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Adaptation of the STRiDE dementia survey into the Indonesian context in North Sumatra

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Abstract

Background:

North Sumatra is one of two provinces in Indonesia in which the prevalence and costs of care of dementia has been completed as part of the STrengthening Responses to dementia In Developing countries (STRiDE) program. The toolkit used in the study was developed in English and thus needed to be cross-culturally adapted into Bahasa Indonesia. Part of this process involved pre-testing as a way to maximize the cultural appropriateness of the toolkit, especially in a multi-ethnic province like North Sumatra. Here we report the adaptation process.

Methods:

The translated toolkit consisted of measures needed within the prevalence survey in North Sumatra. This included cognitive, functional and quality of life measures aimed at older adults and their informants (i.e., family member). The interviewer asked each component of the toolkit in full, making notes on certain questions or items that need to be clarified or rephrased for the participants. Any specific difficulty in understanding the translated sentence or any items that were culture inappropriate were also noted. Data included observation, interviews, verbatim quotes which were constructed in the form of field-notes.

Results/Findings

Several questions and items needed to be paraphrased to achieve greater clarity and make sure that they were in line with the original meanings. This was mainly due to the translatability of the word from the source language to the target language with errors that could be linguistic or cultural. Translating a text from English to Bahasa Indonesia and vice versa may be affected because of the different ways of ellipsis, which is a phenomenon of missing phrasal components, operated in both languages. Although the respondents belonged to different ethnic groups, cultural background did not affect the way they responded to the questions.

Conclusion

Cross-cultural adaptation and pre-testing process played an important role to ensure the toolkit measured and was interpreted as it was originally intended. The STRiDE toolkit was generally accepted and understood, although several items need further explanation or examples.

Keywords: cross-cultural adaptation, dementia, STRiDE

Introduction

In North Sumatera, Indonesia, the population of older adults has increased in recent years. It is the fourth most-populous province in Indonesia with a population of approximately 14 million people in 2019; the proportion of older adults has increased from 7.58% in 2018 to 7.87% in 2019, and this number is predicted to increase in the future.¹ The growing older adult population is likely to increase the risk of several health problems, including dementia. Dementia has a profound impact on people's lives and may subsequently lead to higher burden of care. Whilst there are some estimates of dementia derived from other regions in Indonesia,^{2,3} there is no data available on the prevalence, impact and cost of care of dementia in North Sumatera.

The STRiDE (STrengthening Responses to dementia In Developing countries) programme is intended to support the development of national dementia policy in seven countries with the goal of improving dementia care systems and increasing the quality of life of people with dementia. Within the programme, Indonesia and South Africa were selected to gain the data on prevalence, costs, and impact of dementia.^{4,5} To achieve this a toolkit was compiled to assess domains such as cognitive function, sociodemographic factors, neuropsychiatric symptoms, carer burden, stigma, disability and quality of life. The STRiDE toolkit is intended to be applied in low- and middle-income countries, particularly in non-clinical settings. The toolkit was translated and culturally adapted from the source (original) language(s) to Bahasa Indonesia in line with World Health Organisation (WHO) recommendations.⁶

In translating questionnaires, it is essential to understand the cultural meanings, local context, and specific issues that language carries. The translation process should not be a direct translation (i.e., word for word) across languages.⁷ If translated questions or items in the new language version no longer retain the original meaning, such language versions of the test are of no practical use, even though it might be very accurately translated; hence the need for adaptation.⁸ Cross-cultural adaptation is a way to maximize the cultural appropriateness of an instrument or questionnaire and therefore may minimize bias. Adaptation is a broad term for any procedure that is developed for one cultural group is transferred for usage in another cultural group.⁹

Outside the translation process, pre-testing (sometimes referred to cognitive testing) plays an important role in identifying and potentially reducing measurement error that potentially damages estimation at the population level.¹⁰ In this step, respondents are asked about their understanding of what the question was asking about, whether they could repeat the question in their own words, and what came to their mind when they heard a particular phrase or term.¹¹ Pre-testing in general aims to evaluate whether the target audience properly understands, processes, and responds to the test items. A criterion for the success of a judgmental procedure is that all items and questions of the battery are interpreted as intended.

