



**PSYCHOSOCIAL IMPACTS
OF HEARING IMPAIRMENT
ON ADULTS AND THEIR SPOUSES**

BY

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ABSTRACT

Understanding the psychosocial impact of hearing impairment to patients and their spouses is critical to provide optimal audiological management. Literature revealed that hearing impairment resulted in poor satisfaction between couples leading to deterioration of the quality of life. Despite the reports on psychosocial impacts in both, little attention has been paid to determine the relationship of both (spouse and patient) psychosocial consequences. Introducing coping strategies requires the knowledge on the psychosocial impact severity, subsequently the association in both parties. While there were substantial evidences on the effect of hearing impairment among elderly, there is still scant evident on the effects among adult's population. Present study aimed to investigate the psychosocial impacts on adults with hearing loss (AHL) and their spouses. Study conducted in this thesis was completed in two phases. The first study was the translation and validation of two instruments into Malay language. Fifty-eight AHL and 58 normal hearing adults, together with 32 spouses of AHL and 32 spouses of normal hearing adults participated in this study. Hearing Handicap Inventory for Adult (HHIA) was used to evaluate the psychosocial impact for the AHL while, Significant Other Scale for Hearing Disability (SOSHEAR) was used to evaluate the same issue on the spouse. Both instruments were successfully translated and validated as revealed by the Cronbach alpha 0.97 and 0.98 respectively, and the inter-item correlation for each subscale ranged between 0.31 to 0.81 for HHIA-M and 0.41 to 0.89 for SOSHEAR-M establishing convergent validity in both questionnaires. Significant higher scores were observed in experimental groups for both HHIA-M and SOSHEAR-M than control groups demonstrating good discriminant validity. In second study, the validated questionnaires were used in investigating the existence of self-perceived disability among AHL and spouses, subsequently the association of the psychosocial impacts between them. The HHIA-M total score's average for 58 participants demonstrated the existence of mild psychosocial disability among AHL. Meanwhile, the average of SOSHEAR-M total score for 32 spouses was 0.78 demonstrated mild psychosocial disability among spouses of AHL. Twenty-six couples participated in the survey using these translated questionnaires to determine the association of psychosocial impacts between the two groups. Spearman correlation showed no significant association between HHIA-M and SOSHEAR-M scores ($r_s=0.32$, $p>0.05$). Majority couples (76.92%) had higher SOSHEAR-M scores than HHIA-M suggesting most spouses are more affected by their partners' hearing impairment as compared to the patients themselves. No significant association was found between hearing loss level in AHL and their spouses' SOSHEAR-M score ($r_s=0.26$, $p>0.05$). This study concluded that hearing impairment affects AHL and their spouses' psychosocial functions, with higher impact were observed in most of the spouses than their AHL partners. Hence, a reasonable approach to address this issue could be further investigated to understand how spouses' disability level could affect their daily functioning, subsequently implementing appropriate management plan individually based on their self-reported assessment.

