ADOPTION OF USER-CENTRED DESIGN APPROACH IN ASSISTIVE PRODUCT DESIGN FOR CEREBRAL PALSY CHILDREN WITH MOBILITY IMPAIRMENT

By

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Thesis Submitted to the School of Graduate Studies, Universiti Putra Malaysia, in Fulfilment of the Requirements for the Degree of Master of Science

June 2024

FRSB 2024 11

Abstract of thesis presented to the Senate of Universiti Putra Malaysia in fulfilment of the requirement for the degree of Master of Science

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Cerebral palsy (CP) is the leading cause of physical disability among children, particularly affecting mobility. Despite a global decline in the number of children with CP, a significant number remains across all regions. Assistive technology (AT) is essential in improving the quality of life for children who are diagnosed with CP. Yet, existing AT solutions have not fully met the diverse demands of CP children and their families. The research aims to develop a conceptual framework using a case study methodology that integrates a user-centred design (UCD) approach and processes to pinpoint the essential factors in designing innovative mobility AT for children who suffer from CP-related mobility impairments. For this purpose, the Klang Valley region in Malaysia served as the case study for data collection. The conceptual framework was then validated through the design of a AT for children with CP. Findings reveal that children with CP commonly suffer from congenital issues, multiple associated conditions, uncertain dependence levels, and low participation rate. Wheelchairs are the most extensively studied form of AT and have evolved into multifunctional devices, yet power wheelchairs (PWs) remain underutilized. Factors

influencing AT usage include the healthcare team's involvement, self-assessment, environmental considerations, and perceptions of AT. Data indicate that half of the children with CP are diagnosed before the age of one. Beyond mobility issues, they often face challenges with communication and perception. Most do not attend school, and while many do not exhibit personality disorders, the simplicity of operation and the low cost of learning are crucial for the children. Conversely, parents prioritize the ease of handling and the affordability of AT. Ultimately, a powered wheelchair (PW) was designed in accordance with the findings guided by the conceptual framework.

Keywords: User-Centred Design, Powered Wheelchair, Assistive Technology, Mobility Impairment, Children with Cerebral Palsy

SDG: GOAL 3: Good Health And Well-Being

Abstrak tesis yang dikemukakan kepada Senat Universiti Putra Malaysia sebagai memenuhi keperluan untuk ijazah Master Sains

PENGGUNAAN PENDEKATAN REKA BENTUK BERPUSATKAN PENGGUNA DALAM REKA BENTUK PRODUK BANTU UNTUK KANAK-KANAK CEREBRAL PALSY YANG MENCEGAH MOBILITI

Oleh

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Cerebral palsy (CP) adalah penyebab utama kecacatan fizikal pada kanak-kanak, terutamanya yang menjejaskan pergerakan. Walaupun terdapat penurunan global dalam bilangan kanak-kanak dengan CP, sejumlah besar kekal di semua rantau. Teknologi bantuan (AT) memainkan peranan penting dalam meningkatkan kualiti hidup untuk kanak-kanak dengan CP. Namun, penyelesaian AT sedia ada belum memenuhi sepenuhnya keperluan pelbagai kanak-kanak ini dan keluarga mereka. Penyelidikan ini bertujuan untuk membangunkan rangka kerja konseptual menggunakan metodologi kajian kes yang mengintegrasikan pendekatan dan proses UCD untuk menentukan faktor penting dalam mereka bentuk AT mobiliti baharu untuk kanak-kanak yang mengalami masalah mobiliti berkaitan CP. Untuk tujuan ini, wilayah Lembah Klang di Malaysia berfungsi sebagai kajian kes untuk pengumpulan data. Rangka kerja konseptual kemudiannya disahkan melalui reka bentuk AT baharu untuk kanak-kanak dengan CP. Penemuan mendedahkan bahawa kanak-kanak dengan CP biasanya mempunyai masalah kongenital, pelbagai keadaan yang berkaitan, tahap

