilities, their families, organization, local communities and relevant government and non-government services providers. During the years CBR has been shifting from a

single sector approach towards a more comprehensive strategy for rehabilitation. Evidence for the effectiveness varies, but research and programme evaluation is increasing. Also networking and information sharing is happening through regional CBR networks. (WHO & WorldBank, 2011)

CBR guidelines highlight the development and human rights approach to disability with a focus to following.

- Promote the need for inclusive development for people with disabilities in the mainstream health, education, social, and employment sectors
- Emphasize the need to promote the empowerment of people with disabilities and their family members
- Through the provision of practical suggestions, position CBR as a tool that countries can use to implement the Convention on the Rights of Persons with Disabilities.

(WHO & WorldBank, 2011, p. 13)

#### *2.1.1.2 Rehabilitation in health systems*

Strengthening rehabilitation is a development priority with aim to respond increasing need and demand globally. To make sure that rehabilitation is available and affordable to WHO promotes the importance of integrating it to country's health system. (WHO, 2017)

Rehabilitation is part of universal health coverage. Promoting rehabilitation systems includes promotion of rehabilitation in community settings. Rehabilitation in hospital settings enables early intervention. It can help in recovery and help with timely discharge. However, many people require rehabilitation beyond hospital discharge. Also, people with developmental, sensory and cognitive impairments may create long term need for even life-long interventions. These services are often most effective when provided at school, workplace or home environments. (WHO, 2017)

In many countries, rehabilitation is poorly coordinated between different ministries leading to ineffectiveness and overlapping. Promoting rehabilitation in Health systems recommends that the ministry of health is the governing body rehabilitation coordinating it with other relevant ministries. Rehabilitation in hospitals should be made available through specialized rehabilitation units. Rehabilitation should also be available between primary and tertiary levels. Multi-disciplinary workforce contributes to effective rehabilitation, and therefore governments should focus on long-term investments to education, development, and retention of disciplinary rehabilitation workforce. Assistive devices are an integral part of rehabilitation, and therefore availability and financing should be part of rehabilitation systems. In many countries there are no specific budgets for rehabilitation and services are limited. The governments should address this and minimize out-of-pocket expenses that are major barrier to utilization of services. Insurance coverage, where exists, should cover rehabilitation. (WHO, 2017)

### 2.3.2 Availability of rehabilitation professionals

Most rehabilitation systems are designed based on the availability of rehabilitation professionals. There is a much higher demand for services than the availability of those. This is especially true in low and middle-income countries. Sub-Saharan Africa has less than ten physiotherapists per million people while in high-income countries the average number is closer to thousand per million people. With some other rehabilitation professions, such as speech therapists', situation is much worse. (NCBI, 2011; WHO, 2017)

## **2.4 Mobile technology in Sub-Saharan Africa**

Mobile technology revolution in developing countries has helped many countries to leapfrog in some sectors such as banking. GSMA estimates that by 2025 smartphones from 2017 have increased from around 250 million handsets to around 690 million.

Increased prevalence of smartphones leads to large ecosystem increasing opportunities to scale social innovations among poorest communities. (GSMA, 2018)

Africa is the mobile-only continent. In Tanzania, 1.6% of the people had access to computers in 2012. In 2008 the number was 1%, so the growth has been slow. In Uganda, in 2012 2.2% had access while in Mozambique number was higher reaching 7.2% (Esselaar & Lishan, 2013).

Disruptive innovations around technology such as mobile money show how complete sectors are transformed in a relatively short time. In Kenya, mobile money has lifted around 2% of Kenyan households out of poverty. (Tavneet & Jack, 2016) Similar disruptive innovations are expected to happen in other sectors including health. Many innovation hubs around Africa are developing technology solutions to solve some of the big problems in society including health (GSMA, 2018). Large multinational companies, such as Philips are creating new business models around community health. These also utilize mobile technology in new ways. (Partnership for MCNH, 2018).

## **2.5 Tele-rehabilitation**

Face-to-face rehabilitation means a situation where a rehabilitation provider and the client is located physically in the same space. Tele-rehabilitation is about using different available solutions through technologies such as mobile phones, tablets, computers, and game consoles. Tele-rehabilitation should happen systematically focusing on achieving the set results. According to Kela in Finland, tele-rehabilitation is directed and monitored by the rehabilitation professionals. Normally beginning and end of the rehabilitation are defined. (Salminen, Hiekkala, & Stenberg, 2016)

Tele-rehabilitation can have many benefits. It allows access from everywhere and helps those who have difficulty to move away from home. Tele-rehabilitation can decrease travel costs and minimize other inconveniences caused by traveling to receive services. Tele-rehabilitation can also enhance cooperation with families in their real living environment. Also, a multidisciplinary approach can be enhanced using tele-

rehabilitation. Growing evidence of tele-rehabilitation relating to its efficacy and effectiveness shows similar or better clinical outcomes when compared to more conventional interventions. In some disciplines, tele-rehabilitation is more effective than face-to-face rehabilitation. Also promoting physical activity using distance technology-based solutions has proven to be more effective than usual care. (Salminen, Hiekkala, & Stenberg, 2016; Kairy, Lehoux, Vincent, & Visintin, 2009; Hakala, et al., 2017)

Real-time tele-rehabilitation means a situation where rehabilitation professional and client connect through available technologies. Tele-rehabilitation can also mean a situation where the client is doing therapy independently in his or her own time. Therapy is based on instructions received through some of the above channels. Virtual rehabilitation means a situation where rehabilitation is happening in virtual environments. Virtual rehabilitation is used both in the distance or face-to-face rehabilitation situations. Rehabilitation can also be computer-assisted where rehabilitation support happens through different digital channels. Mobile technology-based rehabilitation means technology where mobile phones, smartphones or tablets are in use. Mobile technology-based rehabilitation can also include additional devices connected to mobiles. (Salminen, Hiekkala, & Stenberg, 2016).

Growing evidence on using mobile phones as part of health care in low-income countries highlights future potential of new disruptions. Although evidence is still limited in number and quality, research already shows impact especially around improving treatment adherence, appointment compliance, data gathering and support networks for health workers. Using the Internet of Things (IoT) and Artificial Intelligence (AI) integrated solutions in mHealth provide many opportunities for developing countries. A limited number of healthcare professionals is a major barrier for wider deployment of mHealth. (Hall, Fottrell, Wilkinson, & Byass, 2014; Siddique, et al., 2017)



Evidence shows that tele-rehabilitation can provide high client-satisfaction and in some cases create financial savings to health care systems. Cost-effectiveness is however related to the type of tele-rehabilitation, and more research on economic benefits will be needed (Salminen, Hiekkala, & Stenberg, 2016; de la Torre-Díez, López-Coronado, Vaca, Aguado, & de Castro, 2015). In resource-poor settings using telemedicine is found to be cost-effective. A study in Ghana showed 80% reduction in the overall cost of primary health care when services were supported by telemedicine. (Otsen & Agyei-Baffour, 2017)

Using tele-rehabilitation as an integral part of CBR is still not widely researched, or many studies could not be found. PubMed found 911 articles for *tele-rehabilitation* but with additional search word *Community Based Rehabilitation* only 58, which three studies were related to the resource-poor setting. Publication dates in search were not limited any specific time-frame. Only one to five articles were found using definitions such as *tele-rehabilitation* and *developing country* or *resource-poor setting* or *low-income setting*. Also, searches were done using *e-* or *tele-* or *physio-* or *occupational* or *speech therapy* or *mobile rehabilitation*. *Tele-medicine* and *developing countries* found 635 articles or ongoing studies. *Rehabilitation* and *developing country* search words returned over 2000 articles.

A study done in Pakistan found how rehabilitation professionals believe that tele-rehabilitation can improve access to healthcare in Pakistan. The same study also concluded that CBR programs can be strengthened by using tele-rehabilitation and that tele-rehabilitation can address the unserved needs of persons with disabilities located in remote areas. (Zahid, et al., 2007)

Neurological disorders are main reason for leading to disability globally. Use of technology, including mobiles, to provide neurological care and education using distance methods is estimated to have the potential to improve and increase access to care for billions of people (Dorsey, Glidden, Holloway, Birbeck, & Schwamm, 2018).

Technologies used in tele-rehabilitation often require professionals to design and monitor rehabilitation (Salminen, Hiekkala, & Stenberg, 2016). Potential of tele-rehabilitation to access to rehabilitation at large scale relates to the ability of technology solutions to overcome a situation where rehabilitation professionals do not exist or are limited in number. Artificial Intelligence (AI) powered solutions would have potential to increase health equity in developing countries (Guo & Li, 2018).

AI means a simulation of intelligent behavior in computers. However, there is no generally agreed definition among experts what constitutes intelligence. Some experts have proposed that something ‘acts intelligently’ when:

- doing is appropriate for its circumstances and its goals
- system is flexible to changing environment and changing goals
- system can learn from experience
- makes appropriate choices given its perceptual and computational limitations.

(Mackworth & Poole, 2010)

High-income countries are already benefiting integrating AI into healthcare systems. There are also many ways how AI could transform health care in resource-poor areas. However, little is documented in academic literature on AI applications for health in resource-poor areas. There are many promising general initiatives as ‘AI for Development’ community publications show. In resource-poor settings solutions can for example, help the physician in diagnosis and deciding about treatment. In some cases they could act in place of a human expert if they do not exist. AI is already used in predicting, modeling and slowing the spread in diseases. Natural language processing (NLP) is used in surveillance and prediction of outbreaks. NLP is also used analysing unstructured text in the medical literature to support clinical decision making. AI is already used in helping Community Health Workers in optimizing and scheduling they visits to households. (Wahl, Cossy-Gantner, Germann, & Schwalbe, 2018)

Development actors such as UNFPA and UKAid, among others, are also investing in innovation challenges such as Amua accelerator in Tanzania. Amua focused on supporting innovation for sexuality. One of the results of innovation challenge is service called eShangazi a chatbot that provides information, education and advice on Sexual Reproductive Health (SRH) via Facebook Messenger. Such innovations demonstrate potential of services where access to the right to health information is an important element to achieve better health. (GSMA, 2018; UKAid, UNFPA, Tanzania, & Sparks, 2018)

Like AI-powered health in resource-poor areas, also AI-powered solutions and services around rehabilitation are still not widely studied. Although the potential of AI is discussed a lot, especially by industry experts and visionaries, no studies or research could be identified relating to automation of CBR in a resource-poor setting.

