

Sains Malaysiana 49(5)(2020): 1037-1044
<http://dx.doi.org/10.17576/jsm-2020-4905-08>

User Perception on the Use of a Custom-Built Augmentative and Alternative Communication (AAC) Device for Elderly with Aphasia in Malaysia (Persepsi Pengguna ke atas Penggunaan Alat Komunikasi Augmentatif dan Alternatif (AAC) dibina secara Khusus untuk Orang Tua dengan Afasia di Malaysia)

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ABSTRACT

Augmentative and alternative communication (AAC) device is one type of AAC which can be used to communicate besides oral speech. It has high potential to assist people with speech disabilities including elderly with aphasia (EWA) to communicate with others. This study was conducted using a newly built AAC device, TalkMate™, as a reference for AAC devices. This study aims to explore the views and perception of users regarding the use of AAC device for elderly with aphasia living in Malaysia. The EWA participants recruited for this study varied in age, severity level and experience with AAC. A qualitative design with five focus groups was conducted. The focus group discussion included caretakers, healthcare professionals and AAC device developers to gain information about multiple perspectives on AAC device use. Thematic analysis yielded four key themes: needs of using AAC, decision on using AAC, resources, and potential improvement of AAC for EWAs. This study highlighted the importance of understanding the needs of EWAs, decision, improvement on the quality of life of the EWAs, and the future of using AAC device. The main barriers of using AAC were identified to be due to funding and access to devices.

Keywords: AAC; Aphasia; assistive technology; rehabilitation

ABSTRAK

Peranti Komunikasi Augmentatif dan Alternatif (AAC) adalah satu jenis AAC yang boleh digunakan untuk berkomunikasi selain ucapan lisan. Ia mempunyai potensi tinggi untuk membantu pertuturan orang kurang upaya termasuk orang tua dengan afasia (EWA) untuk berkomunikasi dengan orang lain. Kajian ini dijalankan menggunakan peranti AAC yang baru dibina, Talkmate™ sebagai rujukan kepada peranti AAC. Kajian ini bertujuan untuk melihat pandangan dan persepsi pengguna tentang penggunaan peranti AAC untuk warga tua dengan afasia yang tinggal di Malaysia. Para peserta, EWA yang direkrut untuk kajian ini bervariasi daripada segi usia, tahap kesakitan dan pengalaman dengan AAC. Kajian kualitatif dengan lima kumpulan berfokus telah dijalankan. Perbincangan kumpulan berfokus juga termasuk penjaga, kumpulan profesional kesihatan dan pemaju peranti AAC untuk mendapat maklumat daripada pelbagai perspektif mengenai penggunaan peranti AAC. Analisis tema menghasilkan empat tema utama: keperluan menggunakan AAC, keputusan menggunakan AAC, sumber dan peningkatan potensi AAC untuk EWA. Kajian ini menekankan kepentingan dalam memahami keperluan EWA, keputusan, peningkatan kualiti hidup EWA dan masa depan menggunakan peranti AAC. Halangan utama menggunakan AAC yang dikenal pasti adalah disebabkan pembiayaan dan akses kepada peranti.

Kata kunci: AAC; Afasia; rehabilitasi; teknologi bantuan

INTRODUCTION

Aphasia treatment has evolved throughout the years. Individuals with severe speech impairment could learn alternative methods of communication especially using Augmentative and Alternative Communication (AAC) (Kraat 1990). Phonology, syntax, and semantics were included in the use of AAC and some could produce synthetic speech (Jacobson 2007). This involvement allowed people with speech impairment to have better alternatives in communication. However, it was reported that people with speech disabilities were not very keen on

using AAC. This might be because they felt that the device differentiates them from the normal society. It might lead to embarrassment for them and might affect their identity (Hodge 2007). Another problem of implementing the AAC usage in the community is that most individuals with speech impairment might have other impairments such as physical, sensory or motor impairments. With that, a complex or a very sophisticated system or design of AAC might be a challenge for the elderly with aphasia in which they may have difficulties to touch the keypad or to choose the menu on the AAC due to their weak or imprecise motor functions of the proximities. This would

slow down the process of communication as well as make them confused, thus further hindering them from using the AAC. Additionally, it was recommended that the device should produce a voice at the time of use to make it more successful (Gonzales et al. 2009).

