**PROJECT PROPOSAL**

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| **Part -A** | | | | | | |
| **1.0** | **Title of the Project** | | | | **:** | Adaptation and Validation of SWAL-QoL In Malayalam |
|  | **Area of Research :** | | | | **:** | Speech, Language, Hearing |
| **1.1** | **Principal Investigator** | | | | **:** | Mrs. Gayathri Krishnan |
| **1.2** | **Principal Co-Investigator(s)** | | | | **:** | Dr. Brajesh Priyadarshi |
| **1.4** | **Collaborating Institution** | | | | **:** | Nil |
| **1.5** | **Total Grants Required**  **(in figures and in words)** | | | |  | `.4,37,500  Four Lakhs Thirty Seven Thousand Five Hundred Only |
| **1.6** | **Duration of the Project** | | | | **:** | One Year |
| **2.0** | **Project Summary:**: | | | | | |
|  | Eating is a basic need of all living beings and it is often disrupted by a disorder of swallow. Management of swallowing disorders is gaining attention in both national and international scenario due to its adverse impact on the quality of life of clients with swallowing disorder as well as their care givers. Understanding the impact of swallowing disorders on an individual’s life is important in planning strategies for rehabilitation as well as in understanding the effectiveness of rehabilitation. The gold-standard in this measure is the Swallowing Quality of Life Questionnaire (SWAL-QoL) developed by McHorney, Bricker, Robbins, Kramer, Rosenbeck and Chingell (2000). There exist many translations of this questionnaire (Finizia, Rudberg, Berqqvist & Ryden, 2012; Lam & Lai, 2011; Vanderwegen, Nuffelen & Bodt, 2013). However there are no adaptations of this questionnaire in Indian languages. The proposed study aims at translating, adapting and validating the SWAL-QoL questionnaire to One Indian Language, Malayalam. The project will involve two phases:  *Phase I:Adaptation and Translation of SWAL-QoL*  International guidelines for translation of health related questionnaires (Guillemin, Bombardier & Beaton, 1993) will be followed for adaptation and translation of SWAL-QoL. This phase will result in adapted Swallowing Quality of Life Questionnaire in Malayalam (SWAL-QoL-M)  *Phase II: Validation of the product*  Reliability, construct validity and content validity of the adapted questionnaire will be established.  The validated product can be published and made available for routine use by professionals involved in rehabilitation of clients with swallowing disorders. | | | | | |
| **3.0** | **Introduction** | | | | | |
|  | 3.1 | | | Definition of the problem: | | |
|  |  | | | Eating is a basic necessity of life. The process of eating involves feeding and swallowing. While feeding involves the process from intent to eat to placement of the bolus into the oral cavity, swallowing involves a complex neuromuscular reflexive action by which the food placed in the oral cavity is transferred into the digestive system. Disorders of eating may be related to feeding or swallowing. These disorders commonly lead to deterioration of overall health and performance of an individual as the disorders reduce the amount of vital nutrients reaching the individual’s body.  Speech-Language Pathologists commonly concur with persons with swallowing disorders as speech and swallowing disorders commonly co-occur. Though the underlying neural controls for these two functions are thought to be different, the end structures that participate in speech and swallowing overlap such as the oral and pharyngeal structures. Thus, Speech-Language Pathologists are commonly involved in rehabilitation of persons with swallowing disorders.  Rehabilitation of swallowing disorders involve understanding the signs and symptoms of swallowing disorder exhibited by the client, attempt to understand the underlying cause of the symptom, assessment of functional abilities and disabilities of the client, impact of the disorders on a client and their caregiver/ family, planning and execution of the best suitable rehabilitation strategy to ensure safe and adequate swallow. These definitely involve a team of experts from medical and non-medical fields because of the interdisciplinary nature of swallowing disorders. The success of rehabilitation depends on the positive changes that could be brought about in a client’s life and the improvements made in the quality of life. However, there exist no quality of life measurements specific to swallowing disorders that can be used with Indian clients with swallowing disorders. | | |
|  | 3.2 | | | Objectives: | | |
