



Faculty of Cognitive Sciences and Human Development

**PECSAYA: A MOBILE-BASED LEARNING USING PICTURE EXCHANGE
COMMUNICATION SYSTEM (PECS) FOR CAREGIVERS WITH AUTISM
SPECTRUM DISORDER (ASD) CHILDREN**

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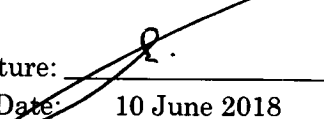
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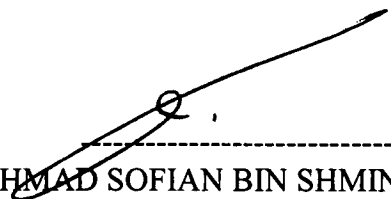
PECSAYA: Mobile based learning using Picture Exchange Communication System (PECS) for caregivers with Autism Spectrum Disorder (ASD) children

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This project is submitted
in a partial fulfilment of the requirements for a
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The project entitled 'PECSAYA: Mobile based learning using Picture Exchange Communication System (PECS) for caregivers with Autism Spectrum Disorder (ASD) children' was prepared by Iffah Syafiqah and submitted to the Faculty of Cognitive Sciences and Human Development in partial fulfillment of the requirements for a Bachelor of Science with Honours (Cognitive Science).

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ABSTRACT

Children with Autism Spectrum Disorders (ASD) often have difficulties in the areas such as social interaction, communication and behaviour. This research focuses on the development and evaluation of PECSaya, the mobile based learning using Picture Exchange Communication System (PECS) in Malay language for caregivers with Autism Spectrum Disorder (ASD) children. PECS is an alternative intervention to teach ASD children to communicate in social context. In this research, the expert and caregivers were evaluated using interviews and questionnaire respectively. To affectively achieve the research objectives, it follows closely the ADDIE (Analysis, Design, Development, Implementation and Evaluation) model which is under the Instructional System Design (ISD) methodology. Furthermore, the content structure of PECSaya includes the introduction, initial preparations, strategies and the activities which are developed mainly using Android Studio. In terms of evaluation, interviews were done to the expert in PECS approach to examine the content and usability testing using questionnaire were done towards the caregivers to know the user acceptance on this mobile based learning. For user acceptance, there were four motivational factors which are Attention, Relevance, Confidence and Satisfaction. The results concluded that 1. the mobile based learning was capable of grabbing the attention of the caregivers 2. the content of the mobile based learning was relevant to the caregivers' areas 3. the caregivers were not completely confident yet using the mobile based learning because it was their first time using the application 4. the caregivers were satisfied with the mobile based learning As a conclusion, the mobile based learning has been developed and evaluated. The issues on limitations and promising directions for future research were elaborated further in this paper.

Keywords: Autism Spectrum Disorder, Picture Exchange Communication System, mobile based learning

ABSTRAK

Kanak-kanak yang menghidapi *Autism Spectrum Disorder* (ASD) sering mengalami masalah dalam interaksi sosial, komunikasi dan tingkah laku. Kajian ini menumpukan kepada pembangunan dan penilaian PECSaya, pembelajaran berasaskan mudah alih yang menggunakan *Picture Exchange Communication System* (PECS) dalam bahasa Malaysia untuk penjaga yang mempunyai kanak-kanak ASD. PECS adalah cara alternatif untuk mengajar anak-anak ASD untuk berkomunikasi dalam konteks sosial. Dalam kajian ini, pakar dan penjaga dinilai menggunakan temu bual dan soal selidik. Untuk mencapai matlamat penyelidikan, model ADDIE (Analisis, Reka Bentuk, Pembangunan, Pelaksanaan dan Penilaian) yang berada di bawah kaedah *Instructional System Design* (ISD) telah digunakan. Selain itu, struktur kandungan PECSaya termasuk pengenalan, persiapan awal, strategi dan aktiviti yang dilakukan telah dibangunkan menggunakan Android Studio. Dari segi penilaian, temu bual menggunakan soal selidik telah dilakukan kepada pakar dalam pendekatan PECS untuk mengkaji kandungan dan pengujian kebolegunaan juga telah dilakukan kepada penjaga kanak-kanak ASD untuk mengetahui penerimaan mereka mengenai aplikasi ini. Terdapat empat faktor motivasi iaitu Perhatian, Relevan, Keyakinan dan Kepuasan. Keputusan soal selidik itu menunjukkan bahawa 1. aplikasi ini mampu menarik perhatian para penjaga 2. kandungan pembelajaran berasaskan mudah alih adalah relevan dengan bidang penjaga 3. para penjaga tidak yakin sepenuhnya menggunakan aplikasi ini kerana berasaskan mudah alih kerana mereka menggunkannya untuk kali pertama 4. para penjaga berpuas hati dengan pembelajaran berasaskan mudah alih. Sebagai kesimpulan, pembelajaran berasaskan mudah alih telah dibangunkan dan dinilai. Isu mengenai batasan dan arah yang berpotensi untuk penyelidikan masa depan telah dijelaskan lebih jauh dalam kertas ini.