## **2.6 Self-management in rehabilitation**

World Confederation for physical therapy states that self-management in rehabilitation is based on education and support provided by a health professional. The aim is to increase the ability and self-confidence of clients in managing their health and rehabilitation should lead into the empowerment of the client. (World Confederation for Physical Therapy, 2017)

Outcomes of self-management interventions are still not widely documented especially when aiming to identify the most effective characteristics from children and youth with physical disabilities. However, self-management interventions have the potential to improve health behavior. Research has shown that self-management interventions for children and youth with spina bifida and arthritis can improve self-management behaviors and health outcomes. Also, it is shown that parents' involvement should be considered in encouraging self-management behaviors at different stages of their child's development. (Lindsay, Kingsnorth, Mcdougall, & Keating, 2014)

Kela, in its report about tele-rehabilitation, makes clear distinction between tele-rehabilitation and self-management including self-care. Self-care or self-treatment means actions done voluntarily by the person to improve their health and wellbeing. Although rehabilitation is defined to be under the responsibility of the individual both rehabilitation and tele-rehabilitation are directed and monitored by rehabilitation professionals. Kela, however, recognizes that it is not always easy, in practice, to distinguish meanings between rehabilitation and self-care. (Salminen, Hiekkala, & Stenberg, 2016)

In developing country context, or communities where there are shortages of rehabilitation professionals, self-management and self-care might be the only alternative. CBR challenges the role of rehabilitation professionals by empowering other members of community or parents having children with disabilities to support each other. These persons are not necessarily formally trained therapists such as physio-, occupational or speech therapists (WHO, 2010)

### 3. AIMS OF THE STUDY

This research aims to answer the question:

*Could mobile technology improve and scale access to rehabilitation in resource-poor setting?*

To answer the research question, data related to following topics was collected:

- How household with disabilities in resource-poor communities see the realization of their rights including access to health, rehabilitation, and other related services
- Identify factors that contribute towards self-management and motivation of households to provide rehabilitation to their children
- Role of mobile phones in the everyday lives of the households
- Views of households with disabilities about the applicability of AI-powered conversation solutions that could support rehabilitation with or without interaction from rehabilitation personnel.

## **4. MATERIALS AND METHODS**

This research has been done using qualitative content analysis. Materials and methods section begins by explaining the research context briefly. This follows explaining how data was collected and giving basic demographics of the participants. Detailed methodology used, both in data collecting and analysis, will be introduced using relevant literature. It also shows how analysis have been done.

### **4.1 Research context**

Tanzania is categorized among least developed countries according to DAC list of ODA recipients (OECD, 2017). According to the Human Development Index Tanzania is a country with low human development being 154 out 189 countries. (UNDP, 2017) Economic growth of Tanzania has been relatively fast over the last decade. Poverty has declined but due to population growth number of poor not. The population is around 55 million people (WorldBank, 2018). Tanzania Communications Regulatory Authority (TCRA) report says that mobile subscribers in the first quarter of 2018 increased to over 41 million. Mobile money accounts are around 20 million. Internet subscribers in 2017 were 23 million (TCRA, 2018)

Data to this study has been collected in Tanga city. Tanga city is regional capital of Tanga region with around 273000 people. According to 2012 census one-third of households in Tanga region were headed by females. People with disabilities were around 7%. (OCGS, 2012)

Data to this research has been collected with support from Youth with Disabilities Community Programme (YDCP). YDCP is only comprehensive CBR programme in Tanga city. YDCP is owned by Free Pentecostal Churches of Tanzania (FPCT). Government of Tanzania contributes towards human resources. Home based

programme is only one part of the many support services provided by YDCP. Most of the community level work is done by in-house trained community rehabilitation workers (CRWs). According to project leadership, present active number of clients is around 500 households with disabilities. Programme was established in 2004 and has reached thousands of households with disabilities during the years.

#### **4.2 Study subjects and data collection**

28 people were selected to be interviewed. Interviews were done by Kari-Pekka Murtonen (K-P M). Interviews were done through six different focus groups. Five focus groups were representatives from households with disabilities. Each group had 4 participants. Sixth group had 8 people from whom 5 were community rehabilitation workers (CRW). Others were supervisor of CRWs, clinical officer and child sponsorship coordinator.

Participants from households with disabilities were selected from YDCP client register. All geographical locations where CRW's work in Tanga city were present. Household representatives were all women from whom 19 were mothers, and one was relative to mother of the child. CBR supervisor made the final selection of the participants. She was also asked by the researcher (K-P M) to evaluate the poverty level of the household and to estimate how active they are towards rehabilitation. Although client register was used, answers to these two questions are more a subjective view of the staff on how they compare study participants to other clients in the registry. Table 1 gives general information from interviewed households.

Table 1: Basic information from interviewed households

		(n)
<b>Number of participants</b>	<i>Men</i>	0
	<i>Women</i>	20
<b>Household type</b>	<i>Married</i>	9
	<i>Single</i>	11
<b>Child's age</b>	<i>U5</i>	16
	<i>5 and above</i>	4
<b>Diagnosis</b>	<i>Cerebral palsy</i>	17
	<i>Hydrocephalus</i>	2
	<i>Down Syndrome</i>	1
<b>Economic level</b>	<i>Very poor</i>	5
	<i>Poor</i>	11
	<i>Average</i>	4
	<i>Above</i>	0
<b>Rehabilitation activeness</b>	<i>Low</i>	3
	<i>Average</i>	14
	<i>High</i>	3
<b>Home visits by CRW in a month</b>	<i>1 visit</i>	5
	<i>2 visits</i>	12
	<i>3 visits</i>	3
<b>Supervisor seen in last 3 months</b>	<i>Yes</i>	11
	<i>No</i>	9

Data was collected through thematic interviews using the interview guide approach. Interview guide lists the guiding general questions or issues to be explored during the interview. It is designed to ensure that all persons interviewed are pursued under similar guideline. Using interview guide approach in this study helps to ensure that objectives can be achieved since returning to further discussions with interviewed persons was not be possible. It also makes the interview more systematic and helps to ensure more focused on getting data that contributes towards objectives. It is also a relevant approach during focus group as it allows individual perspectives but keeps the interaction focused. (Patton, 2002)

The same interview guide approach has been used with both, household members of children with disabilities and in separate focus group discussion with rehabilitation personnel. Rehabilitation personnel was asked questions only from a different



perspective with the aim to confirm or fill in information for the points that had come up interviews with caretakers.

All interviews were voice recorded. The interview guide for households with disabilities was pre-tested by someone who understands and has been working in the context. Time did not allow to pre-test the interview guide with households. However, the first group interview was done two days earlier than others to see if any changes were needed. Interview guide worked well. The only adjustment done was to shorten time used for the interview. Interviews with each focus group, including the testing of AI-powered conversational solution, took around 1,5-2,5 hours each group. Data was collected between the dates 17-21.3.2018. A separate room was arranged for the interviews at the YDCP office. All interviews in focus groups went well, although some distractions happened during interviews. These were due to some mothers having their children with them or people coming to the rooms during the interviews. Interview questions were in English and Swahili. Sometimes only in Swahili. Answers were translated immediately by the CBR supervisor. However, to save time, not all questions were immediately translated. Researcher (K-P M) understands and speaks Swahili and translated the content during transcribing when it was needed. Questions were generally given to the group and not always everyone was expected to answer. In practice, for most of the questions, participants gave their views or said how they agreed or disagreed with the previous speaker.

At the beginning of interviews, anonymity was explained and permission asked from each person to use the information for the research. All this was recorded. Interview guide was divided to following main areas.

- a) General question about the context: general development and community attitudes
- b) Questions about the use of mobile technology
- c) Questions relating to the situation of children with disabilities including costs of disability and access to services following the WHO CBR matrix
- d) Rehabilitation at home
- e) Other related questions

f) Questions about how the participants saw the tested application

To test the AI-powered conversation solution each group was divided to pairs. The aim was to create a situation where the person gets a basic idea how it feels to use a mobile phone for rehabilitation purposes using interactive conversation solution. The pilot was done using Telegram application as a user interface. Telegram is similar to WhatsApp which is very popular in East Africa. Actual conversation backend solution was done with IBM Watson assistant. The language used in solution was Swahili and discussion content was designed by the researcher (K-P M) who is physio- and NDT therapist. Discussion history was not saved and conversation did not include any elements of collecting medical data or asking information that would compromise anonymity. Conversation solution followed general discussion model of local culture including greetings and then moving towards discussing the rehabilitation needs of the child. The solution was designed to evaluate a child's abilities in gross motor, fine motor, communication skills. Depending on answers received, system automatically provided general advice on how to improve the situation as part of daily activities. The test took between 10-15 minutes from parents to complete. All participants managed to complete in given timeframe, which was 15 minutes. During tests, there were no major difficulties in usability. Some rehabilitation personnel, however, started writing longer answers. The solution had taught participants in the beginning how to answer shortly but this was not the problem with parents. General observation about user experience was done during the test and notes were taken. These are not reflected in results but only shortly referred in conclusions when relevant. Observations were not videotaped, or voice recorded.

The study did not include access to medical records of any kind and therefore did not need further approval from authorities. Approval for the research had been received from the YDCP, and YDCP was responsible for any permits if those would have been needed. Participants will be anonymous in the study. Each participant gave recorded consent for participation and use of data at the beginning of the interview.

### **4.3 Analysis of the data**

In qualitative research, data analysis is often the most challenging part. The focus in data analysis will be to analyze data that will contribute to designed objectives. Once transcribing is finished, the material will be read several times to make the researcher familiar with the contents and quality of the data. Data will be then structured and coded by the discovered categories. (Patton, 2002; Tuomi & Sarajärvi, 2018)

Qualitative research is often divided into inductive and deductive analysis. In inductive analysis, findings emerge from data, while in the deductive analysis data is analyzed according to existing theory framework. Other option would be to do an abductive analysis since there are recognized links with existing theories. In this study, the loose link to theory could be that households with disabilities are self-motivated towards the rehabilitation if given support by the society. Community Based Rehabilitation is based on this theory or assumption. Aim, however, has not been to test this or other existing theories. The aim is to deepen and bring new insights related to research aim. Therefore, the analysis was done as inductive, only looking what comes out from the data. This also helped to ensure, that the households with disabilities, will have their say over professional opinions. Therefore, data has been presented, so that rehabilitation personnel views are separated from the parents. (Patton, 2002)

The aim of using inductive analysis in this study is to try to create a framework from the data of interviewed people. The focus is to generate understanding about the situation and generally about phenomena around research aim without results being influenced by theories or interpretations of individual characteristics. Therefore, only basic background data was collected from individuals. (Patton, 2002)

The manifest structure which focuses on, what has been said was used in analysis for this study. Other option would have been to use latent analysis with a focus to, what intended to be said. However, this would be more challenging due to the bi-lingual

research situation and in a relatively challenging interview environment. (Bengtsson, 2016)