|  |  | | | This study is proposed with the following objectives   1. To adapt and translate the SWAL-QOL to Malayalam language (SWAL-QoL-M) 2. To establish reliability, construct validity and sampling validity of SWAL-QoL-M | | |
|  | 3.3 | | | Review of status of research and development in the subject: | | |
|  |  | | | Quality of life measurements are usually done using questionnaires that are answered by the client (or caregiver/ family member). Quality of life questionnaires are commonly used in health related studies to understand the impact of a condition on a client and also to understand the change in quality of life after rehabilitation. The world health organization has developed a 26 item cross culturally compatible quality of life questionnaires (WHOQOL-BREF) in the domains of physical health, psychological health, social relationships and environment. There also exist quality of life questionnaires specific to disorders such as cancer (The European Organization For Research and Treatment of Cancer Quality of Life (EORTC-QOL); Cella et.al., 1993), diabetes (Bott, Overmann, Muhlhauser & Berger, 1998; Nagpal, Kumar, Kakar, & Bhartia, 2010), intellectual disabilities (Cummins, 1990; Cummins & Lau, 2005), Epilepsy (Cramer, Perrine, Devinsky, Bryant-Comstock, Meador & Hermann, 1998; Cramer, Perrine, Devinsky & Meador, 1996; Sabaz, Lawson, Cairs, Duchowny, Reesnick, Dean & Bye, 2003) and also for elderly individuals (Bowling, Hanskins Windle, Bilotta & Grant, 2013). Specific to swallowing disorders, a quality of life questionnaire was developed by McHorney, Robbins, Lomax, Rosenbeck, Chignell and Kramer (2002) called the Swallowing Quality of Life (SWAL-QOL). | | |
|  | 3.4 | | | International and national status: | | |
|  |  | | | The SWAL-QOL questionnaire was validated and was adapted into various foreign languages such as Dutch (Vanderwegen, Nuffelen & Bodt, 2013), Swedish (Finizia, Rudberg, Berqqvist & Ryden, 2012), and Chinese (Lam & Lai, 2011). There are no such adaptations made in any Indian Languages preventing the use of this widely accepted questionnaire in Indian individuals with swallowing difficulties. | | |
|  | 3.5 | | | Importance of the proposed project in the context of current status: | | |
|  |  | | | The incidence of swallowing disorders in Indian population can be expected to be on rise with increased incidence of (sancd.org/uploads/pdf/factsheet\_Stroke.pdf), road traffic accidents (Vidya, 2003, www.livemint.com/Opinion/Taking-note-of-road-deaths-in-India.html), head and neck cancer (Yeole, Sankaranarayanan, unny, Swaminathan & Parkin, 2000), and other neurological conditions. A study by Garg and Hyder (2006) reported that the road traffic accidents in India majorly affected the young population than older. With advancements in medical technology in India (Datta, 2009), the survival rate of these individuals may also increase leaving a large number of persons to survive with swallowing disorders or dysphagia.  Speech-Language Pathologists are one of the leading team members in planning the client centered rehabilitation strategies and they need to equip themselves with the necessary resources and expertise to provide quality rehabilitation services to their clients with dysphagia. This proposed project aims at developing one such quality tool in rehabilitation of swallowing disorders that will highlight the impact of swallowing disorder on the quality of life of an individual with swallowing disorder. | | |
| **4.0** | **Work Plan** | | | |  |  |
|  | **4.1** | | | **Method** |  |  |
|  |  | | | The proposed project will be conducted in two phases:  ***Phase I: Translation and Adaptation of SWAL-QOL to Malayalam.***  The translation of SWAL-QOL will be done keeping in mind the international standards of translation of health related questionnaires given by Guillemin, Bombardier and Beaton (1993).  *Stage I: Translation and Adaptation of SWAL-QOL from English to Malayalam.*  Subjects / Participants:  This stage will include 6 native speakers of Malayalam language (3 Speech-Language Pathologists and 3 others).  Material :  The modified SWAL-QOL questionnaire with the list of questions to be translated  Procedure:  The translators will be provided the SWAL-QOL questionnaire with instructions to go through the questions and independently translate them into their mother tongue. The translators will be blind to the objective of the process to avoid bias.  Output:  6 translated SWAL-QOL questions in Malayalam.  *Stage II: Reverse translation of translated SWAL-QOL from Malayalam to English*  Subjects / Participants:  This stage will include 6 other participants (3 speech-language pathologists and 3 others) with Malayalam as their mother tongue and these participants will necessarily be fluent in English.  