Kata kunci: Autism Spectrum Disorder, Picture Exchange Communication System, pembelajaran mudah alih

CHAPTER ONE

INTRODUCTION

Background of Study

As stated by National Institute of Mental Health (2017), ASD is a term that is described by lasting problems with social communication and social interaction in different settings, repetitive behaviours and unwilling to change the everyday schedules. The symptoms usually begin in early childhood as early as the first two years of life and causing the individuals to need help in their daily life (National Institute of Mental Health, 2017).

A local survey by Hariati Azizan in *The Burden of Autism* (2008) reported that one in every 625 Malaysian children has autism (as cited in Chandran, 2016). The Ministry of Health also reported that autism cases are increasing, but many go undetected until the children are already in school (as cited in Chandran, 2016). It is reported by Nettleton (2008) that early intervention during the ages of 0 to 6 can reduce its impact and improve the child's development (as cited in Chandran, 2016).

Lim (2015) stated that all parents interviewed expressed feelings of being overwhelmed by the intensity of caring for their child as mostly the burden of care fell to the mothers. The fears of their children wandering off unattended, or inadvertently harming themselves or other people generally caused them high levels of anxiety (Lim, 2015). On top of caring for their child, caregivers found that even daily routines and activities were very difficult to carry out, and struggled to find time for themselves and their other children (Lim, 2015). Mothers of ASD children expressed the lack of needed therapies gave parents no choice but to seek the assistance of private therapists, which were "getting more expensive" and cause significant financial problems because of the costs of private therapies (Ilias et al., 2017).

A child with ASD have difficulties in the areas such as social interaction, communication and behaviour (Jack & Ady, 2006). Although some children have some sort of difficulties in these areas, however, not all children are the same so each children might have different pattern of difficulties (Jack & Ady, 2006). Some examples of intervention approaches for ASD children are Applied Behaviour Analysis (ABA), Discrete Trial Training (DTT), TEACCH and Picture Exchange Communication System (PECS).

Problem Statements

PECS is one of the alternative of ASD interventions in the aspect of communication. The mobile application proposed to be developed in this study look into the content structure of PECS approach. PECS was designed to teach young children to communicate in a social context and was developed at the Delaware Autistic Program (DAP) (Bondy & Frost, 1994; Frost & Bondy, 2002 as cited in Collet-Klingenberg, 2008). As stated by Collet-Klingenberg (2008) by using PECS, children are trained to give a picture of a favourable item to a communicative partner in exchange for the item. According to Collet-Klingenberg (2008), there are six phases of PECS instruction, which are: (1) Teaching how to communicate, (2) Expanding spontaneity, (3) Simultaneous discrimination of pictures, (4) Building sentence structure, (5) Answering to, "What do you want?" and (6) Commenting in response to a question.

The outstanding popularity of smartphones over the past decade has been driven by their significant computation, communication, and sensing capabilities, as well as the rich data they have about their users. As a result, platforms such as iOS and Android now have several millions of apps developed for them and billions of users (Statista, n.d.). In fact, it is impossible to know exactly how many apps are there, but as of March 2017 there were 2.8 million apps in Google Play alone, 200 thousand more than in December of the preceding year (Statista, n.d.). On the other hand, Apple Store had gone from 800 apps the month of its

launch in July 2008 to 2.2 million in January 2017 (Statista, n.d.). This shows the rapid growth of mobile applications in both Google Play and Apple Store since the past few years.

Perhaps, more mobile applications have become a medium for communication, learning and healthy lifestyle to some extent and it should not be a revelation since devices like smartphones are equipped with rich-features which boost the development of applications to improve the quality of human life (Voon, Bazilah, Maidin, Jumaat, & Ahmad, 2011). More mobile applications on health-related issues are appearing on the landscape such as applications for sleep problems, diabetes, education and communication applications for Autism Spectrum Disorder (ASD) as well (Voon et al., 2011).