خلاصة البحث

يعتبر فهم الآثار النفسية الاجتماعية لمرضى ضعف السمع ولأزواجهم أمر بالغ الأهمية وذلك حتى يتسنى توفير المعالجة والرعاية السمعية المثلى لهم. الزوج أو الزوجة هو أقرب أفراد العائلة إلى المريض الذي يعاني من ضعف السمع، وقد أظهرت الدراسات السابقة أن ضعف السمع يمكن أن يؤدي إلى سوء الرضا في التواصل بين الأزواج وهذا بدوره يؤدي إلى تدهور نوعية الحياة بينهم. على الرغم من وجود تقارير عن الآثار النفسية الاجتماعية لكل من الأزواج والمرضى، إلا أنه لم يتم إيلاء اهتمام كبير بتحديد علاقة العواقب النفسية الاجتماعية لكلاهما (الأزواج والمرضى). (ومعرفة مثل هذه العلاقة مهمة لتقديم استراتيجيات التكيف حيث تتطلب معرفة مدي خطورة التأثير النفسي الاجتماعي على كلا الطرفين. وعلى الرغم من وجود أدلة جوهرية تثبت تأثير كبار السن بضعف السمع، إلا أنه لا يوجد هناك أي دراسة من الدراسات السابقة بحثت هذه التأثيرات على البالغين بشكل كافي وواضح. تهدف هذه الدراسة إلى بحث الآثار النفسية الاجتماعية على البالغين الذين يعانون من ضعف السمع وعلى أزواجهم. تمت هذه الدراسة على مرحلتين. المرحلة الأولى هي ترجمة اثنين من أدوات القياس إلى لغة الملايو و توثيق مصداقيتها. وشارك في هذه المرحلة 58 شخصا من البالغين من ضعاف السمع مع 35 من أزواجهم، و 58 آخرين من العاديين في السمع مع 35 لتقييم الأثر النفسي الاجتماعي على البالغين من (HHIA) من أزواجهم. استُخدم مقياس قائمة الحصر لمعاقبي السمع للبالغين لتقييم نفس المشكلة في أزواجهم. تم (SOSHEAR) ضعاف السمع، في حين استُخدم مقياس الإعاقة السمعية للأزواج بنجاح ترجمة أداتي القياس وتم التحقق من مصداقيتها على النحو الذي أظهره مقياس كرونباخ ألفا 0.970 و 0.981 على و 0.41 إلى HHIA-M، والتوالي، والارتباط بين العناصر لكل نطاق فرعي يتراوح بين 0.31 إلى 0.81 بالنسبة إلى وذلك للتأكد من الصدق التقاربي لكلا الاستبيانين. و لوحظت نتائج مرتفعة ذات SOSHEAR-M بالنسبة إلى 0.89 مقارنة بالمجموعات المرجعية فأظهرت SOSHEAR-M و HHIA-M أهمية إحصائية في المجموعات التجريبية لكل من صدق تمييزي جيد. وفي المرحلة الثانية، استُخدمت الاستبيانات المصادق عليها في تحقيق وجود التصور الذاتي للإعاقة لدى البالغين الذين يعانون من ضعف السمع ولدي أزواجهم، بالإضافة إلى مدى ارتباط الآثار النفسية الاجتماعية فيما بينهم. وأظهر ل 58 مُشترك وجود عجز نفسي اجتماعي متوسط لدى البالغين الذين يعانون HHIA-M متوسط النتائج الإجمالية لمقياس ل 32 من الأزواج هو 0.78 مما SOSHEAR-M من فقدان السمع. في حين كان متوسط النتائج الإجمالية لمقياس يظهر عجز نفسي اجتماعي متوسط لدي أزواج الذين يعانون من فقدان السمع. وشارك ستة وعشرون زوجا في الدراسة المسحية باستخدام هذه الاستبيانات المترجمة. النتيجة تشير إلى أنه لم يُظهر ارتباط سبيرمان أي ارتباط ذات أهمية إحصائية بين نتائج وكان لدي (rs=0.32, p>0.05). في كلا المجموعتين SOSHEAR-M ونتائج مقياس HHIA-M مقياس مما يشير إلى أن معظم HHIA-M أعلى مقارنة ب SOSHEAR-M أغلبية الأزواج) 76.92% (نتائج مقياس الأزواج أكثر تأثيرا بضعف السمع لشركائهم بالمقارنة مع المرضى أنفسهم. وكذلك لا يوجد ارتباط ذات أهمية إحصائية بين مستوى الأزواج SOSHEAR-M فقدان السمع في المرضى ضعاف السمع و نتيجة الأزواج لمقياس وخلصت هذه الدراسة إلى أن ضعف السمع يؤثر على كلا من البالغين الذين يعانون من ضعف السمع وعلى أزواجهم، ولكن لوحظ أنها لها تأثير أكبر في بعض الأزواج. ولذلك يمكن إجراء مزيد من البحث والدراسة في معالجة هذا الموضوع بطريقة مناسبة لفهم كيفية تأثير مستوى العجز للأزواج على الأداء اليومي، ومن ثم يمكن تنفيذ خطة معالجة مناسبة تعتمد على التقييم الذات

APPROVAL PAGE

I certify that I have supervised and read this study and that in my opinion, it conforms to acceptable standards of scholarly presentation and is fully adequate, in scope and quality, as a thesis for the degree of Master of Health Science (Audiology)

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DECLARATION

I hereby declare that this dissertation is the result of my own investigations, except where otherwise stated. I also declare that it has not been previously or concurrently submitted as a whole for any other degrees at IIUM or other institutions.