pergantungan yang tidak menentu dan kadar penyertaan yang rendah. Kerusi roda ialah bentuk AT yang paling banyak dikaji dan telah berkembang menjadi peranti pelbagai fungsi, namun kerusi roda kuasa (PW) masih kurang digunakan. Faktor yang mempengaruhi penggunaan AT termasuk penglibatan pasukan penjagaan kesihatan, penilaian kendiri, pertimbangan alam sekitar dan persepsi AT. Data menunjukkan bahawa separuh daripada kanak-kanak dengan CP didiagnosis sebelum umur satu tahun. Di sebalik isu mobiliti, mereka sering menghadapi cabaran dengan komunikasi dan persepsi. Kebanyakan tidak menghadiri sekolah, dan walaupun ramai yang tidak menunjukkan gangguan personaliti, kemudahan penggunaan dan kos pembelajaran yang rendah untuk menggunakan AT adalah penting untuk kanak-kanak. Sebaliknya, ibu bapa mengutamakan kemudahan pengendalian dan kemampuan AT.Akhirnya, kerusi roda berkuasa (PW) direka bentuk mengikut penemuan berpandukan rangka kerja konsep.

Kata Kunci: Reka Bentuk Berpusatkan Pengguna, Kerusi Roda Berkuasa, Teknologi Bantuan, Kemerosotan Mobility, Kanak-Kanak Yang Mengalami Cerebral Palsy

SGD: MATLAMAT 3: Kesihatan Yang Baik dan Kesejahteraan

ACKNOWLEDGEMENTS

Here I would like to take this opportunity to express my sincere gratitude:

First and foremost, my deepest appreciation goes to my supervisors, Ts. Dr. Rosalam Che Me and Dr Mazatulfazura Sf Salim , for their invaluable guidance, patience, and consistent communication throughout my thesis process.

I extend my warm thanks to my Malay language teacher, Nur Aimie Nabila Fauzi, for her insightful suggestions on the Malay version of my thesis abstract. I am also deeply grateful to Puan Nursyida Binti Mansor for her valuable advice, which significantly facilitated my graduation process during my Master's studies.

I owe a debt of gratitude to my parents for their unwavering support of my studies, their constant presence, and their spiritual encouragement.

Lastly, I would like to acknowledge my own perseverance, as I never gave up, regardless of the circumstances, throughout my journey.

This thesis was submitted to the Senate of the Universiti Putra Malaysia and has been accepted as fulfilment of the requirement for the degree of Master of Science. The members of the Supervisory Committee were as follows:

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LIST OF ABBREVIATIONS

CP	Cerebral Palsy
AT	Assistive Technology
UCD	User-Centred Design
PW	Powered Wheelchair
WHO	World Health Organization
ATD	Assistive Techonology Device
BCI	Brain-Computer Interface
RQ	Research Questions
RO	Research Objectives
PDS	Product Design Specification
ADL	Activities of Daily Living
IDEA	Individuals with Disabilities Education Act
SLD	Specific Learning Disability
PWDs	Persons with Disabilities
ADHD	Information And Communication Technology
ASD	Norman's Three Levels Theory of Emotional Design
LD	Maslow's Hierarchy of Needs Theory
ID	Emotional variables
ICF	International Classification of Functioning
CIs	Confidence Intervals
LMICs	Low- and Middle-Income Countries
BWSTT	Body Weight-Supported Treadmill Training
ICIDH	International Classification of Impairment, Disability, and Handicap
AAC	Augmentative and Alternative Communication
EPIOC	Electric Powered Indoor/Outdoor Wheelchairs

MACS	Manual Ability Classification System
GFMCS	Gross Motor Function System
CFCS	Communication Function Classification System
EDACS	Eating and Drinking Ability Classification System
GAPS	Gabungan Anak-anak Palsi Serebrum
SPSS	Statistical Package for the Social Sciences
AFO	Ankle Foot Orthoses

CHAPTER 1

INTRODUCTION

1.1 Introduction

This chapter offers a brief overview of the entire research, encompassing the study's context, defining the research problem, outlining the research questions (RQs) and objectives (ROs), and specifying the research scope. Additionally, the structure of the thesis is presented to clarify the progression of the research and enhance understanding of it.