After transcribing the interviews, the analysis started by reading material several times. The reduction was done by separating irrelevant information. In this study, relevant approach to understanding what has been said towards the objective, was to identify meaning units from the original expressions. Some meaning units were one sentence long or shorter. Sometimes meaning units were two or three sentences long. Following the identification of the meaning units researcher (K-P M) checked whether all aspects of the content related to the study aims have been covered. This was done by reading the original data with the list of meaning units. The aim was to distinguish each meaning unit in the text by marking those. When the unmarked text was identified the consideration was be done if those would need to be included. When meaning units were found to answer research questions, those were included. Unimportant information has not been included. However, it needs to be noted that there is a lot of information about the context that might not be directly linked with a research question. All this was still analyzed to understand context better and have a broader base to discuss the research question from a public health perspective. (Tuomi & Sarajärvi, 2018; Bengtsson, 2016)

Following the reduction phase, grouping the data started. This was done by carefully reviewing meaning units and clustering those into sub-categories. Identified themes are done so that no data will fall between different groups. Each sub-category included different, also opposite, views about the same topic. All results have been rooted in the data from which those arise so that each finding can be traced back to original expressions. Sub-categories have been to describe the meaning units as much as possible. (Tuomi & Sarajärvi, 2018)

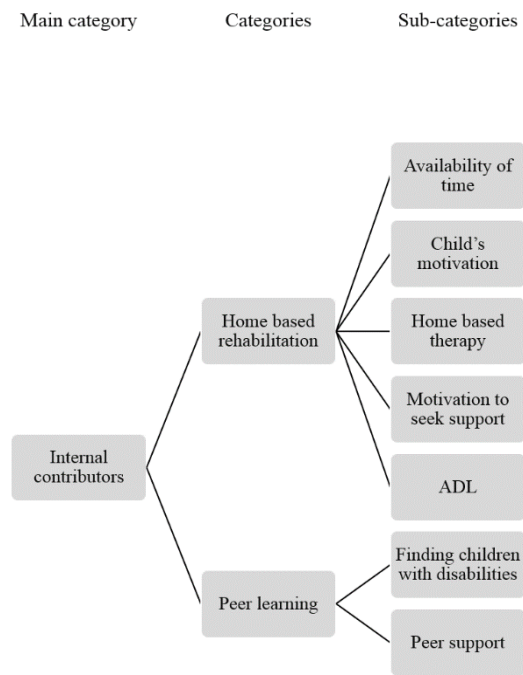
In inductive content analysis categorizing continues so that combining sub-categories categories can be created. All this leads to finding combining categories until the link to the research question is found. After clusters were being created from sub-categories,

actual compilation started. Manifest analysis is being used rather than latent. In a manifest analysis, the researcher works gradually through each identified category and the main categories. The aim is to use the informants' words when possible. (Bengtsson, 2016; Erlingsson & P, 2017)

In this study, quotations from the interviews are used to validate and further clarify points made. When using quotations, the anonymity of the participants is being secured. Any information will not be shared that could lead into the identification of individuals. Information that could lead to identification is focus group identification numbers, location names or references to CBR workers who had selected persons for a interview. Also, any content in quotations, such as words and expressions, that could lead to the identification of the person has been removed.

Seven hundred twenty-six meaning units were identified from the original expressions. These meaning units were then grouped into 50 different sub-categories and then again to 13 higher level categories. Three different main categories have been created from the content to present the findings and answer the research question. Figure 1 shows example how this has been done.

Figure 1: example of grouping



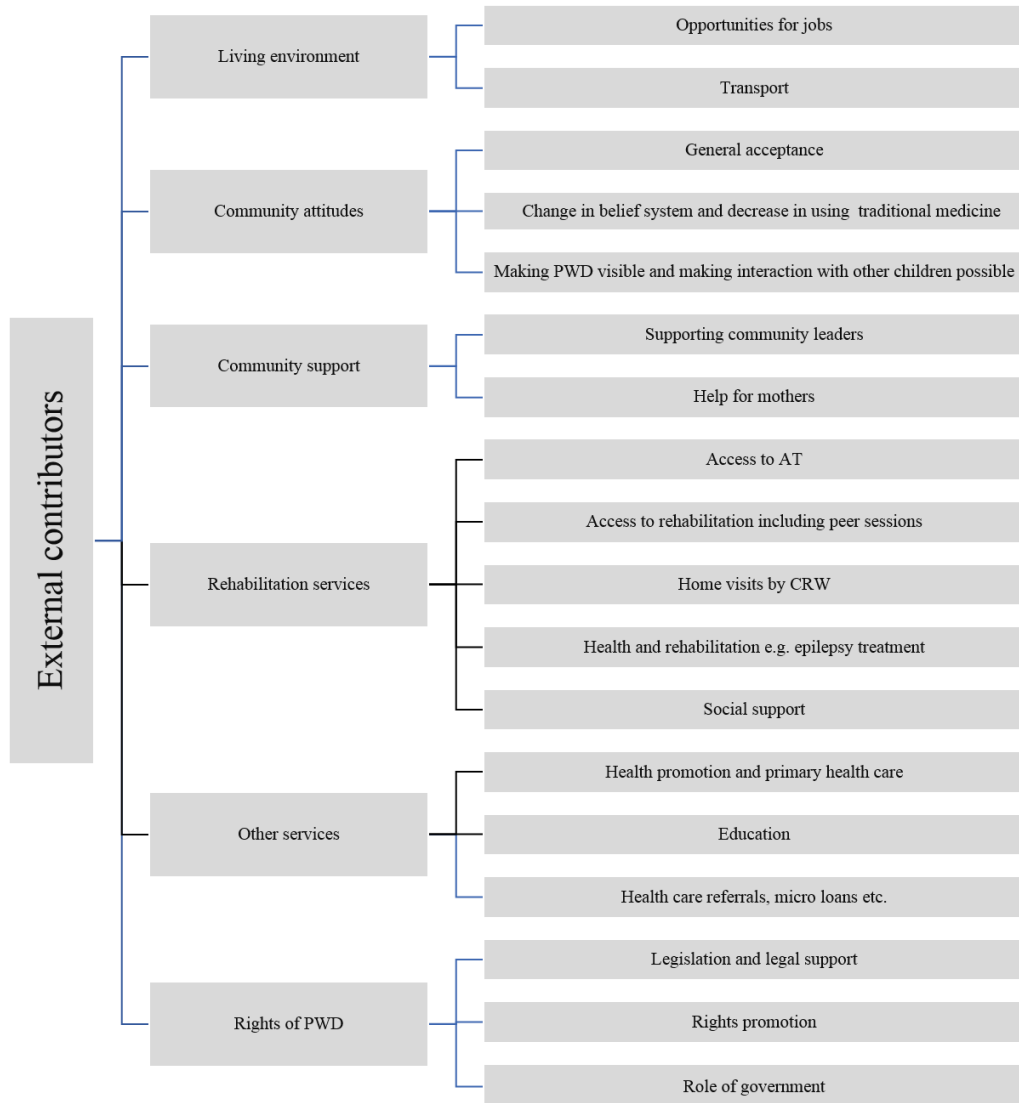
## **5. RESULTS**

Findings of the study are introduced based on categories created through inductive content analysis.

### **5.1 External contributors towards empowerment of households with disabilities**

External contributors towards empowerment of households with disabilities is a category which includes all meaning units relating to services provided by the community and government. It also includes views about attitudes and realization of rights or any other related issue relevant to the research question.

Figure 2: External contributors



### 5.1.1 Inequality and changing living environment

The Tanga city is growing, and infrastructure is improving. In many ways, Tanga is now like other bigger cities in Tanzania. Different small business opportunities are there and generally, city is peaceful without violence. Although all seem to agree with positive developments which are also linked with improved rights of CWD, inequality was also brought up.

*“I think the environment is still not good for us. Some people live in different reality.”*



Main challenges related to the availability of jobs, even for the educated. Also, some people emphasized how life is now harder than before because everything is costly. Many said how transport options are many and those help with a child with disability. However, costs were a challenge, and some people still carry their child everywhere. Also, people living far from city struggle to get services as they cannot join to meet others regularly.

#### 5.1.2 Non-discriminative attitudes and awareness of rights of people with disabilities support rehabilitation

Children with disabilities were said to be many and visible at the community. Children used to be hidden, but the community now understands disability well. Views about community attitudes and perceptions about disabilities varied between individuals. In some cases, attitudes were said to be linked with children's abilities, but mostly this was not the case.

*“even child is not walking or standing, the child is well accepted”*

*“people are positive towards my situation in my area”*

Many positive comments about the present situation were given. Someone stated how changes also encourage them to do best for the children or that children now have equal rights compared to other children.

Some people did not agree and brought up negative experiences or feelings. One person discussed how employers might not give a job when they know that she has CWD. Accepting that people still talk about them or even openly discriminate is hard for parents to accept.

*“It is hard because many times people see that child is not able to do things according to her age”*

Several people said how they should not bother when a stranger is staring or giving comments about their situation. Also having good neighbors helped to accept discrimination faced from other members of the community.

Traditional belief system was said to contribute towards negative perceptions of disability.

*“some people say I have sacrificed the baby to get rich and because of that my child has a disability”*

Most often community advises the use of traditional healers in case of epilepsy. According to the rehabilitation personnel, these beliefs have decreased during the years. Also increase of people seeking for medical services, in case of disability, was said to prove this change. On the other hand, it was also said that some of these traditional beliefs, in case of disability, can be seen among health staff as well.

*“some nurses or doctors also have ‘street beliefs’ about disability, and they blame parents and discriminate them”*

Rehabilitation personnel also confirmed parents’ views about changes in attitudes to be more positive. The community knows where CWD live and help CRWs’ to find them. Advocacy is still done at the community but the challenge brought up was that government health staff is not aware of the specific needs of people with disabilities.

Social interaction between a CWD and other children reflected similar views like when discussing community attitudes. Most people gave examples of how other children try to help and how they come and play with the child. Few parents also emphasized how the presence of other children make their child more active. Some parents told how other children discriminate their children through isolation or even laughing at them.

*“when other children are around, my child is actively trying to talk and play”*

*“other children might isolate when my child cannot walk”*

Children with disabilities take mothers time and finding help with the child is difficult for many households. Due to lack of help many mothers cannot work. According to rehabilitation personnel, this is especially challenging among single-headed households. Sometimes even at family level help was not available because of the child's disability.

*“if someone would look after the child, I could look for small jobs”*

*“life becomes hard because there is no one to help with the child”*

Reasons for people not to help is because in town all are busy and have their responsibilities. Those people who get help, usually get it through their mothers and sisters or sometimes neighbors.

Help from informal community leaders, such as older mothers, can be sometimes helpful and helps to fight stigma. Very few of the mothers had awareness about disability law or laws relating to their situation. This was said to be important by many so that they could protect their children. Rehabilitation personnel said how households do not know about their rights and what to do when problems arise. In case of legal problems, most were planning to go to the police or come to YDCP for advice. Example was given how health service was refused but with help from YDCP, they could take the case to the ministry level.

NGO's and inclusive schools are the main stakeholders promoting rights of people with disabilities. Many said how the government collects data, but nothing has been done or made available to help them. General services like hospital function but disability support from the side government was said not to be there. Rehabilitation personnel said that local government, especially local street leaders, actively participate in joint activities. The government was also said to pay the salary of many professionally trained staff at YDCP.

