

The Relationship Between Signed Languages and the Quality of Life of Deaf Adults in
Malaysia

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ABSTRACT

Various instruments have been used to assess the quality of life (QOL) of individuals. An exhaustive literature review identifies which instruments can be used to evaluate participants' QOL in the deaf community and how those instruments can be employed to assess one's self-acceptance/advocacy, perception of stigma, and participation in society. The primary purpose of this study is to investigate how mode of signing, such as natural Malaysian Sign language compared to contrived systems, in one's childhood and adult life, may influence the QOL of Malaysian deaf adults. The Youth Quality of Life Instrument - Deaf and Hard of Hearing Module (YQOL-DHH) was translated and formatted for online administration in Malaysian Sign Language, Malay, and English. This study examined QOL in relation to demographic variables, satisfaction with signed communication across three settings, and the most commonly used signed communication in these settings during one's previous school years. This study did not find that one's most frequently used signed language during previous schooling, across settings, had a statistically significant impact on QOL for deaf adults in Malaysia; however, satisfaction with signed communication in the past correlated with self-acceptance in adulthood. These findings may provide insight into the intersection between the signed language deaf adults use in their daily lives and their QOL in Malaysia. These findings may provide insight into how *Bahasa Isyarat Malaysia*, (Malaysian Signed Language), might be studied further by researchers and policymakers.

DEDICATION

I dedicate this dissertation to my father, Lee Le Chuan, and my late mother, Ngau Set Lin. This dissertation is what I accomplished because of you. You taught me that education is the key to our successful lives. Despite many attempts, you have always believed that I would be able to climb the ladder without giving up.

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CHAPTER I

Introduction

Introduction to the Study

The World Health Organization (WHO) provides a definition of Quality of Life (QOL) that has been applied in various studies (Freeman, 2014; Gerich & Fellingner, 2011; McAbee, 2015) as “the individuals’ perceptions of their position in life, in the context of the cultural and value systems in which they live and in relation to their goals, expectations, standards and concerns” (World Health Organization, 1995, p. 1405). Studies help researchers and others better understand the experiences of vulnerable individuals and groups who may have been disenfranchised by society, such as women, minorities, the elderly, and people with disabilities (McAbee et al., 2017). According to Trovato (2013), deaf communities in various countries have their own signed languages, which should be protected legally to ensure proper linguistic development and cognitive potential among the deaf. By doing so, their QOL can be improved. However, there is a dearth of literature and research on the QOL within the deaf¹ community in Malaysia. The Malaysian deaf community uses various signed languages, which will be described in this chapter. Since a variety of signed languages are used in Malaysia, this study aims to explore how they influence the QOL, with the potential to determine which sign language has the greatest influence on deaf individuals. Therefore, in this study, I examine the QOL of deaf Malaysians who have graduated from secondary school, are at least 18 years old, and who have experienced signed communication during their school years. Ultimately, the results of this study are intended to enhance our understanding and inform future educational practices for supporting children who are deaf in Malaysia.

¹ The term deaf is used throughout this paper as an inclusive term representing deaf and hard of hearing persons.

Rationale

Signed Languages in Malaysia

Throughout Malaysia's history, various forms of signed languages and oralism have occurred in and after schools. Signed language was discovered to be used at the Federation School for the Deaf (FSD). The school was established in Penang, the north of Peninsular Malaysia, in 1954 (Bell et al., 2015). The FSD was Malaysia's first fully residential school for deaf children from all parts of the country. Deaf children frequently socialized with friends at the residential school, where they lived and carried out all their daily activities. The students communicated meaningfully through the use of natural signed language while they were in the dormitories. However, the teachers used oralism to teach deaf students in the classrooms.

The British brought their way of life, including education, to Malaysia during the British colonization of Malaysia between 1824 and 1957. One of those influences was the use of oralism to teach deaf students. Oralism was introduced to the FSD, which followed the practice of teaching deaf children in Britain. At the FSD, oralism was used in the classrooms, while outside the classroom, deaf children used various forms of gestures or sign language. Saleena Yahaya Isa (formerly known as Lee Kooi Jong before she married a Muslim man and converted to Islam in 1967) was a teacher volunteer at the FSD during the evenings. The lack of English proficiency among the FSD students (Chong, 2014) prompted her to return to England to undertake a one-year program in Special Education for the Hearing Impaired at Manchester University in 1955 (The Straits Times, 1955 & 1956). She learned the "British styles of deaf education that was a form of strict oral education (lipreading and speech skills), which meant that any signing by the students would be punished by the staff and teachers, who were all hearing individuals" (Nakamura, 2022, p. 197). She enforced the oralism method of instruction at the FSD in 1956 (Yahaya-Isa, 2004). With the inception of oralism at the FSD, students were forbidden to use any form of signed language or gesture in the classrooms, so they secretly communicated using signs in their dormitories, outside the classroom, or while their teachers were not present. During this process, they developed the initial signs of Penang Sign Language (Hurlbut, 2000), which was later used in the FSD and locally in Penang.

After five years as a teacher, Saleena Yahaya-Isa (2004) became a principal at the FSD in 1961. She asserted that 72% of deaf students of the FSD who spent 12 years in school did not acquire a reasonable language proficiency standard, and 96% of the FSD students did not learn to speak (Yahaya-Isa, 2004). Additionally, the FSD students' academic performance was based more on oralism than understanding and gaining academic knowledge. During overseas conferences, Saleena asked questions about the concept of pure oralism because she felt it was too narrow and restrictive. She “ . . . looked in earnest for alternative strategies for teaching deaf students that were more in keeping with local realities and needs” (Yahaya-Isa, 2004, p. 92).

A New Approach to Deaf Education in Malaysia

In 1971, an FSD student, Eleanor Culas, who utilized the oral approach and some Penang Sign Language, was the first deaf student from the FSD to successfully pursue her studies at Gallaudet College (now known as Gallaudet University) in Washington, D.C., the United States of America. She began her studies and earned her bachelor's degree from Gallaudet College in 1976 (Nakamura, 2002; Yahaya-Isa, 2004). While at the college, Eleanor was impressed by the sign language used by deaf people, and she also used sign language there. In 1974, during a summer holiday, she returned to Malaysia and visited the FSD. She continued to use sign language there (Eleanor, personal communication, April 18, 2024) when Saleena objected to it. Eleanor spoke out and said, “I am not ashamed to be deaf. I use sign language to let the world know I am deaf” (Parsons, 2005, p. 223). Eleanor's outburst “. . . shocked Saleena into rethinking her perception of how deaf students should be educated” (Parsons, 2005, p.223).

When Eleanor Culas returned to Gallaudet College after her vacation in Malaysia, she met with Frances Parsons, a professor at Gallaudet College. Parsons, a deaf woman who can speak fluently, was known to use Signed English. Eleanor asked her to share her expertise in using Signed English at the FSD when she visited Malaysia. Parsons met with Roy K. Holcomb, the father of Total Communication (TC), to discuss TC (Parsons, 2005). When Holcomb became a deaf supervisor for the hearing impaired program in the Santa Ana Unified School District in California in 1968

(Holcomb, 1971), he stated, "Total Communication is using all means of communication with the children, especially at the earliest possible age....Total Communication, as used in the Santa Ana Program, consists of auditory training, speech, speechreading, fingerspelling, and the language of signs" (Holcomb, 1971, p. 524). One of his famous quotes was, "Communicate with the deaf in any way you can - stand on your head, if necessary." (Holcomb, 1971, p. 524). Parsons was well-known worldwide for sharing the TC philosophy. When Parsons was on a one-year sabbatical leave in 1976, she visited deaf schools in some countries in Asia and Africa, including Malaysia (Yahaya-Isa, 2004; Parsons, 2005) to continue to spread TC.

Total Communication

In March 1976, Frances Parsons visited the FSD and met Saleena. Parsons convinced Saleena that signing was the way of the future for her schoolchildren (Nakamura, 2002). Frances Parson advocated for allowing deaf students to use signed language in the classroom. Parsons recommended the philosophy of Total Communication (TC). TC includes "the full spectrum of language modes, child-devised gestures, the language of signs, speech reading, finger spelling, reading, and writing" (Dento, 1976, p. 4). TC is a comprehensive approach to communication that may include the use of multiple modes such as spoken (oral), manual (signed) language, written language, and visual aids depending on the individual's needs and abilities. Although this was the philosophy and intent of TC, over time, TC was implemented by signing and speaking at the same time, known as simultaneous communication (sim-com).

Signed English

Saleena viewed Signed English, known at the time in Malaysia as Manually Coded English (MCE) as a way to help deaf children integrate into hearing Malaysian society (Nakamura, 2002). Malaysian deaf students who learned English and MCE were able to attend Gallaudet College in the United States. Saleena requested that Frances Parsons teach MCE. Frances Parsons taught a six-week intensive course with the FSD teachers who volunteered their evenings (Chong, 2014; Parson, 2005) to learn MCE.

In 1957, Malaysia became independent from Britain. During the decolonization process, Malaysia changed the medium of instruction from the use of colonizers' English to their own national language, Malay. In the 1970s, Malaysia began the transition from using English to Malay. The primary school was the first phase of the transition from English to Malay as the medium of instruction, while at the same time, English continued to be the medium of instruction at secondary schools. By 1985, English as the medium of instruction was phased out at public (government-funded) schools, including primary and secondary schools as well as public universities in Malaysia.

Signed Malay

During this transition process of the languages as the medium of instruction, the FSD developed a Malay version of sign language known as Signed Malay, which was originally taken from MCE. Signed Malay was to be used by deaf primary school students since they had already begun using Malay as the medium of instruction. At the same time, the FSD adopted MCE. MCE was used when English was the medium of instruction in secondary schools.

Saleena wanted to implement TC at the FSD, but she needed to seek permission to conduct a trial of using TC in a classroom from the Minister of Education (MOE). Saleena arranged a meeting regarding TC between Parsons and Dr. Mahathir Mohamad, who was the Deputy Prime Minister and also the Minister of Education (Parsons, 2005; Yahaya-Isa, 2004). On May 7, 1976, Frances Parsons convinced Dr. Mahathir, who granted the FSD permission to conduct an experimental trial using TC in September 1976. With a five-year grant from the MOE, Saleena established an experimental pilot study with two classes of deaf students to determine the results of children's performance based on the type of communication used. One class used TC, which was implemented through the use of simultaneous speech and Signed Malay, and one class used the oral approach (Parsons, 2005; Yahaya-Isa, 2004).

By 1978, less than three years into the five-year study, the students in the experimental class using sim-com demonstrated marked superiority in the use of language over their peers in the oral classes (Nakamura, 2002; Yahaya-Isa, 2004). As a

result of the successful experiment, the MOE accelerated the implementation date of TC and, therefore, allowed for a more liberal approach to teaching deaf students. The MOE officially announced that the implementation of TC was to begin in all public schools run by the MOE that teach deaf children in Malaysia (Yahaya-Isa, 2004). In March 1978, the MOE formed a working committee to oversee the switch from oralism to TC throughout Malaysia (Chua, 1991) and to be responsible for supporting the National Total Communication Committee. In 1979, Saleena was assigned to the committee, which consisted of a group of academic professionals and teachers who taught deaf children throughout Malaysia (Kementerian Pelajaran Malaysia, 1985). Their goal was to expand Signed Malay to incorporate more signs by including American Sign Language (ASL), Signing Exact English, and "... some local signs and grammatical signs representing affixation of nouns and verbs that are used in the Malay Language" (Ow et al., 2007, p. 168).

Kod Tangan Bahasa Malaysia (KTBM)

Signed Malay later became known as *Kod Tangan Bahasa Malaysia* (KTBM). KTBM is translated in English as Manually Coded Malay. American signs from *A Basic Course in Manual Communication* by Terrence J. O'Rourke (National Association of the Deaf, 1973) formed the basis of KTBM. Pictures of American signs were used, but the written English for each sign was changed to written Malay. When there were no signs for some words, the teachers on the committee invented signs and thereby expanded KTBM. Ultimately, the MOE published a book titled KTBM to be utilized as a medium of instruction at schools with the goal of helping deaf students master the Malay language for reading and writing (Omar, 1978).

As of today, the Department of Special Education under the Ministry of Education still uses KTBM as the primary medium of instruction officially in special education schools and schools where deaf students study. The approach is intended to support spoken Malay, which is not a native language for deaf people. KTBM is considered a manually coded form of Malay or an artificial signed language. Despite the evidence from statistical research worldwide, particularly on sign bilingualism (Griffin, 2018; Tang, 2017), KTBM is still prevalent in Malaysia because of beliefs that it is conducive to the

teaching of reading and writing. KTBM is taught at universities and the Specialist Teacher Training Institute in Malaysia for the preparation of future teachers of the deaf.

American Sign Language (ASL)

In the 1960s, however, American Sign Language (ASL) also had a significant influence on the development of signed language in other parts of Malaysia. A hearing certified pharmacist in Malaysia, Tan Yap, became interested in working with deaf children after he found out about them. Tan Yap took a one-year leave of absence from his work to take sign language interpreting courses at Gallaudet College. In 1964, after completing the courses, he returned to Malaysia to set up a school to teach ASL to deaf people in Johor, which is in the south of Peninsular Malaysia (Chong, 2014), especially to dropouts and those who missed an opportunity for primary or secondary education. Following that, he founded another school for the deaf in Kuala Lumpur, the capital of Malaysia, in 1968. He additionally founded a deaf club at the YMCA Kuala Lumpur in 1973 so that deaf adults could gather together for social interactions. As part of his promotion of ASL, he, with deaf people and those who work with deaf people, conducted sign language classes for various groups in the community, such as government employees, companies, charitable organizations, churches, religious centers, hospitals, and parents of deaf children throughout Malaysia. Due to Tan Yap's work in setting up schools, employment opportunities, and clubs, he is called the "Father of the Deaf" by the deaf community in Malaysia (Hurlbert, 2000).

Bahasa Isyarat Malaysia (BIM)

In addition to KTBM and ASL, a natural sign language called *Bahasa Isyarat Malaysia* (BIM) was discovered, translating into English as Malaysian Sign Language. BIM came into the spotlight in 1998 (Chong, 2014) when the Malaysia Federation of the Deaf (MFD) initiated a research project to collect the existing local signed languages used in deaf people's daily communication in the deaf community. The project was funded both domestically and internationally. Examples of signed languages that influenced BIM include Penang Sign Language (Hurlbut, 2000), which was used by older deaf people in the dormitories when living at the FSD; Selangor Sign Language,

which had roots from American Sign Language (Ow et al., 2007); and Shanghai Sign Language was used by older deaf people who studied in Singapore (Bell et al., 2015; Hurlbut, 2000). MFD documented the signs and printed several BIM books to ensure that BIM was recognized as the native signed language of deaf Malaysians and was used uniformly (Bell et al., 2015).

Although some signs used in BIM are “heavily influenced by ASL” (Gertz & Boudreault, 2016. p. 239), BIM also includes signs from the Malaysians, and it is recognized as an autonomous and independent language. The Malaysian Government has recognized BIM as the official signed language of the Deaf community pursuant to the People with Disabilities Act (2008). Therefore, BIM should be considered the national sign language in Malaysia. However, BIM has not yet been recognized as an official medium of instruction at government schools that provide special education to deaf students (Yusoff & Mohamed, 2012, 2017). In addition, BIM is not widely taught in schools in Malaysia (Yasin et al., 2017). It is their belief that if BIM were used, deaf students would not be able to master the Malay language. In contrast, other government agencies use BIM interpreters to communicate with the deaf community through news, events, and workshops.

Mixed Lexicons from Signed Languages

The Department of Special Education under the MOE continued to keep KTBM as a medium of instruction in schools with the goal of helping deaf students master the Malay language for reading and writing (Omar, 1978). According to Omar (1978), deaf students should learn Malay by using KTBM in school, as it follows the syntactic structure of spoken Malay, which is still used today. However, deaf people continued to use BIM widely in their daily communication and social interactions, both in private and in public, because BIM is their native sign language. Today, KTBM is still used academically in schools, while BIM is still used socially, intellectually, emotionally, culturally, and linguistically in the deaf community.

In the 2010s, the Department of Textbooks, which is under the MOE, developed textbooks specifically for deaf elementary students for subjects such as *Bahasa Isyarat Komunikasi* (BIK), English and Malay. BIK is a language subject intended to teach deaf

students how to communicate using sign language, in the same way that Malay is used to teach language proficiency in Malay. The Department of Textbooks decided that instead of focusing on KTBM or BIM, they would use a mixture of both languages, in which KTBM signs were used first, and if there were no signs, they would then use a sign from BIM. BIM is taught to deaf students as academic content about sign language to help students learn and master sign language to improve their communication skills. The Department of Textbooks wanted to ensure that students could follow the curriculum by adding pictures of signs to texts.

As a member of the English textbook panel for five years, I was responsible for locating and verifying the pictures of signs before inputting them into the English textbooks for Years 1-6, which is for the primary level. Following the policy made by the MOE stating that English words must be supported by English signs, the sign language pictures that were inserted into the English textbooks were Signing Exact English (SEE) obtained from the primary reference text, *Comprehensive Signed English Dictionary*, by Bornstein et al. (1983). If there was no SEE sign for an English word, then an ASL sign was to be used from the *American Sign Language Dictionary* by Martin L. A. Sternberg (1998). KTBM and BIM were to be used if neither SEE nor ASL equivalents were found. In summary, the sequence of locating the pictures for the English vocabulary was from SEE, ASL, KTMB, and BIM as needed based on the MOE policy.

On the other hand, the textbook for the Malay language had a different process than the textbook for English. In regards to the textbook about Malay, following the MOE policy, Malay words must be supported by KTBM signs. BIM pictures could be used if no sign words from KTBM were available to represent the concept. If neither KTBM nor BIM equivalents were available, other sign resources, such as SEE or ASL, could be used. The sequence for locating the pictures for the Malay vocabulary was from KTBM, BIM, SEE, and ASL.

Historically, Malaysia has made concerted efforts to assist deaf students in their education by using natural but foreign signed language (such as ASL) as well as contrived signed language systems (such as SEE and KTBM). However, there has yet to be a recognition of the potential for BIM to be the driving force in the students' development of sign language as a tool for communication and learning. BIM was not

encouraged to be used in the BIK textbook, and instead, the KTBM was prioritized. Since ASL, SEE, and KTBM are either not the native sign languages used by the deaf community in Malaysia or not natural languages, they may not be preferred for schooling by the Malaysian deaf community. Instead, BIM could be considered the preferred language in school. BIM has not yet played a significant role in the education of deaf students in Malaysia due to widespread beliefs that it would hinder literacy development rather than assist it.

Quality of Life of Deaf Malaysians

Studies in Austria and the USA have revealed that deaf individuals generally have a lower quality of life (QOL) than their hearing peers (Fellinger et al., 2005; Gilman et al., 2004). Several studies also examined the correlation between QOL and a variety of variables, including communication (Frajtag & Jelinic, 2017; Holmstram, 2022; Kushalnagar et al., 2011), parents' hearing status (Jombor, 2009; Maxwell, 2011), school settings (Schick et al., 2013; van der Straaten et al., 2020), health (Smeijers et al., 2018), emotional intelligence (Ashor & Jalil-Abkenar, 2021), acculturation levels (Marschark et al., 2018; Maxwell, 2001), family function (Aanonden et al., 2018), parents (Cagulada & Koller, 2022), sign language (Santos et al., 2019; La Grutta et al., 2023), acculturative stress (Aldalur & Pick, 2023), and educational achievement levels (Alsabei, 2020). Some QOL studies have investigated the effect of cochlear implants (CI) on deaf individual's QOL (Denham & Battro, 2012; Meyer et al., 2013; Spencer, Tomblin & Gantz, 2012). A number of these studies, however, have focused on the medical discourse of hearing functioning, viewing hearing loss as a limitation inherent in the deaf individual.

There is little information available regarding the well-being of Malaysian individuals with disabilities, particularly the deaf community. There have been a few studies that have attempted to correlate the QOL of Malaysian individuals who have disabilities with a variety of individual variables, including education levels (Jani et al., 2020a, 2020b) and various areas of one's life, including psychological health, social relationship, environment, autonomy, discrimination, inclusion, and physical health (Aziz et al., 2023). Several studies have proposed to parallel QOL research with deaf

individuals according to a variety of individual characteristics, including the use of hearing aid (Adibi et al., 2013), family (Umat et al., 2019), communication accessibility (Khairuddin et al., 2018), inclusion (Khairuddin & Miles, 2020), educational experiences (Lee et al., 2021) and social experiences (Lee et al., 2022). There are no studies that focused specifically on the impact of the use of natural sign language.

Today, various sign languages are being used in Malaysia, such as KTBM, BIM, SEE, and ASL (Chong & Foster, 2022). The use of foreign natural (e.g., ASL) and contrived signed languages (e.g., SEE) in Malaysia may confuse deaf students who have not yet acquired a solid foundation in the natural Malaysian Sign Language, BIM. Additionally, deaf persons in Malaysia who are exposed only to foreign signed languages or Malay coded sign language (e.g., KTBM) may have difficulty communicating with other members of the Malaysian deaf community who use the natural signed language, BIM. Misunderstandings and miscommunications may adversely affect the QOL of these individuals in some cases. In schools for the deaf, KTBM is the primary medium of instruction, while BIM is the primary language deaf students use in their daily communication (Pregel & Kamenopoulou, 2018). During their schooling, deaf students may be unable to distinguish between KTBM, BIM, SEE, and ASL (Chong & Foster, 2022). It has long been perceived by the Department of Special Education under the MOE and by teachers of the deaf that KTBM, SEE or ASL, rather than BIM, should be used by deaf students for learning the Malay or English language in school. Nevertheless, deaf persons who were exposed to BIM in school, in the dorms, in the deaf community, or by deaf families often continue using the language socially and cognitively into adulthood. This contradiction of educational and social spheres may impact deaf individuals' QOL.

Additionally, the lack of sign language in family settings may impact deaf persons' QOL. A study by Lee et al. (2021) demonstrated the prevalence of "dinner table syndrome" among Malaysian deaf adults. Deaf people can experience dinner table syndrome when they are excluded from conversations with hearing family members during social gatherings, such as meals, because they are not able to participate or understand the conversations and it can cause a feeling of isolation (Meek, 2020). One of the most common childhood traumas experienced by deaf adults is chronic

inaccessibility to communication with hearing parents and relatives (Anderson et al., 2016). According to Lee et al., (2021), one married woman struggled to engage in conversations with her hearing family members to fit into the hearing family conversations due to her limited hearing abilities; however, she could speak and read lips. She felt frustrated, isolated, and excluded in these conversations. This terrible experience may affect how deaf people relate to their families, especially their hearing parents. There is a possibility that this phenomenon may adversely affect the QOL of deaf adults due to communication barriers.

The current study is an inquiry into the signed languages most commonly used by deaf Malaysians today and during their prior schooling, and how sign language may have impacted their QOL. In Malaysia, there are signed languages (e.g., ASL and BIM) and artificial signed communication systems (e.g., KTBM and SEE) being used in schooling and beyond, and a deaf person's experiences with sign language during their schooling may affect their QOL.

Purpose of the Study

In Malaysian schools, KTBM has been widely used to teach deaf students how to read and write in Malay (Omar, 1978) and it is still prevalent today. At the same time, BIM, as the native sign language of deaf people in Malaysia, is used as a means for communication, discussion, storytelling, and social interactions. Therefore, the signed communication often used in school is not the signed communication used by the community outside of school. This may have implications for students' learning and their QOL in adulthood.

The purpose of this study is to investigate the QOL of deaf Malaysians who recently graduated from school and to identify whether QOL differs based on the signed language communication most commonly used during their school years and today. It is proposed that communication during the formative school years may affect the QOL of deaf adults in Malaysia through subsequent positive or adverse life experiences after schooling.

Research Questions

1. Are there demographic variables that relate to higher or lesser QOL outcomes for deaf Malaysians?
 - 1.1. Is there a difference in QOL and QOL domains (participation, self-acceptance / advocacy, and perceived stigma) among deaf adults based on the signed communication most often used?
 - 1.2. Is there a difference in QOL among deaf adults based on gender?
 - 1.3. Is there a difference in QOL among deaf adults based on race?
 - 1.4. Is there a difference in QOL among deaf adults based on deaf or hard of hearing identity?
2. What is the relationship between deaf Malaysians' satisfaction with the signed communication used during one's formative school years and their QOL in adulthood?
 - 2.1. What is the relationship between deaf Malaysians' satisfaction with the signed communication used in the school during the formative school years and their QOL in adulthood?
 - 2.2. What is the relationship between deaf Malaysians' satisfaction with the signed communication used with their family members at home during their formative school years and their QOL in adulthood?
 - 2.3. What is the relationship between deaf Malaysians' satisfaction with the signed communication used with their friends in the dormitories during their formative school years and their QOL in adulthood?
3. Does the signed communication most often used during one's previous school years impact deaf Malaysian's QOL in adulthood?
 - 3.1. Is there a difference in QOL for deaf Malaysians based on the type of signed communication they most often used in their previous schooling?
 - 3.2. Is there a difference in QOL for deaf Malaysians based on the type of signed communication they most often used with their family members at home during their formative school years?