In particular, this chapter discusses the frequency of disabilities among children, with a specific concentration of children who are diagnosed with cerebral palsy (CP). The significant role that mobility impairment due to CP plays in the physical disabilities of children highlights the need to further explore the requirements and dilemmas faced by children with CP. Meanwhile, although numerous studies have been conducted on assistive technology (AT) for children with CP, current AT solutions lack designs that specifically address the requirements of children with CP, leading to various problems in the usage of existing ATs.

To better generate design concepts for this study, it is necessary to introduce and utilize an appropriate design approach. User-Centred Design (UCD) is a multidisciplinary design approach that is based on the active involvement of users to gain a clear understanding of user and task requirements, as well as on the iteration of design and evaluation (Mao et. al., 2001). This study is identified as a qualitative research that adopts case study as the main research method, and incorporates the

Cycle of UCD into the overall research process and develops a UCD-based research framework to ensure that the entire study remains focused on the child with CP. Also, in order to better use the UCD methodology to derive our design concepts, the conceptual framework was developed based on the literature review.

1.2 Background of Study

Prioritizing users is a fundamental principle in designing and developing new products, systems, or services. This principle underlines the conception of the UCD approach, which aids in the creation of products tailored for people. In current markets and research, there has been an increased focus on products that cater to the needs of vulnerable groups, beyond those designed primarily for commercial purposes.

The concept of vulnerability signifies a socially constructed perception, and at times, the reality of a group's diminished social, political, and economic capital compared to the societal norm. Children are often seen as a representation of such vulnerable groups (von Benzon, et al.,2017). Among various demographics, children with disabilities are considered one of the most vulnerable groups globally. Providing care and support for these children is a legal, moral, and compassionate obligation.

The World Disability Report from the World Health Organization (WHO) in 2011 highlights that with the ongoing trends of population growth and aging, there is a steady rise in the number of individuals living with disabilities. Approximately 15% of the global population lives with some form of disability. About 5.1% of children aged 0 to 14, which is roughly 93 million, are reported to have disabilities, while

approximately 0.7% (around 13 million) face severe disabilities (WHO, World Disability Report, 2011).

The number of children with disabilities worldwide has seen a significant rise. The occurrence of childhood disabilities has steadily increased, with a 15.6% rise recorded between 2001-2002 and 2010-2012. In 2010-2011, nearly 6 million children were identified as having disabilities (Houtrow, et al., 2014). Disabilities can generally be categorized into five types: hearing, visual, physical, cognitive, and multiple disabilities. Among these, physical disabilities constitute the majority, accounting for 67.35% (Unicef China, 2011). These conditions are likely to lead to mobility impairment or, at the very least, have a significant impact.

As shown in Figure 1.1, congenital factors are the most significant contributors to physical disabilities in children, followed by accidental injuries and polio. Congenital issues are the leading cause of motor disabilities in children (Liu, et al., 2021). CP has the highest proportion of these congenital causative factors.