A study by Light and McNaughton (2012) reported that the usage of Augmentative and Alternative Communication (AAC) is still low even though the development of AAC is increasing. New technology has not been well accepted especially by those facing difficulties in learning new things such as older people, people with cognitive problem and those incapable of learning new technology. Additionally, the requirement of AAC devices among the elderly might be different from children. Children are reported to have better adaptation and learning abilities when it comes to a newly introduced AAC. They can easily use any particular AAC with more buttons or pictures or more advanced versions more quickly (Torii et al. 2013) than the elderly. On the contrary, the elderly do not have the same capability as the children. They need to have a special device which can promote simplicity of usage. Thus, a custom built AAC device namely Talkmate™ as shown in Figure 1 was developed to promote simplicity of usage with lower cost for the EWAs especially in Malaysia.

Elderly with aphasia (EWA) and their caretakers may have limited knowledge and accessibility to AAC devices. They have doubts as to whether the device can help people with aphasia to facilitate rehabilitation or express their needs easily to others (Avent et al. 2005). This may be due to the lack of exposure and limited choice of devices made for them. With the assistance of healthcare professionals and speech therapists, better exposure can be introduced to the society.

In Malaysia, as a rapidly developing country, professionals, and speech therapist services have been available for more than two decades. Research regarding speech within Malaysia has increased throughout the years (Hasherah et al. 2012). A survey by Hun (2016) reported that the use and practice of AAC in Malaysia are very little. The study also reported limited knowledge and skills regarding AAC. Cultural and linguistic aspects could be the main factors that influenced the low adoption of AAC (Jack et al. 1997). As Malaysia is a multi-cultural country and practices many different languages, there is a need to gather and explore the views and perception of EWA as AAC users, their caretakers and potential providers of AAC devices to EWA in regards to the intervention of AAC.

MATERIALS AND METHOD

STUDY TOOLS

TalkMate™ is a custom-built AAC for EWA in Malaysia (Figure 1). Its design and development were based on a needs analysis conducted with 60 respondents. 30 of the

respondents were from the University of Malaya Medical Centre (UMMC) which included patients with aphasia, doctors, nurses and allied health professionals and caretakers. The other 30 respondents were from the National Stroke Association of Malaysia (NASAM). The surveys were conducted to gather opinions from the respondents regarding the design criteria and features of the device (Lee et al. 2014). The four main basic request buttons featured in TalkMate™ are “I want to eat”, “I want to drink”, “I want to go to the toilet”, and “Thank you”, which may reflect the unique characteristics of people in Malaysia or Asian people in general, as highlighted by Hodge (2007) whereby communication is meant to develop relationship with other individuals (Hodge 2007).



FIGURE 1. TalkMate™ device

PARTICIPANTS

As presented in Table 1, healthcare professionals, elderly with aphasia and their caretakers were invited to participate in the focus group discussion. The researcher and device developer team were also invited in the study to get wider perception and views. The EWA participants were recruited from the University of Malaya Medical Centre (UMMC). The rehabilitation physician in the hospital identified the aphasic patients and all participants were approached personally for their consent. Participation information sheet and consent form were provided during invitation and the participants consented to join the study.

The selection of participants for EWA was based on certain criteria which were: elderly (aged 55 years and above), diagnosed with aphasia, which may be global, Broca's, mixed-non fluent, or Wernicke's aphasia, as verified by a medical personnel, have at least minimal motor function to move their hands as the participants were required to use the device, does not have other communication related disabilities such as blindness and deafness, and cognitively sound which means he/she was able to respond and follow instructions.

All participants were asked as to whether they were current users of TalkMate™ or other AAC devices, previous TalkMate™ or other AAC users, or if they had no experience with any AAC before the focus group discussion was conducted. TalkMate™ researchers

consisting of academician and the developer team were recruited based on their experience in the stroke and aphasia field as well as for those interested in the study of aphasia with AAC.