There are a few related studies regarding the development of mobile applications using PECS intervention approaches such as AutiSay (Voon, Bazilah, Maidin, Jumaat, & Ahmad, 2015), Suara Saya (Ahmad, Hashim, & Nadia, 2017), MOSOCO (Escobedo, Nguyen, Boyd, Hirano, Rangel, Garcia-Rosas, ... & Hayes, 2012), Prospect (Raja, Saringat, Mustapha., & Zainal, 2017), Mi.L.A. (Loizides, Kartapanis, Sella, & Papadima-Sophocleous, 2015), JabTalk (JABTalk, 2016), PECS (PECS, 2017) and AutiPECS (Shminan, Adzani, Sharif, & Lee, 2017). Some of these studies have been implemented into application and published into Google Playstore; however, only some have published articles. All these existing studies and applications are developed by various backgrounds of people and countries. However less of these studies and applications actually implement PECS in a phase by phase learning for caregivers in Malaysian context. One of the study that applies PECS in their mobile application is called Prospect, a PECS-based Instant Messaging Application for ASD individuals which has been developed using agile development model for digital representation of PECS (Raja et al., 2017). According to Raja et al. (2017), a series of cards with certain illustration similar to physical cards will be the subject for the proposed application and with IM functionality, the ASD individuals will be able to send a simple

message easily by combining the cards to form a sentence. Thus, this application is focusing on the ASD individuals rather than caregivers themselves and only applying PECS as a general idea instead of as a learning material in phase by phase of PECS approach. Moreover, the mobile application is in Western context and not available in Malaysian context. Therefore, with all these problems stated, there is a need to build this application.

Research Objectives

General objectives

The purpose of this study is to develop and evaluate a mobile application called PECSaya that may help the caregivers with Autism Spectrum Disorder (ASD) children using Picture Exchange Communication System (PECS) approach that is suitable in Malaysian context.

Specific Objectives

The specific objectives in this research are:

1. To identify the problems faced by caregivers with ASD children.
2. To propose the content structure of PECS approach.
3. To design a mobile-based learning application according to the rules and principles in Human Computer Interaction (HCI).
4. To develop a mobile application for caregivers with ASD children which can be used in Bahasa Malaysia.
5. To evaluate the mobile application whether it is functional and easy to use by the experts in PECS and caregivers of ASD children.

Research Questions

This study is expected to answer the question:

1. What are the problems faced by the caregivers with ASD children?

2. What are the appropriate elements and contents to be integrated into the mobile application?
3. What are the reliable content structure of PECS that can be used to implement into mobile-based learning application?
4. How to design a good content of mobile application for learning PECS approach for the caregivers with ASD children?
5. How to evaluate the application whether it is functional by the experts in PECS approach and the caregivers of ASD children?

Significance of Study

While there have been many mobile applications that have been developed using PECS in general, there is little work to be found in those who are focusing on the caregivers of ASD children and in Malaysian context. Thus, this development of mobile-based learning of PECS approach could very well be help to ease the burden of caregivers who have a difficulty in taking care of their children as they are able to learn PECS approach and understand the content for them to apply to the ASD children.

Scope of Study

This study involves the process of developing a mobile-based learning using PECS approach for caregivers with ASD children. The content structure of PECS approach will be implemented into the mobile application in Malaysian context using Malay as the language. The design of the mobile application will follow the HCI rules and principles in order to get a user-centered interface that is easy to use by the caregivers. Experts in PECS approach will be consulted in order to get feedback about the implemented PECS approach and there will be an evaluation by the caregivers at the end of this study for improvement in the future studies.

Conclusion

Thus, this chapter discusses about the background of study, problem statement, aim and objectives, research questions, significance of study and scope of study.

CHAPTER TWO

LITERATURE REVIEW

Cognitive Sciences

According to Fridenberg and Silverman (2011), cognitive science is the study of the mind which includes psychology, philosophy, artificial intelligence, neuroscience, linguistics and robotics, scientifically. They also mentioned that the name cognitive science denotes to the joint work on detailed problem of all these disciplines (Fridenberg & Silverman, 2011). As stated by Andler (2005), the area of cognitive science requires the mind, or in other words, the mental functions and processes, which are also a part of the brain that consists of psychology area that is pursued by novel means, with the help from disciplines which are also concerned with the mind. They carry a set of methodologies to overcome some of the drastic limitations of the outdated programmes in scientific psychology (Andler, 2005).