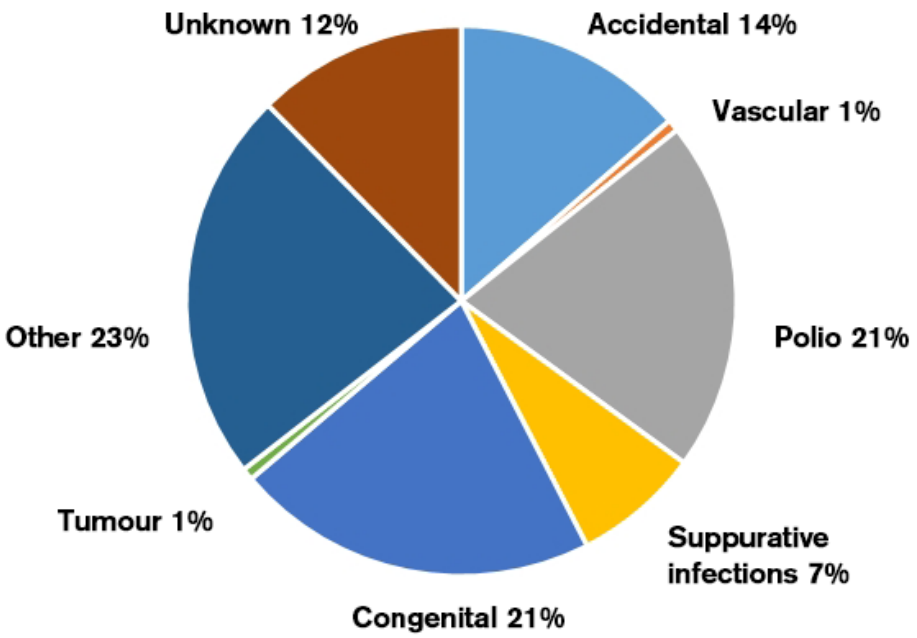

Figure 1.1 : Proportion of Different Disabling Factors for Children with Physical Disabilities in the World (Liu et al., 2021)

Mobility impairment refers to a disability that impacts movement to different extents. Mobility impairment encompasses conditions such as loss or impairment of upper or lower limbs, impaired manual dexterity and damage to one or more organs in the body. This impairment can be present from birth (congenital), develop over time (acquired), or occur due to a specific disease or condition. Compared to other types of physical disabilities, the difficulties faced by children with lower limb disabilities in their families, schools, and during travel can more significantly affect their physical, and mental health. The causes of such conditions are diverse and can be the result of accidents, injuries, illnesses, post-surgical effects, or hereditary factors.

Cerebral palsy (CP) is currently the most common chronic disability in childhood, encompassing a group of movement disorders that usually appear in early childhood (Berker et al., 2008). The symptoms and signs of CP differ greatly among individuals and may also evolve (Haak et al., 2009). Typically, CP conditions include poor

coordination, stiff muscles, weak muscles, and tremors. Individuals with CP may also face challenges related to sensory, vision, hearing, and speech.

To tackle the difficulties encountered by children with mobility impairments resulting from CP, interventions involving AT are often recommended. The products of AT are assistive technology devices (ATDs) or assistive devices. AT refers to any device, equipment, or product system designed to enhance, sustain, or improve the functional abilities of individuals with disabilities (Scherer et al., 2002).

However, the adoption of AT for children still falls short of expectations. Current research on AT tends to focus more on the perspectives of non-children users and caregivers. Usually, the viewpoints of children are neglected. Reports indicate that children always fail to utilise 100 of the functions of AT (Huang, 2009) (Dugan, et al., 2006). They still lack products designed for them in mind, this brings the UCD approach into the picture.

User-Centered Design (UCD) is an approach to product development that relies on information about the end-users to guide the design process (Courage, & Baxter, 2005). UCD is founded on an understanding of the users, their needs, priorities, and experiences, leading to enhanced product usefulness and usability, thereby increasing user satisfaction (Vredenburg, et. al., 2002). The use of UCD enables the process and outcomes of the research to be closely aligned with the needs and circumstances of the research participants.

Therefore, employing UCD helps to better identify the current difficulties and requirements among children with mobility impairments resulting from cerebral palsy (CP), allowing for adaptation and iteration in the later stages of concept development to more closely meet their usage requirements. There is also a noticeable scarcity of studies designed for children with CP using a UCD approach.