Material:  The 6 translated SWAL-QOL questions in Malayalam.  Procedure:  The participants in this stage will be instructed to translate the material provided to them to English as meaningfully as possible. The participants in this stage will be blind to the purpose of the study to avoid any possible bias.  Output:  6 translations in English from Malayalam.  *Stage III: Committee review and finalization of translated SWAL-QOL in Malayalam.*  Procedure:  The investigators will scrutinize the translations and select the best translations by comparing the outputs of Stage I and II. The translations and reverse translations will be compared for meaningfulness with the original SWAL-QOL and the translations that are most similar will be included in the final translated SWAL-QOL in Malayalam (SWAL-QOL-M). The committee will also scrutinize the instructions to be given to the target group.  The final translated questions and instruction will be laid out in the likert scale of SWAL-QOL and readied for field testing.  *Stage IV: Pre-testing*  Subjects / Participants:  This stage will include ten participants with the Malayalam as mother tongue and with swallowing disorders of various etiologies.  Material:  SWAL-QOL-M  Procedure:  The questionnaire in Malayalam will be provided to ten clients with swallowing disorders of various etiologies. The questionnaire may be completed by the client themselves or their caregivers/family members.  To confirm the proper comprehension of questions, open ended probe questions will be incorporated. Any content in the questionnaire that required explanation/ incorrectly understood will be revised. Suggestions from the target group will be incorporated in the questionnaire.  Output:  Final SWAL-QOL-M.  *Phase II: Establishing Reliability and Validity*  Subjects/ Participants:  Group I: A total of 30 participants with Malayalam as their mother tongue with swallowing disorders secondary to stroke, head and neck cancer, neurological disorders and other etiologies (10 participants in each).  Group II: A total of 30 participants with Malayalam as their mother tongue with no symptoms of swallowing disorders.  Material:  Final SWAL-QOL-M.  Procedure:  The final SWAL-QOL-M will be administered on participants in group I and group II. If necessary, the participants in group I will be allowed to use any alternate modes for answering the questions. The questionnaire will be re-administered on a random set of participants for establishing reliability measures.  Analyses:  The completed questionnaire will be scored based on the guidelines provided by the McHorney et.al. (2000). Sum scores will be obtained for each section of the questionnaire. The same will be subjected to statistical analyses for establishing test-re-test reliability, construct validity and content validity.  Output:  An adapted, translated, field tested, validated and reliable tool for measuring the quality of life of persons with swallowing disorders. | | |
| **6.0** | | **Implications of the results of the study** (Illustrative) | | |  |  |
|  | |  | 1. Presentation of scientific papers in professional seminars / publication of articles | | : | Approximate number of outputs from the present study:  Research publications: 2 |
|  | |  | 1. Discussion with professionals | | : | The project will be completed only with the support of medical professionals in various regions of the country for facilitating availability of participants for the project. Various hospitals will be contacted for their consent to access their patients with swallowing difficulties. |
|  | |  | 1. To utilize the results in the development of remediation | | : | The project will produce field tested validated questionnaires in Malayalam for use with clients with swallowing disorders. This will be the first of its kind in India. |
| **7.0** | | **Utilization of results of the study** | | |  | The product of the present study will be a field tested, validated questionnaires for clients with swallowing disorders in Malayalam. With the upcoming center for swallowing disorders, this product will be a useful indigenous product for routine use. The same will be the copyright of this Institute and the product can be made available for other professionals in the country through the institute.  The project involves a methodology that assures quality of the product in each stage. A number of research output are expected from this project data. |