TABLE 1. Summary of participants involved in the focus group

Category	Focus group no.	Participants details	Number of Participants
Health care professionals	1	Technical team and healthcare professionals involved in AAC related research	4
	2	Healthcare professional that have no experience using AAC	2
	3	Researcher, healthcare professional and therapist currently using AAC	2
People with Aphasia and carers	4	Aphasia patients and carers that have no experience using AAC	5
	5	Aphasia patients and carers that had experience using AAC	2

STUDY INSTRUMENT

Focus group with a qualitative design study was used. Consent was obtained from all participants before commencement of the focus group study. A custom built AAC device was given to the participants for familiarising themselves with the device. During the familiarisation process, the participants learnt how to use, turn on and turn off the device. The focus group session began thereafter. This study was approved by the University of Malaya Medical Centre (UMMC) Ethics Committee with the Ethics Reference Number 2017330-5104. A series of survey questions were used during the interview session. Some of the survey questions were adapted from The Stroke and Aphasia Quality of Life Scale (SAQOL) 39 items version (Hilari et al. 2003) and Communicative Activity Log (CAL) (Pulvermuller & Berthier 2008). The questionnaires were not shown to the participants before the session began to avoid unreliable judgement or feedbacks.

STUDY PROCEDURE

Five focus groups, which comprised of small groups of people (Table 1) conversing and discussing with each other, were conducted by two researchers to gather their views. The same researchers conducted all of the sessions to ensure inter-rater reliability. By having the interaction, issues that were not normally raised while doing one to one interaction can be identified. One researcher conducted the discussion and the other researcher made observations and took notes while

the focus group sessions were recorded. The sessions were recorded and further transcribed to analyse each context of the focus group session. In order to have an effective discussion session, the EWA were assisted by their caretakers during the study. The caregivers assisted the EWA by using personalised sign language and communication methods that were commonly used and effective among them.

TalkMate™ was used as a tool in the study to gather the user perception regarding the use of AAC in general for elderly with aphasia in Malaysia. Only the TalkMate™ device was physically present during all focus group sessions. However, one of the EWA participants from focus group 5 had a lettered cardboard as a form of AAC on his bedside while the session was conducted.

DATA COLLECTION

The study was conducted in University of Malaya Medical Centre (UMMC). The study lasted for 20 to 30 min for each person in the focus group. The session was recorded for transcribing process. This study was approved by the University of Malaya Medical Centre (UMMC) Ethics Committee (Ethics Reference number 2017330-5104).

DATA ANALYSIS

Focus group with a qualitative design study was used. Consent was obtained from all participants before commencement of the focus group study. A custom built

AAC device was given to the participants for familiarising themselves with the device. During the familiarisation process, the participants learnt how to use, turn on and turn off the device. The focus group session began thereafter. This study was approved by the University of Malaya Medical Centre (UMMC) Ethics Committee with the Ethics Reference Number 2017330-5104. A series of survey questions were used during the interview session. Some of the survey questions were adapted from The Stroke and Aphasia Quality of Life Scale (SAQOL) 39 items version (Hilari et al. 2003) and Communicative Activity Log (CAL) (Pulvermuller & Berthier 2008). The questionnaires were not shown to the participants before the session began to avoid unreliable judgement or feedbacks.

RESULTS

Four themes were yielded related to the usage of Augmentative and Alternative Communication (AAC). They were: decision to use AAC device, improvement of quality of life, funding and resources and iv) potential improvement of AAC for EWA.