- 3.3. Is there a difference in QOL for deaf Malaysians based on the type of signed communication they most often used with their friends in the dormitories during their formative school years?

Definition of Terms

Kod Tangan Bahasa Isyarat (KTBM) is a signed code in which each word in the Malay language is given a corresponding sign. It is intended to assist in learning the Malay language. When it comes to learning the English language, it is similar to Sign Exact English (SEE) or Manually Coded English (Zainuddine et al., 2010). KTBM is known as Sign Exact Malay or Manually Coded Malay. It is not a native signed language for deaf people in Malaysia.

Bahasa Isyarat Malaysia (BIM) is a genuine native sign language that is used by the deaf Malaysian community for their daily communication. Generally, it is similar to American Sign Language in terms of its syntax and grammar rules.

Simultaneous Communication (sim-com) involves the use of both spoken language and a manually coded system of signs at the same time.

There are four additional chapters following this dissertation introduction. In the following chapters, a literature review supporting the study is presented. This chapter examines theoretical orientations that underpin the QOL of people who are deaf. A description of the research design is provided in Chapter 3, along with information on participants, data sources, and methods for analyzing the study results in Chapter 4. A discussion of the findings, limitations of the study, and future directions for research on the use of signed communication modes within the context of the QOL of the deaf community is presented in Chapter 5.

CHAPTER II

Literature Review

Quality of Life (QOL)

The World Health Organization (WHO) defines Quality of Life (QOL) as “an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (WHOQOL Group, 1993). QOL refers to the degree to which one perceives satisfaction with one's life conditions. Different people value different aspects of life and character, so "quality of life" means different things to different people. QOL emphasizes culture which strongly influences QOL. Within society, humans have different elements or demographic group identities such as gender and define their own conception of QOL (McCall, 1975). QOL is an integrative concept encompassing human, social, and health sciences; it incorporates the philosophical notion of happiness, psychology's conception of subjective well-being, and medical sciences' ideas of physical and mental health (Bowling, 2003; McCall, 1975). Comparing studies on QOL is challenging due to the variety of definitions of the concept and its amorphous nature.

Felce and Perry (1995) propose that Quality of Life (QOL) can be understood at three levels: personal values, personal life satisfaction, and objective living conditions. They describe personal values as including good physical health (health, mobility, efficiency, safety), financial stability (income, housing, communication, social security), strong social relationships (personal relationships, social bonds, support), positive emotional well-being (positive emotions, mental health, resistance to stress, leisure), and opportunities for development and productivity (talent, productivity, self-esteem, faith, sex). On the first level, personal values influence the individual's perception of a good QOL. Felce and Perry (1995) describe personal life satisfaction as “satisfaction in a number of life domains: (a) material comforts, health work, recreation, learning, and creative expression; (b) living situation, relations with family, social relations, leisure, work, finances, safety, health, and religion; and, (c) marriage, family life, friendships, standard of living, work, neighborhood, city or town of residence, the state of the nation,

housing, education, health, and the self" (p. 56). The second level, personal life satisfaction, refers to the individual's subjective evaluation of their own life, precisely their level of satisfaction with various aspects of their lives. Lastly, objective living conditions can influence how an individual achieves personal life satisfaction by defining personal values (Daszykowska, 2010). The individual subjectively assesses the relationship between all three levels, and this is dependent upon how they perceive their physical, material, social, or emotional well-being, their development, and their activities.

Teoli & Bhardwaj (2023) emphasize that the concept of QOL captures both positive and negative aspects of an individual's existence within a specified period of time. For instance, typical aspects of quality of life encompass personal health (such as physical, mental, and spiritual well-being), relationships, educational attainments, work environment, social status, financial stability, security and safety, liberty, autonomy in decision-making, social belonging, one's physical environments. Physical health, material wealth, and social relationships are tangible aspects of an individual's life. However, as they point out, the concept of QOL extends beyond these tangible aspects. For individuals who are deaf or hard of hearing, for example, their QOL may also be influenced by factors such as access to communication, inclusion in social activities, and support from the community. These intangible elements play a significant role in determining an individual's overall satisfaction and well-being.

Standard indicators of the QOL contain financial, employment, the environment, physical and mental health, education, recreation and leisure time, social belonging, religious beliefs, safety, security, and freedom (Barcaccia, 2013, Gregory et al., 2011; Nussbaum & Sen, 1993). QOL spans contexts, including the fields of international development, healthcare, politics, and employment. Health-related QOL (or HRQOL) evaluates QOL and its relationship with health (Andrew, 2002). Medicine and public health is generally concerned with improving quality of life of special education of the low functional ability group (Kober & Eggleton, 2002; Raphael et al., 1999), the relationship between spirituality and health (Sawatzky et al., 2005), sociology (Bowling et al., 2003), and psychology and mental health of the deaf people (Fellinger et al., 2007; Flanagan, 1978; Frisch et al., 1992).

From an economic perspective (Fox, 1974), QOL is viewed as one's "total income" obtained through one's behavior or directed by one's choices, whereby income maximizes the individual's total utility, satisfaction, or happiness. According to Sirgy et al. (1982) and Sirgy et al. (1985), in marketing, QOL is construed as long-term life satisfaction in terms of the relative "goodness" of a marketing program that generates long-term satisfaction while providing marketing value.

From an ecological perspective, Bubolz et al. (1980) examined QOL through the concepts of what they call "the human-enviored unit", the environment, and interactions. The concept of "human-enviored unit" refers to social units that exist within an ecological context. The environment provides energy and matter (resources) to sustain a "human-enviored unit". The interaction among the components of "the human-enviored" unit, the components of the environment, and between the human environment unit and the environment occurs. The "human-enviored unit" views the QOL as a high level of satisfaction across various life domains. An environment providing sufficient resources to meet the needs of all humans is defined as providing QOL from the perspective of the environment.

Public health and medicine experts have also conceptualized QOL from a need assessment perspective. Basically, need assessment involves collecting information about a particular population and utilizing that information to develop and/or modify programs aimed at that population (Bell et al., 1983; Nguyen et al., 1983; Siegel et al., 1978). The majority of research in the area of deafness focuses on QOL and outcomes for cochlear implant recipients, including language development, health, and self-esteem, as well as the assessment of children's and their parents' QOL (Loy et al., 2010; Preisler et al., 2005; Sparreboom et al., 2012). Research on QOL among the Deaf and Hard of Hearing population exists in the medical field; however, most of this research concerns mental health (Fellinger et al., 2005, 2007; Tambs, 2004).

Maslow's Theory of Hierarchy of Needs

From a theoretical perspective, QOL is viewed through Abraham Maslow's perspective of the human community. The theory of QOL argues that the higher the need satisfaction level of most members in a society, the greater the QOL of that

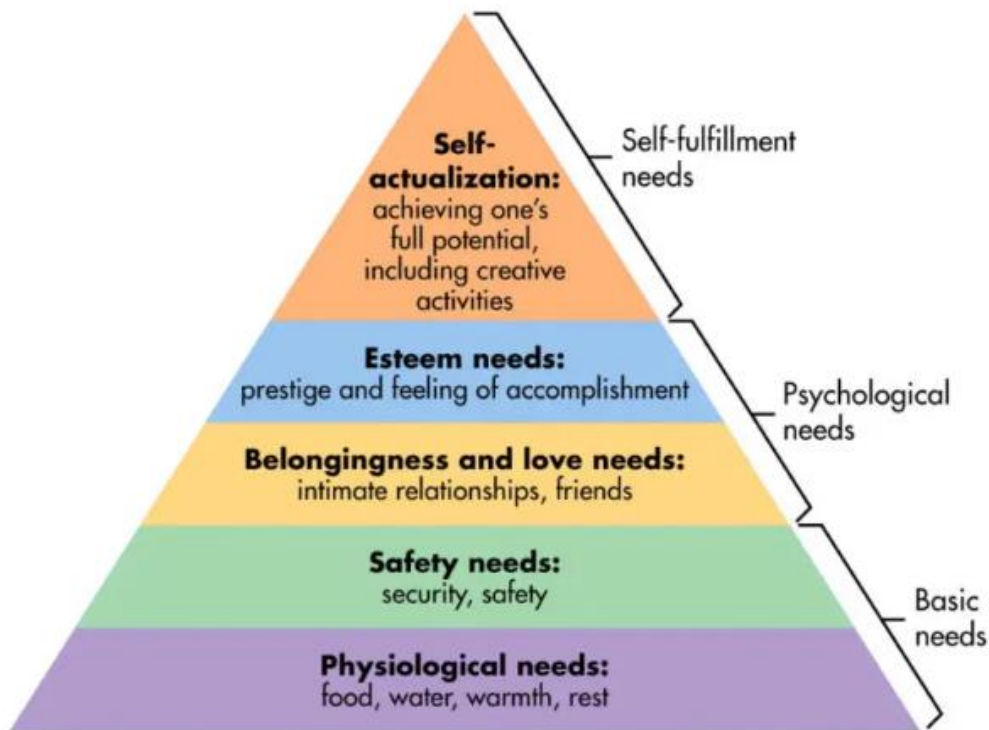
society. QOL is also viewed from the environment perspective as a setting that provides sufficient resources to meet the needs of the human community (Sirgy, 1986).

The QOL theory is derived from Abraham Maslow's human developmental perspective. Even though many attempts have been made to construct social indicators and measure systems, few have been attempted to construct QOL theories (Carley, 1981). Although social indicator systems have been developed "pragmatically" through intuition and political compromise, QOL research requires theoretical orientation. Developing and refining the QOL theory from which social indicators can be measured should be a priority for social scientists. Without theory, there may be questions regarding the construct validity of existing social indicators. The development of meaningful indicators is based on the understanding of the dynamics underlying quality of life and the development of QOL theories. As a result, the development of indicators provides a framework for evaluating the effectiveness of social policies and understanding how the indicators affect the QOL.

Maslow refined his theory over a number of decades based on the concept of the hierarchy of needs (Maslow, 1943, 1962 & 1987). The most basic needs occupy the lowest levels of the pyramid of the hierarchy of needs. The more complex the need, the closer it appears to the top. The most basic needs must be met before moving on to the next level until the more complex needs can be fulfilled. Figure 1 shows a pyramid representing Maslow's hierarchy of needs.

Physiological needs refer to what the body requires for survival, such as food, water, breathable air, and shelter as part of the pyramid at the bottom level. A higher level of security and safety is required to ensure that a person is free from danger and physical harm. These include the need for financial security, health, and wellness. These needs can often be met by having a job, health insurance, and choosing a safe neighborhood to live in. Higher level, social needs include the needs to belong and acceptance, which includes the need for love, family, and friends. These needs are often met through social groups, church, or romantic relationships. In addition to the need for appreciation and respect from others, esteem needs also include self-esteem, which is fulfilled through personal accomplishments and contributions to the world.

Figure 1



Maslow's Hierarchy of Needs

Note. Reprinted image from "Maslow's Hierarchy of Needs," by S. McLeod, 2024, *Simply Psychology*, (<https://www.simplypsychology.org/maslow.html>)

Self-actualizing needs are at the pinnacle of the pyramid. These include the need to fulfill one's potential as a person. According to Couture et al. (2007), self-actualization can be described as the psychological process that enables one to maximize the use of one's abilities and resources. The process may vary from one person to another. According to McCall (1975), most of Maslow's needs belong to the category of psychological needs. Fulfilling a psychological need is to achieve a state of psychological well-being or happiness.

German-American neurologist Kurt Goldstein (born 1878, died 1965) coined the term self-actualization in reference to "individuation" or the process of becoming

independent from one's environment (Whitehead, 2017). However, the term is most well-known as coined by American psychologist Abraham Maslow (born 1908, died 1970). In his 1943 theory to explain human behavior, Maslow placed self-actualization at the top of a human's hierarchy of needs. According to Maslow (1943), fulfilling one's potential is not only a noble undertaking or an admirable trait but a human necessity. Even so, self-actualization is not often achieved. One of the reasons for this is that most people are concerned with meeting the most urgent needs in the hierarchy. A person's ability to achieve self-actualization is often described as developing one's capabilities, which includes an appreciation of and full participation in life. However, each individual's potential is unique to them and varies from person to person. Therefore, self-actualization is a personal process that differs from person to person.

In conclusion, the perspective adopted is that of human development, based on Maslow's theory (Maslow, 1943). The concept of quality of life is based on a hierarchy of satisfaction needs shared by all members of society. Generally, the higher the level of satisfaction needed (from lower-order to higher-order needs), the better the quality of life in that society.

Quality of Life Concept

English economist Arthur Cecil Pigou introduced the concept of QOL in his 1920 book, *The Economics of Welfare* (Arsic & Djordjevic, 2017). John F. Kennedy, as President of the United States, used the term to describe the state of the nation a few decades later, it became mainstream. QOL was developed as an opportunity to unify concepts, set goals for providing services, and evaluate the impact of the services on people daily. According to Felice (1997), in nature, experiences, and lifestyles, QOL encompasses a variety of developmental changes in individuals and their identity. Among his philosophical services are integration, maintaining relationships, and leading an everyday and social existence.

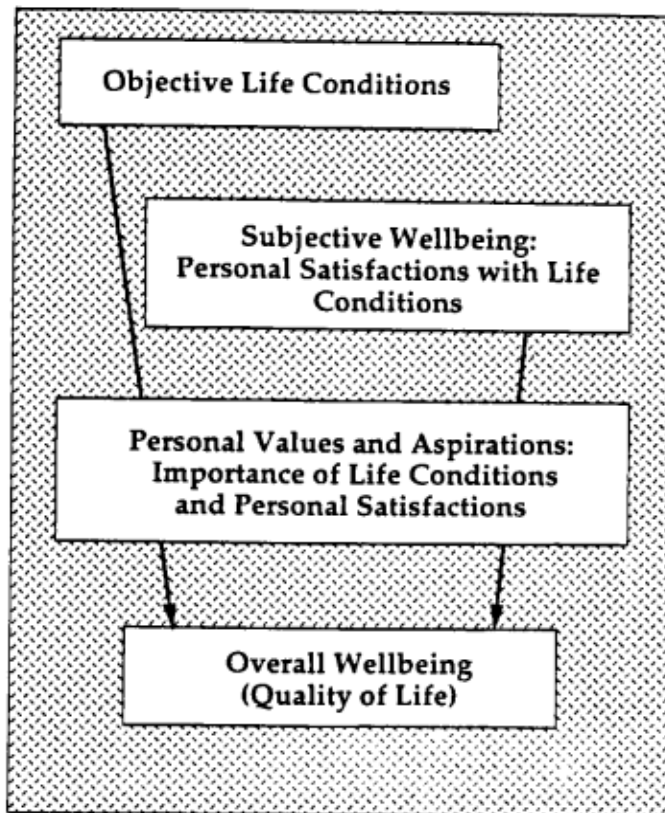
The concept of QOL is a multidimensional construct (Felce, 1997), as can be seen in the three-element model (see Figure 2), in which values, life conditions, and personal satisfaction interact with personal values and aspirations to determine the QOL (Felce & Perry 1995):

1. An individual's life circumstances describe their objective conditions.
2. An individual's subjective well-being is how satisfied they are with their living conditions or lifestyles.
3. Values and aspirations reflect an individual's prioritization of different aspects of their subjective well-being and objective well-being.

This QOL model is based on other formulations summarized by Borthwick-Duffy (1992) and the importance of individual values outlined by Cummins (1997). A starting point (see Figure 3a) is to suggest that QOL is the sum of the objectively measurable life conditions experienced by an individual. In such conditions, personal satisfaction with life is an indicator of a subjective response to life. In this model, citizens are not guaranteed satisfaction with life, but only a right to live and reasonable living conditions. Although life conditions can significantly impact an individual's satisfaction with life, neither this potential relationship nor the subjective appraisal itself is relevant to the QOL assessment. Assessing the variety of life conditions across the population may be able to establish general indicators of QOL. The life conditions of a specific subgroup, such as deaf persons, could be identified based on their position within the population distribution.

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Figure 2



A Model of Quality of Life

Note. Reprinted image from "Defining and Applying the Concept of Quality of Life" by D. Felce, 1997, *Journal of Intellectual Disability Research*, 41(2), p.126 (<https://doi.org/10.1111/j.1365-2788.1997.tb00689.x>).

However, many authors caution against defining a reasonable or decent QOL based on objective standards (Edgerton 1990). Expressed satisfaction with life (Figure 3b) is the essential criterion of QOL because individuals differ in what they enjoy and what they want from life or find important. The proposition is that people's views about their lives will reflect their QOL more sensitively than an imposed objective measure.

Nevertheless, using described satisfaction as a reflection on the QOL - as a fulfillment of expectations - is not unproblematic. Firstly, the perception of well-being may be influenced more by internal rather than external conditions. The term

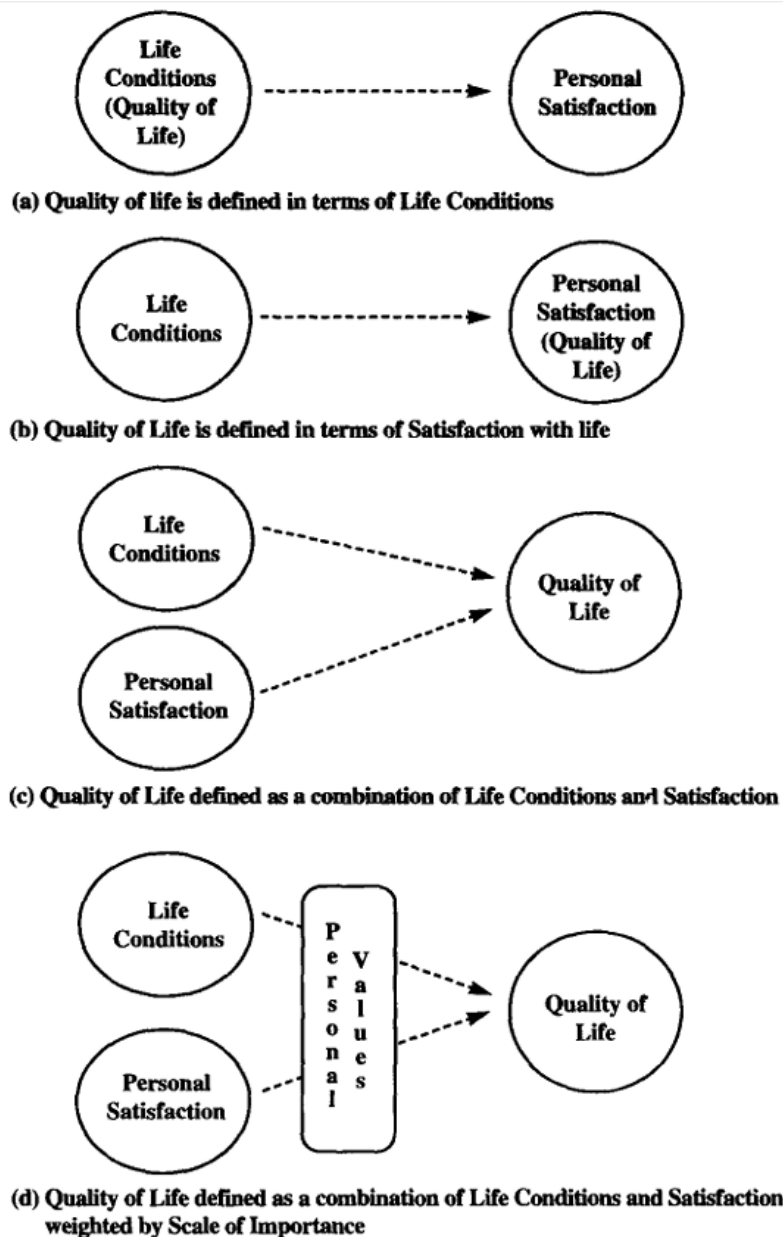
"regression to characteristic level" refers to the process where over time, an individual's satisfaction levels tend to stabilize around a baseline based on the individual's inherent characteristics and past experiences. Thus, a longitudinal pattern can be relatively stable, with previous satisfaction being among the best indicators of current satisfaction. There is no evidence that satisfaction is the indirect indicator of QOL that is often assumed. Instead, it is a nonresponsive indicator that is sensitive to only gross and sudden changes in life circumstances. Secondly, satisfaction is a measure of comparison between people and within people over time (Felce, 1997). It is impossible to isolate expressions of satisfaction from their context. The individual's expressions of satisfaction may be adjusted to habitual life conditions if the experience indicates that there are pervasive life conditions that are typical for them and their class. QOL is defined as the individual's personal satisfaction regardless of various life conditions. If social stratification is not considered, this formulation is less appealing. Many people with substantial disabilities lack independence and experience constrained autonomy to maintain or change life conditions based on their subjective appraisals, similar to other societal groups that are disadvantaged economically, educationally, by class, racial origin, or other factors. It is possible that this reality will affect the satisfaction reports.

Those with low expectations due to their circumstances or status are more likely to report satisfaction instead of dissatisfaction regardless of adverse circumstances. Adults with moderate or mild intellectual disabilities who live independently have provided evidence consistent with this prediction. According to studies (Close & Halpern, 1988; Edgerton et al., 1984) that have explored the perspectives of individuals with developmental disabilities, the people with developmental disabilities were satisfied with their present lives and exceptionally positive about their future. In spite of dreadful living conditions, such as poverty, inadequate housing, health and safety risks, victimization, social isolation, personal loss, and the inability to obtain or maintain employment, they remain satisfied with their present situation. Holland (1990) also found that residents of various living environments, from hospitals with poor conditions to common community housing, expressed the same high satisfaction with their circumstances.

As a result of Cummins's (1995) review of empirical studies of lifestyle satisfaction, there was remarkable consistency in the results of large-scale studies of the general population. The researcher obtained the following results (see Figure 4). There is a difference in the assessed QOL between the rich and the poor and among different ethnic groups (at least in the USA). The QOL of persons with physical disabilities and chronic medical conditions is lower than the average QOL for the general population. For people with intellectual disabilities, however, all results are within the normal range. It can be concluded that either the problem we perceive as a problem has already been resolved, or that a definition of QOL which relies solely on subjective evaluation fails to provide adequate safeguards for vulnerable individuals that need to be associated with this measure. The adequacy of social policy in general and the level of service support in particular should be evaluated according to this criterion.

Commentators have therefore viewed quality in Figure 3c as a combination of objective and subjective components (Bigelow et al., 1991; Schalock, 1994), but there is a pitfall that the way scores are accumulated across issues is pragmatic in nature. Biological, material, social, behavioral, and psychological indicators may be used to evaluate life domains objectively. Reports of satisfaction and well-being may also reflect subjective feelings about each aspect of life. Similarly, the QOL measures have been developed for individuals with mental retardation that account for both subjective and objective aspects (Schalock, Keith, & Hoffman, 1990). This formulation allows the individual to maintain an independent perspective on his or her own life circumstances. This model does not specify how to combine objective and subjective assessments across relevant issues.

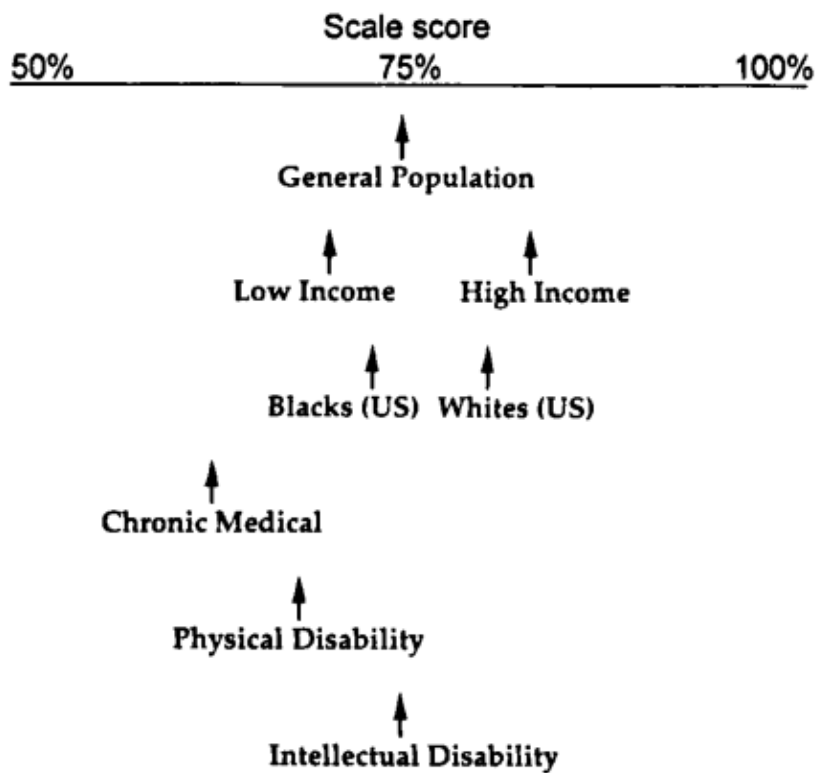
Figure 3



Conceptualization of Quality of Life

Note. QOL is defined in terms of (a) life conditions, (b) satisfaction with life, (c) a combination of life conditions and satisfaction, and (d) a combination of life conditions and satisfaction weighted by the scale of importance. See Figure 6 for an extension of (d) only. Reprinted image from “Quality of Life: Its Definition and Measurement,” by D. Felce and J. Perry, 1995, *Research in Developmental Disabilities*, 16(1), p. 55 ([https://doi.org/10.1016/0891-4222\(94\)00028-8](https://doi.org/10.1016/0891-4222(94)00028-8)).