### 5.1.3 Success stories on outcomes of rehabilitation

Most rehabilitation services that households actively engage with are focused on supporting rehabilitation at home. Parents are highly satisfied how the children are developing, as the result of rehabilitation. Only one person said that there is no change and how she hopes next year to be better. Epilepsy is sometimes linked to child's poor progress, but situation was said to be better after adjusting the dosage at YDCP clinic. Child's improvement is closely linked with motivation to seek support for rehabilitation. The progress motivates parents to talk to other households with disabilities, and they encourage them to bring children for registration. Often change was said to be big as a child could not sit, reach objects and communicate when therapy started.

*“child is now improving and has ability to control neck, reach objects and responds to sounds”*

*“when seeing progress, it gives the motivation to continue and do more as it helps in future”*

*“I encouraged another family to bring their child to YDCP and child is now walking”*

In some cases, parents expressed hope that if they keep doing exercises, the child will become non-disabled. Active rehabilitation was also said to be linked with other issues such as the child's appetite.

Rehabilitation personnel views are in line with parents' statements. Rehabilitation outcomes were said to be linked with parents' activeness. Children are now registered early and therefore rehabilitation outcomes are better.

*“all newly registered children are under five years old but most are under two years old. Even some babies are registered.”*

Positive rehabilitation outcomes also motivate rehabilitation personnel who are working with households. It has been much harder to see improvement when children have been older at time of registration. In the beginning, over ten years ago, children were often

registered much later. Despite the challenge, many of these children, now older, are doing well. Especially those who have a moderate disability are going to school and attending vocation training. Access to inclusive and special schools had helped children to become more independent. According to rehabilitation personnel, it is not only parents who recognize these changes but also the ecommunity. Access to epilepsy treatment increases parents' satisfaction and is main reason why parents were said actively asking YDCP to increase the scope of services.

YDCP is the main provider of comprehensive rehabilitation services in Tanga municipality and surrounding areas. Regional and district hospitals refer clients to the programme even when physiotherapy is available at the regional hospital. Some other service providers are there but only a few had gone to those. Mostly parents only knew YDCP.

*“here we get what we need, but health services are limited”*

*“any places take so much money to get support, but here we can progress”*

*“this place has given skills and knowledge what to do with child”*

*“for therapy it is YDCP”*

Getting access to comprehensive services was said to improve the quality of life. Main services utilized are weekly joint therapy session and home visits done by the CRWs. Observation how therapy is done and doing the same at home was said to be way of learning. Those having child with epilepsy normally come to the clinic on Mondays.

Rehabilitation personnel confirms parents' views stating how they get a comprehensive package from them and how services elsewhere are limited. Other non-governmental service providers use regional hospital therapists as part-time workers. These other service providers refer clients also to YDCP especially in case of assistive technology. YDCP was said to be still main service provider. Others were said to have challenges with quality or limited scope of services. Role of hospitals and clinics in medical rehabilitation is limited. Many said how at hospitals sickness is treated, but no advise or

support given towards disability related issues. However, few people mentioned how hospital staff encourages exercises and being active with the child. They also encourage to bring the child to YDCP. For general health promotion, CRWs also have important role. This is often linked with nutrition support given to undernourished children.

Home visits by community rehabilitation workers are integral part of providing access to rehabilitation services. Institutional services in rehabilitation are limited to joint weekly therapy sessions and around 40-50 caretakers come. Many parents, but not all, said they utilize these services. Sometimes they also visit YDCP to get new exercises. Intensive therapy weeks to teach parents are not available, either by YDCP or another service providers. All have someone visiting from YDCP regularly. Many people said how they are visited weekly, while some said monthly or even more rarely.

*“fieldworkers say there are many families and cannot visit so often”*

*“if lucky fieldworkers come but not necessarily every month”*

*“fieldworkers come weekly and teach what needs to be done next”*

Home visits are highly appreciated and were said to support learning. Fieldworkers do therapy with the child but also give advice. Regular visits are important and valued especially from the learning perspective. Parents appreciate changing the exercises and doing the therapy together.

*“they give advice and encourage school”*

*“very good that they come and give advice”*

Rehabilitation personnel confirms what parents say and how they teach therapy in practice. Each community rehabilitation worker has between 67-95 households to visit. Clients are prioritized and the aim is to visit 20 household in a week. Those requiring more support or have more severe disabilities are visited more often. Parents also actively contact them. If they have not visited the household for a while, they might contact to ask why.

Assistive technology has an important role in rehabilitation and inclusion. Standing frames and corner chairs were generally said to help the child to be active, learn and play with others. Access to assistive technology was mainly through YDCP, but someone had got corner chair from CCBRT Dar es Salaam. Getting assistive devices such as corner chair, standing frame, wheelchair or orthopedic shoes or splints requires parents to contribute financially. The contribution is based on the parent's ability to pay but those who can afford, generally pay the full amount. Someone said how she received free the required assistive device as she did not have any money. According to many, access to assistive technology is a challenge. Many said how the child would need a bigger size assistive device or how they are waiting for one. Someone said that her child would need a corner chair and special shoes but cannot afford.

Rehabilitation personnel agreed with this adding how all who need or would benefit from assistive technology will not have access. Wheelchairs, especially to those with severe disabilities is a problem. At YDCP, CBR supervisor is consulted whenever assistive technology is needed. Assistive technology like corner chairs and standing frames with tables can be produced locally. Several parents say how they got it made locally.

*“neighbor who has a child with similar type disability made corner chair for my child”*

*“father is a carpenter and made corner chair with instructions from the YDCP”*

#### 5.1.4 Access to other relevant services supporting rehabilitation

Interviewed persons talked about many different needs that contribute into their situation. Other support services utilized were primary health care, health promotion, education, and several randomly mentioned services. Few mentioned challenges in access to microfinance. Some parents who had tried to get microloan said they did not qualify, while one parent said that she had got a loan.

Schools and hospitals were said to be available and accessible for CWD. Equal treatment at primary health care centers was mentioned by most interviewed. Someone explained how she needs to travel every few months to a national hospital in Dar es Salaam for a referral service. Someone else mentioned how she has been referred to operation months ago but still waiting.

When a child is sick parents go directly to the government or private clinic. Children are said to get services well, and many say that hospitals really help. Some said she contacts YDCP first. Health services for under five are free, and all parents said this. However, access to medicines was main complaint.

*”got medicine for my CWD after getting paper from the government but government not advocating the option”*

*“sometimes we get medicine and sometimes not”*

Nutrition support is received through YDCP. Even there is general satisfaction towards health services, some parents complain about nurses how they are not polite especially when a child is not gaining weight.

Hospital/clinic staff monitor how the child is doing according to his/her age. Hospital and clinics occasionally do health promotion. Health promotion mostly relates to nutrition and hygiene. Many parents say how health information is mainly received through YDCP. Someone said how all the health information she has received is through CRWs during home visits.

*“fieldworkers also teach about food, cleaning and even how to take care of the house”*

Rehabilitation personnel says that health promotion done during home visits is more effective than health awareness done at clinics. Health center and hospital staff were said not to know real situations in homes. As CRWs visit homes, they can adapt teaching to what are the real needs.



*“when families visit clinics, the child is often washed and clean. However, situation at home can be very different”*

Opportunities to enroll children with disabilities to education have increased. Parents say how CWDs are accepted to schools. Especially inclusive education opportunities have increased. Inclusive education was seen important, but also concerns were shared.

*“inclusive education is important since children interact with others better”*

*“inclusive education can be challenging as CWD can be neglected”*

Many parents would like to send their child to early education but are concerned that child is not or will be independent enough. Opinions about the skills required were different depending on the caretaker. Some say, they will send the child to school when the time is right.

*“child understands everything and therefore could go to inclusive school”*

*“child understands everything but not talking, therefore would like to take her to school”*

*“I see the importance of education but a child cannot do anything like hold objects and only say few words so difficult to imagine school”*

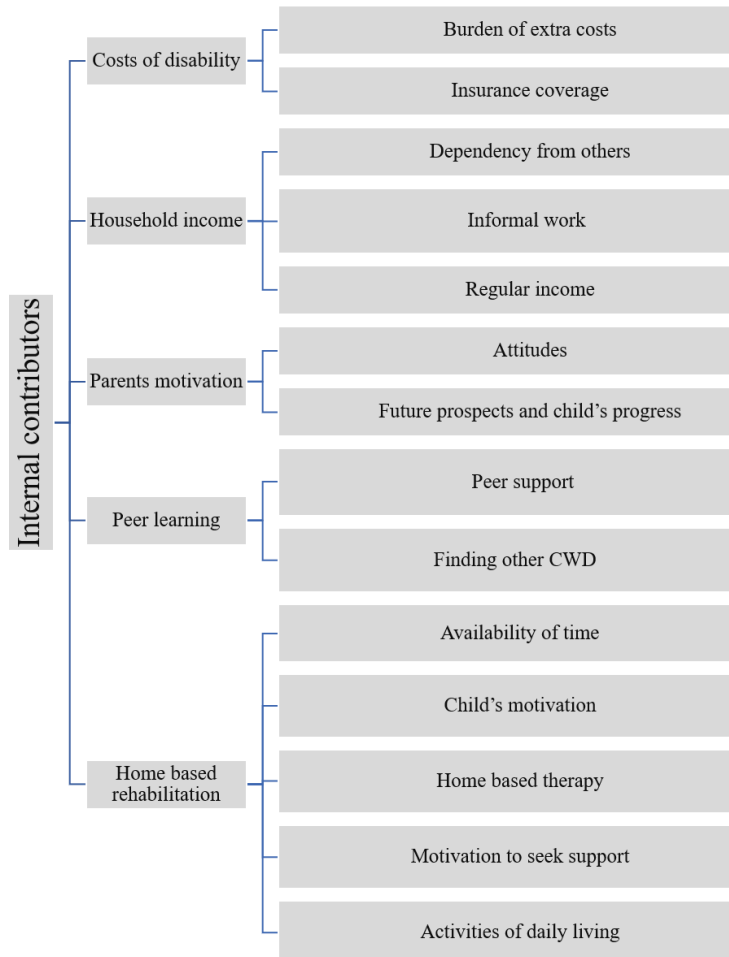
Private schools said to be best option, but affordability was a challenge. Someone hoped that YDCP could open a school for the children. According to rehabilitation personnel, most school-age children they visit go to school. They also help to facilitate enrollment when the child reaches school age.

## **5.2 Internal contributors of the households towards child wellbeing and rehabilitation**

Internal contributors' category includes issues such as parents' general motivation, livelihoods, costs relating to disability, home based rehabilitation and cooperation with

other caretakers.