Tengku Zulaila Hasma binti Tengku Zam Zam

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*To my parents for all their love and support in putting me through
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LIST OF ABBREVIATIONS

AHL	Adult with hearing loss
ASHA	American Speech and Hearing Association
SO	Significant other
HHIA	Hearing Handicap Inventory for Adult
HHIA-M	Bahasa Malaysia version of Hearing Handicap Inventory for Adult
SOSHEAR	Significant Other Scale for Hearing Disability
SOSHEAR-M	Bahasa Malaysia version of Significant Other Scale for Hearing Disability
CPHI	Communication Profile for Hearing Impaired

LIST OF SYMBOLS

α	Alpha
=	Equal to
>	Larger/more than
<	Smaller/less than
\geq	Larger or equal than
\leq	Smaller or equal than
dB HL	Unit to measure sound intensity (decibel hearing level)

CHAPTER ONE

INTRODUCTION AND OVERVIEW

1.1 BACKGROUND OF THE STUDY

1.1.1 Hearing Impairment and the ICF

The International classification of functioning, disability and health (ICF) was released in 2001 by World Health Organization (WHO) as a new standardize framework to describe disability, replacing the 1980 original version, International Classification of Impairments, Disabilities and Handicaps (ICIDH) (Functioning and Disability Reference Group, 2010). The ICF is constructed to benefit various disciplines such as education and transportation, as well as in health and community services in different countries and cultures (World Health Organization, 2010). Thus, the benefits of the ICF framework is extended to patients and their family members instead of for the health practitioners alone (Nund et al., 2015). Figure 1.1 shows the diagram of the ICF framework.

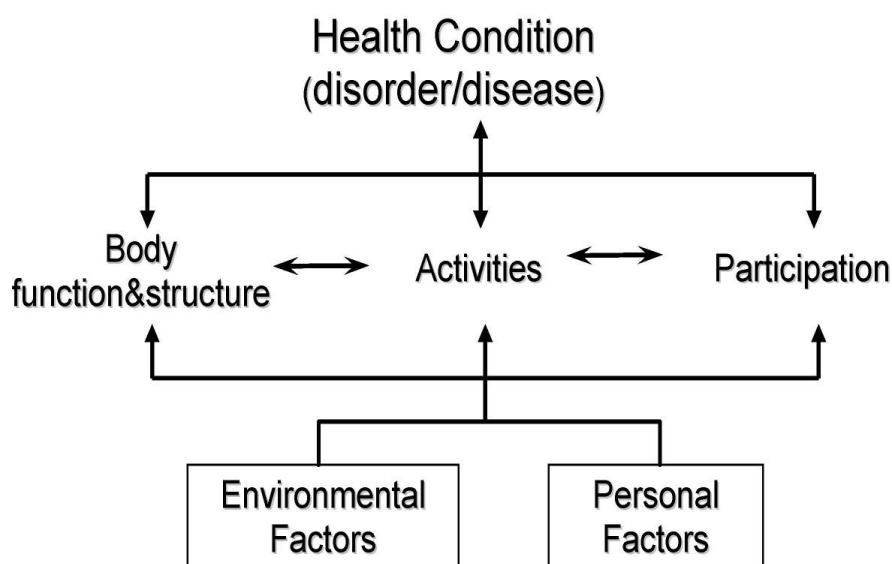


Figure 1.1: The International Classification of Functioning, Disability and Health

A person's level of functioning was deliberated in the ICF as an interaction between her or his health conditions, environmental factors, and personal factors (World Health Organization, 2010). As the ICF is a multi-dimensional concept, it is further conceptualized into two; (1) functioning as a dynamic interaction between her or his health conditions, environmental factors, and personal factors, and, (2) disability which was based on an integration of the social and medical models of disability (World Health Organization, 2010). In clinical settings, the ICF can be used as a framework to establish rehabilitation program (Danermark et al., 2010), for example, to describe the disability experience of adult with hearing loss (AHL). There were few studies discussing about ICF and its implication on rehabilitation process among hearing-impaired (B. Danermark et al., 2010; Grawburg, Howe, Worrall, & Scarinci, 2014; Scarinci, Worrall, & Hickson, 2009). As the ICF granted an international and scientific tool to study disability, this study will be using the ICF as main framework to describe the psychosocial impact on adults with hearing impairment and their spouses.