1.3 Problem Statement

The research problem arises from gaps identified in existing literature reviews regarding children diagnosed with CP. Furthermore, there is a lack of attention in AT studies specifically focused on children with CP. The current landscape in the AT field does not adequately address the needs of children facing mobility impairments due to CP. Therefore, it is crucial to assess the current needs of children with CP and the shortcomings of the available AT. This assessment will inform the design of AT that is suitable for children with CP by integrating relevant design theories.

While the leading cause of mobility impairments is usually considered to be CP, and nearly all children with CP need assistive technology (AT) to manage these impairments, there are numerous other related conditions of CP to take into account. Presently, only a limited number of mobility assistive technologies have been tailor-made to target mobility impairments resulting from specific conditions such as CP.

In a study by Taherian et al. (2018), perceptions and attitudes towards AT from different groups associated with AT were collected. The effectiveness of AT use is highly dependent on various environments. AT should be designed more detailedly and diversely based on different groups of people and usage scenarios, ideally

achieving personalized customization. In the studies of Huang et al. (2009), the importance of considering children's own views and perceptions of AT in its selection and use was also recognized. Children with CP usually experience more than just lower limb problems; training and learning to use AT is another challenge for CP children (Frank et al., 2017)(Guerette et al., 2005). This is one of the reasons why contemporary AT does not fully meet children's needs

AT is not only about the users. The utilization and selection of AT for children with CP should not rely solely on the advice of doctors and AT service providers (Taherian et al., 2018). Service providers require further education regarding the various types of assistive technology (AT) available, understanding how these technologies function and their intended users, as well as being informed about available upgrades. Many CP children and their caregivers often do not receive the latest information on AT when making choices, thus missing out on ATs that are truly suitable for them (Taylor, 2014).

While there have been studies that embrace the UCD approach to design ATs for children who are affected by CP, these studies still lack advancements in improving mobility AT specifically designed for them.

While the UCD approach is widely adopted in design and is effective for developing designs customized to users' specific needs, a review of current studies on mobility AT for children with CP revealed no instances where UCD was used in the design process.

Currently, the UCD approach has been significantly more applied in the interaction domain related to children with CP. There are examples of UCD being used in software or interactive products in areas involving CP children, such as gaming and communication. For instance, research by Weightman et al. (2010) evaluated two devices, namely a computer game and a force feedback interface for upper limb rehabilitation for children with CP—using the UCD approach. In research by Taherian et al. (2017), a user-centered method was employed to explore the potential of Brain-computer interface (BCI) technology for CP children. However, there is still a lack of case studies on the design of mobility AT.

1.4 Research Questions (RQs)

In light of the established research problem, several RQs have been formulated to assist in acquiring the necessary knowledge to address it, particularly in developing a suitable methodology for this research. The RQs have been derived from the gap that indicated the research problem above.

RQ1: What are the characteristics of children with CP who have mobility impairments?

RQ2: What are the requirements of children with CP in AT?

RQ3: How can the UCD approach be applied in proposing AT for children with mobility impairments due to CP?

1.5 Research Objectives (ROs)

The goal of this research is to develop a product design concept for children with mobility impairments due to CP using AT, grounded in the UCD approach. The ROs crucial for achieving this goal are:

RO1: To identify the characteristics of children with mobility impairments due to CP.

RO2: To evaluate the requirements of children with CP in AT.

RO3: To apply the UCD approach in proposing a conceptual framework and a product design concept for children with CP.

1.6 Research Scope

The scope of this research study is narrowly defined from the outset, focusing on the conceptual development of AT for children with mobility impairments due to CP.

This study seeks to create a new assistive technology (AT) for children with mobility challenges due to cerebral palsy (CP). The work scope includes the conceptual design of the proposed AT for children with CP, developed through a product design process combined with the UCD approach. This process encompasses several key steps, including establishing design requirements, developing product design specifications (PDS), iterating, and modelling.