Figure 3: Internal contributors towards rehabilitation outcomes



### 5.2.1 Caretakers acceptance and attitudes impact rehabilitation

Parents motivation towards rehabilitation and taking care of the child is closely related with belief systems and ability to adapt to the situation. Acceptance of the situation despite many challenges was evident. Acceptance is also linked to community attitudes and behaviors.

*“at first, I was feeling bad and comparing my child to others but now I am used to it”*

*“not all accept disability, that’s how it is”*

*“having CWD is my destiny, we talk, we laugh, and life goes on”*

Parents explain how in the beginning they were looking for reasons why their child had a disability. Some were thinking if it is related to witchcraft. Some take it as something God has given to them. Most parents say that they take their child with disability as any child.

Some mothers shared their experience how the father of the child had run away while others gave credit for fathers making their effort. Many households are single-headed households. It seems to be quite common that fathers leave the mother alone with the child at some point.

*“first, they seek help everywhere and when the situation does not improve father decides to leave the mother (CRW)”*

Rehabilitation personnel explains that sometimes it is hard for parents to understand the real problem and need for long-term support. CWD are also seen as a burden and the whole family might share a child’s nutrition support because the situation is so challenging. Once parents learn to accept the situation and become active, they also take the role to fight discrimination and prejudice. Also, the future was seen mainly in a positive light being linked to the child development and learning. Parents also explain how children could do big things. Someone, however, said that there is a lot of uncertainty.

*“we also advise community and educate them about rights of our children”*

*“child wants to be president and I see good future for him due to improvement”*

### 5.2.2 Child's disability leads to poverty hindering success in rehabilitation

Only very few households said that disability is not causing them extra or additional costs related to children without disabilities. Most people say that costs are higher because of extra health costs and assistive technology. Most commonly mentioned reason for additional household expenditure was a medication that is often not available from the hospitals and needs to be purchased separately. Assistive technology creates one-off costs. Other cost mentioned several times was better nutrition and then buying hygiene products such as diapers. Also, transport was mentioned to contribute towards extra costs.

*“need for transport increases my cost, while non-disabled children could walk”*

Parents also felt despair saying that children should eat better food, but they cannot provide. Also need to be admitted to the hospital every few months was said to be really challenging . The main indirect challenge was an opportunity to work. Child disability needs mother's attention often full time and therefore mothers cannot take available jobs.

Rehabilitation personnel describes that how parents, especially in the beginning, go everywhere to seek support and spent extra money on trying to get child better. They also say that poverty and disability are very closely linked as they need extra money for their children. Not all are households with disability are extremely poor, but most.

Only a few have insurance coverage. Those who have insurance say it helps with health-related costs. Insurance does not cover rehabilitation, but one person said it covers referral services to national hospital. Most were depending on others for income. Some mentioned that the husband is working. Most depend their own parents, relatives, and others. Some lived with their grandmothers or mother in law after husband ran away. In these situations, living with elderly, all were dependent on money given by the children of elderly people.

Only one mother was on a government contract with regular income. Those who had husbands supporting talked less about challenges. Many do informal work like selling food items on the roadside, carrying firewood or doing other small jobs. A child with a disability was a challenge in these situations as well.

*“when doing business to sell small food items, I need to carry a child with me”*

*“people are not willing to give me smalls jobs when carrying the child”*

One mother explains how she needs to search for jobs all the time asking people if they need cleaning or washing laundry. Other mother says that she needs, in addition to everything else, to take care of the husband who does not have work.

#### 5.2.4 Parents active in home based rehabilitation

Most parents see themselves as being active with home based therapy. CRWs’ confirm this but add that all are not as active as they say. All parents say they do therapy with their child at least once a day. However, most say they do therapy more, even three times a day. Someone said that as she is at home, doing therapy has become the normal daily routine. Home based therapy is based on instructions received through YDCP. Many say they link therapy with activities of daily living or play. Also, other specific exercises are done as instructed. Therapy is linked with different phases of child development.

*“now my child can sit independently., so I keep the child in standing position a lot”*

Therapy at home is done mostly by mothers themselves, but some say that the grandmother is helping, or sister is helping. The main reason not allowing others to do therapy related to the level of knowledge on what to do. Only one person said that father is involved in therapy. Someone else said that father refuses because he is scared to hurt the child.

*“I am concerned that others do not well when not trained and they can hurt the child”*

*“other family members also learn from me how to do therapy”*

Children were said to be motivated toward therapy at home. Although, someone added that children do not enjoy exercises especially when it causes pain. Some caretakers describe how child sometimes refuses the therapy or cries. Someone, however, argued that crying is the result of exercise not done correctly. Parents also share how they try with juice and other foods to please the child. Few said that children did not enjoy therapy in the beginning, but now they are mostly happy. Parents said that children are happy when CRWs' come to visit and enjoy when exercises are changing. Some children view therapy as playtime with mother. Many parents emphasized the importance of trying to have therapy as part of the daily routine with a focus to support the child to overcome limitations.

*“my main therapy is just to encourage my child to use affected side”*

*“feeding is my most common exercise, and it is about teaching child to be independent”*

Assistive technology such as standing frame is part of daily therapy. Assistive technology such as corners chairs and standing frames were said to help also social interaction.

*“I put the child to standing frame and leave the child to play with other children”*

Few parents say how therapy is so important to their child that even day without it makes the child very stiff. Motivation towards being active with the home-based therapy was related to the observed change with the child. Also understanding the importance of preventing contractures was mentioned. Changing therapy regularly was said to be important.

For those working away from home, therapy was more challenging, as no-one looking after the child. Also, therapy is seen time-consuming and taking mothers time away from other things. Especially those whose children have more severe disabilities feel that ADL takes a lot of time as the child needs help in everything.

*“I need to go to work far, and when I am back child is not fed well or therapy is not being done”*

Rehabilitation personnel says that some parents are willing to bring children to YDCP for therapy but not willing to do themselves. However, this was said to relatively uncommon practice these days as when the families see children improving it motivates them.

#### 5.2.5 Peer learning and support is integral to rehabilitation

Mothers say how they identify other children with disabilities and provide peer support to each other. Teaching other mothers what they have learned is common practice. Sharing information is often based on own experiences. Parents encourage registration to YDCP and sometimes join to visit to make sure that it happens.

*“I share my experience and encourage other families to bring their children to YDCP”*

*“I use my own experience how the situation has improved to encourage other mothers”*

Communication between mothers and staying in touch with each other is happening regularly, but parents do not come together systematically without the facilitation of the third party.

*“We might meet someone on the street or talk and share, but we don’t have regular meetings”*

The distance was a challenge for peer support as sometimes people live in different parts of the city, but they have become friends through joint sessions at YDCP. When meeting with other mother's, children issues are discussed. Parents exchange numbers and call each other to discuss how their children are progressing. Parents work well together and encourage each other. This was confirmed by rehabilitation personnel.

### **5.3 Mobile revolution in everyday lives of households with disabilities**

Mobile technology has changed everyday life, making things easier for everyone.

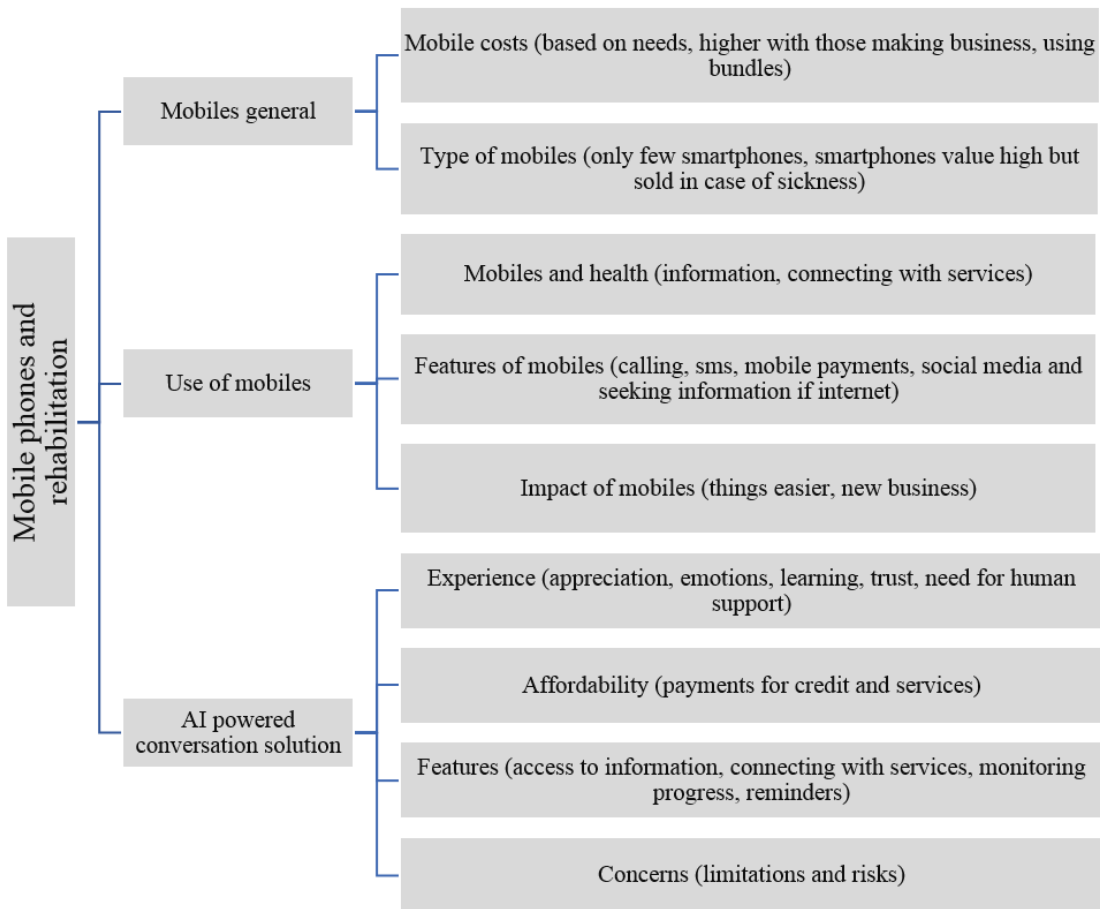
*“before money was given in envelopes to the bus driver to take it to the person in other city but not money can be transferred immediately”*

Mobiles are used for business, and those help some mothers with disabilities to do business. Others can do small business even from home. Those few having internet enabled feature phones are active in social media connecting with people and searching for information.

*Mobile phones in rehabilitation* category include all aspects relating to the use of mobiles. These include costs, features and understanding how mobiles are used to support rehabilitation and health needs of the child. This category also includes caretakers' views after testing the AI-powered conversational solution.



Figure 2: Mobile phones and rehabilitation



5.4.1 Households with disabilities have mobile phones but smartphones are few

All people had mobile phones except one person interviewed. Most phones are basic phones costing less than 50 000 TZS. These phones are without access to the internet, but few have smartphones. Owning a smartphone is valued high, and everyone would like to buy one. However, all say that buying a better phone is not a reason to compromise a child’s health. Also investing in small business was a priority before the new phone.