Figure 4



Total Population and Subgroup Comparisons of Satisfaction with Life

Note. Reprinted image from "Defining and Applying the Concept of Quality of Life" by D. Felce, 1997, *Journal of Intellectual Disability Research*, 41(2), p.129 (<https://doi.org/10.1111/j.1365-2788.1997.tb00689.x>).

Cummins (1997) suggested that people's subjective assessments across various aspects of their lives should be aggregated according to the relative importance they attach to these aspects based on their subjective assessments. As a result of extending this idea to both objective and subjective assessments, the three-part model is shown in Figure 3d. There may also be a consideration of the individual's scale of values when determining the significance of objective life conditions. A three-factor model is proposed in which personal values, life conditions, and life satisfaction interact to determine the QOL (Fig. 3d). Whether a life domain is subjective or objectively

assessed is only meaningful in the context of the individual's perception of its importance.

Operationalization of the Construction of QOL

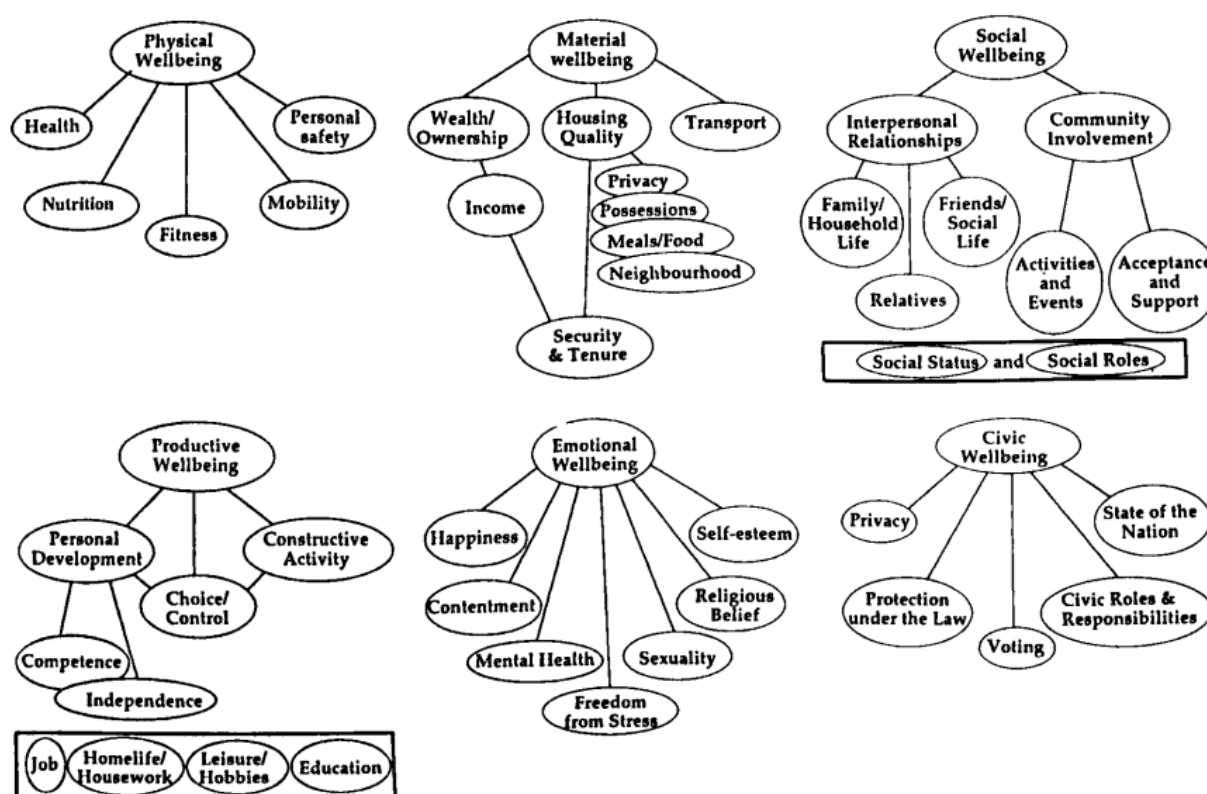
The definition of QOL differs among researchers, but there is considerable agreement on relevant domains for assessment. Fifteen key literature sources have been reviewed that describe conceptual models or operationalizations of QOL (Schalock, 1996). During this review, there were two important considerations: (1) the complexity of life demands a multi-element, multi-focus assessment framework and (2) at a broad level of generalization.

A six-heading categorization was developed based on the review of studies. Figure 5 illustrates the domains relevant to the QOL as determined by Andrews & Withey (2012); Baker & Intagliata (1982); Bigelow et al. (1991); Blunden (1988); Borthwick-Duffy et al. (1992); Brown & Bayer (1992); Campbell et al. (1976); Cummins (1997); Flanagan (1978); Franklin et al., (1986); Heal & Chadsey-Rusch (1985); O'Brien (1987); Parmenter (1988); Schalock et al. (1990); and, Stark and Goldsbury (1990). Most aspects mentioned in these sources can be grouped under six domain headings: (1) Physical well-being; (2) Material well-being; (3) Social well-being; (4) Productive well-being; (5) Emotional well-being; and (6) Civic well-being.

Physical well-being is the primary sub-construct in Bhmden's classification (1988), which includes health, nutrition, fitness, mobility, and personal safety, as aspects of physical ability, fitness, and mobility can be defined as functional capacities relative to specific activities. The consideration of these aspects overlaps with the consideration of development and activity. According to Cella (1994), in the physical dimension, pain, nausea, and fatigue constitute perceived and observed bodily functions and disruptions. Symptoms associated with disease, treatment side effects, and general well-being are all considered physical well-being by the patient. Clinicians/observers need to distinguish between disease and treatment-induced physical disruptions when determining treatment options. For patients, this distinction may not be as crucial. People implicitly combining these experiences with patients may

misinterpret symptoms as side effects or vice versa. Additionally, safety is an aspect of emotional well-being, as Schalock (1996) has classified it, or a civic right.

Figure 5



Quality of Life Domains

Note. Reprinted image from “Defining and Applying the Concept of Quality of Life” by D. Felce, 1997, *Journal of Intellectual Disability Research*, 41(2), p.130 (<https://doi.org/10.1111/j.1365-2788.1997.tb00689.x>).

Material well-being was operationalized by Blunden (1988). Wealth or ownership, income, various aspects of the living environment, transportation, security, and tenure are all included in material well-being. The quality of one's housing, furnishings, equipment, food, possessions, and the neighborhood's character all contribute to the quality of one's accommodation. Transportation is a factor that influences a person's

ability to maintain or extend their participation in social, work, educational, civic, and leisure pursuits, which underpins many other aspects of their well-being.

Social well-being includes two major dimensions, according to Schalock's (1996) classification: (1) the depth and quality of interpersonal and mutual relationships within the family, with relatives and friends, and with acquaintances, and (2) the level of community acceptance or support given by the community in relation to the activities undertaken. Both dimensions can be classified as social status or social roles.

Productive well-being encompasses three interlinked areas: (1) personal development, which involves learning skills or personal competence or independence; (2) self-determination, which involves autonomy, choices, and control; and (3) constructive activity, which involves the ability to utilize one's time constructively according to one's tenets. There are many ways in which individuals can express themselves, including through pursuits at home, at work, at leisure, and in educational settings.

Emotional well-being includes happiness, being stress-free, mental health, self-esteem, spirituality or religious beliefs, sexuality, and contentment. Accordingly, the stress level is determined by the conditions under which social and functional activities are conducted, and it may affect the degree of enjoyment one derives from them, thus contributing to or detracting from one's sense of well-being. Individuals' self-esteem and satisfaction, religious beliefs, and personal sexual orientation can influence their psychological or emotional well-being.

Civic well-being (Citizenship well-being) encompasses one's right to privacy, the right to legal protection under the law, the right to vote, the democratic process, and civic responsibility. Schalock (1996) mentioned the core domain, but Felce and Ferry (1995) omitted it.

Quality of Life: A Multi-dimensional & Multi-element Framework

Figure 6 illustrates a model of quality of life that combines the categorization of life domains with objective circumstances, subjective appraisal, and relative values (Felce, 1997). This model is an assessment of general well-being that includes objective and subjective measures of physical, social, economic, psychological, and civic well-

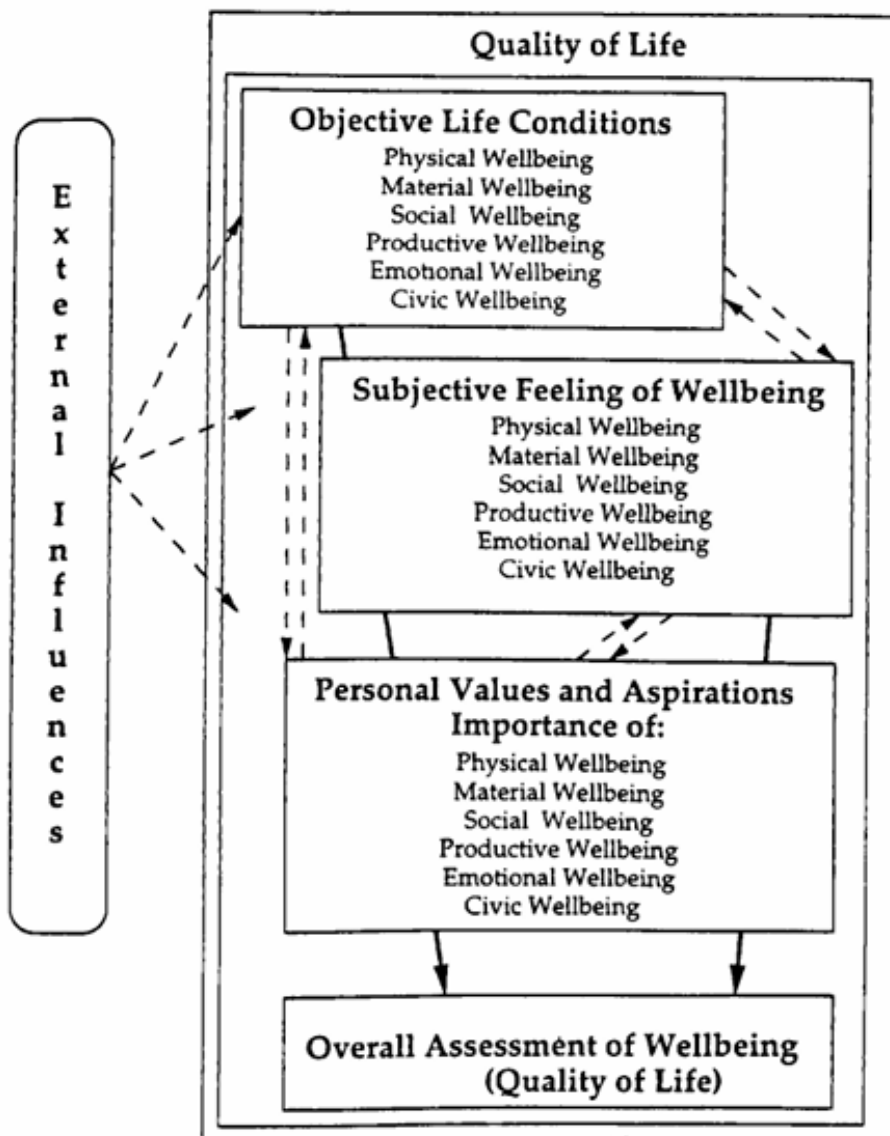
being, weighed according to personal values. All three major dimensions are shown to interact dynamically with each other and to be potentially interdependent at all times. It is important to note that QOL is a far-reaching goal that requires the consideration of personal priorities and preferences to the extent that these can be established reliably and accurately.

QOL for a Model of Disability

There are growing areas of agreement as special interest QOL groups continue to refine their original statement sets with paradigm shifts to arrive at a more coherent framework of QOL (Schalock et al., 2022). The special interest QOL groups representing various disabilities included six viewpoints: (a) the international classification of functioning, disability, and health that emphasized participation and functioning (World Health Organization, 2001); (b) international human and civil rights covenants, including the *United Nations Convention on the Rights of Persons with Disability* (United Nations, 2006); (c) advocacy by family, self-advocacy, and disability rights groups for policies and practices that ensure inclusion, empowerment, and human and civil rights of people with intellectual and developmental disabilities (IDD) (Fleischer & Zamas, 2011); (d) public laws and system changes related to equity, inclusion, empowerment, community participation, and self-determination (Wehmeyer, 2014); (e) the integration of individualized supports and support systems into policies and practices at the organizational and system levels (Luckasson et al., 1992; Thompson et al., 2014; Wehmeyer et al., 2017); and lastly, (f) involvement of professional organizations such as the American Association on Intellectual and Developmental Disabilities (AAIDD)

There are three important characteristics of the new paradigm highlighted by these catalysts. First, its formulation and expression have progressed to incorporate evolutionary changes in the field. Second, it is derived from international policy and practice changes and, therefore, can be applied widely and universally. Third, it combines a set of values, assumptions, perceptions, and concepts that provide a framework for developing IDD policies and practices and evaluating their implementation.

Figure 6



An Overall Model of Quality of Life

Note. Reprinted image from “Defining and Applying the Concept of Quality of Life” by D. Felce, 1997,) *Journal of Intellectual Disability Research*, 41(2), p.131
<https://doi.org/10.1111/j.1365-2788.1997.tb00689.x>).

Four QOL conceptualization principles are incorporated into the latest interaction. The construct: (1) is multidimensional and influenced by both personal and

environmental factors and their interactions; (2) has the same components for everyone; (3) contains subjective and objective components; and (4) is influenced by self-determination, resources, purpose, and belonging (Cummins, 2005).

According to Cummins (2005), There are five essential characteristics of QOL concepts that can be found in the four principles. (1) QOL has two completely different forms - an objective domain and a subjective domain. An objective domain consists of physical quantities and frequencies that can be observed and measured within the public domain. Subjective domain refers to entities that exist only in the individual's private consciousness, and which can only be verified by frequent responses from the person who is involved.

(2) QOL should not be mainly based on its objective or subjective domain. There is a weak relationship between the two, and both appear to be valid indicators of life quality. One consequence of the dichotomy is that any comprehensive estimate of life quality must comprise both subjective and objective measures (Brown et al., 1994; Cummins, 2005; International Wellbeing Group, 2024; Raphael et al., 1996).

(3) The basic composition of QOL is the same for all people, irrespective of culture, socio-economic status, or disability. Thus, it is feasible to develop generic QOL instruments which can be applied with validity to any group. Furthermore, one should approach the interpretation of scores from a non-generic QOL instrument with caution (Cummins & Lau 2005). The instrument disregards the importance of quality of life and either sets the standards too low or assumes that the lack of pathology identifies as a high QOL (Cummins et al. 2004).

(4) Life quality should not be described by needs since low needs do not necessarily correlate with QOL. (5) QOL should not refer to 'opportunity'. This is due to two factors. First, the individual may not perceive some opportunities positively such as job enhancement. Secondly, the opportunity for QOL enhancement is a causal variable instead of an end state.

Raphael et al. (1996) conducted a study using a standard QOL questionnaire with people with disabilities. They explored the experiences of adults with developmental disabilities living in group homes to determine their definition of QOL. Through the interviews, researchers found that the individuals who rated low on several

items from the standard QOL actually viewed them as high based on their experiences. They reported the people with developmental disabilities in this study's QOL were related to opportunities for meaningful relationships, meaningful activities, and a sense of security that met their needs. The authors used this information to modify and improve the QOL questionnaire for people with disabilities. They concluded that the modification of the QOL questionnaire was necessary for adults with developmental disabilities (Raphael et al., 1996).

In summary, Cummins (2005) recommended two approaches for researching QOL: finding indicator variables based on core QOL domains and specifying causal variables that are correlated to one another and the indicator variables.

Applying QOL to Deaf Communities Globally

In general, the concept of QOL refers to the individual's level of well-being (Ferrans, 1990; Werngren-Elgstrom et al., 2003), and is frequently used to evaluate the effectiveness of programs (Grasso & Canova, 2008; Nakaji, 2008). Well-being is represented by persons who are developing to be productive individuals that can make positive contributions to society (Marks & Shah, 2014). Research on QOL can lead to improvements in individual well-being and contributions to societal change (Schalock & Alonso, 2002). Researchers have used QOL measures to make sure people's well-being are based on their heritage and culture; to promote change at the personal, programmatic, community, and national levels; and to improve people's personal control and opportunity (Schalock & Alonso, 2002).

Even though much attention has been paid to the development of quality of life research for marginalized groups and individuals, there is a dearth of research on QOL for the deaf community, which is particularly underserved. Most of the research on deafness has focused on QOL and cochlear implant outcomes in areas such as language development, health, and self-esteem (Loy et al., 2010; Preisler, 2005; Sparreboom et al., 2012). However, the number of individuals who have received cochlear implants is only a fraction of the deaf community.

McAbee et al. (2017) concluded that a number of factors contribute to the uniqueness of the deaf population, making QOL research necessary. The study of

McAbee et al. (2017) summarized three assumptions. First, it is a field with a well-established and well-documented history and culture (Lane, 1992). Second, deaf people comprise the only group in society regarded as disabled while not viewing themselves as having a disability (Lane et al., 1996). Finally, historically, the nondisabled people made decisions on behalf of deaf people (Lane et al., 1996).

Assessing QOL in the Deaf Community

During the last decades, there has been a growing number of studies that examined the QOL of deaf and hard of hearing (DHH) children and adolescents, targeting primarily on children with cochlear implants (Aanondsen et al., 2021; Fellingner et al., 2010). In addition, studies with DHH children and adolescents has defined QOL differently, ranging from health-related QOL (HRQOL) to social well-being. The different definitions have led to a variety of measures, including qualitative reports from parents after their children received cochlear implantations. There are also different participants (i.e., parents, children, adolescents, and adults) who have various kinds of access to communication and peers. Demographic data that contribute to the significant differences in DHH children and adolescents' QOL may include the age of participants, their preferred mode of communication, and levels of hearing loss (Aanondsen et al., 2021). To include deaf persons who use sign language as their preferred language, it is necessary to have reliable and valid QOL instruments available in sign language so that DHH persons can provide the most accurate reports (Aanondsen et al., 2021).

According to Fellingner et al. (2010), assessments are typically conducted using written questionnaires, which exclude individuals with poor reading abilities. Paper-pencil tests are inappropriate for prelingually deaf people because their average reading level is far below that of the general population. Written assessments should be presented in simple text at the level presented in a daily newspaper according to international data on the reading of the deaf (Holt, 1994). Or, psychological tests and assessments that can be presented in sign language do not automatically interfere with the ability to understand different concepts and terms (Fellingner et al., 2010).

Deaf people's mental health needs are best assessed by self-administration to get information, especially when QOL questionnaires are combined with measures of

mental distress (Felling et al., 2010). Interactive video questionnaires can be developed for the deaf (Lipton et al., 1996, Steinberg et al., 1998). However, reliable data is available based on significant community samples with diverse competence in signed and written language.

Translation into National Written Languages and Sign Languages

The systemic review that this researcher conducted indicated that some countries had adapted and translated the English version of QOL surveys into the printed national language. Most researchers translated the English QOL questionnaires into versions to be used in the countries where they conducted their research. English versions of QOL surveys have been translated into Arabic (AlNowaiser et al., 2023; Lotfy, 2020), Chinese in China (Cheng & Zhang, 2017; Liu et al., 2016; Qi et al., 2020; Zhang et al., 2017;), Italian in Italy (Gagnaniello et al., 2021), Persian in Iran (Ashori & Rashidi, 2020; Borujeni et al., 201), Portuguese in Brazil (Duarte et al., 2021), Turkish in Türkiye (Budak et al., 2022), and Malay in Malaysia (Adibi et al., 2013; Rusyda et al., 2022; Umat et al., 2019).

In some countries, such as the United States (Gilman et al., 2004; Kushalnagar et al., 2017; Kushalnagar et al., 2020; Patrick et al., 2011), Austria (Fellinger et al., 2005a; Fellinger et al., 2005b), United Kingdom (Rogers et al., 2018), Australia (Cornes & Brown, 2012), Brazil (Duarte et al., 2021), and Italy (Gagnaniello et al., 2021), researchers validated a sign language video translation of QOL surveys before distribution to participants to obtain accurate data on the QOL of deaf individuals. In other cases, the QOL surveys in written Serbia (Arsic & Djordjevic, 2017), and written Chinese (Qi et al., 2020) were administered to DHH participants with the assistance of sign language interpreters to ensure the DHH participants understood the questionnaires.

Nevertheless, two studies were found where the surveys were provided in their national language, albeit without the use of a signed video format or a sign language interpreter. These were conducted for deaf and hard of hearing children and adolescents in Türkiye (Budak et al., 2022), and Indonesia (Cahyani et al., 2022). Deaf participants in the study may be assumed and considered not to require any assistance

with signed language since they can speak with or without their hearing devices, including hearing aids or cochlear implants.

QOL Instruments for Deaf Persons

Generic QOL instruments measure the perceptions people have of their overall health. They are widely used to compare the QOL of deaf people with hearing people about a variety of diseases and disabilities (Qi, et al, 2020). The generic QOL evaluation instruments are too general for investigating specific issues or a specific condition. Nevertheless, some studies indicated that these instruments are sensitive enough due to the significant impact that hearing loss has on a child's life (Morettin et al., 2013).

Audiologists use disease-specific QOL instruments like the Communication Profile for the Hearing Impaired (CPHH), Hearing Environment and Reflections and QOL (HEAR-QL), and the International Outcomes Inventory-Hearing Aids (IOI-HA) (Kelly-Campbell & Atcherson 2012). Disease-specific QOL instruments focus on the perceptions of hearing impairment and the effect of hearing loss on the respondents' daily activities (Qi et al., 2020).

World Health Organization Quality of Life (WHO-QOL)

An online assessment package for the assessment of deaf people's QOL and mental health was undertaken. Fellingner and his team researched the QOL among the deaf community of Upper Austria in 2002/2003 (Fellinger et al., 2005a; Fellinger et al., 2005b; & Fellinger et al., 2010). They used the Brief version of the WHO-QOL, a 12-item General Health Questionnaire (GHQ-12), and five subscales of the Brief Symptom Inventory (BSI). They translated the instruments into sign language, videotaped them, and integrated them into the computer program ANIMAQU for self-administered interviews with an interface designed to meet the specific needs of the deaf. Fellinger et al. (2005a) found that the reliability of the versions for deaf participants was lower than the written versions for the general population but still within acceptable limits, for both the WHO-QOL and the GHQ-12. The reliability of the BSI was even higher than that of the general population. Thus, with the use of carefully translated standardized instruments of WHO-QOL, it is possible to assess the QOL and mental distress

effectively and reliably for deaf individuals whose preferred communication is sign language (Fellinger et al., 2005).

According to Fellinger et al. (2005a), deaf Europeans had a lower QOL than the general population and were more likely to develop mental illnesses. This may be a result of the emotional and social challenges deaf people encounter daily. In all areas measured, hard of hearing people had poorer social relationships than deaf people who are signing (Fellinger, 2007). As in this study, one factor related to QOL is the degree of satisfaction with the quality of hearing achieved through hearing aids.

Jani et al. (2018) utilized the WHO-QOL to examine existing knowledge and better understand the QOL of disabled and non-disabled youth in Malaysia. The WHO-QOL questionnaire consisted of 26 items encompassing physical, psychological, social, and environmental domains. In this study, one item related to social relationships was excluded due to its relation to sexual behavior, which was incompatible with the culture of students in Malaysian higher education institutions due to cross-cultural conflicts (Chen et al. 2006). The item on sex read, “Are you satisfied with your sex life?”. Accordingly, only 25 items were utilized to measure the QOL of the respondents in the study. Among students with disabilities, hearing-impaired students had the lowest mean total QOL score and the lowest score in the domain of social relationships.

According to Kushalnagar et al. (2014), generic QOL measures, such as the WHOQOL global health measure, are insufficient to capture the unique experiences of deaf adults, particularly those who become deaf early in life. People who have been deaf for most of their lives may share many similarities in their QOL, which can differ greatly from people who gradually lose their hearing function as adults. An individual who was born deaf, for example, may experience stressors at an early age as a result of struggling to understand family conversations or feeling left out.

Health-Related Quality of Life (HRQoL)

In the health-related quality of life (HRQoL) survey, people are asked to evaluate their subjective perceptions of how their current health status, health care, and health-promoting activities affect their ability to achieve and maintain a level of overall functioning that enables them to pursue valued life goals as well as a feeling of general

well-being. (Hinds, 2011). HRQoL survey measures can be used as general instruments and/or for specific diseases, particularly health issues that affect an individual's QOL (Said, 2017) and sense of overall well-being and function (Cella, 1995). HRQoL for DHH individuals was reported based on physical, emotional, and psychological functioning (Hawthorne et al., 2004; Huber, 2005; Karinen, 2001; Wake, 2004).