THEME 1: DECISION TO USE AAC DEVICE

The discussion regarding the use of AAC device for EWA are one of the topics mostly discussed by medical practitioners, caretakers and also the patients themselves. Elderly with aphasia (EWA) cannot utter proper speech. They tend to have a slurred speech which is not easily understandable by others. However, there are some individuals with aphasia who experience total loss of speech and undergo depression. *"The EWA are mostly in a state where they are depressed because of their inability to talk or express themselves"* (HCP, FG1). It is a matter of how they handle the depression. *"There are so many thoughts that were circling in our mind, how to communicate with people, how can I not burden others, is there any way to help me"* (EWA, FG4). The statement was translated by confirming with the EWA whether it is the context that the EWA wanted to relay. The statement was supported by the carers: *"At first, before I was introduced to this device, I wonder is there any device or technology to help my mother and us as carers?"* (Carer, FG4). The statement portrayed the needs of using an AAC to aid the rehabilitation of the EWA. Their caretakers and EWA shown their interest in TalkMate™. In fact, their caretakers said *"I believe that TalkMate™ will help my mom in a way of rehabilitation or to have a conversation with us"* (Carer, FG4). Agreeing with the statement, *"(..she nodded her head...)"* (EWA, FG4). However, the acceptance of the EWA was also discussed with the healthcare professionals (HCPs) when it came to the AAC design, and criterion. *"Their understanding and acceptance need to be addressed, what are their biggest needs which can help them in any way"* (HCP, FG2). Another HCP added *"As a service provider, one can't simply make any AAC to be used for everyone. A*

different AAC would be suitable for different patients. So, in-depth knowledge regarding the design criteria, needs and purposes of the AAC need to be addressed first before providing the service" (HCP, FG3). Some inquiries were made by the carers *"Can we use it everywhere? Or is it intended just to be used in the bed or ward?"* (Carer, FG5). Such inquiry arose from the discussion which the carers were very keen into using the AAC in their daily life, based on their statement: *"I do really believe, this medium of communication would help us as carers to assist, help and converse with the patients"* (Carer, FG4 - FG5).

THEME 2: IMPROVEMENT OF QUALITY OF LIFE

There were a lot of discussions within the focus group regarding the improvement of quality of life of the EWA. *"Does AAC device actually improve the quality of life of the patients?"* (HCP, FG2). The EWA saw the usefulness of the AAC. They were excited when they were exposed to the new technology, TalkMate™. *"... one patient cried when using the TalkMate™ and when we asked what happened, whether it was bad or good, he showed a good hand signage"* (Developer team, FG1). *"Currently, the patients need to use a cardboard to spell a word in order to communicate. Sometimes, we tend to misunderstand what they are actually trying to say, even if we missed one or two alphabet. We need to reconfirm the words with the patient all over again. So, by having the AAC, it will help them to simplify and express their needs straightforwardly"* (HCP, FG1). The AAC had given much impact for them to communicate. A caretaker said *"It actually helps us the caretakers by having this device. We can easily understand their basic needs. Not only that, the TalkMate™ itself has an alarm button which will alert us if the EWA pressed it. This will surely help us to improve the communication between me and the EWA"* (Carers, FG4-FG5). Similarly, a study reported that the usage of assistive device improved harmony, lifestyle and the user's quality of life (Ripat & Strock 2004). By developing the AAC, the-EWAs would feel appreciated as their needs were addressed by others. Their confidence and survival needs were increased which is good for their rehabilitation. They would also not give up easily to recover into their condition before aphasia.

THEME 3: FUNDING AND RESOURCES

The discussion among the focus group was triggered into funding and resources. The funding and resources were one of the most important factors in making the decision of whether or not to use AAC. A question that was asked during the focus group session was: *"Where can I find the right AAC to use but still within my budget?"* (Carers, FG4). Instead of using the readily made AAC which helps them to promote recovery, they preferred the locally made and locally oriented AAC device. *"The user mostly are elderly people, they didn't possess an advanced*

proficiency of foreign language which made them difficult to use. Instead, they are really fond of having their own mother language made devices" (HCP, FG1). When TalkMate™ was used during the focus group session, a caretaker asked *"Can I buy this? How much is the price?"* (Carers, FG5). Based on the statement, not only the elderly people suffering from Aphasia would want to use the AAC, the caretakers themselves would like to have the AAC for their loved ones. However, they preferred a locally oriented AAC device as it is easier for them to use. Besides, the cost of the AAC device in the market is expensive because it must be imported from overseas. That was why they preferred it to be locally made as it would be more economical and better suited to their budget. Some might be able to afford and acquire the high technology and expensive devices, but many others are not capable of owning one due to their lack of funding and budget.