One of the provinces in which novel data has been collected in STRiDE is North Sumatra. It covers an area of around 72,981 km² and is currently divided into 25 regencies and 8 autonomous cities. North Sumatra is a multi-ethnic province with at least 11 ethnic groups; the majority of which is Batak who make up almost half of the population although the Malay people are regarded as the native people of this province. In general, the widely used language is Bahasa Indonesia, although there are many local languages that are commonly used in rural areas.¹² According to the Central Bureau of Statistics in North Sumatra (*Biro*

Pusat Statistik Sumatra Utara) more than 95 percent of older adults in North Sumatra are able to read and write, with those residing in urban areas having the highest literacy rates.¹ This paper aims to describe the pre-testing of the STRIDE toolkit in Medan, North Sumatra by highlighting the overall comprehension, grammar, meaning, and sociocultural appropriateness of the toolkit.

Methods

STRiDE Toolkit

The questionnaires within the STRiDE toolkit were identified through a series of consensus events amongst the research team. Once selected they underwent a rigorous forward and back translation process with native Indonesian Bahasa speakers. The toolkit consists of measures for older adult and informant questionnaires, informant only questionnaires and older adult only questionnaires. Further details about the cross-cultural adaptation process and STRiDE toolkit can be read elsewhere.¹³

Older adult and informant questionnaires:

- *Client Service receipt Inventory (CSRI)* – a tool to collect information on service utilization, income, accommodation and other cost-related variables.¹⁴ Additional items spanning sociodemographic, lifestyle and household information were also captured.
- *Community Screening Interview for Dementia (CSID)* consists of two components, a cognitive test for the older adult and an informant interview regarding cognitive and functional impairment in daily activities.¹⁵
- *World Health Organization Disability Assessment Schedule (WHODAS 2.0)* – a single, generic instrument for assessing the health status and disability in different cultures and settings.¹⁶ The WHODAS 2.0 was adapted for use in Indonesia and showed good results for all six domains.¹⁷
- *The Washington Group Short Set of Questions on Disability* – assesses the difficulties that may occur while performing certain activities as a result of a health problem.¹⁸
- *The self-report EQ-5D-5L* consists of two parts: the five dimensions assessment of mobility, self-care, usual activities, pain/discomfort, anxiety/depression; and the EQ VAS that records the patient's self-rated health on a vertical visual analogue scale.¹⁹
- *Stigma questionnaire* assesses knowledge, attitudes-prejudice, and behaviour/intentions. Items from the World Alzheimer's Report 2019.²⁰

Informant only questionnaires:

- *Dementia severity Rating Scale (DSRS)* – an informant-based, multiple-choice questionnaire that assesses severity from mild to severe stages in the major functional and cognitive domains affected.²¹
- *Observable Social Cognition: A Rating Scale (OSCARS)* a measure of social cognition incorporating informant ratings.²²
- *Neuropsychiatric Inventory Questionnaire (NPI-Q)* a measure of neuropsychiatric symptoms of dementia.²³
- *Caregiver Abuse Screen (CASE)* – a measure for identifying abuse in older adult by the carer.²⁴
- *Zarit Burden Inventory Short Form (ZBI-12)* is a tool to measures care burden.²⁵

- *Lawton Instrumental Activities Daily Living Scale (Lawton IADL)* is an instrument to assess the ability to perform activities in daily living.²⁶

Older adult only questionnaires:

- Subjective memory complaints items taken from the Geriatric Mental State examination.²⁷
- *EURO-D* – 12 items assessing depression, pessimism, suicidality, guilt, sleep, interest, irritability, appetite, fatigue, concentration, enjoyment, and tearfulness.²⁸
- *Elder Abuse Screening Tool (EAST)* – to assess for risk and suspected elder abuse.²⁹
- *DEMQOL* – an assessment of health-related quality of life of people with dementia.³⁰
- *Mini-Cog* – a brief cognitive test that consists of three-word registration, clock drawing test and three-word recall.³¹

Participants

Respondents were recruited based on existing contacts, community groups or patients seen in outpatient clinics in teaching hospitals who had the capacity to consent to participate in the study. There were no strict criteria concerning who could participate in the pre-testing, though they needed to be older adults that had some form of family carer. The researchers contacted the participants and made appointment based on the preferred participants' schedule.

Procedures

Written informed consent was obtained from all participants. Each dyad was interviewed by a pair of researchers (neurologists, who had undergone formal training led by researchers involved in the compilation and translation of the toolkit)—one interviewed the older person, and the other the carer. The toolkit was administered as a paper-and-pencil test. Interviews took place at the participants' house. The researchers asked each component of the toolkit in full, making notes on certain questions or items that need to be clarified or rephrased for the participants before responding, any specific difficulty in understanding the translated sentence or any items that were particularly associated with culture context. Data were collected via observation, interviews, verbatim quotes which were constructed in the form of field-notes.

Analysis

No formal statistical analysis of data was conducted on the pre-testing. Field-notes and observations were summarized and narratively grouped into key themes based around individual questionnaires or key themes.

Results/Findings

There were 10 older adults and 10 carers involved in this pre-testing interviews. The respondents were predominantly female, eight for older adults and nine for carers, respectively. The age of older adults ranged from 60 to 67 years, while the age of carers ranged from 25-46 years. Most of the respondents were Batak, followed by Javanese and Malay. All of the respondents used Bahasa Indonesia in their daily life. All participants had at least a primary level of education (6 years of education).

Overall comprehension and time of completion

The toolkit was generally well understood by the respondents, although several questions needed to be paraphrased to achieve greater clarity (discussed below). The length of measure was more of an issue for older adults but not for the carers. The median time required to complete the STRIDE toolkit for older adult and for carer were 92 minutes and 65 minutes respectively. For the older adult questions, the length of time to complete ranged from 50-108 minutes; the carer interview ranged from 52-78 minutes. In instances, the older persons had to be visited twice to complete the toolkit.

The grammar, meaning, and sociocultural appropriateness of the toolkit

During pre-testing there were several instances in which, despite rigorous and independent translation occurring, specific items did not make sense to participants or needed additional clarification. Here we provide exemplars of such instances and subsequent changes made to the toolkit.

CSRI and household survey: There were several questions regarding health conditions or diseases that were not readily understood, such as *'sistiserkosis'* (cysticercosis), *'angina'*, and *'ulkus decubitus'* (pressure sores). For these medical terms, further guidance was provided to the researcher so that they could explain terms to the participant. Questions about the "head of household" would sometimes cause confusion in defining who is the head of the household. In North Sumatra it is not uncommon for an older adult to still live with a child who has already has a family of their own. In answering the questions about income and expenses, most respondents were reluctant to state the exact numbers, so it was identified that providing a categorical range for finances were useful. Finances were also seen as quite a sensitive subject particularly for respondents who were no longer in employment and were supported by relatives or children. The term *'kelompok agama'* (religious group) was occasionally misunderstood as having affiliation with a certain sect or group, so it was more convenient to ask, 'what is your religion?' directly, instead of 'are you a member of a religious group?'