The general HRQoL questionnaire does not describe the QOL-specific health conditions and the validity for subgroups with special conditions, such as cancer patients or children with hearing loss. Gurková, E. (2011) coined that the study should focus on HRQoL instruments and issues in HRQoL conceptualization - the relationship and distinction between "QOL" and "health-related QOL"; the distinction between "health" and "QOL"; the distinction between HRQoL indicators and predictors; or the distinction between the indicator and causal variables of QOL. Because the HRQoL confounds functional outcomes such as hearing better with better quality of life, it likely does not adequately capture the experiences of DHH individuals who do not perceive their hearing condition as a disability (Patrick et al., 2011). While the HRQoL includes hearing loss in hearing ranges and whether hearing loss was caused by sickness such as high fever, it may not be an ideal instrument for capturing the life experiences of DHH individuals.

In a study by Tsimpida et al. (2018), Greek DHH adults' health were affected more than the general population for chronic conditions, such as the underdiagnosis and undertreatment of tobacco and alcohol dependency. With a lack of understanding health information, it may lead to a lack of treatment of other minor illnesses. There is no sign language information available in health for Deaf people, which may affect their abilities to make decisions about health in everyday life (Tsimpida et al., 2018). Kushalnagar et al. (2014) concluded that HRQoL could not capture certain factors. From deaf adults' self-perception, issues affected both generic and deaf-specific quality of life outcomes on three factors. They are health status (acceptance of self, coping with limitations), intrinsic (functional communication skills, navigating barriers, persistence/resilience) and extrinsic (acceptance by others, access to information, social participation, educating others).

KINDLR is a generic instrument for health-related quality of life (HRQoL). KINDL is not an abbreviation for another name but a proper name derived from the German word for lighting a fire. Originally it was KINDL and over time they made a revision which resulted in KINDLR. KINDLR has a 24-item QOL questionnaire developed in Germany and validated for use with children and adolescents from 8 to 16 years of age (Ravens-Sieberer & Bullinger, 1998). It comprises 6 scales: physiological and psychological well-being, self-esteem, family, friends, and functioning. Huber (2005) surveyed 65 Austrian children and adolescents with cochlear implants using the KINDLR, which was translated from German into Austrian German. Children with severe reading comprehension difficulties were excluded from the study after consulting their teachers via structured telephone interviews. DHH children did not have access to a sign language version of the HRQoL.

Lin and Niparko (2006) reported that because there are no well-validated HRQoL instruments, researchers must use their judgment to interpret the HRQoL data as it relates to DHH children and youth.

Pediatric Quality of Life Inventory (PedsQL)

According to Varni et al. (2001), Pediatrics Quality of Life Inventory (PedsQL) version 4.0 is one of the generic QOL questionnaires intended to evaluate children ages 8 to 18. PedsQL consists of 23 questions organized according to four scales and responses: Emotional functioning (8 items); Social functioning (5 items); School functioning (5 items); and Physical functioning (5 items). PedsQL was originally developed by James W. Varni in France. PedsQL items have reliability and validity as demonstrated by studies (Varni et al., 2001, 2006).

PedsQL is used with hearing children and adolescents in studying interventions related to QOL, but it is not a good match for those with hearing loss (Ronner et al., 2020). Skrbic et al. (2013) investigated adolescent Serbians and found that their hearing loss had a negative impact on all areas of their QOL. They suggested that the stakeholders get together to discuss the answers that best reflect the adolescents with hearing loss. For the solution to this challenge, Judith Lieu's team at Washington

University developed the Hearing Environment and Reflection on Quality of Life (HEAR-QL) survey to evaluate hearing-specific QOL (Umansky et al. 2011; Varni, 2003).

The Hearing Environments and Reflection on Quality of Life (HEAR-QL)

Prior to the HEAR-QL, there were a limited number of QOL assessment tools for children with specific chronic conditions, and none specifically designed for children with hearing loss (Lin & Niparko, 2006). Umansky et al. (2011) mentioned that HEAR-QL fills the assessment gap and identifies QOL challenges for children with hearing loss. The HEAR-QL was developed for children ages 7-12 years with hearing loss in response to this need (Steaufert, 2010). The HEAR-QL questionnaire is a condition-specific QOL measure that is designed to evaluate these children's perceptions of their hearing level's social and emotional impact (Umansky et al., 2011). The HEAR-QL questionnaire provides clinicians with information to determine when an intervention should be attempted to improve a child's overall well-being. The HEAR-QL is a valid and reliable hearing-specific QOL questionnaire for children with hearing loss; it has greater sensitivity than the PedsQL (Umansky et al. 2011). The HEAR-QL could better distinguish between children with and without hearing loss, and it can help determine interventions for children than the PedsQL.

The HEAR-QL questionnaire has been translated into a Persian version in Türkiye (previously known as Turkey) and was examined for validity and reliability for children and adolescents with hearing loss (Budak et al., 2022). The result of the study demonstrates that Turkish versions of the HEAR-QL questionnaire are sensitive, reliable, and valid measurement tools for evaluating the hearing-related QOL of children and adolescents aged between 8 and 18 years.

According to AlNowaiser et al. (2023), the team of researchers used forward and backward translation to translate the English version of the HEAR-QL questionnaire into an Arabic version for an Arabic-speaking population in the Arab region. The questionnaire was then administered to a sample of Arabic-speaking individuals to assess its reliability and validity. The results showed that the Arabic version of the HEAR-QL questionnaire was reliable and valid.

The HEAR-QL was developed specifically for children with hearing loss, focusing on response to hearing in a variety of environments and reflection on the hearing of the children (Umansky et al., 2011). However, it essentially assesses the hearing abilities of DHH persons who use hearing devices and speak, rather than those who use different signed communication. Audiological interventions such as cochlear implants and hearing aids may assist deaf adults in reducing hearing difficulties, however, modifiable lifestyle factors, such as self-acceptance and health advocacy, that interact with functional communication skills, can also significantly contribute to a healthy quality of life for deaf adults (Kushalagar et al., 2014).

The Inventory of Life Quality in Children and Adolescents (ILC)

The Inventory of Life Quality of Children and Adolescents (ILC), developed by Fritz Mattejat and his team in German, is a multi-information assessment for QOL to measure health-related QOL in children and adolescents aged 6-21 years. It is a screening instrument developed for hearing students that consists of seven items: school performance, family functioning, peer relations, autonomy in play (play/hobbies when alone), physical health, mental health, and a global wellbeing assessment. (Aanondsen et al., 2021; Aanondsen et al., 2023; Jozefiak et al., 2008). The child or adolescent themselves can complete the ILC by self-report. The ILC is a screening procedure that may not provide us with a complete picture of HRQOL because it provides a rough estimate of QOL (Hintermair, 2011).

The ILC has only been used to study QOL in DHH in Germany, Austria, and Norway. ILC was translated into written versions for DHH mainstreamed children and adolescents who prefer spoken language (Aanondsen et al. 2021). The Norwegian version of the ILC has been translated into Norwegian Sign Language (ILC-NSL) and has shown good psychometric properties to gain more accurate reports from DHH children and adolescents (Aanondsen et al., 2021). It can be used for clinical and research purposes to assess the QOL of children and adolescents with various conditions, such as deafness, hearing loss, or mental health problems.

Hintermair (2011) used the ILC to compare the QOL of 212 hearing-impaired children in mainstream schools in Germany with that of hearing children. There was no

significant difference found between the groups. However, it was found that there were significant relationships between QOL scores and communicative competence, intelligence, academic achievement, and participation (Hintermair, 2011).

Once again, using the ILC, Hintermair (2011) examined the QOL of a multitude of German elementary students who were in conventional classrooms, and its results showed the DHH children had a significantly better quality of life compared to the hearing students, and they were satisfied with their schooling. The researcher found no differences between DHH and hearing groups in satisfaction with family relationships or social contact with peers. Hintermair (2011) assessed students' perceptions of the quality of their interaction with their teachers and peers and discovered that their satisfaction with school, social contact with peers, mental health, and overall QOL were highly correlated.

Youth Quality of Life for Deaf and Hard of Hearing (YQOL-DHH)

As has been described, QOL instruments specifically designed for children who are DHH and have access to sound have items that refer to a child being able to communicate by speaking from a distance or by using the telephone (Patrick et al., 2011). Then, a QOL instrument was developed for DHH students, called the Youth Quality of Life for Deaf and Hard of Hearing (YQOL-DHH), which differs from other DHH-specific QOL instruments in that it has developed to assess DHH youth's perceived QOL, including aspects such as communication, participation, and regard for oneself, regardless of their mode of communication including sign language or speech (Patrick et al., 2011; Schick et al., 2013).

The YQOL-DHH is unique because the instrument was developed through gathering data from adolescents, parents, and adults who were DHH or from specialists who work with DHH such as healthcare professionals. The YQOL-DHH is relevant and applicable to youth who communicate with spoken or signed language, including those who use either American Sign Language or English-like signing as their primary mode of communication. YQOL-DHH emphasizes the quality of social relationships, satisfaction with friendships, interactions with family, and other aspects, regardless of whether they communicate in speaking or signed language (Patrick et al., 2011). YQOL-

DHH demonstrated good reliability and validity for assessing DHH adolescents ages 11-18 (Patrick et al., 2011). It allows the comparison of DHH students across school placements and includes students with a range of hearing loss. Directly assessing how DHH youth perceive their communication with others, such as parent-youth communication, is essential for understanding their needs.

A group of researchers developed, validated cross-sectionally, and published the YQOL-DHH module (Meyer et al., 2013; Patrick et al., 2011). YQOL-DHH module was developed based on the perceptions of DHH youth with three domains including self-acceptance/ advocacy, participation, and perceived stigma. DHH youth reflected on who they are and how these domains are important in their lives. The YQOL-DHH allows for a detailed analysis of how home communication, educational practices, and educational placement affect a youth's perception of their well-being (Schick et al., 2013).

The YQOL-DHH has been used in 16 various research studies to evaluate the QOL of DDH children and adolescents. Other countries outside of the United States of America that have used the YQOL-DHH include: China (Zhang et al., 2017), Indonesia (Setiawan et al., 2019), Iran (Ashori & Rashidi, 2020; Ashori & Jalil-Abkenar, 2021; Siadatian, 2022) Serbia (Todorović, 2021) and Saudi Arabia (Alsabei, 2020). These studies demonstrate that YQOL-DHH is an effective tool for assessing the QOL of deaf children and adolescents in different countries. Further, the YQOL-DHH is a standardized tool that allows researchers to compare the QOL of deaf children and adolescents worldwide.

The YQOL-DHH has been proven to be a reliable and valid tool in various countries and has been used successfully to measure the QOL for deaf children and adolescents. The YQOL-DHH is available in English and ASL versions in the United States of America (USA). The instrument was provided in sign language because studies such as Harris et al. (2017) and Marschark et al. (2007, 2009) indicated that deaf children and adolescents preferred ASL as their first language instead of written language because they struggled with reading. The YQOL-DHH survey has been translated into other written languages and sign languages to administer the survey to deaf children and adolescents outside the USA. These languages have included Italian and Italian Sign Language (Gragnaniello, 2021) and Arabic and Saudi Arabian Sign

Language (Alsabei, 2020). However, translation of the tool into signed language is not available in all countries, which limits its use. This is the case in China, where the YQOL-DHH translation to Chinese has good reliability and validity and can be used to measure the QOL of deaf youth in China; however, there is not an available signed language version of the tool (Zheng et al. 2017). In Iran, the YQOL-DHH has been translated into Persian and shows validity and reliability for evaluating the QOL in DHH children and adolescents (Ashori & Rashidi, 2020). Again, no equivalent signed version is available.

According to Kushalnagar et al. (2011), adolescents between the ages of 11 and 18 report a higher QOL when they report understanding the majority of their parents' expressive communication, regardless of the type of communication they prefer or their level of hearing loss. However, adolescents who preferred only speech experienced more stigma than adolescents who used both sign language and speech (Kushalnagar et al., 2011). The study found that youth's perception of their level of communication is related to their QOL, which is an important contribution to this study.

A study conducted by Alsabei (2020) examined the QOL of DHH adults with various educational backgrounds, specifically those whose education degrees enhanced QOL in Saudi Arabia. This study was undertaken as a result of a movement to provide college programs for DHH individuals. The study found that factors such as higher educational degrees, modes of communication, hearing status, and school placements were not statistically significant to QOL. In contrast, participants who were financially self-sufficient reported a higher QOL. According to prior research, a person's job in Saudi Arabia, regardless of their educational degree, significantly influences their QOL. Interestingly, women reported higher QOL than men, which may be explained by the honor and respect women have in society. Alsabei's study applied the YQOL-DHH survey, which was designed for deaf participants aged 11 to 18 years, with older participants over the age of 18. The pilot study showed that the results were reliable for older adults. According to Marschark et al. (2018), the survey was also used for deaf students who were all first-year college students aged 17.7 to 23.5 years with a mean age of 19 years ($SD = 1.20$) in examining psychosocial functioning and language abilities among deaf adolescents with and without cochlear implants.

Opportunities and Barriers to the QOL for Deaf Malaysians

In Malaysia, there are opportunities for people with disabilities, particularly DHH people, to improve their QOL. The Malaysian Government has adopted disability equality international policy guidelines, including the Standard Rules on Equalization of Opportunities for Persons with Disabilities in 1993 and the United Nations Convention on the Rights of Persons with Disabilities in 2008. The government policy for people with disabilities is essential to providing better services and opportunities for them, such as education, transportation, technology, employment, health, welfare, and housing. This policy should also include measures to protect the human rights of people with disabilities, such as access to healthcare, access to justice, and freedom from discrimination. Additionally, the government should provide support to help people with disabilities reach their full potential.

The Government of Malaysia became a signatory to the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD) on April 7, 2008, and ratified the treaty on July 19, 2010. Malaysia developed a law to protect the rights of people with disabilities prior to the UN CRPD ratification by collaborating with various stakeholders, including the Malaysian Bar and non-governmental organizations (NGOs) representing individuals with disabilities. As an advisor to the Government of Malaysia, the Human Rights Commission of Malaysia (Suruhanjaya Hak Asas Manusia Malaysia: SUHAKMA) provides adviser and material references to the government.

Policies and Legislation

The World Federation of the Deaf (WFD) declared in 2016 that the key factors contributing to support the full education and human rights of deaf and hard of hearing children and adults is for them to be provided with both their nation's native sign language and written languages (World Federation of the Deaf, 2016). In 1994, Malaysia signed the Salamanca Statement and Framework for Action on Special Needs Education, a declaration of the United Nations Educational, Scientific, and Cultural Organization (UNESCO, 1994). In the Salamanca Statement, educational policies should completely account for individual differences and situations. UNESCO (1994)

recommends that sign language be recognized as the communication medium for the deaf, and that all deaf children have access to education in their national sign language. The Malaysian government was aware of the challenges and issues facing the deaf community, but it had not yet implemented the necessary policies to address them. The deaf community recognized the need for greater advocacy, and it proposed initiatives to increase public awareness and pressure the government to implement the necessary policies.

As a result of Malaysia's commitment to international obligations stipulated under the UN CRPD (Tah, 2013; Tah & Mokhtar, 2016), in 2008, Malaysia enacted the Persons with Disabilities Act 685 to protect the rights of people with disabilities. Although not yet studied, people with disabilities were provided with the opportunity to develop and enhance their QOL and well-being by enacting the Persons with Disabilities Act 2018. In addition, better accessibility to facilities such as services, buildings, public transportation, and public amenities is also promoted. Moreover, this statute encourages and supports appropriate measures for recognizing skills at work, creating employment opportunities for the disabled, particularly DHH people, ensuring that children with disabilities receive a proper level of education, training professionals in rehabilitation services, and a number of other functions directed by the Minister for the proper implementation of the Act (Aziz et al., 2023).

Under the Persons with Disabilities Act (2008), the Malaysian Government recognizes Bahasa Isyarat Malaysia (BIM) as the official language of the Deaf community. The BIM enjoys legal status as one of the languages in the country that could potentially have a positive impact on many aspects of the deaf community's life. Furthermore, the act defines the term 'communication' as referring to various means of communication, including BIM, accessible communications, and information technologies.

The government initially provided BIM interpreters on a 30-minute daily national news program on government-owned telecommunications to provide accessible information to the deaf community. Additionally, open captioning is available for TV channels and theater movies, both foreign and local, to facilitate access to information by the deaf community. Interpreting is also available via telecommunications during

parliament debates. Some social media platforms also provide open captions. MFD and *Persatuan Bahasa Isyarat Malaysia dan Pengajian Pekak* (Malaysian Sign Language and Deaf Studies of Association) actively promote BIM on social media such as telegram, WhatsApp, and YouTube in the public. MFD collaborates with government agencies, universities, and the public to provide BIM courses and training for interpreters. In addition, deaf individuals are provided with BIM interpreters in public places to communicate more effectively. MFD advocates for the rights of deaf people in Malaysia and promotes awareness of their language and culture.

The Persons with Disabilities Act 2008, also known as the 'soft law,' was adopted voluntarily and is not legally binding, preventing people with disabilities from having full and equal recognition under federal law so they do not have the right to sue the government or another party for failing to provide services. It is still a grey area in Malaysia because there is no specific law that deals with special education for children with disabilities, even though they are promised the same rights as other children (Othman et al., 2022).

Welfare

All people with disabilities (PWD) have guaranteed access to public accommodations, healthcare, and recreation under the Act. Additionally, the Act required the establishment of a National Council for Persons with Disabilities to oversee legislative recommendations for people with disabilities to the Government and to provide employment opportunities for them. There is an official record of people with disabilities in each district that is managed by the council. A medical professional verifies PWD status at the Malaysian Department of Social Welfare, but it is voluntary. To be eligible for certain government services concerning people with disabilities, those who register as PWDs should be verified by a medical professional and have their status confirmed by the Malaysian Department of Social Welfare. Registering as PWD identification is an entirely voluntary decision. With the PWD identification, those eligible can prove eligibility for certain government services. The registration process includes receiving healthcare benefits, vocational and academic training in special schools and institutions, financial assistance, and job placement opportunities. Those, including deaf

people who register with the Department of Social Welfare, get benefits and improve their QOL.

Education

The Salamanca Statement was signed in 1994 by Malaysia, and the government implemented it in 1996, ensuring that inclusive education was provided to students with disabilities and/or special educational needs in primary and secondary schools, allowing them to temporarily or permanently integrate into mainstream classrooms (Ali, Mustapha, & Jelas, 2006). In Malaysia, the United Nations Convention on the Rights of Persons with Disabilities (CRPD) was signed in 2008 and ratified in 2010 (United Nations, 2006). The Malaysian government also passed a bill, the Persons with Disabilities Act 2008, to prevent segregation of and the discrimination against people with disabilities (Government of Malaysia, 2008). According to Clark, Brown, & Karrapaya (2012), these legislations had a limited impact because there were no punishments or fines for not following them. Rather, adherence was determined more by people's charity. Many barriers continued for people with disabilities including overcrowded classes, unclear policies, a lack of resources, and inconsistent collaborations with expert specialists in which full inclusion remains very limited (Wah, 2010). In Malaysia, primary education has been made compulsory since 2003, and enrollment in public schools is free and open to all children, including those in hospitals, private schools, and homeschooling. Education (Amendment) Act 2002 that students are only required to complete school until Year Six (Grades 1-6). The parents may be fined up to RM 5,000 (US \$1,064) or six months imprisonment if they fail to send their kids to school. Due to the law, parents are encouraged to send their children, particularly deaf children, to school. Unlike deaf adults who did not have access to formal education in their previous school before 2003, deaf students have the opportunity to learn formal education at school. deaf children can benefit from the mandatory provision of primary education.

There are many choices of provided programs that the parents of deaf children can choose: (1) special education schools, (2) the Special Education Integration Program - units attached to mainstream schools (Program Pendidikan Khas Integrasi:

PPKI), and (3) the Inclusive Education Program - a government initiative that caters to students with disabilities in mainstream classrooms (Program Pendidikan Inklusif: PPI). Inclusive education is defined in the national policy as the “concept of placing Special Educational Needs (SEN) that students into mainstream classes to be educated alongside their peers, either with or without additional support and within the present school system” (Ministry of Education, 2004).

There are no formal policies to support the inclusion of deaf children aged 3-13 in mainstream classrooms (Khairuddin et al., 2020). In some mainstream schools, those who cannot speak are learning under the curriculum for students with learning disabilities. The mainstream schools in Malaysia may or may not provide sign language assistance, but speaking is an essential prerequisite for participating equally in examination-oriented mainstream schools (Khairuddin et al., 2018). Deaf children performing lower academically should not take the national examination because the national examination is very advanced and based on the national curriculum and standards that the hearing students have received. The deaf students did not get the opportunity for the same exposure (Jelas & Ali, 2012). Deaf students may experience barriers to communicating with others outside their community. They experience greater discrimination than those with physical disabilities (Jani et al., 2020b). Special teachers who are knowledgeable about BIM may or may not be available outside of the established special education services, such as PPKI and PPI, to support deaf children.

The academic attainment of deaf children with cochlear implants in Malaysia is lower than the national average (Mukair, Ling, and Ghain, 2007). In addition to delayed language and communication development, this results from inflexibility in pedagogy, curriculum, and formal assessment of the education system (Yasin et al., 2021). There is a significant difference between the academic attainment of deaf children, regardless of whether they are using hearing aids or cochlear implants. According to the research, deaf children do not perform as well as typical students in the United Kingdom, even though there are relatively developed support systems (Harris et al., 2017). Deaf children often cannot follow the fast-paced, examination-oriented curriculum. Thus they often have gaps in their learning or do not finish the curriculum, and their examination results are not satisfactory.

Although primary communication in school is oriented towards using signs, parents prefer to have their deaf children fitted with hearing assistive devices, including hearing aids and cochlear implants, to communicate orally with their deaf children. As a result, the communication practices in schools do not meet the recommendation of the World Federation of the Deaf (WFD) that "All deaf children have a right to a sign language." National sign language(s) are the only fully accessible language for deaf children from birth onwards."

Deaf students have opportunities to further their education despite the requirement of academic attainment to pursue higher education. Community colleges, technical schools, and vocational training programs in the vocational school for special education and mainstream schools are available to provide vocational training programs, transition, and skills development with Malaysian Skills Certificate, *Sijil Kemahiran Malaysia (SKM)* to deaf students throughout Malaysia. SKM is accredited by the Department of Skills Development, a government agency under the Ministry of Human Resources. Polytechnical colleges also provide training programs for deaf students who have completed high school. These programs equip them with the necessary skills and knowledge to be successful in the workplace. They also provide opportunities to network with potential employers. With the certification and skills, deaf students can get good career opportunities after completing their high school education. A better education and occupation can improve the QOL for deaf students.

In Malaysia, hearing people often do not understand deaf culture and the challenges with written languages that deaf people face. Also, they see deaf people as grouped under the concept of "disabilities" (Lee et al., 2022). According to Wilson & Winiarczyk (2014), three important factors that are helpful to support deaf Malaysians' needs during interviewing and facilitating focus groups are their challenges, priority lists, and resources. Through focus group discussion, deaf Malaysians were able to describe the realities of their lives. Deaf Malaysians reflected on their situation and gave suggestions for improving their quality of life. Their suggestions were to have policies enforcing early childhood education, deaf education, and accessibility, because the lack of policies adversely affected their QOL. Therefore, they were active in advocating policy changes.

Employment

In Malaysia since 1987, there is legislation supporting the rights of people with disabilities related to employment. The government has allocated 1% of the jobs available to people with disabilities, including deaf people. The Ministry of Human Resources and the Ministry of Social Welfare has worked toward this goal and has urged the private sector to allocate these jobs. As a result of the 1% quota policy, all government agencies are encouraged to open their doors to people with disabilities, but the quota has not yet been realized in either government and private sectors. Deaf people are still disadvantaged by the education requirement to have a Malaysian Certificate of Education, *Sijil Pelajaran Malaysia (SPM)*, to attain employment opportunities in the government sector. It is necessary for high school students to pass five compulsory subjects, including Malay and English Language, to obtain the SPM. The majority of deaf people face difficulties getting the SPM due to difficulty mastering languages, which negatively impacts their QOL.

There are more opportunities for deaf people in the public sector than in the government sector, regardless of the degree of education required. In the 1980s, the first world's KFC store was established in Malaysia, specially designed to provide deaf employees with the opportunity to manage the operations on their own with the assistance of one hearing employee. The Society for the Deaf had co-operated with KFC to employ 17 deaf employees at KFC (Jayasoorie et al.,1997). Deaf staff can use simple signs to communicate with hearing customs by pointing to menus with pictures and using simple signs in front of the cash register. Three KFCs employ deaf employees throughout Malaysia. Similarly to KFC, in 2016 Starbucks Signing Store set up the first world's Starbucks store in Malaysia, where deaf employees currently manage the operations independently. Three stores in Malaysia are specifically designed for deaf employees. They can become more financially independent and improve their QOL through employment opportunities in the food chain, industry, and service, such as driving a Grab cab and delivering food.