*“it is interesting to see how some people we know at the community do not own even proper house but have a smartphone”*

*“first is the nutrition and the medical needs and after those you can save little and buy a phone”*

*“we would like to buy a smartphone but when problem come we sell it”*

Few people said how they had smartphones but had to sell those to get medicines. At household level, many people have access to smartphones even if they do not have smartphone themselves. Smartphones are owned by husbands, relatives or other people sharing accommodation or neighbors. Some say they could use these mobiles when needed. In practice, people were said to work late and not being around.

All rehabilitation personnel have smartphones, and most use the internet actively. All households CRWs work with at the community have mobile phones at household level. Still reaching mothers can be difficult when they do not have personal phones.

*“when the father has a mobile, he might be out late or work in another area so reaching mother is difficult”*

Costs are involved when using the phones. Expenditure on buying credit varied widely. Some people spent more than 20 000 TZS a month while others only 500 TZS. Those spending more said it is because they use phones for business. Internet user said to use more, around 10 000 TZS a month. People are generally price-conscious knowing price differences between networks and how different bundles can save costs. When using other persons' mobile, people charged those with credit, if they had money.

#### 5.4.2 Mobile phones are increasingly used to support rehabilitation

All say they have used mobile payments for sending money. Electricity and water bills are paid by mobile phone. Those few using the internet, use it mainly for news but sometimes also for other issues relevant to them.

*“I use mobile phone for reading blogs and understanding how other women are doing”*

Most people use mobiles for calling and receiving calls especially when phone functions are limited. SMS is used actively, especially when not reaching by calling. Some people said that sometimes even 1-2 weeks go without using the phone. Those with mobile internet say they use Facebook or messenger for communication. If they have a student in the household, the internet is used for searching information. Some had also observed how their neighbors use social media.

Many say how they communicate with YDCP using phones and sometimes through SMS. They might call if the child is sick or need nutrition support. Calling and SMS are also relatively common for connecting transport, hospital and schools. Smartphone users use Google, Facebook and Instagram for information. Two different people used Google to search health information or information about rehabilitation.

*“I have tried to learn about nutrition and find information on how to raise a child through google and Facebook”*

CRWs’ use phones to get advice from the supervisor. Facebook, Messenger, and WhatsApp are being used mostly for connecting with friends and relatives. Some say how they refresh their professional knowledge using the internet and look information for learning.

*“I am using internet for learning more about CP and epilepsy”*

All rehabilitation personnel use mobile to communicate with registered clients. Communication is done by using SMS and calling. Mobiles are said to help manage a big number of clients. Sometimes they call a neighbor to get in touch with the family. Mobiles have also made easier to get information about child’s sickness fast, helping to ensure that the child is correctly treated.

*“when a child is doing well we just contact the family by mobile to give advice rather than going there”*

Some ideas were shared how they could use mobile to improve mobile clinics. Someone shared an idea to record video advise for therapy and send it to parent. Low prevalence of smartphones was said to be present limitation to these ideas.

#### 5.4.3 AI-powered conversation solution could support households in rehabilitation

Interviewed were given the opportunity to test the AI-powered conversational solution in pairs. No one had used anything similar before. Most people, in all focus groups, say how it felt natural and how it was like chatting with human. Several people said that it gives hope to them as the system shows interest towards their situation.

*“got hope and would like to have this system for myself”*

*“it can really help and be useful to help the child”*

*“if I had something like this, I could learn so much from it”*

People all said how they would use the solution or similar system if made available to them. Someone even said that since it brings good things to them, it must be human who their chat with and not the machine.

*“I would use the system all the time as it is easy to use and it would help me”*

Different emotions were expressed during the interview after testing the solutions or at the time of using the service. People said how they were laughing and had fun using it or how they did not feel any frustration. Someone said how she enjoyed getting advice after answering questions relating to her child.

*“I am surprised to hear it is not human but machine, it is very human like”*

Some people said that they know it is a machine, but they feel good using it and how to enjoy interactive features. Someone said how it gives a feeling of being valued while someone called it being witchcraft.

*“don't know who I was chatting with but don't really care, it made me happy”*

All people said that they could trust information received. However, it was also said that knowing who gives information is important. Someone said that if the advice they get through the system helps, then information could be trusted.

*“person needs to be behind to teach, and anyway discussion needs to be designed by human”*

Some people say how they learned new things and it helped them to understand importance of exercise better.

*“it helped me to understand importance of communication with child”*

*“could immediately link it to daily household activities”*

Rehabilitation personnel all agreed how the solution could motivate parents to do therapy. Most parents in their view would use it. The solution was said to save time. Someone said with laughter that the solution could replace them.

*“this solution is like CRW, and we will lose our jobs”*

Rehabilitation personnel also saw that solution could increase parent’s independence as they can get information directly when needed. The solution could help families who are far but cannot regularly come for therapy or they cannot visit them. Families from long distance could only come for monitoring while the system would help giving therapy advice. It was also said how it could help in those areas where there are no human resources to help to train therapy.

The main expected outcome from using the service is improved access to information. Getting knowledge was said to be the most important feature where they would see immediate benefits. Information needs to be related to issues such as nutrition and health but equally also learning about rehabilitation was said to be important. Someone mentioned the need for understanding about disability rights and law while someone was hoping to get the opportunity to use mobile for learning about economics.

*“learning how to generally take care of the child would be important”*

*“would like to use it to get information about therapy but also nutrition”*

*“getting advice for economics would important, so I could help child more”*

Someone said that, if mobiles can help them, many things are needed. Other expected features were to have automatic reminders for relevant issues such as daily therapy. Several people discussed importance of this. Connecting and linking with service providers was mentioned, but only by one person. Several people discussed how and if this kind of system could support children directly to stimulate their development.

*“it would be good if the child could use this independently like when she comes from school she would reminded about exercise”*

*“we see value directly supporting kid as they can benefit greatly from attention and stimulation, but parents don’t have time”*

Ability to register their child with disability would be important to some. Also, importance of having a general discussion was mentioned as expected feature. Some telemedicine features were proposed, such as helping to evaluate the need to go to the hospital in case of sickness. In addition to access to information, another proposed feature, by many, was to help them to understand the child’s progress.

*“would like to use for understanding about child progress”*

*“important to see how my child is progressing and to know if therapy should be somehow changed”*

Few people also discussed the opportunity to connect socially with others to learn together

*“could help others as we could get together and use this system to get help and discuss”*

Question and answer type of way communicating and learning through the system was mentioned by few to be good for them. Someone mentioned the importance of just being

able to ask someone through when there is a problem. Some people hoped that system would encourage inclusions such as reminding to take the child out to the community and the beach. Also learning about rights was said to be important.

*“if child is hidden at home, system could encourage to take him/her out to the community”*

Rehabilitation personnel said how system could support to teach the same issues what they teach parents. One challenge highlighted was that in peer learning groups not all learn equally well and need more repetition. Also providing support between the home visits was said to be an important feature. It was also said to help to decrease pressure from the families when there is no time to visit all.

*“we could teach for example eating and after a month monitor the progress. Meanwhile, system could support the family rather than them spending time explaining why there is no time to visit them more often”*

Using credit for internet or sending and receiving messages was not seen a problem at all. All were willing to buy credit for the purpose if the system provides them benefits.

*“if I want to discuss my child issues, I will buy credit, but the system needs to help me”*

*“would buy some credit to have the service and maybe even get monthly bundle”*

The issue about paying extra to access to use the service was also discussed. Payments were positively received saying how they are willing to pay since they need service like this. Some people were willing to pay relatively large amounts compared to the general costs of using mobiles.

*“10-20 thousand a month would not be problem if it helps the child”*

*“I would definitely pay extra to use the system”*

One person, however, said that, if there is no money, cannot pay extra even if she needs the system.

Few limitations were evident when testing the system. Some people said that system should support instruction through video. Several said that at least picture would be needed. This related mostly to learn how to do therapy.

*“video would be really good, and then I could learn better”*

Limited features were also seen as risk of the system. Some caretakers brought up that chatting can be done, but it can lead to misunderstanding what to do.

*“chatting can be done but mistakes can happen when doing exercises”*

The main risk for wider use was said to be a low number of people having smartphones. Also, someone said that how not knowing whom they chat with was confusing.

Rehabilitation personnel saw risk that people are not used to this kind of solutions, and those who cannot read will not be able to use the system. Also getting false information where parents are not telling the truth could impact and lead to wrong advice. Someone said how some parents might not have time to chat.



## 6. DISCUSSION

This research aims to answer research question *Could mobile technology improve and scale rehabilitation in resource-poor setting?*

Results from this study show how mobile technology has changed the lives of households with disabilities, even the poorest, and is already being used different ways to improve CBR. There is a high potential in using AI-powered solutions to support households with disabilities in self-management, with or without rehabilitation professionals. The main challenge in wider adaption of technology in rehabilitation at resource-poor setting relates to connectivity, access to smart devices and need for comprehensive support.

This study also found that general development, including economic growth, is not necessarily benefiting poorest households. Disability is closely linked with abject poverty. Disability increases costs and having a child with disability also leads to loss of income as caretakers often need to take care of the child. The burden is often on females in the households. Results show how Community Based Rehabilitation can help to decrease discrimination in communities. Finding indicate that self-managed rehabilitation at home can be effective, especially when households have access to relevant knowledge. Assistive technology, referral medical services, and epilepsy medication are related services needed to succeed in home-based rehabilitation.

To discuss results more in-depth, the discussion begins discussing context and rehabilitation outcomes. This follows discussion about results related to the role of technology in rehabilitation in a resource-poor context.

## 6.1 Discussion about results

This study found that home-based therapy done by caretakers with support from CRWs can be effective in achieving functioning and independence. However, making a further conclusion about whether maximal or even optimal potential of children have been reached cannot be done. Findings suggest that comprehensive or holistic approach is required to provide and succeed with rehabilitation among children with disabilities in a resource-poor setting. This is in-line with WHO CBR guidelines (WHO, 2010). Several studies globally support finding that home-based rehabilitation can be effective. Home-based rehabilitation with children with cerebral palsy (CP) can ensure the valuable, more family-centered approach to achieve increased treatment intensity (Ferre, et al., 2017). Home-based care among children with CP also seems to support better quality of life than institutionalized cared. Home based care is also more cost-effective (Sharif, Ravanbakhsh, Torabipour, Amiri, & Haghhighzade, 2015).