1.1.2 Psychosocial Functions and Hearing Impairment

Hearing impairment was evident to negatively affect elderly psychosocial functions in previous studies (Dalton et al., 2003; Ringdahl & Grimby, 2000; Scarinci, Worrall, & Hickson, 2008a; Scarinci, Yi, Lim, Hickson, & Worrall, 2010; Tambs, 2004). The psychosocial areas mostly associated with hearing impairment are depression (Kramer, Kapteyn, Kuik, & Deeg, 2002), loneliness (Kramer et al., 2002), and poor social interaction (Ringdahl & Grimby, 2000). Then again, most of the literature that investigated the psychosocial effect was conducted in elderly population, in which the impact on younger adults is still disputable as different age groups are likely to have different psychosocial issues. This is due to the different in their lifestyle, work obligation, communication needs and listening demands (Nachtegaal, Kuik, et al., 2009).

1.1.3 Introduction to Third-Party Disability on Spouses of Adults with Hearing Loss

The effects of hearing loss are not only experienced by the adults with hearing loss themselves, but may also affect their SO's including parents, spouse, children and relatives. These consequences can be associated with the term used by the World Health Organization (WHO) — third-party disability. The classification of TPD derived from the ICF framework where in the context of hearing impairment, it is possible for a normal hearing spouse to have similar hearing disability as their hearing loss partner. Previous research conducted in developed countries, namely Australia and

the United States, has shown that TPD exists among spouses of the elderly population and among parents who have hearing loss children (Scarinci et al., 2009).

1.1.4 Psychosocial Disability on Spouses Extended from Partner's Hearing Loss

Getty & Héту (1991) reported that hearing impairment directly affect communication. As communication is a two-way process, hearing loss does not only cause communication problems for the individuals with hearing impairment, but also to the people surrounding them. Therefore, spouses are the most affected persons, because they are the closest communication partner to the hearing-impaired patient (Stark & Hickson, 2004). Scarinci et al. (2009) reported that hearing loss may affect the spouses' emotional well-being, caused by the need for psychological support from their hearing-impaired partner. Communication difficulties between the spouse and the hearing-impaired partner were reported to be the major contributor to stress and depression (Scarinci, Worrall, & Hickson, 2012); 98% of elderly spouses were found to experience some level of TPD in which 36% fell under severe-to-complete disability (Scarinci et al., 2012). This finding is supported by Stephens & Héту (1991a) who reported that spouses may share the disability of the adults with hearing loss in which the disabilities include depression, social isolation, poor social interactions, reduced health-related quality of life, cognitive dysfunction, reduced emotional, behavioral, social wellbeing and communication difficulties.

1.1.5 Psychosocial Disability on Spouses Extended from Partner's Hearing Loss

Although it is normal for spouse to come along with their hearing-impaired partners to audiological follow-ups, the communication needs of the normal-hearing spouse are

often neglected (Scarinci et al., 2008a). Past studies reported that spouse of hearing-impaired patients experienced almost the same frustration and anxiety as their partner (Armero, 2001; Brooks, Hallam, & Mellor, 2001; Héту, Jones, & Getty, 1993; Stark & Hickson, 2004). Therefore, it is demanded for audiologist to extend their service towards the spouse of hearing-impaired patients through support, information and/or direction (Tye-Murray, Spry, & Mauzé, 2009).

As much as the acknowledgement on the existence of TPD among spouses of hearing-impaired patients, at this moment, there were only a few numbers of studies investigated the involvement of spouses in aural rehabilitation (Habanec & Kelly-Campbell, 2015; Hickson, Laplante-Lévesque, & Wong, 2013; Preminger, 2003; Preminger & Meeks, 2010; Tye-Murray et al., 2009). It is reported that spouses' involvement in aural rehabilitation has shown to improve psychosocial wellbeing for their hearing-impaired partner (Preminger & Meeks, 2010). However, despite significant positive improvement that being shown by hearing-impaired patients, spouses do not perceive as much improvement as their partners' (Preminger & Yoo, 2010). It is speculated that this outcome is due to lack of rehabilitation program that focus specifically on significant-other (Habanec & Kelly-Campbell, 2015; Preminger & Yoo, 2010) and spouses' tendencies on underestimating the progress following the program (Preminger, 2003).