THEME 4: POTENTIAL IMPROVEMENT OF AAC FOR EWA

The future or potential improvement of AAC in helping the EWA were discussed within the focus group. The healthcare professionals saw this as a potential to enhance and improve the AAC device to be better than it was at the time of the interview. One of the healthcare professionals mentioned that *"The AAC can be improved, however it must not be a tech-savvy, too complicated or a sophisticated device"* (HCP, FG3). Another healthcare professional also said *"The reason it can't be too sophisticated is because the target group of the AAC is for people with stroke, aphasia and most of them are elderly. Elder people wouldn't want to use something that is intricate for them"* (HCP, FG1). The caretakers also agreed and said the same thing based on their experience of taking care of the EWA. They said *"It is surely difficult for my mum to use an iPad or any tablet, because it is difficult for them to handle it. Not just that, it is difficult for them to understand how the device or software works if it is too complex"* (Carer, FG4).

The caretakers also suggested some improvements for the AAC devices in the future. They said *"Currently, locally made devices developed are already having the local language, but it also can be improved by adding new features such as the device's option can be customised by the carers to suit the EWA needs"* (Carer, FG5). There were other suggestions received by the engineering team was *"the healthcare professional as well as the caretakers are hoping that the devices can be integrated with a mobile phone, while maintaining the simplicity of the current AAC device"* (Engineering team, FG1). One healthcare professional said *"The integration of the device with the mobile phone is a good addition because the carers holding the phone can receive the message or alarm pressed by the EWA wirelessly. It will enhance the reliability and flexibility of the AAC itself"* (HCP, FG1).

DISCUSSION

There are many ways for patients to regain good health conditions. With the help and support of their family, friends and caretakers, EWA would be provided with a boost or spirit to undergo their healing process and get better. The purpose of the study was to explore the views and perception of users regarding the usage of AAC for EWAs. A better study or understanding of user acceptance on a specific device is needed as it would improve the interventions of assistive technology in terms of its effectiveness and user satisfaction (Phillips & Zhao 1993). Four themes were identified namely: the decision of using AAC, improvement of quality of life, funding and resources and potential improvement of AAC for EWA. Throughout the focus group, participants discussed on the decisions of using a particular AAC. Some of the participants reported to have little or no knowledge regarding AAC, especially AAC for EWA. The AAC was introduced to the users through this study, especially to the carers and patients. When TalkMate™ was introduced to them, they seemed excited and eager to know more about the AAC and TalkMate™ itself. Some asked where to find it, how can they own it and enquired the price. Throughout the group, most of the EWA required attention and care by the carers and society for them to converse, socialise and rehabilitate themselves with the use of appropriate AAC.

The use of AAC devices would also help them to communicate and converse with others throughout the rehabilitation process. The conversations between the carers and EWA had changed before the onset of aphasia. Similarly, it is reported that the carers acknowledged that the conversations they had were less enjoyable and less meaningful compared to the time before the patients had aphasia (Johansson et al. 2012). Even though the development and future research of AAC devices are growing, the professionals must truly ensure that the development and introduction to the AAC device were aimed to the help those who are in need and not because of pursuing popularity or wealth from the invention. Unwanted situations tend to happen when patients' communication is not the priority but technology is instead (Meder & Gillispie 2012). The development of the AAC should not be triggered by the excitement of individuals to produce or launch the products with new upgrades and features that might lead to a complex system. By doing that, the users would have to bear the effects of increasing level of difficulties in using the AAC device. One needs to have a very deep knowledge and understanding of the situation, criteria, and requirements of the needy in order to prevent the misconception of developing AAC because of wealth and popularity (Light & McNaughton 2013). There is a need to provide the assistive technology service in an efficient way. The service must have a high outcome but at a reasonable cost (Deruyter 1995).