Conclusion

Numerous approaches are used to define QOL, including theory, concept, objective, subjective well-being, personal values, life satisfaction, and objective living conditions (Fece & Perry., 1995; Fece, 1997). Numeral quantitative and qualitative methodologies are employed in the QOL research literature, although most current research on QOL within DHH populations is quantitative. Quantitative research, such as surveys and questionnaires, provides an objective view of the topic on the QOL of DHH individuals. The research allows researchers to measure and compare different variables, such as various QOL measures, to determine their effects on multiple populations, which can help inform policy decisions. On the other hand, qualitative research can provide a more in-depth understanding of the individual's experiences and feelings, which can help to inform and shape policy decisions and intervention strategies.

QOL instruments on DHH individuals, such as WHOQOL (Fellinger et al., 2005a), HRQoL (Huber, 2005), PedsQL (Arsic & Djordjevic., 2017), HEAR-QL (Umansky et al., 2011), ILC (Hintermair, 2010), and YQOL-DHH (Skalicky et al., 2010; Patrick et al., 2011), play a crucial role in measuring and comparing variables related to QOL. Each instrument serves a specific purpose and has its own strengths and weaknesses, which should be considered when researching the QOL of DHH individuals. YQOL-DHH is the latest instrument of QOL designed to meet the needs of DHH individuals by delineating the relationships between health status, and intrinsic and extrinsic factors based specifically on the feedback and opinions of deaf adults about the issues that affect both their generic and deaf-specific QOL (Kushalnagar et al., 2015). The initial validation of the instrument showed good psychometric properties and was sensitive to adolescent concerns. It's a significant step towards understanding and improving the QOL for deaf and hard-of-hearing youth.

This literature review has revealed that researchers currently focus on DHH children with cochlear implants about how their hearing loss affects their QOL (Brewis et al., 2020; Cejas et al., 2023; Crowson et al., 2017; Hofmann et al., 2020; Huber' 2005; Looi et al., 2016; Marschark et al. 2018; Umat et al., 2019) and how they are affected by it. In some studies related to QOL, there is a focus on specific educational settings

and their comparisons (Arsic & Djordjevic, 2017; Chen, 2020; Gilman et al., 2004; Qi et al., 2020; Schick et al., 2013). For example, studies focus on the differences in QOL between residential school students and those who were enrolled in inclusion programs for elementary, middle, and high school (van der Straaten et al., 2020). Other researchers have studied deaf participants' self-esteem based on their communication at home and at school, whether using oral methods, Sim-Com, or signed language (Hintermair, 2008; Kushalnagar et al., 2011). Such factors, particularly the use of signed language, have been known to affect the QOL outcome (Grutta et al., 2023; Holmstram, 2022). Other studies of QOL have compared QOL constructs between students with and without disabilities (Hintermair, 2011; Schlesinger, 2000). Some studies focus on the mental health in the QOL among DHH individuals (Aanodsen et al., 2018; Aanodsen et al., 2023; Ashori & Abkenar, 2021; Fellingner, 2007).

This literature review provided me with the necessary information to conduct a study on the effects of mode communication on the QOL of DHH adults who have completed their schooling. However, there is a gap in the current literature on the QOL among DHH individuals as a result of this study. It has been found that most studies on DHH students concentrate on children and adolescents. Therefore, there is a need for research that focuses on the QOL for DHH adults. This would help lead to a better understanding of the challenges and successes of DHH individuals as adults.

CHAPTER III

Methodology

Introduction

The study aims to investigate whether methods of communication (i.e., BIM, KTBM, Sim-Com) during the formative school years affect the QOL of deaf adults in Malaysia through subsequent positive or adverse life experiences after schooling. Data are collected via a questionnaire with three sections. Section 1 measures levels of satisfaction on the signed languages used by deaf Malaysians. Section 2 is the YQOL-DHH survey with minor modification. Section 3 is for the collection of demographic information. This survey, called the Adapted Quality of Life for Deaf and Hard of Hearing (AQOL-DHH) survey, is used to investigate three categories of research questions.

Research Questions

1. Are there demographic variables that relate to higher or lesser QOL outcomes for deaf Malaysians?
 - 1.1. Is there a difference in QOL and QOL domains (participation, self-acceptance/advocacy, and perceived stigma) among deaf adults based on the signed communication most often used?
 - 1.2. Is there a difference in QOL among deaf adults based on gender?
 - 1.3. Is there a difference in QOL among deaf adults based on race?
 - 1.4. Is there a difference in QOL among deaf adults based on deaf or hard of hearing identity?
2. What is the relationship between deaf Malaysians' satisfaction with the signed communication used during one's formative school years and their QOL in adulthood?
 - 2.1. What is the relationship between deaf Malaysians' satisfaction with the signed communication used in the school during the formative school years and their QOL in adulthood?

- 2.2. What is the relationship between deaf Malaysians' satisfaction with the signed communication used with their family members at home during their formative school years and their QOL in adulthood?
 - 2.3. What is the relationship between deaf Malaysians' satisfaction with the signed communication used with their friends in the dormitories during their formative school years and their QOL in adulthood?
3. Does the signed communication most often used during one's previous school years impact deaf Malaysian's QOL in adulthood?
 - 3.1. Is there a difference in QOL for deaf Malaysians based on the type of signed communication they most often used in their previous schooling?
 - 3.2. Is there a difference in QOL for deaf Malaysians based on the type of signed communication they most often used with their family members at home during their formative school years?
 - 3.3. Is there a difference in QOL for deaf Malaysians based on the type of signed communication they most often used with their friends in the dormitories during their formative school years?

Study Setting

The survey was distributed to participants through social media accounts of Deaf organizations and friends of the Deaf Community in Malaysia. The participants completed the survey on the Qualtrics survey platform (<https://www.qualtrics.com>) by clicking on the survey link on their phones or computers. The anticipated length of administration of the YQOL-DHH in Qualtrics is between 20-25 minutes. The Qualtrics platform not only creates and distributes surveys but also analyzes results and reveals valuable insights. Data can be collected, organized, and understood through this platform. Further, the tool provides participants with the ability to select a language other than English, such as Malay or sign language, once those translations are inserted.

Ethics and Pilot Study

To conduct my research ethically, I adhered to various research standards during the data collection and analysis process and beyond. In compliance with ethical research standards, I received Institutional Review Board (IRB) approval for my pilot study, which involved administering the YQOL-DHH instrument to a small group of deaf Malaysian participants and then revising the survey based on their feedback. The original YQOL-DHH instrument was translated using forward-backward translation and adjusted to meet cross-cultural needs. Cognitive debriefing occurred to inform the revision of the survey which is being used in this dissertation research. Cognitive debriefing was used to identify respondents' difficulties in understanding the survey instructions, and whether intended concepts were understood through the language translations utilized (García, 2011; Patrik & Edwards, 2013; Willis, 2004). According to the feedback from the pilot study, most of the signing videos were improved to assist the participants in understanding the survey better. Thus, the revised survey being used in this study has gone through a rigorous translation and validation process. In the pilot study, all participants signed an informed consent. In the current dissertation research, ethics clearance similarly was sought before collecting data.

Sampling Procedure

Convenience sampling was used in this study to recruit sufficient numbers of participants who use various communication methods (i.e., BIM, KTBM, Sim-Com). I requested the assistance of several groups and people to distribute the survey to the target participants. They included a group of deaf teachers, associations that serve deaf Malaysians, the Malaysia Federation of the Deaf (MFD), and its associations that represent each state in Malaysia. I had a group of deaf teachers assist me in distributing the survey to their former students. In addition, the survey was distributed through social media outlets such as Facebook Messenger, Telegram, and WhatsApp. WhatsApp is a popular instant messaging application that deaf Malaysians use to communicate, network, and recruit participants. Word of mouth communication from the above sources may also enlist additional participants who are deaf and use various

communication methods. There are no incentives or payments offered to participants. Participation was voluntary and collected data remained confidential.

Participants

The current study focuses on participants who are deaf, including those who use hearing aids and/or cochlear implants. Deaf participants with other disabilities such as blindness or learning disabilities are excluded from this research. Participants identified themselves as deaf or hard of hearing. They were not asked to provide audiograms or any medical reports. Participants in this study chose the category that best matched their identities.

The population of interest includes deaf adults who have had experience with signed communication during their previous schooling or college and have graduated at least from high school, polytechnic, college, or university.

A power analysis with three groups (BIM, KTBM, Sim-Com) of 40 participants each was conducted using an alpha of .05 and a power of 0.80. Based on this analysis, the size of the effect the study would be able to detect is $f=.287$, which is a medium-sized effect equivalent to Cohen's d of 0.57 or an R -squared of .076.

Instrument

Patrick and his team at Seattle Quality of Life Group invented and developed a Youth Quality of Life survey for deaf and hard of hearing students (YQOL-DHH; Patrick et al., 2011). The YQOL-DHH instrument is self-administered and shows good cross-sectional reliability and validity for information such as gender, age, education and race for Deaf and hard of hearing participants (Patrick et al., 2011). I have adapted the YQOL-DHH survey for this research.

The YQOL-DHH was explicitly designed to measure QOL for children and adolescents who are deaf and hard of hearing (DHH) ages 11-18 (Patrick et al., 2011). The instrument evaluates a DHH person on their QOL across three categories including participation, self-acceptance and advocacy, and perceived stigma. It contains 32 total perceptual items. The self-acceptance/advocacy domain contains fourteen items, the perceived stigma domain contains eight items, and the participation domain contains

ten items. The items are presented on an 11-point Likert scale ranging from very unsatisfied (0) to very satisfied (10) for each item.

The YQOL-DHH is a reliable QOL instrument for children and adolescents who are DHH aged between 11 and 18 years old. See Table 1 for Cronbach Alpha data as reported in a US study conducted with students of this age range (Patrick et al., 2011); reliability for items associated with each domain ranged from 0.84-0.86. Additionally, Alsabei (2020) and Marschark et al. (2018) have used the instrument to examine participants ranging in age from 18 to 60 years old. The study by Alsabei (2020) was conducted with adults in Saudi Arabia; the Cronbach Alpha of items by domain ranged from 0.82 to 0.92 and also Ashori & Rashidi (2020) (see Table 1). Based on these data, the YQOL-DHH has good reliability for each construct when applied to children and adults alike.

Table 1

Cronbach's Alpha for the scales from studies using the YQOL-DHH

Study		Patrick et al. (2011)	Alsabei (2020)	Ashori & Rashidi (2020)	This study
The country the study examined		United States of America	Saudi Arabia	Iran	Malaysia
Age		11 - 18 years old	18 - 60 years old	11 - 19 years old	18 - 60 years old
Domain	Self-acceptance/ advocacy	0.84	0.92	0.84	0.87
	Perceived stigma	0.85	0.82	0.81	0.85
	Participation	0.86	0.88	0.83	0.87

According to Schick et al. (2013), QOL questions often discuss a person's self, social relationships, and relationship with their social environment, for example, "I feel

good about myself” (self), “People my age treat me with respect” (social), or “I feel safe when I am at school” (environment). There are also subdomains for different groups, such as deaf and hard of hearing persons, that gather specific information about their abilities to hear, their interactions with families and peers, and their psychosocial, emotional, and academic development (Gilman et al., 2004; Hintermair, 2011; Kushalnagar et al., 2011; Lin & Niparko, 2006). Two examples of questions for DHH in the YQOL-DHH are “As a person who is Deaf or hard of hearing, I feel accepted by students at my school” or “As a person who is Deaf or hard of hearing, I am satisfied with the ways I have to communicate.”

YQOL-DHH Survey Modification

Because the YQOL-DHH had not been administered previously in Malaysia, minor modifications were made to the questions to account for cross-cultural and current day differences. YQOL-DHH survey modification is found in Section 2 of AQOL-DHH survey. For example, one question in the YQOL-DHH survey was “I feel I have enough technology, such as paggers, videophones, texting, and/or internet to communicate as a person who is deaf or hard of hearing”. The underlined text is my emphasis. The statement was mostly the same except I omitted “paggers” and replaced it with “WhatsApp, Instagram, and Facebook Messenger” which now read as “I feel I have enough technology, such as WhatsApp, Telegram, Instagram, FB Messenger, videophones, texting, and/or the internet, to communicate as a person who is deaf or hard of hearing.”

Then the instrument was translated into Malay and BIM. Administering reliable and valid QOL instruments in sign language facilitates the collection of accurate reports from DHH persons who use sign language as their preferred language. After revisions and translations were completed, a pilot study was conducted between November and December 2022 with 10 deaf adult Malaysians to determine if the respondents’ understandings aligned with the intent of the translated questions, thereby giving content validity to the translated instrument. In Appendix A, there is a description of the translation process, the findings of the pilot study, and revisions made to the survey.

AQOL-DHH Survey Questions

To collect data that would answer the research questions, the Adapted Quality of Life for Deaf and Hard of Hearing (AQOL-DHH) survey was developed. See full survey in Appendix B). The survey consists of three sections, each structured around three key variables I intended to analyze: (1) the level of satisfaction with the signed communication used during one's previous school years that may impact quality of life, (2) the modified YQOL-DHH, and (3) demographic variables related to the range of QOL outcomes.

- (1) Section 1: There are 7 questions in this section that ask the respondent to identify the sign language they use in daily life currently and previously, their preference and frequency of using the signed language in their previous schooling, family and dormitory. Responses to these questions are provided on an 4-point Likert scale, from 'very unsatisfied' to 'very satisfied'. These questions were adopted from language and modality usage of Colorado Individual Performance Profile (CIPP) student demographic information (Colorado Department of Education, 2002).
- (2) Section 2: There are 32 questions in this section that were derived and slightly modified from the YQOL-DHH Survey. Responses to these questions are provided on an 11-point Likert scale, from 'not at all' to 'very much'.
- (3) Section 3: There are 13 questions in this section designed to collect demographic information, including age, sex, race, hearing status, type of hearing aid used, type of school, educational level, relationship with family, occupation, parents' hearing status, and parents' educational level.

Study Procedures

The study procedures are outlined below.

1. The revised YQOL-DHH was translated into BIM in video format and Malay written language. (See Appendix B for translation process and pilot study.)
2. The revised and finalized survey containing questions on the participants' demographics, satisfaction with their signed communication, and QOL was created using the Qualtrics software. As a result of Qualtrics' ability to provide

both print and video formats, the survey was made available in two formats: English and Malay or Malay and BIM.

3. The survey was distributed throughout Malaysia via messaging platforms such as WhatsApp, Facebook Messenger, and Telegram. Participants distributed the survey to their friends through messaging platforms or by word of mouth.
4. The participants are requested to read and respond completely to the survey questionnaires.
5. After collecting the data, they were cleaned, including removing missing data or errors, to improve their quality and reliability. The researcher analyzed the data using SPSS to obtain the results.

Variables

The variables were derived from the Youth QOL instrument - Deaf and Hard of Hearing (YQOL-DHH) which measured three domains: participation, self-acceptance and advocacy, and perceived stigma. Participants were asked to rate each item on a scale of 0 to 10. The scores were converted to a scale of 0 to 100 points for each domain. The domain scores were a calculation of the mean across items. YQOL-DHH found the presence of high scores on the participation and the self-acceptance and advocacy domains indicate a high level of QOL while resistance to perceived stigma showed low QOL. A total QOL score is also derived by averaging all items across the three QOL domains (after reversing the stigma-related items). Table 2 presents the names and descriptions of the variables in the study.

Design

In this study, a quantitative research approach has been employed to investigate the QOL of the Deaf population in Malaysia and validate the relationship between the dependent and independent variables (Creswell, 2022). Non-experimental research designs, specifically causal-comparative ones, have been used in this study. According to Gall et al. (2007), ex post facto research identifies differences in the dependent variable between groups of individuals in which the independent variable is present, absent, or present at various levels. Grouping variables in this research are education,

various signed communications, gender, race, hearing status, communication with family, communication with previous teachers, communication with friends, and one's satisfaction in their communication. QOL is considered the dependent variable. Changes over time have not been addressed through any intervention.

Table 2

Variables of the study

Variables	Description
Mode of signed communication in the current daily life	The communication used most often by deaf adults - BIM, KTBM, Sim-Com (both speaking and signing), or another signed communication.
Mode of signed communication with previous teachers	Communication with teachers during previous schooling including BIM, KTBM, Sim-Com or other.
Level of satisfaction with previous teachers' communication	1-4 Likert satisfaction scale from very unsatisfied to very satisfied.
Mode of signed communication in the family	Communication with family members in the home during previous schooling including BIM, KTBM, Sim-Com, or other.
Level of satisfaction with family's communication	1-4 Likert satisfaction scale from very unsatisfied to very satisfied.
Mode of signed communication in dormitories	Communication with friends in the dormitory during previous schooling including BIM, KTBM, Sim-Com, or other.

Table 2 Continued

Level of satisfaction with dormitory's communication	1-4 Likert satisfaction scale from very unsatisfied to very satisfied.
QOL	QOL domains are self-acceptance/advocacy, perceived stigma, and participation. The score for each scale of each domain was transformed to a 0-100 range. For self-acceptance/advocacy, the higher score indicates a better QOL. For the perceived stigma and participation scales, the lower score indicates higher QOL. To calculate the total QOL score, the perceived stigma and participation score is deducted from 100, and then the three scores of each domain are averaged. Higher scores indicate a better QOL.
Levels of education	Highest degree the participant has attained (high school, vocational school, bachelor, and master's)
Gender	Self-identified (Male, Female, and others)
Race	Self-identified as Malay, Chinese, Indian, Orang Asli (Indigenous), or other
Identification as Deaf or Hard of Hearing	Self-identified as Deaf or hard of hearing. The researcher did not ask for audiogram documentation.
School Placement	Self-identified as Residential school, day school, Integration Education Program, or Mainstreaming Education Program). Participants can choose as many as they have experienced.

Data Analysis

I cleaned the data prior to performing any analyses. The Statistical Package for the Social Sciences (SPSS) was used for the data cleaning and analysis process. There were no missing data, outliers, or incorrect data. After no errors were found, I conducted a frequency analysis and descriptive statistics for the data summary. Then, t-tests and ANOVAs were conducted to compare group means for overall QOL. MANOVA was conducted to compare demographic variables across the QOL subdomains. A Spearman correlation was conducted to determine the relationship between satisfaction of sign language used during one's childhood with one's QOL in adulthood. Upon statistically significant MANOVA results, one-way ANOVAs were conducted along with Least Significant Differences (LSD) post-hoc analyses. For Bonferroni correction, an alpha level of .05 was divided by the number of the tests and the new alpha would be considered statistically significant for the subdomains. The analyses by research question are provided in Table 3. The statistical analysis results are interpreted in the context of the research question and the existing literature. Finally, the results are reported in a clear and concise manner, following the guidelines of the relevant reporting standards, APA

Table 3

Analysis by Questions

Question	Analysis
1. Are there demographic variables that relate to higher or lesser QOL outcomes for deaf Malaysians?	

Table 3 Continued

1.1. Is there a difference in QOL and QOL domains (participation, self-acceptance/advocacy, and perceived stigma) among deaf adults based on the signed communication most often used?	T-test: compare BIM and KTBM most often used in one's daily life in terms of the overall QOL. MANOVA: compare the signed communication most often used in one's daily life in terms of each subdomain with a condition of Bonferroni correction.
1.2. Is there a difference in QOL among deaf adults based on gender?	T-test: compare male and female in terms of the overall QOL. MANOVA: compare male and female in terms of each subdomain with a condition of Bonferroni correction.
1.3. Is there a difference in QOL among deaf adults based on race?	ANOVA: compare groups based on race in terms of the overall QOL. MANOVA: compare among races in terms of each subdomain with a condition of Bonferroni correction.
1.4. Is there a difference in QOL among deaf adults based on deaf or hard of hearing identity?	T-test: compare deaf and hard of hearing in terms of the overall QOL. MANOVA: compare deaf and hard of hearing in terms of each subdomain with a condition of Bonferroni correction.

Table 3 Continued

2. What is the relationship between deaf Malaysians' satisfaction with the signed communication used during one's formative school years and their QOL in adulthood?	
2.1. What is the relationship between deaf Malaysians' satisfaction with the signed communication used in the school during the formative school years and their QOL in adulthood?	Spearman correlations for overall and subdomains based on the level of satisfaction with the signed communication used in the school during their formative school years.
2.2. What is the relationship between deaf Malaysians' satisfaction with the signed communication used with their family members at home during their formative school years and their QOL in adulthood?	Spearman correlations for overall and subdomains based on the level of satisfaction with the signed communication with their family members at home during their formative school years.
2.3. What is the relationship between deaf Malaysians' satisfaction with the signed communication used with their friends in the dormitories during their formative school years and their QOL in adulthood?	Spearman correlations for overall and subdomains based on the level of satisfaction with the signed communication in the dormitories during their formative school years.
3. Does the signed communication most often used during one's previous school years impact deaf Malaysian's QOL in adulthood?	

Table 3 Continued

3.1. Is there a difference in QOL for deaf Malaysians based on the type of signed communication they most often used in their previous schooling?	T-test for overall QOL. MANOVA for QOL subdomains.
3.2. Is there a difference in QOL for deaf Malaysians based on the type of signed communication they most often used with their family members at home during their formative school years?	T-test for overall QOL. MANOVA for QOL subdomains.
3.3. Is there a difference in QOL for deaf Malaysians based on the type of signed communication they most often used with their friends in the dormitories during their formative school years?	T-test for overall QOL. MANOVA for subdomains.

CHAPTER IV

Results

The questionnaire for this study was distributed widely among DHH adults in Malaysia. Of 244 participants who launched the questionnaire, 220 completed all of the scales' questions in two weeks. Respondents spent on average 27 minutes completing the questionnaire. In the analysis of the YQOL-DHH survey, the score for each scale (self-acceptance/advocacy, perceived stigma, participation) was transformed to a 0-100 range. Scores for negative statements of the perceived stigma scale and participation scale were reversed, as the lower scores in perceived stigma and participation indicated higher QOL of self-acceptance/advocacy.

Descriptive Statistics of Survey Respondents

Participants' ages ranged from 18 to 60 years old. Of the participants, 50.9% (N = 112) were male, and 49.1% (N = 108) of the participants were female. The hearing status of the participants varied into two groups, including deaf and hard of hearing. Of the participants, 84.1% (N = 185) self-identified as deaf while 15.9% (N = 35) identified as hard of hearing.

There are three main races in Malaysia: Malay, Chinese and Indians. Of the participants, 44.1% (N = 97) were Malays, 45% (N = 99) were Chinese, 4.6% (N = 10) were Indians and the rest (6.4%, N = 14) were Indigenous and others.

In terms of higher education, 20.9% (N = 46) of the participants had completed their high school level, 26.4% (N = 58) had earned a Malaysian Skills Certificate (*Skim Kemahiran Malaysia*), 22.7% (N = 50) Malaysian Certificate of Education, 7.3% (N = 16) a diploma, 8.6% (N = 19) a bachelor degree, and 1.8% (N = 4) a master's degree. Of the participants, 10% (N = 22) reported having various certificates including Polytechnical Certificates.

More than half of the participants responded that they are currently employed. The participants who reported being employed full time were 71.4% (N = 157) of the participants. Of the remaining participants, 10.5% (N = 23) were employed part-time, and 14.1% (N = 31) were unemployed at the time of their responses.

Most of the participants reported that they have hearing parents. Of the participants, 74.6% (N = 164) reported that they have hearing fathers, and 80.5% (N = 177) have hearing mothers. Furthermore, 14.1% (N = 31) of the participants have deaf fathers, and 9.1% have deaf mothers. Only 5% (N = 11) of the participants have hard of hearing fathers, and 1.8% (N = 4) have hard of hearing mothers. Of the participants, 6.4% did not report fathers' hearing status, and 8.6% (N = 19) reported mothers' unknown hearing status.

Results of the Research Questions

In this section, each question is listed with its findings and tables. Questions are listed in order as stated in Chapter III. Before starting with the questions, it is worthwhile to mention that the reliability of each scale had been checked. The reliability statistics showed high internal consistency for each subdomain and overall. Cronbach's Alpha for the reliability of QOL were as follows: self-acceptance/advocacy was .873, perceived stigma was .849, and participation was .868. The overall QOL scale was .828. These scores illustrate the high level of reliability of the items that can measure each construct. This researcher examined the assumptions underlying the statistical tests prior to the analysis. The assumptions required for the statistical analyses were evaluated. The Shapiro-Wilks tests indicated no significant violations of normality. Box's M tests were all non-significant, suggesting the assumption of homogeneity of variance-covariance matrices was sustained. Additionally, because group sizes were approximately equal, ANOVA, MANOVA, and t-tests were robust to minor deviations in variances.

Research Question 1

1. Are there demographic variables that relate to higher or lower QOL outcomes for deaf Malaysians?

- 1.1 Is there a difference in QOL and QOL domains (participation, self-acceptance / advocacy, and perceived stigma) among deaf adults based on the signed communication most often used?

An independent sample t-test was conducted to compare the effect of the signed communication most often used (Independent Variable [IV]) on overall QOL (Dependent Variable [DV]). There were three groups planned in this study (BIM, KTBM, Sim-Com); however, the data received was not balanced and did not meet the expectation of at least 40 participants for each group. Over half of the participants reported BIM as their preferred mode of communication in their daily lives. The participants who reported utilizing BIM were 72.3% (N = 159) of the respondents. Of the remaining participants, 3.6% (N = 8) reported using KTBM, 20.5% (N = 45) used Sim-Com, and 8% (N = 8) used another form of communication. The following analysis includes the two groups with at least 40 participants. KTBM and Sim-Com were merged into one group known as KTBM because they are both sign systems created to teach the written language, and they utilize similar signs and grammar aligned with the written language. Thus, the BIM group was 72.3% (N = 159) of the participants and the KTBM group was 24.1% (N = 53) of participants. There was no significant difference in the overall QOL for BIM (M = 54.40, SD = 12.62) and KTBM (M = 54.53, SD = 13.78) conditions; $t(210) = -.065$, $p = .948$, Cohen's $d = .01$, indicating a small effect.