In this research, word rehabilitation has been used for both habilitation and rehabilitation. According to World Report on Disability by WHO and World Bank, Swedish disability policy 2006 described *habilitation* as aim to help those who get disability congenitally or early in life to reach maximal functioning. *Rehabilitation* is used when assisting those who have experienced loss in function later in life to regain their maximal functioning. The concept of maximal functioning is challenging and can include different approaches to disability and rights. WHO makes, in relation to United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities, following statement: “States should ensure the provision of rehabilitation services to people with disabilities in order for them to reach and sustain their optimum level of independence and functioning” (WHO, 2018). Optimum level is often also described to be related to persons living environment. To achieve the optimum independence and functioning, world report on disability states that rehabilitation is multi-disciplinary and supported by health professionals in conjunction with other specialists. The report also recognizes that in resource-poor contexts rehabilitation may involve non-specialist workers such as community-based rehabilitation workers and household and community members. (WHO & WorldBank, 2011; WHO, 2018)

Available global research cannot provide full evidence on the appropriate amount of therapy, benefits of assistive devices or make a conclusion between different rehabilitation approaches in providing support to achieve a maximal or optimum level of functionality. Even though, for example, physiotherapy and occupational therapy are an integral part of rehabilitation programmes around the world, there is surprisingly little evidence on the impact of the different interventions. However, it has been recognized that the role of therapist and multidisciplinary workforce can be central towards positive functional adaptability to disability. Therapy can be successful when linked to concrete and realistic goals in everyday life. (Heiskala, 2000; Lucas, et al., 2016; Anttila, Autti-Rämö, Suoranta, Mäkelä, & Malmivaara, 2008).

Caretakers and rehabilitation personnel views, without professional assessment of children, can be used to conclude that rehabilitation is effective. Caretakers of children with disabilities understand best the functional adaptability in a home environment. Also person-centered health care support the role of using health care users as evaluators of health care services. Person-centered health care can also improve access to health care for all, not just some. Evidence also suggests that health care organizations can have better coordination, cooperation, and social trust when operated person-and people-centered way (Cloninger, et al., 2014; WHO, 2016). Health ministers from various Organisation for Economic Co-operation and Development (OECD) countries recently concluded that reliance on mortality rates and clinical indicators gives only a partial view of the value of health care. Measurement focus should be more on citizens wellbeing and their ability to play an active role in society. Only, way to evaluate this, is to allow people to give their opinions themselves (Coulter, 2017).

Caretakers interviewed in this study describe how children progress and develop new skills. These views are confirmed by the rehabilitation personnel who visit and know home environments. In resource-poor setting like Tanga, Tanzania not all people access rehabilitation services. The challenge can be due to distance or through limited resources

of service providers such as government or other actors to meet the demand. In such situations, self-management and self-care skills are important. It could be argued, based on findings of this study, that first element in any rehabilitation system should be to ensure access to basic reliable health and rehabilitation related information. Access would ensure that households with disabilities can practice evidence-based self-management and self-care in situations where systems fail to provide comprehensive support on equal levels to all. Access to information and understanding how children develop was valued high by households with disabilities also when discussing the role of mobile technology.

Ensuring access to health information is in-line with WHO statement that “all people should have right to a system of health protection that gives everyone an equal opportunity to enjoy the highest attainable level of health” (WHO, 2017) Part of the right to health is access to health information and education, that allows people to make informed decisions. Also, in any rehabilitation systems, the optimum level of independence and functionality cannot be reached, unless people themselves, or in case of children, caretakers are motivated and active. Health care providers should see people with disabilities as right holders whom they are accountable. (WHO, 2017; OHCHR & WHO, 2008).

*External contributors* supporting home-based rehabilitation include living environment, community attitudes, community support mechanisms, availability of rehabilitation and other relevant services, including general recognition of the rights of people with disabilities. Caratakers of CWDs explained how general development is not benefiting them and inequality is a reality. Primary health care services are functioning and helping in case of sickness. Parents feel that epilepsy treatment from the government is not working or is poor quality. Referral services and epilepsy clinic at YDCP are important services valued by caretakers. Access to assistive technology is also important but not accessible to all. This gap in services contributes towards inequality since some can afford to contribute and others not. Community attitudes and support has a key role in empowering or disempowering households with disabilities. Results also show that

negative attitudes can be overcome and parents and children themselves have a role in teaching the community. To do this effectively, there is a need to access to information, learning and support services. Home-based services are valued high as those help caretakers with knowledge and skills.

*Internal contributors* to support rehabilitation include costs of disability, household income sources, caretakers' motivation, activeness in home-based rehabilitation and different ways of peer learning. Many households with disabilities interviewed in this study were among poorest and most disadvantaged people of the community. Sixteen out of 20 households were said to be poor or very poor while four households were average. Disability creates extra costs for household and sometimes leads to loss of income as caretaker cannot work. Insurance coverage is very low and related only to health care cost recovery, not including rehabilitation. When the family gets a child with disability they spent money and time searching for help to find answers and faster solution. It takes time to accept the situation and commit to long-term rehabilitation. Sometimes father divorces the mother when the situation does not improve. Once the situation stables, mothers are mostly in charge of rehabilitation. All caretakers, except one person, described how their children are improving and how achievements motivate them to continue being active with home-based therapy. Most caretakers also explain how the community is increasingly accepting disability. When negative attitudes such as stigma and discrimination were mentioned, caretakers felt they could overcome those.

Conclusions from the results of this study strongly support the view that resource-poor countries should focus on finding alternative and more cost-effective models of rehabilitation that are less dependent on availability of rehabilitation professionals. Rehabilitation systems should be based on the empowerment of households with disabilities. This study shows how rehabilitation at home is done actively and children progress. Cycle of poverty and disempowerment in urban settings is related to availability of support for mothers e.g. someone to look after the child when going to work. Financing services that include heavy investments such as long-term training needs of rehabilitation professionals should not be a reason not to ensure immediate

access to information, equipping caretakers for home-based rehabilitation and providing highly needed community-level social services.

Rehabilitation achievements by caretakers is happening in a situation where rehabilitation services are limited and mainly dependent on non-specialists such as CRWs or peer support by other households with disabilities. Presently, at YDCP, there is only one rehabilitation professional per around 500 households with disabilities. During the last three months, at time of the interview, formally trained rehabilitation professional had seen 11 out of 20 households once and nine out 20 zero times. Achievements described by caretakers are therefore mostly based on households' own activeness and self-management skills. However, it is evident that caretakers have learned skills and gained knowledge through CRWs visiting households regularly. In addition to advice, CRWs also support households holistically providing nutrition advise and support, hygiene training or facilitating school enrollments. CRWs receive knowledge and supervision from a rehabilitation professional. Both, caretakers and rehabilitation personnel views highlight how access to assistive devices, epilepsy medication, referral services, and inclusive and special needs education all seem to contribute towards positive rehabilitation outcomes. Assistive devices were seen very central in facilitating social interaction as well as allowing time for mother for other duties. The discussion paper by UNICEF and WHO relating to assistive technology and inclusion also supports this view (UNICEF & WHO, 2015).

External and internal contributors show many needs and provide insights to understand how support systems for children with disabilities need to be comprehensive. In resource-poor setting, services are often limited, and not all needs can be met. Also having the multidisciplinary workforce to support rehabilitation is not always possible. The findings indicates that empowering households with disabilities towards self-management and self-care can be a most effective way towards ensuring the rights of children with disabilities. Role of rehabilitation professionals can be important even in resource-poor setting, but mainly as a source of evidence-based information as well as for monitoring of child progress. In rehabilitation professional driven rehabilitation in

resource-poor setting, fewer people will benefit as a number of households one person can support is limited.

Mobile technology can improve and scale rehabilitation in contexts like Tanga, Tanzania. Mobile technology at YDCP is already used to communicate with households. One CRW can have over 90 households to visit, support and monitor. Mobile technology helps to manage this. Advice for therapy is sometimes provided through mobile phones rather than going physically to the home. Mobile technology can help to save time, manage referrals and consult supervisors as well as maintain and update skills of rehabilitation personnel. However, there is no systematic approach or model in place at YDCP to do this. How mobile technology is presently utilized is based on the interest of individual rehabilitation personnel or activeness of households with disabilities to seek contact through use of mobile technology.

Those few caretakers who have smartphones seek information and try to learn to do more for their children using the internet to find information. Mobile technology is an integral part of people's lives and owning a smartphone is valued high. People buy smartphones but sometimes need to sell those when a child gets sick. In future, cheap smartphones will be owned by most households including mothers. Presently only a few have those. Rehabilitation personnel during the interviews already suggested different ways how they could support households by sending videos or pictures to advise therapy. Main concern, however, is limited number of smartphones among families. Use of mobiles and prevalence of smartphones among interviewed persons correlate with reports from GSMA Intelligence (GSMA, 2018). As the prevalence of smartphones is foreseen to increase in future, developing tele-rehabilitation services that utilize features of smartphones could lead to new innovation and disruptions. Presently these services could focus more supporting CRWs. Some ideas shared by rehabilitation professional included also using technology in group therapy sessions around the community where occupational therapist could be consulted from many places at once.

This research included testing of the AI-powered conversational solution. Technology can be used through social media channels such as Messenger, WhatsApp, Telegram etc. Users do not need to download and update separate apps as automated discussion is done through above channels. Tested solution was designed to assess child's development using chat feature and provide basic advise to caretakers. The aim was to evaluate how caretakes feel about automated advise and support provided without direct human interaction. Caretakers and rehabilitation personnel both found tested solution to be relevant in the context, if access to smartphones could be ensured. Added value was seen especially in places where there are no rehabilitation personnel available. Parents were even willing to pay monthly fees to have access to the service. In practice, this could lead to inequality in access if this kind of system would be made the integral part of CBR. Connectivity and limited availability of smartphones will require careful consideration. Rehabilitation personnel suggested an approach where they could focus monitoring and providing more overall advise while weekly therapy would be supported through mobile technology. This way more people could be assisted. This could be done without or with minimal human interaction depending on how technology would be developed. In view of households with disabilities, automated solutions need to be able to share information widely and need to be designed so that learning is ensured multiple ways e.g. using pictures and videos. Getting access to health and rehabilitation related information and getting support to monitor child's progress were highly expected features by caretakers. A limited number of research makes it challenging to discuss these findings further. There is however some supporting evidence from a study done in Iran how training through mobile technology can improve the knowledge of caregivers about the daily care of children with cerebral palsy (Ghazisaeedi, Safari, Sheikhtaheri, & Dalvand, 2016).