Device or technology is used to help and assist the needy. Society must strictly not stray from the main objective of developing the AAC (Light & McNaughton 2013). The AAC device would assist them to converse, express and relay their needs or messages to others. A wider range of AAC development is good, however it must come with different options to make it flexible to use depending on the user condition (Light & McNaughton 2012). Therefore, comprehensive knowledge about the target users and the required restructuring of the AAC design are necessary to ensure that the needs and capability of the EWA are met. A study for child with AAC a study reported in Malaysia by Singh (2017) suggested that Malaysian therapists should conduct assessments thoroughly to determine which AAC is suitable for any particular children as they may have different capabilities in comprehending or adapting. This kind of assessment should be made for the elderly as well to determine which AAC device is suitable with them (Susheel et al. 2017). The initiative for design reconsideration is important for those who are suffering from cognitive impairment, aging and language impairment as well as development of AAC devices in the future. On the other hand, SLP services should be widely introduced to the society for them to seek help as required. The clinicians should also emphasise the benefit of using or searching for other alternatives or any different kinds of aphasia rehabilitation services (Johansson et al. 2012). The impacts on the patients using an electronic aid device to their daily life, their feeling and quality of life requires further exploration (Ripat & Strock 2004).

The findings of this study provide an overview on society perception about the use of AAC device for EWA. The study was done in a setting that reflected the current healthcare culture, patients, professionals, and system. This qualitative study provided deeper views regarding the issues, needs, and rehabilitation of EWA requiring the use of AAC devices. The market of AAC in Malaysia is expected to increase because of the high group. Research shows in 2040, the number of elderly people will be three times higher than the population in 2010. Malaysia will slowly become an aging population with more than 7.1% in the elder group in 2021 (Department of Statistics Malaysia 2013) compared to 6.2% in 2017 (Department of Statistics Malaysia 2017). Therefore, the need of developing AAC devices for the future is very essential.

The overall findings of this study would provide a brief guideline or overview for future research and clinical studies of EWA using AAC. Wider views from healthcare professionals, researchers, and caretakers who either had the experience or did not have the experience of using AAC would contribute to a deeper understanding of the subject. Due to the limited number of EWA, the recruitment of respondents for this study was considerably less compared to the recruitment of healthcare professionals and engineering team.

CONCLUSION

Elderly with aphasia, their carers, healthcare professionals, and researchers were the four groups of participants recruited in this study. This study provided a preliminary finding on people's perception, opinion and views on AAC for elderly with aphasia in Malaysia. The participants' key decision factors on using AAC were gathered. The main issues of not using AAC were the funding and access to the AAC. AAC devices are not well used yet in Malaysia due to the lack of its exposure in the society.

LIMITATIONS

The sample size of the focus group participants is relatively small and the study focused on the Malaysian context. The study was done in Malaysia which reflects the current healthcare culture, patients, professionals and system in Malaysia. There is a chance of bias during the study.

ACKNOWLEDGEMENTS

This project was supported by the RU019C-2014C grant. The authors would like to thank all focus group participants for their valuable insights. The authors have no conflict of interest to declare.

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- Received: 6 May 2019
 Accepted: 15 January 2020

APPENDIX

Talkmate™ consists of six large basic need options including 'Yes' and 'No' buttons, one volume dial, and one language selector switch to change between three different languages. The features for this device were selected from a survey conducted with 30 respondents from NASAM. The same message could be 'spoken' as a voice output in different languages. The device has the capability to record family member's voice or other words personalised to the user's degree of aphasic condition as the voice output. It is rectangular in shape and lightweight thus easy to handle. During the period of the study conducted, the four main basic needs buttons were able to 'say' four main requests as determined by

Lee et al. (2014), which are "I want to eat", "I want to drink", "I want to go to the toilet", and "Thank you", in three different languages. In our case, the three most common languages were pre-programmed into it, namely Bahasa Melayu, English and Mandarin, while the device has the capacity to record, store and project other languages not limited to the three. The authors were impressed by the word "Thank you" being in the top most requested items, as even though it is not directly related to the physiological basic needs, it reflects the users' need to express their appreciation to others around them including their caretakers, more than their other physiological needs such as 'watching television' and 'to walk outside'.