1.2 PROBLEM STATEMENT

Although there were numerous reports and researches being conducted to study the effect of hearing-impairment in adult (Erdma & Demorest, 1998; Foley, Frick, & Lin, 2014; Helvik, Jacobsen, & Hallberg, 2006; J. Nachtegaal, Festen, & Kramer, 2011;

Janneke Nachtegaal, Smit, et al., 2009; Tambs, 2004), there are only a few reports on the TPD among spouses or significant others (SO) of the hearing-impaired (Armero, 2001; Meyer & Hickson, 2012; Scarinci et al., 2008a, 2012; Stark & Hickson, 2004). Information on the following is either not reported or not thoroughly explored, (i) the third-party disabilities among other populations in addition to the elderly and children, (ii) psychosocial impact of hearing loss in adult with hearing impairment and the spouse in less-developed countries and, (iii) the relationship between psychosocial level in adults with hearing impairment and their spouses. These will be discussed in turn.

First, most of the previous studies investigated the impact of hearing losses on the SO focusing only on the spouses of the elderly (Scarinci et al., 2008a); there has been limited research investigating the extent of the TPD among spouses in the adult population ranging from the age of 18 to 59 years old. Habanec & Kelly-Campbell (2015) investigated the effects of Group Aural Rehabilitation (GAR) to both AHL and spouse among 24 couples. Whilst the authors found significant improvement in both AHL and spouse psychosocial disability following GAR program, the authors did not clearly mention the existence of TPD and their findings among their adult population. It is crucial to investigate further on this matter, given the problem experienced by the spouses of elderly may not be the same as that of adults due to different lifestyles (Demura & Sato, 2003; Grawburg et al., 2014; Myint et al., 2011). In which, adults reported more changes in their daily routines, especially at work and in financial stability compared to elderly couples who had already retired (Grawburg et al., 2014). This notion is supported by findings involving other disorders, such as aphasia, that showed significant differences in the level of third-party disabilities experienced by family members of elderly and adult study participants (N Scarinci et al., 2009).

Second, most of the reports on the third-party disabilities among spouses of individuals with hearing loss were conducted in developed countries (Habanec & Kelly-Campbell, 2015; N Scarinci et al., 2009; Stark & Hickson, 2004), not in less developed countries such as Malaysia. The report from developed countries may not be applicable to Malaysia's context owing to the socioeconomic, sociocultural and health policies diversions (Lazzarino, Yiengprugsawan, Seubsman, Steptoe, & Sleight, 2014). For example, hearing aids are provided free in most developed countries, (e.g in Australia and in United Kingdom), and most of hearing loss individuals are fitted with hearing aids. Therefore, the problems faced by family members of adults with hearing loss patients who do not wear a hearing aid may be different from those of patients who have been fitted with a hearing aid (Kim, Lee, & Lee, 2014; Stark & Hickson, 2004).

Thirdly, there is insufficient research investigating the relationship between the hearing handicap severity in AHL and their spouses to our knowledge (Habanec & Kelly-Campbell, 2015; Héту & Getty, 1991; Preminger & Meeks, 2010; Stark & Hickson, 2004). In the recent study by Habanec & Kelly-Campbell (2015), the improvement in psychosocial disability shown by the spouses following intervention were relatively small with the improvement score was less than 0.5 of the total score of each domain. It can be argued that the small improvement shown in this study could be contributed by the high variation of the TPD level between spouses, and the need to apply different amount of interventions (e.g. more counselling sessions) according to the level of TPD in each spouse. In Habanec & Kelly-Campbell (2015) study, the group intervention session was conducted concurrently with AHL's counselling session; this approach did not take into considerations significant-others' individual psychosocial disabilities and the possibility that the AHL may have different level of