Specifically, the research concentrated on delineating the characteristics displayed by CP patients with low age in comparison to typical children. These characteristics are not solely physical but also psychological and behavioural. Moreover, this study examined factors affecting the utilization of mobility ATs, including those influencing the selection of AT, factors leading to the abandonment of AT, and factors affecting the effectiveness of AT in actual use. This study also reviewed various CP-related mobility AT studies available today and summarized the types of AT that currently exist, as well as their availability and characteristics.

Data of CP children in the Klang Valley region of Malaysia were collected as a primary sample. A random sample of people who are diagnosed with CP and aged from 0 to 14 years were involved. The study did not restrict the gender or family background of the children. However, data collection required input from caregivers and other individuals associated with children with CP. More detailed descriptions of the users' characteristics will be provided in Chapter 4.

This study exclusively focuses on the requirements of children with cerebral palsy (CP), considering both mobility and emotional aspects. The aim is to develop a conceptual framework that will serve as a guideline for designing concepts and collecting data.

1.7 Significance of Study

The UCD approach utilized in this research has the potential to significantly improve the effectiveness of ensuring successful mobility in AT products designed for children with CP. The outcomes of this research could pave the way for an effective strategy in the development of such products. On one hand, this study provides a methodology and research process for conducting mobility AT research using the UCD approach; on the other hand, the conceptual framework of this study offers elements and variables to be considered in product conceptual design. This framework can serve as a reference for others or designers working in this field.

Additionally, data from this research can help fill the current informational gap regarding AT for children with CP. In this study, both semi-structured questionnaires and in-depth interviews were utilized to collect information from different

perspectives on activities of daily living (ADLs), AT usage status, and expectations of AT among children with CP in the Klang Valley. This can be used as a reference for studies in both the Malaysian region and other unspecified regions.

Finally, the research design of this study incorporates the UCD methodology process by refining the activities and expected outcomes of each step to suit the content and characteristics of this study, based on the basic process of ISO 9241-210:2010. The conceptual development of the design of mobility AT for children with CP using the UCD methodology also fills a gap in the field.

1.8 Research Framework

A research framework illustrates the overall structure and design that guides a research study. It can provide a systematic and organized plan for conducting research, outlining the key components, concepts, variables, and relationships that will be explored. The framework serves as a blueprint for the research process, helping researchers define their RQ, objectives, and the methodology they will employ.

The research framework is illlustrated in Figure 1.2. Besides the process of the research, the flow of knowledge can help to understand the iteration of each process. The whole research were divided into two stages, including the preliminary stage and development stage.