A multivariate analysis of variance (MANOVA) was used to examine the effect of signed communication, such as BIM and KTBM, in each subdomain of the QOL. For BIM, the means of each subdomain of QOL are: Self Accept (M = 69.20, SD = 17.99), Perceived Stigma (M = 49.03, SD = 25.66), Participation (M = 37.98, SD = 23.43). For KTBM, the means of each subdomain of QOL are: Self Accept (M = 65.81, SD = 17.83), Perceived Stigma (M = 51.25, SD = 23.97), Participation (M = 41.38, SD = 19.43). Prior to interpreting the MANOVA, Box's M test was conducted to assess the assumption of homogeneity of covariance matrices. The test was not significant, indicating that the assumption was met [Box's $M = 7.71$, $F(6, 58102) = 1.26$, $p = .274$]. The results of the MANOVA indicate that there was no significant difference across QOL domains between BIM and KTBM among Malaysian deaf people at the $p < .05$ for the two groups [$F(3, 208) = .614$, $p = .607$, Wilk's $\lambda = .991$, partial $\eta^2 = .009$].

1.2 Is there a difference in QOL among deaf adults based on gender?

An independent t-test was conducted to compare overall QOL by gender. There was not a significant difference in the scores for male ($M = 54.31$, $SD = 12.54$) and female ($M = 54.49$, $SD = 13.05$) conditions: $t(218) = -.104$, $p = .917$, Cohen's $d = .014$, indicating a small effect.

A multivariate analysis of variance (MANOVA) was used to examine the effect of gender, each subdomain of the QOL. For males ($N = 112$), the means of each subdomain of QOL are: Self Accept ($M = 66.9$, $SD = 18.83$), Perceived Stigma ($M = 51.45$, $SD = 25.64$), Participation ($M = 38.96$, $SD = 23.94$). For females ($N = 108$), the means of each subdomain of QOL are: Self Accept ($M = 70.09$, $SD = 16.76$), Perceived Stigma ($M = 47.46$, $SD = 24.08$), Participation ($M = 38.96$, $SD = 23.94$). The results of the MANOVA indicate that there was no significant difference in QOL domains among males and females in Malaysia at the $p < .05$ for the two groups [Box's $M = 6.7$, $p = .360$; MANOVA $F(3, 216) = 1.32$, $p = .269$, Wilk's $\lambda = .982$, partial $\eta^2 = .018$].

1.3 Is there a difference in QOL among deaf adults based on race?

A one-way ANOVA was conducted to compare the race in overall QOL. There was no significant difference in the overall QOL between races, including Malay, Chinese, and Indian; conditions: $F(2, 203) = .932$, $p = .395$, partial $\eta^2 = .009$. Table 4 describes the means for three races.

The means for the QOL subdomain by race are in Table 5. A MANOVA found a statistically significant difference in the races, such as Malay, Chinese, and Indian, for at least one subdomain of QOL ($F(6, 402) = 2.313$, $p = .033$, Wilk's $\lambda = .934$, partial $\eta^2 = .033$). Individual ANOVAs were run to determine which subdomains differed by race. Self-acceptance/advocacy [$F(2, 203) = 3.141$, $p = .045$, partial $\eta^2 = .03$] and Perceived Stigma [$F(2, 203) = 3.729$, $p = .026$, partial $\eta^2 = .035$] significantly differed by race. Participation did not differ [$F(2, 203) = 2.551$, $p = .080$, partial $\eta^2 = .08$].

Table 4*Overall Quality of Life based on Race*

Descriptives			
	N	Mean	Std. Deviation
Malay	97	53.87	12.28
Chinese	99	53.93	12.80
Indian	10	59.47	13.37
Total	206	54.17	12.58

In Table 6, the post-hoc Fisher's Least Significant Difference (LSD) test was used to control for Type 1 error across the three pairwise comparisons. This is essentially no adjustment for multiple comparisons. The Mean Square(Error) = 495.543. The post hoc pairwise comparisons found that Malay has significantly higher self-acceptance/advocacy than Chinese ($p = .029$). Self-acceptance/advocacy of Indian does not differ from Malay ($p = .102$) or Chinese ($p = .485$). Perceived Stigma is significantly lower for Malay than Indian ($p = .023$). Perceived Stigma for Chinese does not differ from Malay ($p=0.054$) or Indian ($p = .144$).

To control for family-wise error, a Bonferroni correction was applied, which adjusted the significance level to $\alpha = .0167$ ($.05/3$). The univariate tests were not significant under this corrected threshold (all $p > .0167$). Therefore, post hoc comparisons should be interpreted as exploratory in nature.

Table 5*Mean and Standard Deviation of QOL by Subdomain and Race*

	Descriptive Statistics			N
	Race	Mean	Std. Deviation	
Self Acceptance / Advocacy	Malay	71.186	18.96	97
	Chinese	65.60	16.58	99
	Indian	61.50	16.56	10
	Total	68.03	17.93	206
Perceived Stigma	Malay	45.17	25.94	97
	Chinese	51.96	23.74	99
	Indian	63.88	15.22	10
	Total	49.34	24.83	206
Participation	Malay	36.59	22.51	97
	Chinese	39.18	22.36	99
	Indian	53.10	18.11	10
	Total	38.64	22.43	206

Table 6

Post-hoc Least Significant Difference (LSD) Test by Subdomain and Race

Multiple Comparisons							
Dependent Variable	(I) Race	(J) Race	Mean Difference (I-J)	Std. Error	Sig.	95% Confidence Interval	
						Lower Bound	Upper Bound
Self Acceptance / Advocacy	Malay	Chinese	5.5867*	2.53489	.029	.5886	10.5848
		Indian	9.6856	5.89305	.102	-1.9339	21.3050
	Chinese	Malay	-5.5867*	2.53489	.029	-10.5848	-.5886
		Indian	4.0988	5.88748	.487	-7.5096	15.7073
	Indian	Malay	-9.6856	5.89305	.102	-21.3050	1.9339
		Chinese	-4.0988	5.88748	.487	-15.7073	7.5096
Perceived Stigma	Malay	Chinese	-6.7895	3.50108	.054	-13.6927	.1136
		Indian	-18.7075*	8.13923	.023	-34.7558	-2.6592
	Chinese	Malay	6.7895	3.50108	.054	-.1136	13.6927
		Indian	-11.9179	8.13155	.144	-27.9511	4.1152
	Indian	Malay	18.7075*	8.13923	.023	2.6592	34.7558
		Chinese	11.9179	8.13155	.144	-4.1152	27.9511

Note. Based on observed means.

The error term is Mean Square(Error) = 495.543.

*. The mean difference is significant at the .05 level.

1.4 Is there a difference in QOL among deaf adults based on deaf or hard of hearing identity?

An independent t-test was conducted to compare two groups in Table 7. The independent t-test result indicated no significant difference between the deaf and hard of hearing [$t(218) = -0.548$, $p = .584$, Cohen's $d = .1$, indicating a small effect].

A multivariate analysis of variance (MANOVA) was used to compare two groups, such as deaf and hard of hearing, in each subdomain of the QOL. Table 8 indicates the means and standard deviations for each group. The results of the MANOVA indicate that there was no significant difference between deaf and hard of hearing, in each QOL subdomain at the $p < .05$ for the two groups [Box's $M = 4.26$, $p = .660$, MANOVA $F(3, 216) = 1.702$, $p = .168$, Wilk's $\lambda = .977$, partial $\eta^2 = .023$].

Table 7

Independent Samples T-Test Comparing Deaf and Hard of Hearing

Group Statistics					
	Hearing Status	N	Mean	Std. Deviation	Std. Error Mean
Overall QOL	Deaf	185	54.19	12.74	.93702
	Hard of Hearing	35	55.48	12.99	2.19650

Table 8

Mean and Standard Deviation of Subdomains of QOL by Hearing Status

Descriptive Statistics				
	Hearing Status	Mean	Std. Deviation	N
Self Acceptance / Advocacy	Deaf	69.32	18.15	185
	Hard of Hearing	63.92	15.83	35
	Total	68.46	17.87	220
	Deaf	48.73	25.13	185

Perceived Stigma	Hard of Hearing	53.54	23.65	35
	Total	49.49	24.91	220
Participation	Deaf	37.37	22.43	185
	Hard of Hearing	45.23	21.61	35
	Total	38.62	22.44	220

Research Question 2

2. What is the relationship between deaf Malaysians' satisfaction with the signed communication used during one's formative school years and their QOL in adulthood?

Spearman's rank-order correlations were used to examine the relationship between participants' satisfaction with signed communication and their reported QOL. In Table 9, there was a significant relationship with overall QOL with school ($\rho = .22$, $p = .001$) and family ($\rho = .24$, $p < .001$), but not with the dorm. Self-acceptance/advocacy was significantly related to school, family, and dorm.

Table 9*Nonparametric Correlations*

		School	Family	Dorm
Self Acceptance / Advocacy	Correlation Coefficient	.241**	.288**	.312**
	Sig. (2-tailed)	<.001	<.001	.002
	N	220	220	100
Perceived Stigma	Correlation Coefficient	.027	.089	-.016
	Sig. (2-tailed)	.691	.188	.875
	N	220	220	100
Participation	Correlation Coefficient	.118	.067	-.109
	Sig. (2-tailed)	.081	.325	.279
	N	220	220	100
Overall QOL	Correlation Coefficient	.219**	.240**	.139
	Sig. (2-tailed)	.001	<.001	.169
	N	220	220	100

Note. ** $p < .001$

2.1 What is the relationship between deaf Malaysians' satisfaction with the signed communication used in the school during the formative school years and their QOL in adulthood?

In Table 9, Spearman correlations that were conducted indicated that satisfaction with school is significantly related to self-acceptance/advocacy ($\rho = .24$, $p < .001$) and overall QOL ($\rho = .22$, $p = .001$), as satisfaction with school increases, self-

acceptance/advocacy and overall QOL increase. No relationship was found with perceived stigma ($\rho = .027$, $p = .69$) or with participation ($\rho = .12$, $p = .081$).

Table 10

Frequency and Percentage of Respondents by the Level of Satisfaction of Signed Communication Used at School

		At School		
		Frequency	Percent	Valid Percent
Valid	Very unsatisfied	11	5.0	5.0
	Unsatisfied	63	28.6	28.6
	Satisfied	115	52.3	52.3
	Very Satisfied	31	14.1	14.1
	Total	220	100.0	100.0

2.2 What is the relationship between deaf Malaysians' satisfaction with the signed communication used with their family members at home during their formative school years and their QOL in adulthood?

In Table 9, Satisfaction with family is significantly related to self-acceptance/advocacy ($\rho = .29$, $p < .001$), and overall QOL ($\rho = .24$, $p < .001$). No relationship was found with perceived stigma ($\rho = .089$, $p = .19$) or participation ($\rho = .067$, $p = .325$). The relationship between self-acceptance/advocacy and family

satisfaction is significant. Satisfaction with family increases, self-acceptance/advocacy, and overall QOL increases.

Table 11

Frequency and Percentage of Respondents by the Level of Satisfaction of Signed Communication Used at Home

		At Home		
		Frequency	Percent	Valid Percent
Valid	Very unsatisfied	11	5.0	5.0
	Unsatisfied	60	27.3	27.3
	Satisfied	128	58.2	58.2
	Very Satisfied	21	9.5	9.5
	Total	220	100.0	100.0

2.3 What is the relationship between deaf Malaysians' satisfaction with the signed communication used with their friends in the dormitories during their formative school years and their QOL in adulthood?

In Table 9, satisfaction with dorm is significantly related to self acceptance/advocacy ($\rho = .32$, $p = .002$). No relationship was found with perceived stigma ($\rho = -0.016$, $p = .88$), participation ($\rho = -0.11$, $p = .28$), or overall QOL ($\rho = .14$, $p = .17$). Satisfaction with dorm increases, self-acceptance/advocacy increases.

Table 12

Frequency and Percentage of Respondents by the Level of Satisfaction of Signed Communication Used at Dormitories

		At Dormitories		
		Frequency	Percent	Valid Percent
Valid	Very unsatisfied	3	1.4	3.0
	Unsatisfied	12	5.5	12.0
	Satisfied	52	23.6	52.0
	Very Satisfied	33	15.0	33.0
	Total	100	45.5	100.0
Missing	System	120	54.5	
Total		220	100.0	

Research Question 3

3. Does the signed communication most often used during one's previous school years impact deaf Malaysians' QOL in adulthood?

3.1 Is there a difference in QOL for deaf Malaysians based on the type of signed communication they most often used in their previous schooling?

An independent sample t-test was conducted to compare the effect of the type of signed communication they most often used, such as BIM and KTBM in their previous schooling. In Table 13, there was no significant difference in the overall QOL for BIM ($M = 56.47$, $SD = 12.12$) and KTBM ($M = 53.78$, $SD = 13.16$) conditions; $t(203) = 1.45$, $p = .150$, Cohen's $d = .21$

A multivariate analysis of variance (MANOVA) was used to examine the effect of the type of signed communication, such as BIM and KTBM, in each subdomain of the

QOL, in their previous schooling. In Table 13 for BIM, the means of each subdomain of QOL are: Self Accept (M = 71.03, SD = 16.86), Perceived Stigma (M = 50.56, SD = 25.62), Participation (M = 40.81, SD = 24.47). For KTBM, the means of each subdomain of QOL are: Self Accept (M = 67.17, SD = 18.89), Perceived Stigma (M = 49.49, SD = 24.85), Participation (M = 38.46, SD = 21.64). The results of the MANOVA indicate that there was no significant difference between BIM and KTBM, on each subdomain of QOL, in deaf Malaysians' previous schooling [$F(3, 201) = 1.226$, $p = .301$, Wilks' $\lambda = .982$, partial $\eta^2 = .958$].

Table 13

Mean and Standard Deviation of Subdomains by Signed Communication at School

Descriptive Statistics				
	At school	Mean	Std. Deviation	N
Self Acceptance / Advocacy	BIM	71.0328	16.85719	74
	KTBM	67.1701	18.89249	131
	Total	68.5645	18.23727	205
Perceived Stigma	BIM	50.5574	25.61917	74
	KTBM	49.4943	24.85234	131
	Total	49.8780	25.07435	205
Participation	BIM	40.8108	24.47122	74
	KTBM	38.4580	21.63909	131
	Total	39.3073	22.67088	205

3.2 Is there a difference in QOL for deaf Malaysians based on the type of signed communication they most often used with their family members at home during their formative school years?

An independent sample t-test was conducted to compare the effect of the type of signed communication they most often used, such as BIM and KTBM with their family members at home during their formative school years. In Table 14 and Table 15, there was no significant difference in the overall QOL for BIM ($M = 56.20$, $SD = 12.06$) and KTBM ($M = 54.47$, $SD = 12.73$) conditions; $t(179) = .894$, $p = .372$, Cohen's $d = .139$.

Table 14

Mean and Standard Deviation of QOL by Signed Communication at Home

Group Statistics					
	Family	N	Mean	Std. Deviation	Std. Error Mean
Overall QOL	BIM	65	56.1971	12.05666	1.49544
	KTBM	116	54.4666	12.72775	1.18174

A multivariate analysis of variance (MANOVA) was used to examine the effect of the type of signed communication with family members at home during their formative school years, in each subdomain of the QOL. In Table 16 for BIM, the means of each subdomain of QOL are: Self Accept ($M = 72.73$, $SD = 15.99$), Perceived Stigma ($M = 47.90$, $SD = 24.72$), Participation ($M = 39.69$, $SD = 25.18$). For KTBM, the means of each subdomain of QOL are: Self Accept ($M = 66.62$, $SD = 19.11$), Perceived Stigma ($M = 51.31$, $SD = 25.24$), Participation ($M = 39.97$, $SD = 22.10$). The results of the MANOVA indicate that there was no significant difference between BIM and KTBM, on each subdomain of QOL, [$F(3, 177) = 2.305$, $p = .079$, Wilks' $\lambda = .962$, partial $\eta^2 = .038$] (See table 17).

Table 15*Independent Samples T-test Comparing BIM and KTBM*

Independent Samples Test											
		Levene's Test for Equality of Variances		t-test for Equality of Means							
		F	Sig.	t	df	Significance		Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
						One-Sided p	Two-Sided p			Lower	Upper
Overall QOL	Equal variances assumed	.293	.589	.894	179	.186	.372	1.731	1.935	-2.089	5.550
	Equal variances not assumed			.908	138.772	.183	.365	1.731	1.906	-2.038	5.500

Table 16*Mean and Standard Deviation of Subdomains by Signed Communication in Family*

Descriptive Statistics				
	Family	Mean	Std. Deviation	N
Self Acceptance / Advocacy	BIM	72.7253	15.98982	65
	KTBM	66.6195	19.11307	116
	Total	68.8122	18.24627	181
Perceived Stigma	BIM	47.9038	24.71627	65
	KTBM	51.3147	25.23899	116
	Total	50.0898	25.03748	181
Participation	BIM	39.6923	25.17745	65
	KTBM	39.9741	22.10153	116
	Total	39.8729	23.18382	181

Table 17

A Multivariate Analysis of Variance (MANOVA) on the Type of Signed Communication at Home

Multivariate Tests ^a							
Effect		Value	F	Hypothesis df	Error df	Sig.	Partial Eta Squared
Intercept	Pillai's Trace	.961	1462.048 ^b	3.000	177.000	<.001	.961
	Wilks' Lambda	.039	1462.048 ^b	3.000	177.000	<.001	.961
	Hotelling's Trace	24.780	1462.048 ^b	3.000	177.000	<.001	.961
	Roy's Largest Root	24.780	1462.048 ^b	3.000	177.000	<.001	.961
Family at Home	Pillai's Trace	.038	2.305 ^b	3.000	177.000	.079	.038
	Wilks' Lambda	.962	2.305 ^b	3.000	177.000	.079	.038
	Hotelling's Trace	.039	2.305 ^b	3.000	177.000	.079	.038
	Roy's Largest Root	.039	2.305 ^b	3.000	177.000	.079	.038

Note. a. Design: Intercept + family_comm

b. Exact statistic

3.3 Is there a difference in QOL for deaf Malaysians based on the type of signed communication they most often used with their friends in the dormitories during their formative school years?

Table 18

Mean and Standard Deviation of Overall QOL by Signed Communication in Dormitories

Group Statistics					
	Dormitories	N	Mean	Std. Deviation	Std. Error Mean
Overall QOL	BIM	57	54.1502	10.78703	1.42878
	KTBM	37	52.3818	11.50119	1.89078

An independent sample t-test was conducted to compare the effect of the type of signed communication they most often used, such as BIM and KTBM with their friends in the dormitories during their formative school years. In Table 18 and 19, there was no significant difference in the overall QOL for BIM ($M = 54.15$, $SD = 10.79$) and KTBM ($M = 52.38$, $SD = 11.50$) conditions; $t(92) = .757$, $p = 0.451$, Cohen's $d = .16$.

A multivariate analysis of variance (MANOVA) was used to examine the effect of the type of signed communication, such as BIM and KTBM with friends in the dorm, in each subdomain of the QOL. In Table 20, for BIM, the means of each subdomain of QOL are: Self Accept ($M = 72.69$, $SD = 15.84$), Perceived Stigma ($M = 44.10$, $SD = 20.41$), Participation ($M = 36.23$, $SD = 21.34$). For KTBM, the means of each subdomain of QOL are: Self Accept ($M = 69.82$, $SD = 18.28$), Perceived Stigma ($M = 42.40$, $SD = 21.38$), Participation ($M = 35.95$, $SD = 20.35$). The results of the MANOVA indicate that there was no significant difference between BIM and KTBM in the dormitories at the $p < .05$ for the two groups [$F(3, 90) = .33$, $p = .804$, Wilk's $\lambda = .989$, partial $\eta^2 = .011$].

Table 19*Independent Samples T-test Comparing BIM and KTBM*

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means							
		F	Sig.	t	df	Significance		Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
						One-Sided p	Two-Sided p			Lower	Upper
Overall QOL	Equal variances assumed	.279	.599	.757	92	.226	.451	1.76846	2.33749	-2.874	6.411
	Equal variances not assumed			.746	73.454	.229	.458	1.76846	2.36991	-2.954	6.491

Table 20*Mean and Standard Deviation of Subdomains of QOL by Signed Communication in Dormitories*

Descriptive Statistics

	Dormitories	Mean	Std. Deviation	N
Self Acceptance / Advocacy	BIM	72.6942	15.83903	57
	KTBM	69.8263	18.28023	37
	Total	71.5653	16.80487	94
Perceived Stigma	BIM	44.1009	20.40843	57
	KTBM	42.3986	21.37703	37
	Total	43.4309	20.69762	94
Participation	BIM	36.2281	21.34079	57
	KTBM	35.9459	20.34692	37
	Total	36.1170	20.84498	94

Table 21

A Multivariate Analysis of Variance (MANOVA) on the Type of Signed Communication in Dormitories

Multivariate Tests ^a							
Effect		Value	F	Hypothesis df	Error df	Sig.	Partial Eta Squared
Intercept	Pillai's Trace	.968	894.647 ^b	3.000	90.000	<.001	.968
	Wilks' Lambda	.032	894.647 ^b	3.000	90.000	<.001	.968
	Hotelling's Trace	29.822	894.647 ^b	3.000	90.000	<.001	.968
	Roy's Largest Root	29.822	894.647 ^b	3.000	90.000	<.001	.968
Dorm	Pillai's Trace	.011	.330 ^b	3.000	90.000	.804	.011
	Wilks' Lambda	.989	.330 ^b	3.000	90.000	.804	.011
	Hotelling's Trace	.011	.330 ^b	3.000	90.000	.804	.011
	Roy's Largest Root	.011	.330 ^b	3.000	90.000	.804	.011

Note. a. Design: Intercept + dorm

b. Exact statistic

Summary

This study primarily investigated the relationship between the signed communication and QOL of deaf individuals. The unexpected results countered my prediction that signed communication affects the QOL. There were no significant differences between BIM and KTBM users on QOL and its subdomains. There was a significant relationship between overall QOL and one's satisfaction of signed communication used in school and home settings during childhood, but there was not a significant relationship with the dormitories setting. Even so, one's satisfaction of signed communication in school, home, and dormitories during childhood correlated with the

self-acceptance/advocacy domain. The findings were not statistically significant for the type of signed communication previously used across the three settings (i.e., home, school and dorm).

CHAPTER V

Discussion, Limitations, and Future Research

244 participants responded to the instrument used in this study, however only 220 participants agreed with the consent form to participate for further analysis. Most of the participants were deaf (N = 185) compared to hard of hearing (N = 35). Of the participants, 159 reported that they utilize BIM as their daily communication whereas only 53 reported that they use KTBM.

Summary of the Research Analyses

In the current research, this researcher studied the QOL of Malaysian deaf adults with respect to the following factors: (1) the status of deaf Malaysians' QOL outcomes related to demographic variables, (2) the relationship of QOL and the satisfaction of signed communication at three settings including school, home, and dormitory, and (3) the difference in QOL based on signed communication most often used during one's previous school years. There were three main research questions conducted by this researcher. First, this researcher examined demographic variables such as gender, race and hearing status related to higher or lesser QOL outcomes for deaf Malaysians. T-test and MANOVA analyses were conducted to determine the relationship between those factors. The findings with regard to QOL demonstrated that gender and hearing status were not statistically significant in the T-test for overall QOL and not statistically significant in the MANOVA for its subdomains. Findings related to race from the MANOVA analysis were statistically significant. According to the univariate analyses in this current study, Malay participants reported higher self-acceptance/advocacy levels than Chinese participants, and lower levels of perceived stigma than Indian participants. There were not statistically significant differences among the races for the participation domain or overall QOL. However, after Bonferroni correction, the univariate analyses for individual subdomains didn't remain statistically significant. Prior to correction, the factors of self-acceptance/advocacy and perceived stigma differed modestly by race, suggesting potential trends that should be explored in more detail. Secondly, Spearman correlations were conducted for overall QOL and its subdomains in relation

to the satisfaction level of one's signed communication across three settings during one's previous school year (i.e., school, at home with family, and in the dormitories with friends). Self-acceptance/advocacy was correlated with satisfaction with signed communication in all three settings. Overall QOL was significantly correlated with satisfaction with signed communication in school and home settings; however, there was not a significant relationship with the dormitory setting. Lastly, using T-test and MANOVA analysis, this researcher investigated if the type of signed communication most often used during one's previous school years (such as BIM and KTBM) impacted deaf Malaysians' QOL in adulthood. The findings were not statistically significant for the type of signed communication previously used across the three settings (i.e., home, school and dorm).