Cognitive Psychology

Cognitive psychology is an area of psychology which is concerned with cognitive mental processes. As stated by Sternberg and Sternberg, cognitive psychology is the study of how individuals learn, perceive, think and remember about knowledge (2009). Solso (2005) gave another description of cognitive psychology as the study of processes underlying mental events (Sternberg & Sternberg, 2009). Thus, cognitive psychology can be described as the area of psychology which is dealing with how individuals acquire, store, transform, use and communicate language (Sternberg & Sternberg, 2009). This being said, the cognitive psychologists study a number of cognitive processes which include attention, perception, pattern recognition, and memory (Sternberg & Sternberg, 2009).

Learning Disabilities

Learning disabilities, or known as learning disorders, are a general word that described a number of learning problems that are not affect the intelligence or motivation (Kemp, Smith & Segal, 2017). In facts, it affects the understanding, retention, acquisition, organization or use of verbal or non-verbal information as how they obtain and practise information (Kemp, Smith & Segal, 2017). Thus, it can cause difficulties for individuals with learning disabilities in learning new skills and information, as well as using them as they see, hear, and understand things differently (Kemp, Smith & Segal, 2017). Kemp, Smith and Segal (2017) also mentioned that typically, those with learning disabilities have a problem with writing, listening, reading, reasoning, math, and speaking. They also mentioned that Attention Deficit Hyperactive Disorder (ADHD) and Autism usually occur together or are mixed up with learning disabilities.

Autism Spectrum Disorder (ASD)

As stated by National Institute of Mental Health (2017), ASD is a term that is described by lasting problems with social communication and social interaction in different settings, repetitive behaviours and unwilling to change the everyday schedules. The symptoms usually begin in early childhood as early as the first two years of life and causing the individuals to need help in their daily life (National Institute of Mental Health, 2017). Moreover, National Institute of Mental Health mentioned that the word “spectrum” talks about the wide range of symptoms, strengths, and levels of impairment that individuals with ASD may have (2017). Autistic disorder, Asperger’s syndrome and pervasive developmental disorder (not otherwise specified) are included in the diagnosis of ASD (National Institute of Mental Health, 2017).

According to Lord, Cook, Leventhal and Amaral (2013), observations and descriptions of behaviour is the fundamental of a diagnosis of ASD. Abrahams and

Geschwind stated that there is not yet a valid biomarker of biological test to show that autism is a neurodevelopmental disorder even though there is ample evidence that show it does (as cited in Lord, Cook, Leventhal & Amaral, 2013). Autism occurs about four times more often in males than females, thus, the utmost risk factor for ASD is being male (Lord, Cook, Leventhal & Amaral, 2013). Granting the percentage has reduced from 75% to 50% over recent decades, intellectual disability frequently occurs together with ASD (Centers for Disease Control and Prevention, as cited in Lord, Cook, Leventhal & Amaral, 2013).

A local survey by Hariati Azizan in *The Burden of Autism* (2008) reported that one in every 625 Malaysian children has autism (as cited in Chandran, 2016). The Ministry of Health also reported that autism cases are increasing, but many go undetected until the children are already in school (as cited in Chandran, 2016). It is reported by Nettleton (2008) that early intervention can reduce its effect and increase the child's development (as cited in Chandran, 2016).

ASD Interventions. According to the past researches, a child with ASD have difficulties in these three areas—social interaction, communication and behaviour (Jack & Ady, 2006). Although some children have some sort of difficulties in these areas, however, not all children are the same so each children might have different pattern of difficulties (Jack & Ady, 2006). This is why it is called autism spectrum disorder, as it is to represent the wide range of abilities and challenges found in them (Jack & Ady, 2006). Thus, a clear diagnosis and thorough assessment are necessary in order to know what works best for the children (Jack & Ady, 2006).

A range of ASD interventions and its examples are as shown in Table 1.