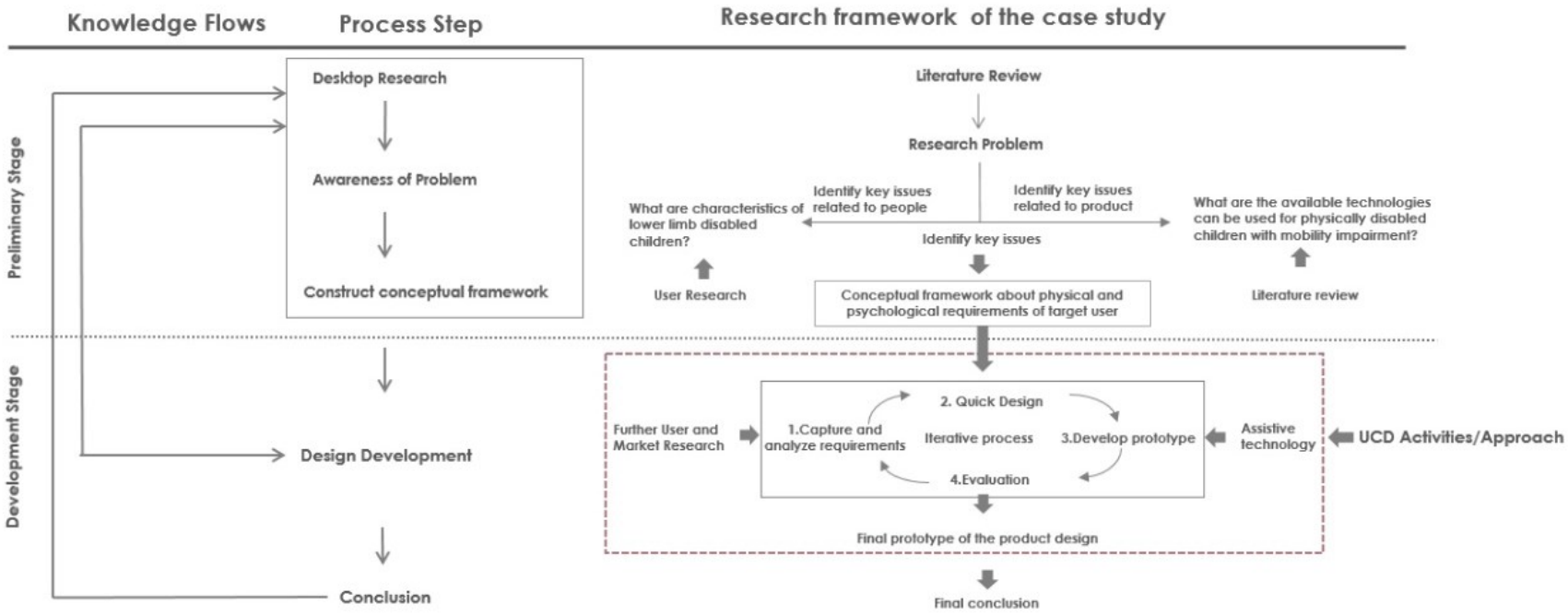

Figure 1.2 : Research Framework

In the preliminary stage, a literature review was conducted to identify a significant research gap in this field. Then the problem was explained to gain a fundamental understanding of the design and knowledge of the entire study. Subsequently, identifying the key issues was required. This study is classified as research through design, utilizing a case study approach to validate the conceptual framework, with the design serving as the case. The conceptual framework was developed by breaking down the key issues into user (people) and technical (product) elements, facilitating the construction of the framework.

Next, data collection was initiated from two perspectives: target users and products/technologies. After analyzing the data, the author was able to start developing the design concept. In the development stage, the basic structure was a cycle consisting of capturing the requirements, quick design, prototype development, and evaluation. The prototype and conclusion were finalized once the evaluation indicated the desired results.

The entire research process is based on UCD activities and processes. The preliminary stage basically corresponds to understanding the user's context. The development stage, on the other hand, corresponds to the UCD activities of user requirements, design solutions, and evaluation. This study also follows the feature that UCD can be iterated at any time.

1.9 Thesis Structure

The research is organized as follows:

Chapter One provides an introduction to the research, addressing the theme, key issues, motivation, limitations, expected outcomes, and the questions that the research aims to answer.

Chapter Two encompasses the literature review, which provides the possibility to identify gaps and contribute to the theoretical foundation. It reviews previous studies concerning the target population to uncover unaddressed challenges and unmet needs. The current AT products are summarized and examined to determine their impact on the target population and any shortcomings they present. The literature on the UCD approach and UCD activities is also scrutinized to discern components applicable to the research framework.

Chapter Three details the construction of the research methodology and the design of the research process. This chapter clarifies which methodologies, theories, and design principles are being adopted, contributing to a clear and controlled flow of the research, including milestone setting and timeline planning. It also presents the data collection process and preliminary results in the form of data exploration.

Chapter Four, one of the main sections of the research, presents data analysis and the development of the design concept. Building on the previous chapter's explanation of data exploration and visualization for a more intuitive presentation for better data analysis, this chapter elucidates the data analysis methods and processes. Following

the establishment of requirements and product identification, the design concept development process is described step by step.

Chapter Five concludes the research and offers recommendations, discussing several aspects of future work, including further investigations and improvements of the device. The potential market analysis for the device is discussed at the end of the chapter.

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