Preferred Signed Communication in Malaysia

The results related to signed communication indicate that BIM and KTBM (both the communication preferred today and that used during childhood used across settings) do not appear to affect the QOL of deaf adults differently. It can also be noted that participants preferred BIM over KTBM by a significant margin in terms of the percentage of participants (72%) who identified BIM as their preferred language.

Deaf Malaysians may have been confused which sign language to identify as their own preferred sign language, as there are a mix of messages about BIM and KTBM in Malaysia on social media or in their previous schooling. This occurrence is not specific to Malaysia. In Australia, for example, members of the deaf community showed similar confusion about their sign language, thinking it was British Sign Language or Signed English rather than their native Australian Sign Language (Johnston, 1989). I have learned from my doctoral studies about natural sign languages and their grammar properties, and what differentiates natural sign languages from contrived sign systems (Sandler & Lillo-Martin, 2001); however, most deaf Malaysians have not received similar education about their sign language histories and usage (Chong & Mohd, 2021; Trovato, 2013). This researcher identified the signed language that some deaf Malaysian participants used as BIM; however, they thought their signed language was ASL or KTBM. This indicates that the percentage of participants who identified BIM as

their preferred language may, in reality, be higher than what is reported here. Additionally, the analysis of QOL by type of signed communication may have been impacted by participants' confusion on this question. Malaysians may not understand the difference between BIM and KTBM, and may not correctly identify which signed language they most often use.

Satisfaction of the signed communication, such as BIM or KTBM used with friends at school, family at home, and with others in the dorms are significantly related to the self acceptance/advocacy domain of QOL. As satisfaction of the signed communication across these settings increases, self-acceptance/advocacy in adulthood also increases. The relationship between satisfaction of the signed communication in the school and home were additionally related to the overall QOL. The relationship between satisfaction of the signed communication in the dormitory was not significantly correlated with overall QOL.

According to Maslow's hierarchy (Maslow, 1943, 1962 & 1987; McLeod, 2024), the students at the dormitory may have their basic physiological needs met by having a place to sleep and food to eat, but they may not have their safety needs provided by the dormitory staff, indicated through a lower QOL. The needs of safety, belongingness and love, and esteem in Maslow's Hierarchy might not be provided sufficiently to meet the needs of deaf children who stay at the dormitory during their previous schooling to show a relation in the overall QOL. According to this researcher's observation, dorm staff's responsibilities are to ensure the children are fed and safe, while not always being intentional about interacting or communicating with the children. As a result, they are not providing fully for children's needs for safety, love, and belonging through communication or engaging with them as much as they could. Rather, it is treated as a job. However, one's satisfaction with dormitory communication did relate to one's self-acceptance/advocacy in adulthood. As compared to communication at school and with families at home, they may strive to ensure their deaf children have enough of these needs met. The satisfaction of one's needs might affect the QOL of deaf adults related to Maslow's Hierarchy (Maslow, 1987) during previous schooling despite the satisfaction of the signed communication. School settings such as dormitories that did not satisfy the needs of the deaf is related to lower QOL among deaf adults. However, schools and

homes generally seem to meet the communication needs of the deaf to accept themselves later in life and have a higher QOL overall.

One explanation for the discrepancy between the study results and the theoretical model of this research might have to do with the cultural expectations surrounding signed communication in Malaysia. These results indicated that BIM and KTBM used in three settings such as school, home, and dormitories in their previous schooling do not affect the QOL of deaf adults differently in their adulthood. However, it can be noted that participants preferred BIM over KTBM by a significant margin in terms of the number of persons who identify BIM as their preferred language, which they most often used in their previous schooling. Additionally with the observed participant confusion between BIM and KTBM, there are limitations to collecting valid data about signed communication via a survey as was employed in this study.

Perceptions of Deaf People on QOL

The study results indicated that there were no statistically significant differences in QOL across the demographic variables such as one's preferred signed communication, gender, and hearing status. Regarding race, there were statistically significant differences for the Malay group in the QOL subdomains.

According to the result of this study, QOL did not differ for deaf adults by gender; rather, the QOL of deaf Malaysians is equal for men and women. Generally, women more often reported using signed language than men (Mitchell & Young, 2023), which has been known to contribute to higher QOL (La Grutta al. et, 2023). In Malaysia, there were not noted differences in the percentage of use among the genders. Prior literature has detected differences in QOL by gender. In Saudi Arabia, deaf Saudi women reported statistically higher QOL than their male counterparts since, according to Islam, women should be given respect and kindness (Alsabei, 2020). In Tumin et al.(2017), they indicated that Malaysian women have lower QOL compared to men in HRQoL with differences ranging between two and five percent. However, in the current study, there were no statistically significant differences between the genders in QOL.

The Malay participants reported a higher level of self-acceptance/advocacy than the Chinese participants, and a lower level of perceived stigma than the Indian

participants. Although these trends are not statistically robust after adjustment for multiple comparisons, they may be influenced by cultural or social factors within different communities that influence perceptions of self and stigma. Furthermore, the effect sizes of these QOL subdomains indicated that race accounted for small-to-moderate proportions of variance, suggesting that race and each subdomain may be meaningful in practice. Perhaps interestingly, for race in terms of the self-acceptance and advocacy subdomain of QOL, Malays generally have a more positive or higher rating than Malaysian Chinese. They also have lower perceived stigma than Malaysian Indians. According to the Federal Constitution of Malaysia, it is widely recognized that Malays classify as Muslims who accept God's will. As a part of their faith, they believe strongly in the concept of surrendering to God and accepting their fate (Nygard,1996). This acceptance of fate and positive outlook may contribute to a higher quality of life for Malays, even in the face of challenges. These cultural and religious perspectives might explain why they report better QOL subdomains compared to other racial groups.

In interpreting the results of the current research, the unexpected result indicated that the deaf and hard of hearing are equal in the QOL. The practice of total communication, which is still a traditional approach for deaf children in Malaysia, may be a contributing factor to the satisfaction of deaf and hard of hearing people. In contrast, the literature (Chong, 2014; Chong & Hussain, 2021; Lee et al. 2022) indicates that deaf people face language barriers in Malaysia. Factors such as sign production errors by teachers (Lee et al. 2022) create difficulties in understanding through signed communication for deaf students, whereas hard of hearing students have more access to spoken language used by the teacher. These communication barriers may contribute to lower QOL for deaf people.

Limitations

There are four limitations to this current study. First, there is a limitation to the survey translation. The YQOL-DHH in Malay and Bahasa Isyarat Malaysia (BIM) versions were unavailable before this pilot study was conducted in Malaysia. Prior to conducting the study, this researcher made minor revisions to the survey to make it culturally appropriate and translated the YQOL-DHH into Malay and BIM versions with

the assistance of professionals. Through a pilot study, this researcher examined whether respondents were understanding the intended meaning of the questions. The pilot study helped to identify misunderstandings that may have been influenced by the translations, and further revisions were made. While errors associated with translations into Malay and BIM have been minimized through this process, respondents may still understand questions differently from the original survey due to the language choices of the translations.

The second limitation of the current study was the use of a fully online instrument to collect self-reported data. The deaf participants, particularly from rural areas, did not have experience with taking online surveys. Some struggled to complete the survey through an online link. The participants needed either assistance from the researcher or their friends who did the survey on how to use technology properly since they were unfamiliar with online surveys on Qualtrics. They were not sure how to access the survey and translations, play the videos repeatedly, how to click the question responses, nor how to click to progress in the survey. Therefore, those who had already completed the survey were assisting and explaining to others on how to use the technology to complete the survey. The survey contained several questions provided in Malay, English, and BIM video format, which lengthened the time it took for participants to complete the survey. It is suspected this may have further caused boredom and disengagement. Those who completed the survey reported to this researcher via video call after they filled it out or met with this researcher in person. Although they said they almost disengaged from the survey, they ended up completing the survey fully as a commitment to the research. Accordingly, the survey could be improved by reducing the long duration of administering it. Additionally, the use of a qualitative method such as post-survey interviews or focus groups would have assisted this researcher in getting a clearer understanding of the QOL indicators, including additional cultural or linguistic indicators, affecting deaf adults in Malaysia.

The third limitation was related to data collection of sufficient numbers by demographic variable groups. Those participants who did not complete the survey due to limited or prepaid internet access had to be excluded from the original pool of participants, which made the sample smaller than intended. This researcher failed to

achieve at least 40 participants in each signed communication group. There was a need to merge those using KTBM (N=8, 3.6%) and Sim-Com (N=45, 20.5%). KTBM and Sim-Com were merged into one group known as KTBM due to their similar natures; however, these were two distinct groups at the start of the study. Additionally, there was a slight imbalance in race among the participants with 44.1% Malay and about 45% Chinese participants. While these are similar in percent, they do not reflect the general population in Malaysia which is 69% Malay and 22% Chinese. Lastly, the number of hard of hearing participants was small compared to the number of deaf participants. The number of participants in the current study may have been insufficient to provide significant results by signed communication, race groups, and deaf/ hard of hearing groups. This study used a convenience sample and thus has limited generalizability.

The last limitation was the use of mobile phones. Almost all of the participants used their mobile phones as a necessary communication tool. The videos for the study appeared small on the mobile phones, which made it harder for the participants to fully view the BIM translations and comprehend the questions. See pictures in Appendix C. They also needed to have a good and stable internet signal on their mobile phone so the videos would play at a normal speed without the interruption or loading. Using a laptop or computer should be recommended to complete online surveys of this nature in order for participants to read, view, and understand what to do more clearly.

Future Research

The results of the current study showed the necessity for further exploration of the QOL of deaf people in Malaysia. A larger sample would be needed to increase the statistical power of the analyses and improve the ability to detect meaningful differences. Two ways could result in more participants. The first is to include deaf people in the age category of 18-60 years old.

The second is to locate more people who have graduated within the last 10 years who are most likely to have a better recollection of their sign communication experiences in school, family, and dorm. Additionally focus-group interviews should be used along with the nationwide survey and integrated in a mixed method analysis of the topic. (Creswell & Cerewell, 2021). Given the limitations provided around technology

use and understanding of one's own sign language, focus groups would stimulate further necessary information and provide greater resources to the participants in conveying their experiences (Wilson & Winiarczyk, 2014).

Also, the surveys could also be conducted physically, particularly in rural areas where deaf people are most unfamiliar with online surveys on Qualtrics. Support would be readily available to those who need assistance with how to use the technology to complete the survey. As an example, Gallaudet University's Center for Deaf Health Equity conducted research using surveys to address cancer health equity with DHH. During the distribution of the survey in person, the respondents had the opportunity to ask clarifying questions, such as what certain terms meant. Center team members answered their questions in ASL. They distributed the survey in person so that respondents could clarify their understanding of the terms. With the QOL survey, brief explanations of BIM, KTBM, and a mixture of these could be provided to participants before giving them the survey to complete. This may reduce the confusion of the various sign languages. In the future, a workshop for the community could be conducted regarding the signed languages.

Conclusion

The current study focused on the QOL among deaf people in Malaysia. This study did not find that one's signed language most often used today or in one's previous schooling across settings had a statistically significant impact on QOL for the deaf people in Malaysia. Despite these findings, BIM is widely used in both the deaf and hearing communities in Malaysia, and it continues to grow in popularity due to the awareness of its importance and the use of BIM in social media. A curriculum about BIM as an additional language subject for Year 1 is in the process and is expected to be released in 2027 for both deaf and hearing students. The deaf schools should be able to adopt BIM for deaf students since KTBM is being used less in schools. Curricula for additional years will also be developed.

Furthermore, in this study, one's satisfaction in sign communication used in previous school, home, and dormitory did relate to self-acceptance and advocacy in adulthood. Demographic variables, such as gender and deaf/hard of hearing, were not

statistically significant. However, regarding race, Malay deaf people demonstrated the highest self-acceptance and advocacy among races as well as low perceived stigma.

Finally, the current study was a significantly beneficial initiative in researching the QOL of deaf Malaysians. It contributes to understanding the QOL within the DHH community on their signed communication in Malaysia. More studies are needed to continue to investigate the significance by which signed languages in childhood and adulthood affect the quality of deaf Malaysian's lives.

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Appendices

Appendix A

YQOL-DHH Survey Modification

Because the YQOL-DHH had not been administered previously in Malaysia, minor modifications were made to the questions to account for cross-cultural differences and then the instrument was translated into Malay and BIM (video format). This survey was adapted from the YQOL-DHH with permission from the University of Washington and Patrick, who developed the instrument. After revisions and translations were completed, the survey was set up in English, Malay, and BIM using Qualtrics software which has capacity to provide the survey in print and video formats. A pilot study was conducted in November and December 2022 with 10 deaf adult Malaysians to determine if the respondents' understandings aligned with the intent of the translated questions, thereby giving validity to the translated instrument. Following feedback from pilot study participants, the BIM version was revised and recorded again for the sake of clarity. The text below provides detailed information about the translation process, the pilot study findings, and final revisions to the survey.

Initial Revisions to Survey Questions

Minor modifications were made to the questions on the YQOL-DHH survey to account for cross-cultural and current day differences. Question #4 included outdated technology: "I feel I have enough technology, such as pagers, videophones, texting, and/or internet to communicate as a person who is deaf or hard of hearing". The statement was revised by omitting "pagers" and replacing it with "WhatsApp, Instagram, and Facebook Messenger."

Translation

The YQOL-DHH instrument has been translated into other languages, including sign languages (Ashori & Rashidi, 2020; Gragnaniello et al., 2021 & Patrick et al., 2011), using an interactive process of forward and back translation, independent

reviews by bilingual experts, and pretesting on a population with characteristics similar to the target population (Patrick et al., 2011). By developing reliable and valid QOL instruments in sign language, DHH children, adolescents, and adults who use sign language as their preferred language will be able to provide accurate and significant reports on their lived experiences (Aanondsen et al. 2021).

For the purpose of this research, the survey was translated into Malay and BIM, so that the deaf participants can access each question in written Malay and BIM, written English and Malay, or all three languages. In the case of the Malay and BIM versions of the questionnaire, the forward-backward translation was conducted to translate the English questionnaire according to the steps described by Guillemin et al. (1993).

In non-English-speaking countries, Guillemin et al. (1993) suggested two options: (1) developing a new measure and (2) using a measure already developed in another language. This researcher chose the second option to translate an established and highly reliable measurement in additional languages. During the translation process, the researcher considered the following: (1) the level of language should be similar to the original survey so as to not compromise the content, (2) questions should be culturally relevant based on the country's living context. For the current pilot study, the researcher followed the steps suggested by Quillemin et al. (1993) except the weighting of scores that required a larger number of participants. See Table A-1.

Table A-1*Steps of the Translation and Cross-cultural Adaptation*

	Translation • Produce several translations. • Use qualified translators.
	Back-translation • Produce as many back-translations as translations. • Use appropriate back-translators.
	Committee review • Constitute a committee to compare source and final versions. • Membership of the committee should be multidisciplinary. • Use structured techniques to resolve discrepancies. • Modify instructions or format, modify/reject inappropriate items, and generate new items. • Ensure that the translation is fully comprehensible. • Verify cross-cultural equivalence of source and final versions.
	Pre-testing • Check for equivalence in source and final versions using a pre-test technique. • Either use a probe technique. • Or submit the source and final versions to bilingual laypeople. • Immigrants: Choose the language of administration or use a dual-format measure.
	Cognitive debriefing • Ten deaf adults voluntarily participated in the pilot study with the researcher to ensure the understandability of the YQOL instrument.
	Final Malay Language and BIM version. • Review of cognitive debriefing notes based on feedback received. • Revise and rerecord the BIM videos as necessary.

Forward-Backward Translation Process

As a native Malay Language user, I completed the translation of the YQOL-DHH questionnaire from English to the Malay Language with the assistance of Google Translate, which has powered Artificial Intelligence features. After that, I checked the translations twice and made final edits. Then, one native Malay speaker who has taught English for 15 years in Malaysia was asked to complete the back translation with me. After, they participated with me in a committee review of the accuracy and appropriateness of the forward and back translations by comparing the Malay and English versions.

The forward and back translation process for the BIM version was started after the Malay translation was complete. A BIM sign language interpreter was asked to translate the English and Malay Language versions into BIM equivalents on video. At the time, the professional interpreter had 7 years of experience translating printed books and presentations from English versions into BIM. I completed the BIM to English back translations with the interpreter. The committee that reviewed the forward- and back-translations consisted of the expert and me. We compared the two versions for content accuracy. We reviewed the accuracy and appropriateness of the translations and whether they upheld the meaning of the original survey version. The English survey was then finalized with Malay and BIM versions.

The survey was set up in Qualtrics so that Malay, BIM, and English versions were all available to the participants. The participants could choose one of three options for administering the survey according to their multilingual preferences:

1. “English + Malay Language” survey administration

For the web-based survey application Qualtrics, the survey was able to provide English and Malay Language on each item while supporting hidden BIM videos. Respondents could view items and respond in both languages.

2. “English + Malay Language + BIM” survey administration

BIM videos and supporting texts in English and Malay languages were available to respondents in this subsample in Qualtrics.

3. “Malay Language + BIM” survey administration

The Qualtrics survey application could provide Malay text and a BIM video on each item while hiding the supporting English text. Respondents could view items and responses in both Malay and BIM.

After the participants completed the survey, they participated in cognitive debriefing interviews. Cognitive debriefing was performed to test the translated version’s understandability, interpretation, and cultural relevance among a small group of relevant respondents (Patrick & Edwards, 2013). This enables one to detect any items that may be inappropriate or identify any that may be confusing, perceived differently from the original survey, or misleading (Collins, 2003). The data collected as a part of this study have identified where the participants’ understandings and the intentions of the questions aligned, providing more significant validation for the translations available to deaf Malaysian participants. It also led to identifying misconceptions or confusion about survey items presented in Malay or BIM and where revisions should be made to improve the instrument’s translations.

Pilot Study

This pilot study reports the findings of the cognitive debriefing interviews and subsequent steps taken to revise and finalize the survey. Deaf people in Malaysia were invited to participate in the pilot study using social media platforms such as WhatsApp and Facebook Messenger. Of 10 persons who had completed the survey in December 2022, 8 persons (5 men and 3 women) participated in cognitive debriefing interviews. Two participants were unable to complete the interview due to time constraints and technological difficulties.

I proceeded with interviews in a semi-structured format, and asked each participant to expand on their responses. In this way, the interviewees could identify where their understandings aligned with the intent of the questions and where they

misunderstood the meaning of the translated items. I conducted each interview for approximately one to two hours. I originally planned for focus groups with up to five participants each. However, due to the low internet speeds, time constraints, and the number of persons connecting via mobile phones, one-to-one interviews were more feasible than focus groups. I carried out two focus groups of only two participants each; the remaining four were individual interviews.

The ten participants largely preferred accessing the survey questions through BIM rather than reading the questions in Malay or English. “A preferred language is the person’s ‘language of the heart,’ the one that they want to speak when they feel at their most vulnerable” (Squires et al., 2019, p. 707). According to the respondents’ feedback, 10 of the 32 survey questions in BIM (31.2%) were clearly conveyed. However, it was recommended that the remaining 22 questions (68.8%) be revised to improve the respondents’ understanding of the translated meanings. In the interview data, five themes guiding the additional revisions were identified: (1) the difference between rural and urban signs, (2) the need for sign language expansion, (3) inaccurate sign translation, (4) missed concepts need additional signs to be added, and (5) the survey of structure techniques. Each category is described with example data collected from interviews, and then I present a solution to each identified problem. In 16 of 32 questions (72.7%) at least one respondent did not ascertain the meaning. The issues were addressed by re-recording the BIM videos for better understanding.

Themes

1. **The Difference Between Rural and Urban Signs.** In Malaysia, there are differences between the sign languages used in urban and rural settings. Deaf people from different settings may use and prefer different signs to convey the same meaning. This may have come about due to the evolution and dynamic nature of signed language. There is acceptance of new sign language seen through social media and physical interaction. The participants reported four words in the survey that have different urban and rural signs. In question # 4, the sign on the video for “Instagram” (i.e., an I handshape combined with baby-C) is understood by deaf people in urban areas only. This is

the latest sign for “Instagram,” which is used widely on social media. An alternate sign of I-G in fingerspelling is recognized more widely by deaf people in rural and urban areas. In question # 8, the sign for “public places” (“tempat awam” in KTBM) on the video is used by people in urban areas only, while persons in the rural use “*awam*” (public) by fingerspelling. In question # 9, the sign on video for “strange” (tidak dikenali) in BIM was not recognized by persons in the rural areas who use the KTBM sign. Lastly, in question #32, the sign on the video for “life” was the letter “L” shaking which is used in the urban areas, while persons in the rural areas use the letter “H.”

One solution to make the survey accessible to urban and rural respondents is to include both signs in the signed translation. In sign language, it is not uncommon for a signer to link signs of the same or slightly similar meanings to give fuller understanding and access to meaning. In revised videos, signs for rural and urban areas were chained (signed in succession) to ensure greater access and understanding.

2. **The Need for Expansion in Sign Language.** In 16 of 22 questions (72.7%) at least one respondent did not ascertain the meaning. In general, there is a preference among the deaf community for receiving information in depth and in advance. There is expansion through specific language applications and phrasing needed in BIM that does not occur in Malay or other written languages such as English. Lawrence (1994) identified seven expansion features utilized by native signers such as explaining by adding examples, reiterating, or using 3D space in one’s signing.

There were questions identified by the interviewees that needed more detailed explanations in BIM that were not necessary in Malay. In questions #1, #2, #5, #7, #9, #10, #15, #16, #17, #19, #22, #23, #24, #27, #28 and #29 of Section 2, the participants indicated that the signing on the videos was unclear and that the full meaning of the written questions was not adequately conveyed in BIM. For example, the BIM translation in Question #10 was unclear for the phrase “how to communicate with others in different ways.” The participants indicated that the signer should explain more about the phrase’s meaning, “in different ways”. A more intelligible BIM expression would

include different communication methods such as signing, mime, using a pen with paper, or acting.

The participants did not understand the signing in Question #16 for the word “protect.” They understood the meaning to be “control.” It was suggested that the video translation include a technique called faceting (Lawrence, 2003) whereby several different signs are produced sequentially to provide a closer understanding of the meaning. It was suggested that the signer add the following signs: not allow (tidak benar), keep an eye on the children (jaga anak), and don’t do something (tidak boleh buat). In this example the signer needs to use faceting to provide a closer equivalent to the written text.

It was determined that the BIM video recordings should be reviewed and re-recorded to create new signing videos with sign language expansion features identified by Lawrence (1994). The videos were revised to include an increased amount of faceting, sandwiching (i.e., pairing a sign with fingerspelling or a printed word), providing more examples, and using facial expressions and hand gestures. The sign language translations have been revised to address the unique language expansions of this mode as compared to written language. To address the issue of needing additional explanations or faceting, eleven questions were re-recorded.

3. **Inaccurate Sign Translation.** The respondents indicated difficulty understanding the BIM translation on 9 of the questions due to the interpreter inaccuracies with signs or phrases. For example, respondents misconstrued the meaning of question #8 to mean “the public sees me” rather than “public places”. It was interpreted as “I am seen by the public”. The respondents suggested that the interpreter spell and use the sign in KTBM for this situation. In question #17, the sign for “treat badly” was understood by the respondents as “serving people.” In question #19, the sign used for “bully” needed to be corrected with accurate sign movement. In question #29, the sign for “limited” also needed to be corrected for handshape and movement.

4. **Missed Concepts Needed to be Reinforced with Additional Signs.** There were some concepts in the written version of the questions that were omitted in the signed translation. Participants noted that including these concepts would lead to a more accurate understanding. This occurred on three questions. On question #11, respondents noted that the sign "youth" was missing in the BIM translation. On question #12, respondents found the sign "deal with others" missing. They recommended that the signed translation should include "affair" or "business" for greater equivalence with the written question. Lastly, respondents noted that the concept "larger group" was missing from the sign translation on question #28. These excluded concepts have now been added into the revised BIM translations.

5. **The Survey of Structure Techniques.** There were six additional suggestions that the participants had which were structure-related and therefore clumped together under this theme: (a) No signing video in some sections of the survey; (b) two languages in one survey, (c) The rating scale of 0-10; (d) The word "Hard of Hearing"; (e) Signing video speed, and (f) Reorganizing survey sections. These areas of feedback related to survey structure were addressed in ways that enhance survey clarity and understanding.
(a) No Signing Video in Some Sections of the Survey. In the survey section 1 (a measure of satisfaction on the signed languages used by deaf Malaysians and communication mode within families, schools, and dormitories) and section 3 (demographics), there were no sign language videos because it was assumed the deaf respondents could read the Malay version of the survey in section 1 and 3, which consisted of simple and easy to understand sentences. However, the respondents preferred sign language for the entire section of the survey. For example, some respondents did not know what *Implan koklea* (cochlear implant) was in Malay in the demographic section since it did not have an accompanying video. Several respondents suggested including an embedded image of the cochlear implant or a signing video. The content was improved by adding videos into both sections 1 and 3.

(b) Two Languages in One Survey. The survey included three languages, two written languages, and one sign language. Because the internet speed was slow, respondents struggled to complete the survey using their mobile phones. The respondents suggested that the surveys be restructured by conducting the surveys separately in two different written languages. The survey is now restructured into two options. The Malay Language and BIM are provided together, while the English and Malay survey are provided without the sign language. The respondents can choose Malay and BIM or English and Malay. English is not their preferred language in the majority of deaf Malaysians, nor is it their national language, therefore, they will not require BIM for the English survey. A minority of deaf Malaysians with college or university education prefer English and Malay to BIM.