As mentioned earlier, household with disabilities need comprehensive services to succeed with home based rehabilitation. Mobile technology can also provide support in most of these needs, if not all. Many households with epilepsy mentioned access to quality treatment as an important contributor to rehabilitation outcomes. The WHO has a strategy for non-physician health workers (NPHWs) to diagnose and manage people with untreated epilepsy. The success of strategy depends on them having access to



suitable tools. The study was done in India how NPHWs compared with making diagnosis by local physicians and a neurologist. NPHWs used an mobile application developed for the purpose. In the study, NPHWs achieved similar misdiagnosis rates when compared to local physicians. Findings suggest that epilepsy diagnosis and management could be done by NPHWs if enabled with appropriate technology. (Patterson, et al., 2018)

Mobile technology can also be used to provide advice how to make assistive devices locally. Many have locally manufactured devices that have been done based on advice from YDCP. Motivation, UK based NGO, is piloting 3D printing wheelchair parts with Google (Motivation, 2018). 3D PrintAbility is an innovative toolchain that Nia Technologies, an innovative Canadian not-for-profit organisation has developed with researchers at the University of Toronto. “Toolchain improves on the traditional way of making prosthetics and orthotics by reducing the amount of time and money needed to make a device” (Nia Technologies, 2018). Mobile technology can also help in advocating the rights of people with disabilities with the aim to change community behavior towards people with disabilities. Evidence indicates that especially in low- and middle-income countries the high prevalence of mobile phones highlight a opportunity to impact health behaviors globally (Zhao, Freeman, & Li, 2016).

As shown above, technology can help different ways in resource-poor setting also when comprehensive services are needed. CRWs in Tanga Tanzania, help households to navigate these different needs for service and provide support comprehensively. Tele-rehabilitation in resource-poor setting should be designed to help to navigate all these different services similar way. Should this be done using technology or equipping community mobilisers such as CRWs or parents themselves to be digital focal points to others will most likely depend on context and resources.

Even if technology is not used as described above in future, it is important to ensure access to evidence-based health and rehabilitation information. Households with

disabilities and rehabilitation personnel seek health and rehabilitation information when they have access to the internet. This can lead to several risks in situations where health systems are broken or limited, and people seek knowledge using mobiles. Ensuring evidence-based health information around community health and making it digitally available for people could mitigate these challenges (Braun, Catalani, Wimbush, & Israelski, 2013).

More research is urgently needed in all areas of rehabilitation in resources-poor settings. Also, research is needed to make better conclusions about how mobile technology can contribute towards improving access to rehabilitation at a larger scale. An important area of future research is to study the role of different support services and how those contribute to caretakers motivation and activeness towards home-based rehabilitation. Caretakers felt how tested technology could give them human-like encouragement and motivation. For example, randomized controlled trials could help to understand if mobile technology can facilitate caretakers' activeness at similar levels as now is happening.

This research also found how caretakers are active, supportive and teach others. Further research would be needed to understand how to extent these peer learning mechanisms to be integral part of rehabilitation systems and what role technology could have. Most families are very poor and do not have access to the smartphones. Also, economic analyses and research on cost-effectiveness is needed to understand whether subsidizing mobile phones for households could be used to enhance rehabilitation outcomes and decrease disparities.

Main future research area, related to this study, would be development of new technologies. Machine learning and AI can provide many opportunities to enhance tele-rehabilitation to be less human dependent. Simple advice and shared knowledge can be beneficial to caretakers, and this can be easily digitalized. However, understanding how

rehabilitation in a complex environment can be managed and supported digitally using AI can prove to be difficult in practice.

## **6.2 Strengths and limitations of the study**

Limitation and strengths are identified in both, collection and analysis of data. Different limitations are recognized in this research.

Research was done in resource-poor community where most interviewed people are among poorest people in the world. These people have access to some rehabilitation services which is not the case everywhere. To answer research question, this was required allowing participants to discuss more in-depth how mobile technology presently helps and how it could help rehabilitation in the future. This could have been difficult in situation where households would not have had any previous experience from accessing rehabilitation services.

The main limitation regarding the data relates to the relationship between the researcher (K-P M) and people interviewed. For example, gender and position of the interviewer can have an impact to the ways interviewees answer. This research was done in an environment where language and interpretations including cross-cultural communication can have an impact to data. Participants might have the interest to please researcher, want to emphasize something based on their interests or said things can have different meanings than being said. (Hofstede, Hofstede, & Minkov, 2010; Taylor, 2005)

Researcher (K-P M) recognized the above limitations and the effect his role can have for the study. Therefore, the researcher (K-P M) could minimize these effects during the interviews. Some strengths that helped to do this study in cross-cultural situation were that researcher (K-P M) speaks the local language, understand the culture and tradition

after spending a big part of childhood and later part of the adulthood in the context. This allowed researcher (K-P M) to have in-depth discussions with interviewed people and capture interviewed persons own words also without the translator. (Hofstede, Hofstede, & Minkov, 2010; Taylor, 2005)

Limitations during the analysis relate mostly to the researcher (K-P M). Researcher (K-P M) has worked many years developing and advocating home and community based rehabilitation services in developing country context. Also, researcher (K-P M) was working at YDCP when it started in 2004 and worked there until 2009. This history could influence some pre-assumptions and have an impact especially to analysis of the data. To overcome these biases careful consideration and interpretation of the data was done. Original expressions have been reviewed several times. Translations have been checked carefully to understand the real meaning and to overcome biases. Before data collection, researcher (K-P M) made a list of some pre-assumptions on possible conclusions related to the aims of the study. This list has been used to reflect findings against pre-assumptions to ensure more objective views towards the findings. (Tuomi & Sarajärvi, 2018)

The staff of YDCP selected households with disabilities for interviews. Selection can have impact in the study when making a conclusions and when discussing possible public health consequences of the study. This is because selected persons might represent only clients with certain motivation levels or interests, rather than whole client base. Results of the AI-powered conversation solution could include some biases. All people said to dream about having smartphones. Test was done with more expensive smartphones leading to the situation where participants could have enjoyed the use of phone rather than just the solution. People could also have said positive things to please the researcher.

### **6.3 Ethical considerations**

Parts of ethical considerations have already been integrated into discussion. Main ethical issues in using mobile technology in rehabilitation relate to finding the balance between equal access, quality, and role of self-management. Findings from this study supports the view that access to information should be integral part of rehabilitation services. In the situation where services are limited, equal access to information will ensure that households with disabilities could provide at least some support to the person with disability.

Mobile technology can enable information sharing already now but more in the future as mobile prevalence increases. Important ethical consideration, therefore, relates to access to mobiles and connectivity (GSMA, 2018). The digital divide between men and women or poor and rich is major development challenge of future. Digital divide is not only about access to devices and connectivity but skills and digital literacy (Singh, 2017). The internet enables connections between people. Different tele-rehabilitation services can enable getting access to rehabilitation without borders. However, this is not always easy legally or even ethically possible (Anthony, 2015). When designing tele-rehabilitation services cognitive, motor and visual perceptual skills of the person seeking rehabilitation need to be assessed (Brennan, et al., 2011). As results of this study show, this will not always be possible due to a limited number of rehabilitation professionals or lack of service. Also, other issues such as illiteracy among caretakers need to be considered.

Before providing services using tele-rehabilitation technologies, providers need to be familiar with laws and regulation of the country. Important is to understand legislation relating to materials created with the client and how data is stored. Data privacy and protection needs to be ensured (Schmeler, et al., 2010; Brennan, et al., 2011) This study shows that using communication channels such as Messenger, WhatsApp, Telegram etc. can be good way to connect with clients. However, data privacy and protection could

be comprised and will require further consideration when designing automated, easy to use services. Other recognized challenge is a lack of legislation and legal protection. This study also showed that people are not always aware of the rights of disabilities or how to get legal support. Same challenge will be related if scaling the use of mobiles in rehabilitation. Service providers need to recognize the need for cultural capacities including language and ethnicity. All these can impact quality of services and results to be expected (Schmeler, et al., 2010)

This study suggests further studies relating to use of technologies such as AI and machine learning to further understand how rehabilitation could be automated. This will require a separate ethical framework. Kela in Finland, in its report on tele-rehabilitation, concludes that level of quality of tele-rehabilitation needs to be at least on same level with face-to-face services. Report also states that it is ethically important that users of tele-rehabilitation are satisfied with the service (Salminen, Hiekkala, & Stenberg, 2016). When discussing the role of automated services, same principals could guide the work. Also, in resource-poor setting, extending basic services more equally to all is a relevant ethical argument for trying different technologies. The other side of this discussion is a situation where responsibility of rehabilitation through use of technology could be increasingly left to households with disabilities. On other hand, enabling access of households with disabilities to evidence-based information relating to disability is important ethical discussion. This study shows how once people get access to the internet, information is used to support self-management or provide advise to others. If evidence-based information is not available in easily accessible format, there could many risks especially in areas where professional support is limited or not available to transfer correct information to caretakers.

As mentioned in the literature review, research related to using technology in rehabilitation in resource-poor setting is limited. This makes ethical discussion also complicated. Global research should focus more on rights-based approach finding innovative solutions to fulfill UN convention on rights of people with disabilities. Ethical discussion is also needed in the research community and how resources are

allocated. Now much of the global research is done based on high-income country interests that does not serve global needs or needs of resource-poor communities.

## 7. CONCLUSIONS

This research found that mobile technology can help to improve and scale rehabilitation of children with disabilities in resource-poor areas. However, increasing global access to rehabilitation using technology will be challenging without further discussion on the role of self-management and self-care in rehabilitation systems. CBR provides an opportunity for tele-rehabilitation and especially for using AI-powered technologies to automate rehabilitation advice and support. Based on findings of this study, views where rehabilitation professionals are required to direct and monitor rehabilitation, could be challenged. More important, than availability of rehabilitation professionals, is to ensure households with disabilities to have access to evidence-based information and learning.

Globally, tele-rehabilitation is often designed or legislated to be strongly dependent on the availability of rehabilitation professionals. Professionally driven rehabilitation is a challenge in a resource-poor setting as rehabilitation professionals are few and having multidisciplinary rehabilitation teams will often not be possible. AI-powered technologies, that can perform simple assessments, learn from context and suggest treatment with or without human monitoring, could help to ensure basic access to rehabilitation. Increase of smart devices and ensuring affordable connectivity in Sub-Saharan Africa will enable this at large scale in future. In wider adaption of technology, rehabilitation systems will need to focus to ensure that no-one is left behind.

Rehabilitation can be successful even when rehabilitation professionals are few or not available or when the context is complex and challenging. This study contributes towards growing evidence that comprehensive CBR can lead to improved rights of people with disabilities in resource-poor areas. Views about positive rehabilitation outcomes among study participants are closely related to household's own activeness and motivation. Knowledge and support are received through CRWs and is highly appreciated by households. Households with disabilities in this study see mobile technology-based automated and smart solutions as a relevant option to support home-



based rehabilitation. In their view, solutions need to be able to share information widely and need to be designed so that learning is ensured multiple ways such as through using video and pictures. Important for caretakers is to understand and observe the child's progress.

This research cannot conclude, if technology can facilitate household activeness on similar levels that CRWs now most likely can. More research is also required to better understand how different technologies can be utilized widely in situations where many supportive services for home-based rehabilitation are non-existent. The potential of mobile technology to increase access to rehabilitation and ensure more equal rights to health for millions of people, however, is evident.

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