Table 1

The ASD interventions and the examples of method and therapy

A range of ASD interventions	Examples of method and therapy
Behavioural intervention	Applied Behaviour Analysis (ABA) Discrete Trial Training (DTT) Douglass Developmental Disabilities (DDDC) Program Incidental teaching Lovaas Program Pivotal Response Treatment (PRT) Positive Behaviour Support (PBS) Princeton Child Development Institute Program
Combined interventions	Early Start Denver Model SCERTS® Model TEACCH
Developmental interventions	Developmental social-pragmatic (DSP) model DIR®/Floortime® Relationship Development Intervention® (RDI®) Responsive teaching
Family-based intervention	More Than Words®
Medical interventions	Atypical antipsychotics Typical antipsychotics Stimulants
Therapy-based interventions	Functional Communication Training (FCT) Sign language Picture Exchange Communication System (PECS)

(Raising Children Network, 2017)

Challenges faced by the caregivers of ASD children in Malaysia. According to Ozonoff et al. (2011), all kinds of pressures arise within a family with a child with autism, and the resulting strain that is often placed on marriages (as cited in Lim, 2015). Parents of children with autism have to balance the needs of their child, busy therapy schedules, and perpetual financial worries (Lim, 2015). Lim (2015) stated that there may be serious disagreements between parents, and even the extended family, on best way of action. In the initial phases, parents may also go through a grieving process for the fact that their child will never be 'normal' (Lim, 2015).

A study by Lim (2015) stated that all parents interviewed expressed feelings of being overwhelmed by the intensity of caring for their child as mostly the burden of care fell to the

mothers. The fears of their children wandering off unattended, or inadvertently harming themselves or other people generally caused them high levels of anxiety (Lim, 2015). On top of caring for their child, caregivers found that even daily routines and activities were very difficult to carry out, and struggled to find time for themselves and their other children (Lim, 2015). Although it is very common amongst middle to higher income families to hire a live-in helper, this situation is not ideal for caregiving as there is a clear mismatch of skills – the hired help is a substitute measure that allows parents to better manage day-to-day life, but does not meet the need for high quality care for children with autism (Lim, 2015). According to Lim (2015), for the low and middle income parents, the main issue with hired help was cost while for the high income parent, there was a lack of trust that untrained live-in help would be able to provide the kind of quality they desired, as well as cost, given that they had many other expenses associated with caring for their children (Lim, 2015). Again, the most common response to this gap in services resulted in mothers giving up their careers (Lim, 2015). Those who could, relied on family members who were able and willing to provide some form of care, but this help varied from family to family (Lim, 2015). It is rare for parents to have formalised break or replacement care, which would provide trained caregivers for short time periods and allow parents a window of time to do activities without their child (Lim, 2015).

A study by Ilias et al. (2017) reported that all mothers with autism children shared their realisation of the need for more support from the government in terms of more special schools for their children, therapeutic services, financial aid, and employment opportunities. They also stated that the mothers residing more on the city outskirts faced more challenges finding resources. From this study as well, it expressed the lack of needed therapies gave parents no choice but to seek the assistance of private therapists, which were “getting more expensive” and cause significant financial problems because of the costs of private therapies

(Ilias et al., 2017). Conflicts also seemed to arise from perceived caregiving role imbalances, differing acceptance levels, and mostly from stress and fatigue dealing with behavioural challenges (Ilias et al., 2017). This can also be seen in a study by Nikmat, Ahmad, Oon, and Razali (2008) as they found that 90.4% of parents demonstrated significant parenting stress on the Parenting Stress Index – Short Form (PSI-SF), and 53.8% of Malaysian parents of children with autism showed a clinical disturbance in psychological well being, conceptualized as clinically elevated scores on the General Health Questionnaire (GHQ-28).

In some families, parents without a normally developing child feel strongly obligated to try for another child that is ‘normal’ (Lim, 2015). This was an interesting finding, given that studies show that the risk of autism recurrence in siblings is estimated at around 2 to 18 percent (Ozonoff et al., 2011; Sumi et al., 2006 as cited in Lim, 2015). According to Lim (2015), the desire for a typically developing child led parents to try a second and even a third time, leaving them with the responsibility of caring for three children with autism. Part of this seemingly irrational behaviour may be due to the lack of available child care and long term planning as parents may feel the need to have at least one normally developing child who will in the long run shoulder some of the responsibility for the care of the sibling(s) with autism (Lim, 2015). As stated by Lim (2015), parents of children with autism expressed a feeling of ultimately being alone in their journey, thus, they require many different kinds of support in any occasion. While some parents were encouraged to seek counselling, child care or cost constraints often prevented them from pursuing this option (Lim, 2015).

Picture Exchange Communication System (PECS)

The Picture Exchange Communication System (PECS) was designed to teach young children to communicate in a social context and was developed at the Delaware Autistic Program (DAP) (Bondy & Frost, 1994; Frost & Bondy, 2002 as cited in Collet-Klingenberg, 2008). Collet-Klingenberg (2008) stated that by using PECS, children are trained to give a