(c) The Rating Scale of 0-10. Respondents were overwhelmed by the rating scale of 0-10, and they said it was difficult for them to decide which rating to give. A rating scale of 0-10 created the impression that decisions are complex. Additionally, most respondents responded to the survey using their mobile phones. Because of the size of their mobile phones' screens, it was difficult for them to reply to the lengthy scale. The respondents suggested providing a rating scale of 1-5 rather than a rating scale of 0-10. However, this revision was not made because the YQOL-DHH is a published survey with reliability and validity, and changing the 0-10 scale would make it difficult to interpret the findings of this study in relation to previous studies that used the YQOL-DHH survey.

(d) The Word “Hard of Hearing”. One respondent felt that he was not comfortable with “*kurang pendengaran*” (Hard of Hearing) in printed Malay because it is not similar to the deaf community. The respondent preferred to remove “*kurang pendengaran*”. The researcher found that academic research articles in the Malay Language widely used the term “*kurang pendengaran*” (hard of hearing), so the researcher made the decision to leave the term in the survey. At the same time, the deaf community prefers to use ‘pekak’ (deaf). The term ‘deaf’ is used to respect the deaf community's needs in Malaysia as a deaf person. There were no changes made to the items of the questionnaire.

(e) Signing Video Speed. Some respondents noted that the signed video in question #2 was too fast and easy to miss. Therefore, the signed video for question #2 has been recorded again to ensure a standard-speed video.

(f) Reorganizing survey sections. Originally Section 1 was for demographics, Section 2 was for measuring satisfaction of the use of signed language, and Section 3 was for the YQOL-DHH survey with minor modification. Since the demographics could be completed with very little thought by the participants compared to the other sections, it was determined that it should be last in the survey. It became Section 3, moving the satisfaction questions to Section 1 and YQOL-DHH to Section 2.

Conclusion

The participants in the pilot study preferred accessing the survey questions through Malaysian Sign Language (Bahasa Isyarat Malaysia) rather than reading the questions in English or Malaysian (Bahasa Malaysia). “A preferred language is the person’s ‘language of the heart,’ which they want to speak when they feel at their most vulnerable” (Squires et al., 2019, p. 707). For example, one participant said, “I feel more comfortable using sign language than reading. I feel like I can express myself better that way.” The results of the pilot study indicated that a sign language inclusive design for the online survey supported the translanguaging practices and meaning-making processes (Young et al., 2021) of deaf multilingual Malaysians.

Several of the BIM videos were videotaped again to correct for the five ways that meaning was misconstrued to the respondents. The interpreter revised the videos so that accurate and widely accessible signs were chosen. Some concepts were expanded to give greater clarity with meaning. The videos have been re-recorded to ensure meaningful understanding of the signed language translations in equivalence to the written language meanings. The feedback from the participants’ interviews significantly improved Bahasa Isyarat Malaysia provided in the video formats.

Appendix B

The Adapted Youth Quality of Life - Deaf and Hearing of Hard (AQOL-DHH) Survey

	English	Malay Language (Bahasa Malaysia)
	Section 1	Bahagian 1
A.	In your daily life today, what type of communication do you use most often? ● BIM ● KTBM ● Both speaking and signing ● Others: _____	Dalam kehidupan harian anda masa ini, apakah jenis komunikasi yang paling kerap anda gunakan? ● BIM ● KTBM ● Kedua-dua bercakap dan berisyarat ● Lain: _____
B.	Schooling	Persekolahan
	In your previous schooling, what type of communication did you use most often with previous teachers? ● BIM ● KTBM ● Both speaking and signing ● Others: _____	Apakah jenis komunikasi yang paling kerap anda gunakan dengan guru-guru dahulu semasa zaman persekolahan anda sebelum ini? ● BIM ● KTBM ● Kedua-dua bercakap dan berisyarat ● Lain: _____
	How satisfied were you with the way the majority of your previous teachers communicated with you? ● Very unsatisfied ● Unsatisfied ● Satisfied ● Very Satisfied	Sejauh manakah anda berpuas hati dengan cara guru anda sebelum ini berkomunikasi dengan anda? ● Sangat tidak berpuas hati ● Tidak berpuas hati ● Berpuas hati ● Sangat berpuas hati

C.	Family	Keluarga
	During your school years, what type of communication did you use most often with your family? • BIM • KTBM • Both speaking and signing (Sim-Com) • Others: _____	Apakah jenis komunikasi yang paling kerap anda gunakan dengan keluarga semasa zaman persekolahan anda? • BIM • KTBM • Kedua-dua bercakap dan berisyarat • Lain: _____
	During your school years, how satisfied were you with your communication with your family? • Very unsatisfied • Unsatisfied • Satisfied • Very Satisfied	Sejauh manakah kepuasan komunikasi anda dengan keluarga semasa zaman persekolahan anda? • Sangat tidak berpuas hati • Tidak berpuas hati • Berpuas hati • Sangat berpuas hati
D.	Dormitory	Asrama
	Did you live in a dorm as a child? • Yes • No (If no, proceed to Section B)	Adakah anda tinggal di asrama semasa kecil? • Ya • Tidak (Kalau tidak, terus ke Bahagian B)
	In your previous dormitory, what type of communication did you use most often? • BIM • KTBM • Both speaking and signing (Sim-Com) • Others: _____	Apakah jenis komunikasi yang paling kerap anda gunakan di asrama anda sebelum ini? • BIM • KTBM • Kedua-dua bercakap dan berisyarat • Lain: _____

	How satisfied were you with the way communication was happening in your previous dorm? • Very unsatisfied • Unsatisfied • Satisfied • Very Satisfied	Sejauh manakah anda berpuas hati dengan cara komunikasi di asrama sebelum ini? • Sangat tidak berpuas hati • Tidak berpuas hati • Berpuas hati • Sangat berpuas hati
	<u>Section 2</u>	<u>Bahagian 2</u>
Items		
	Domain: Self-acceptance/advocacy	Domain: Penerimaan diri/advokasi
1	As a person who is deaf or hard of hearing, I feel my parents give me the same amount of independence as others my age. (Please circle one number) NOT AT ALL 0 1 2 3 4 5 6 7 8 9 10 VERY MUCH)	Sebagai seorang yang pekak atau kurang pendengaran, ibu bapa saya memberi kebebasan untuk berdikari yang saksama seperti orang lain sebaya saya. (Sila bulatkan satu nombor) TIADA 0 1 2 3 4 5 6 7 8 9 10 BANYAK)
2	I feel included in the things my family does together. (Please circle one number) NOT AT ALL 0 1 2 3 4 5 6 7 8 9 10 VERY MUCH	Saya rasa terlibat dalam pengurusan hal ehwal yang keluarga saya. (Sila bulatkan satu nombor) TIADA 0 1 2 3 4 5 6 7 8 9 10 BANYAK)
3	I feel okay telling my teacher about my needs. (Please circle one number) NOT AT ALL 0 1 2 3 4 5 6 7 8 9 10 VERY MUCH)	Saya rasa okay untuk memberitahu guru saya tentang keperluan saya. (Sila bulatkan satu nombor) TIADA 0 1 2 3 4 5 6 7 8 9 10 BANYAK)

4	I feel I have enough technology, such as WhatsApp, Telegram, Instagram, FB Messenger, videophones, texting, and/or the internet, to communicate as a person who is deaf or hard of hearing. (Please circle one number) NOT AT ALL 0 1 2 3 4 5 6 7 8 9 10 VERY MUCH)	Saya rasa saya mempunyai teknologi yang mantap, seperti WhatsApp, Telegram, Instagram, FB Messenger, telefon video, teks dan/atau internet, untuk berkomunikasi sebagai orang yang pekak atau kurang pendengaran. (Sila bulatkan satu nombor) TIADA 0 1 2 3 4 5 6 7 8 9 10 BANYAK)
5	I feel okay explaining to others that I am deaf or hard of hearing. (Please circle one number) NOT AT ALL 0 1 2 3 4 5 6 7 8 9 10 VERY MUCH)	Saya rasa okay untuk menerangkan kepada orang lain bahawa saya pekak atau kurang pendengaran. (Sila bulatkan satu nombor) TIADA 0 1 2 3 4 5 6 7 8 9 10 BANYAK)
6	As a person who is deaf or hard of hearing, I feel okay asking for help when I need it. (Please circle one number) NOT AT ALL 0 1 2 3 4 5 6 7 8 9 10 VERY MUCH)	Sebagai seorang yang pekak atau kurang pendengaran, saya berasa okay untuk meminta bantuan apabila saya memerlukannya. (Sila bulatkan satu nombor) TIADA 0 1 2 3 4 5 6 7 8 9 10 BANYAK)
7	I know how to stand up or speak up for myself as a person who is deaf or hard of hearing. (Please circle one number) NOT AT ALL 0 1 2 3 4 5 6 7 8 9 10 VERY MUCH)	Saya tahu bagaimana untuk membela atau bercakap untuk diri saya sebagai seorang yang pekak atau kurang pendengaran. (Sila bulatkan satu nombor) TIADA 0 1 2 3 4 5 6 7 8 9 10 BANYAK)
8	As a person who is deaf or hard of hearing, I feel okay asking for what I want in public places.	Sebagai seorang yang pekak atau kurang pendengaran, saya rasa okay untuk meminta apa yang saya perlukan di tempat awam.

	(Please circle one number) NOT AT ALL 0 1 2 3 4 5 6 7 8 9 10 VERY MUCH)	(Sila bulatkan satu nombor) TIADA 0 1 2 3 4 5 6 7 8 9 10 BANYAK)
9	As a person who is deaf or hard of hearing, it is easy for me to start talking to people I do not know. (Please circle one number) NOT AT ALL 0 1 2 3 4 5 6 7 8 9 10 VERY MUCH)	Sebagai seorang yang pekak atau kurang pendengaran, memang mudah untuk saya mula bercakap dengan orang yang saya tidak kenali. (Sila bulatkan satu nombor) TIADA 0 1 2 3 4 5 6 7 8 9 10 BANYAK)
10	As a person who is deaf or hard of hearing, I am satisfied with the ways I have to communicate. (Please circle one number) NOT AT ALL 0 1 2 3 4 5 6 7 8 9 10 VERY MUCH)	Sebagai seorang yang pekak atau kurang pendengaran, saya berpuas hati dengan cara yang saya sedia ada untuk berkomunikasi. (Sila bulatkan satu nombor) TIADA 0 1 2 3 4 5 6 7 8 9 10 BANYAK)
11	I feel other youths are willing to help me when I need it as a person who is deaf or hard of hearing. (Please circle one number) NOT AT ALL 0 1 2 3 4 5 6 7 8 9 10 VERY MUCH)	Sebagai seorang yang pekak atau kurang pendengaran, Saya rasa terdapat belia lain yang sudi membantu saya bila saya perlu. (Sila bulatkan satu nombor) TIADA 0 1 2 3 4 5 6 7 8 9 10 BANYAK)
12	My previous teacher(s) helped me to communicate easier in the classroom as a person who is deaf or hard of hearing.	Sebagai seorang yang pekak atau kurang pendengaran, guru saya sebelum ini membantu saya berkomunikasi dengan lebih mudah di dalam bilik darjah.

	(Please circle one number) NOT AT ALL 0 1 2 3 4 5 6 7 8 9 10 VERY MUCH)	(Sila bulatkan satu nombor) TIADA 0 1 2 3 4 5 6 7 8 9 10 BANYAK)
13	As a person who is deaf or hard of hearing, I feel there are enough things to do with people other than my family. (Please circle one number) NOT AT ALL 0 1 2 3 4 5 6 7 8 9 10 VERY MUCH)	Sebagai seorang yang pekak atau kurang pendengaran, saya rasa saya melakukan urusan yang baik dengan orang selain keluarga saya. (Sila bulatkan satu nombor) TIADA 0 1 2 3 4 5 6 7 8 9 10 BANYAK)
14	As a person who is deaf or hard of hearing, I feel accepted by students at my school. (Please circle one number) NOT AT ALL 0 1 2 3 4 5 6 7 8 9 10 VERY MUCH)	Sebagai seorang yang pekak atau kurang pendengaran, saya rasa diterima oleh pelajar di sekolah saya. (Sila bulatkan satu nombor) TIADA 0 1 2 3 4 5 6 7 8 9 10 BANYAK)
	Domain: Perceived Stigma	Domain: Persepsi Stigma
15	I get upset when people do not understand what I am saying because I am deaf or hard of hearing. (Please circle one number) NOT AT ALL 0 1 2 3 4 5 6 7 8 9 10 VERY MUCH)	Saya marah apabila ada orang tidak memahami apa yang saya katakan kerana saya pekak atau kurang pendengaran. (Sila bulatkan satu nombor) TIADA 0 1 2 3 4 5 6 7 8 9 10 BANYAK)
16	I feel like my parents protect me too much because I am deaf or hard of hearing. (Please circle one number)	Saya rasa ibu bapa saya terlalu melindungi saya kerana saya pekak atau kurang mendengar.

	NOT AT ALL 0 1 2 3 4 5 6 7 8 9 10 VERY MUCH)	(Sila bulatkan satu nombor) TIADA 0 1 2 3 4 5 6 7 8 9 10 BANYAK)
17	I feel people who are hearing treat me badly because I am deaf or hard of hearing. (Please circle one number) NOT AT ALL 0 1 2 3 4 5 6 7 8 9 10 VERY MUCH)	Saya merasakan orang yang mendengar melayan saya dengan teruk kerana saya pekak atau kurang mendengar. (Sila bulatkan satu nombor) TIADA 0 1 2 3 4 5 6 7 8 9 10 BANYAK)
18	I feel people think I am dumb because I am deaf or hard of hearing. (Please circle one number) NOT AT ALL 0 1 2 3 4 5 6 7 8 9 10 VERY MUCH)	Saya rasa orang anggap saya bodoh kerana saya pekak atau kurang pendengaran. (Sila bulatkan satu nombor) TIADA 0 1 2 3 4 5 6 7 8 9 10 BANYAK)
19	I feel people bully me because I am deaf or hard of hearing. (Please circle one number) NOT AT ALL 0 1 2 3 4 5 6 7 8 9 10 VERY MUCH)	Saya rasa orang membuli saya kerana saya pekak atau kurang pendengaran. (Sila bulatkan satu nombor) TIADA 0 1 2 3 4 5 6 7 8 9 10 BANYAK)
20	I feel people make fun of me because I am deaf or hard of hearing. (Please circle one number) NOT AT ALL 0 1 2 3 4 5 6 7 8 9 10 VERY MUCH)	Saya rasa orang mengejek saya kerana saya pekak atau kurang pendengaran. (Sila bulatkan satu nombor) TIADA 0 1 2 3 4 5 6 7 8 9 10 BANYAK)
21	I feel embarrassed when people stare at me because I am deaf or hard of hearing. (Please circle one number)	Saya berasa malu apabila orang merenung saya kerana saya pekak atau kurang pendengaran. (Sila bulatkan satu nombor)

	NOT AT ALL 0 1 2 3 4 5 6 7 8 9 10 VERY MUCH)	TIADA 0 1 2 3 4 5 6 7 8 9 10 BANYAK)
22	I feel embarrassed to ask people to repeat themselves because I am deaf or hard of hearing. (Please circle one number) NOT AT ALL 0 1 2 3 4 5 6 7 8 9 10 VERY MUCH)	Saya berasa malu untuk meminta orang ramai mengulangi cakap mereka kerana saya pekak atau sukar mendengar. (Sila bulatkan satu nombor) TIADA 0 1 2 3 4 5 6 7 8 9 10 BANYAK)
	Domain: Participation	Domain: Penyertaan
23	Because I am deaf or hard of hearing, I feel left out of family conversations. (Please circle one number) NOT AT ALL 0 1 2 3 4 5 6 7 8 9 10 VERY MUCH)	Saya rasa terpinggir daripada perbualan keluarga kerana saya pekak atau kurang pendengaran. (Sila bulatkan satu nombor) TIADA 0 1 2 3 4 5 6 7 8 9 10 BANYAK)
24	I feel I miss things when talking with people who are deaf or hard of hearing. (Please circle one number) NOT AT ALL 0 1 2 3 4 5 6 7 8 9 10 VERY MUCH)	Saya rasa saya tidak dapat apa-apa apabila bercakap dengan orang yang pekak atau kurang pendengaran. (Sila bulatkan satu nombor) TIADA 0 1 2 3 4 5 6 7 8 9 10 BANYAK)
25	Because I am deaf or hard of hearing, I feel I miss out on activities and things I want to do. (Please circle one number) NOT AT ALL 0 1 2 3 4 5 6 7 8 9 10 VERY MUCH)	Saya rasa saya terlepas aktiviti dan perkara yang ingin saya lakukan kerana saya pekak atau kurang pendengaran, (Sila bulatkan satu nombor) TIADA 0 1 2 3 4 5 6 7 8 9 10 BANYAK)

26	I feel I miss what is important for me to know because I am deaf or hard of hearing. (Please circle one number) NOT AT ALL 0 1 2 3 4 5 6 7 8 9 10 VERY MUCH)	Saya rasa saya terlepas perkara yang penting untuk saya ketahui kerana saya pekak atau kurang pendengaran. (Sila bulatkan satu nombor) TIADA 0 1 2 3 4 5 6 7 8 9 10 BANYAK)
27	Because I am deaf or hard of hearing, I have to work harder than other youth to do the things I want to do. (Please circle one number) NOT AT ALL 0 1 2 3 4 5 6 7 8 9 10 VERY MUCH)	Saya perlu bekerja lebih keras daripada belia lain untuk melakukan perkara yang saya mahu lakukan kerana saya pekak atau kurang pendengaran. (Sila bulatkan satu nombor) TIADA 0 1 2 3 4 5 6 7 8 9 10 BANYAK)
28	Because I am deaf or hard of hearing, I feel it is hard to participate in large groups. (Please circle one number) NOT AT ALL 0 1 2 3 4 5 6 7 8 9 10 VERY MUCH)	Saya rasa sukar untuk menyertai kumpulan besar kerana saya pekak atau kurang pendengaran. (Sila bulatkan satu nombor) TIADA 0 1 2 3 4 5 6 7 8 9 10 BANYAK)
29	Because I am deaf or hard of hearing, I feel what I want to do in the future is limited. (Please circle one number) NOT AT ALL 0 1 2 3 4 5 6 7 8 9 10 VERY MUCH)	Saya rasa apa yang saya mahu lakukan pada masa hadapan adalah terhad kerana saya pekak atau kurang pendengaran. (Sila bulatkan satu nombor) TIADA 0 1 2 3 4 5 6 7 8 9 10 BANYAK)
30	I feel it is hard for me to understand what people are saying because I am deaf or hard of hearing. (Please circle one number) NOT AT ALL 0 1 2 3 4 5 6 7 8 9 10 VERY MUCH)	Saya rasa sukar untuk saya memahami apa yang orang cakap kerana saya pekak atau kurang pendengaran. (Sila bulatkan satu nombor) TIADA 0 1 2 3 4 5 6 7 8 9 10 BANYAK)

31	Because I am deaf or hard of hearing, I feel I miss things when talking with people who are hearing. (Please circle one number) NOT AT ALL 0 1 2 3 4 5 6 7 8 9 10 VERY MUCH)	Saya rasa saya tidak dapat apa-apa apabila bercakap dengan orang yang mendengar kerana saya pekak atau kurang pendengaran. (Sila bulatkan satu nombor) TIADA 0 1 2 3 4 5 6 7 8 9 10 BANYAK)
32	I feel life is harder for me because I am deaf or hard of hearing. (Please circle one number) NOT AT ALL 0 1 2 3 4 5 6 7 8 9 10 VERY MUCH)	Saya rasa kehidupan saya menjadi lebih sukar kerana saya pekak atau kurang pendengaran. (Sila bulatkan satu nombor) TIADA 0 1 2 3 4 5 6 7 8 9 10 BANYAK)
	Section 3	Bahagian 3
	Demographic Items: Age: _____	Item Demografi: Umur: _____
	Sex: • Male • Female	Jantina: • Lelaki • Perempuan
	Race: • Malay • Chinese • Indian • Indigenous: _____ • Others: _____	Bangsa: • Melayu • Cina • India • Orang Asli: _____ • Lain-lain: _____
	Hearing Status: • Deaf • Hard of hearing	Status Pendengaran: • Pekak • Kurang Upaya Pendengaran

	Do you currently use: ● Cochlear Implant ● Hearing aids ● None	Anda sedang menggunakan: ● Implan koklea ● Alat pendengaran ● Tiada
	What school did you attend for elementary, and middle school/high school? (You can choose more than one if applicable) ● School for the Deaf (Stay at residential) ● School for the Deaf (Day school) ● Integration Education Program ● Mainstreaming Education Program	Apakah sekolah yang anda hadiri untuk sekolah rendah, dan sekolah menengah rendah/menengah atas? (Anda boleh memilih lebih daripada satu jika berkenaan) ● Sekolah Pendidikan Khas (Duduk di asrama) ● Sekolah Pendidikan Khas (Harian) ● Program Pendidikan Khas Integrasi (PPKI) ● Program Pendidikan Inklusif
	What is the highest educational degree you have obtained? ● Elementary school/Primary school ● High school/Secondary school ● Malaysian Skills Certificate (Skim Kemahiran Malaysia) ● Malaysian Certificate of Education (Sijil Pelajaran Malaysia) ● Bachelor degree ● Other _____	Apa tahap pendidikan tertinggi anda peroleh? ● Sekolah Rendah ● Sekolah Menengah ● Skim Kemahiran Malaysia (SKM) ● Sijil Pelajaran Malaysia (SPM) ● Ijazah Sarjana Muda ● Lain: _____
	How satisfied were you with your relationship with your parents and siblings while growing up? ● Very unsatisfied ● Unsatisfied ● Satisfied ● Very satisfied	Sejauh manakah anda berpuas hati dengan hubungan anda dengan ibu bapa dan adik-beradik semasa membesar? ● Sangat tidak berpuas hati ● Tidak berpuas hati ● Berpuas hati ● Sangat berpuas hati

	Your current job status: • Full-time employment • Part-time employment • Unemployment • Other: _____	Status pekerjaan anda sekarang: • Bekerja sepenuh masa • Bekerja sambilan • Pengangguran • Lain: _____
	What is your father's hearing status? • Deaf • Hard of hearing • Hearing • Unknown	Apakah status pendengaran bapa anda? • Pekak • Kurang pendengaran • Pendengaran • Tidak diketahui
	What is the highest educational degree your father has obtained? • No school • Elementary school/primary school • High school/secondary school • Malaysian Certificate of Education (Sijil Pelajaran Malaysia) • Bachelor Degree • Other: _____	Apa tahap pendidikan tertinggi yang diperoleh oleh bapa anda? • Tidak bersekolah • Sekolah Rendah • Sekolah Menengah • Sijil Pelajaran Malaysia (SPM) • Ijazah Sarjana Muda • Lain: _____
	What is your mother's hearing status? • Deaf • Hard of hearing • Hearing • Unknown	Apakah status pendengaran ibu anda? • Pekak • Kurang pendengaran • Pendengaran • Tidak diketahui
	What is the highest educational degree your mother has obtained? • No school • Elementary school/primary school • High school/secondary school • Malaysian Certificate of Education (Sijil Pelajaran Malaysia) • Bachelor Degree	Apa tahap pendidikan tertinggi yang diperoleh oleh ibu anda? • Tidak bersekolah • Sekolah Rendah • Sekolah Menengah • Sijil Pelajaran Malaysia (SPM) • Ijazah Sarjana Muda

	• Other: _____	• Lain: _____
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Appendix C

Demonstrating the Survey in various Languages (English, Malay and BIM)

My previous teacher(s) helped me to communicate easier in the classroom as a person who is deaf or hard of hearing.

Sebagai seorang yang pekak atau kurang pendengaran, guru saya sebelum ini membantu saya berkomunikasi dengan lebih mudah di dalam bilik darjah.



Not at all										
Tiada	1	2	3	4	5	6	7	8	9	Very much
0										Bi
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	

Surveys conducted using a computer or laptop



The use of a mobile phone for a survey

Vita

Mr. Tur Chung, Lee has been a profoundly deaf person since he was born. He grew up with a younger deaf sibling. He has worked with deaf students ranging from 5 years old to 19 years old for over 15 years. In 1998, He was one of the first batch of disabled people to be accepted into the Specialist Teachers' Training Institute in Malaysia. He became a trained teacher after graduating with a diploma in teaching in 2001. He received a Bachelor of Education in Special Education in 2006 and a Master of Education degree in Special Education in 2019 from National University of Malaysia in Malaysia. To study for a Ph.D. degree in a foreign country instead of a local university, he stepped out of his comfort zone. Through the Fulbright scholarship, he studied in the USA to broaden his perspective in deaf education and enhance his skills on a global scale. He graduated from the University of Tennessee in Knoxville, Tennessee with a doctorate degree in Teacher Education with a concentration in Special Education, Deaf Education, and Interpreter Education in 2025.