Stigma questionnaire: Respondents were not always familiar with the word Alzheimer's or dementia and were more familiar with the word *'pikun'*, which was used interchangeably with *'demensia'* in daily conversation. There were also several statements in this questionnaire that needed to be rephrased to in more colloquial language, such as *'cara orang tersebut dibesarkan'* (the way the person was raised) to be *'pola asuh seseorang'* (parenting way), and *'Kebanyakan orang tidak menganggap serius pendapat orang dengan demensia'* (most people take the opinions of people with dementia less seriously) to be *'pendapat orang dengan demensia sering tidak dianggap serius oleh orang lain'* (opinions of people with dementia rarely taken seriously).

CSID: most of the respondents had no experience in using the word *'palu'* for 'hammer', as *'martil'* is more commonly used. Within the questionnaire, participants are asked the season, which led to some difficulty as the weather does not always match with the current season. Also, there is a period between the two seasons—dry and rainy—which is called *'pancaroba'*, in which the weather might change from one day to another. There were also questions that were similar and considered the same by the respondents such as *'Apakah ia sering melupakan dimana ia meletakkan barang-barang?'* (does she forget where she has put things?) and *'apakah ia lupa tempat barang-barang biasa disimpan?'* (does she forget where things are usually kept?). Additional guidance about scoring these questions were subsequently developed.

DEMQOL: within the items referring to emotions, many respondents struggled to differentiate between them and tended to give similar responses across items, such as '*frustasi*' (frustration), '*sedih*' (sad), '*tertekan*' (depressed), '*mudah marah*' (irritable) and '*muak*' (fed up) which all indicated negative emotions.

CASE and EAST: Completing these elder abuse questionnaires were problematic, especially because the interviews were done in a small home setting, in which any family member could be overheard. Elder abuse was seen a sensitive subject by both the respondent and the researcher, so there was a tendency to avoid and skip answering the questions or just simply ignore it by saying they did not know. Subsequently, the questionnaires about elder abuse were removed from the toolkit over concerns about data quality.

Discussion

Questionnaires aim to obtain reliable and standardized information from respondents. Cross-cultural adaptation of a questionnaire is essential if an instrument has not been developed within a target population. The cross-cultural adaptation process should not only cover the word translation, but also comprehend how the language is related to local context. Therefore, the language of questionnaires should also be at the respondents' level of understanding and not be interpreted differently by the respondents to minimize the possibility of wrong answers and bias of responses.⁷ It is of importance to pre-test questionnaires in target population as it allows for researchers to find out whether there is wording that better suits their usual language preference.¹¹

The pre-testing results of the STRiDE toolkit showed that it was generally accepted and understandable by most of the respondents in a North Sumatran setting. There were several questions or statements that needed to be paraphrased or further explained in order to achieve clarity and make sure that they were in line with the original meanings. This was mainly due to the translatability of some words from the source language (English) to the target language (Bahasa Indonesia). Translatability is the extent to which the translated version can be "loyal" to the original. Translation is an attempted practice to replace a written or verbal message in one language by the same written or verbal message in another language, involving some kind of loss of meaning, owing to various factors. In this situation, the more meaning is lost, the less translatable it will be; the less meaning is lost, the more translatable it will be. Moreover, according Catford (1965), there were two parts of untranslatability: linguistic and cultural untranslatability. Linguistic untranslatability; when the target language has no corresponding words, tenses, phonetic or grammatical entities that occur in the source language, and cultural untranslatability; when the target language and its culture lack a relevant situational feature for the source language text.³² Both of these must be taken into account when translating questionnaires that are going to be used in another cultural setting that is different from the source of questionnaire.

Another challenge in the translation process is ellipsis; a phenomenon of missing phrasal constituents and might involve phonology (due to its similarity to deaccenting), syntax (by virtue of its distribution), semantics (evidenced by its apparent licensing conditions) and pragmatics (because of the cognitive load it imposes). Ellipsis may perhaps be claimed as a very dominant characteristic of Bahasa Indonesia, both spoken and written. Translating a text from English to Bahasa Indonesia and vice versa is complicated because of the different ways ellipsis operated in both languages. Most of the elliptical constructions in Indonesia do not

seem to correspond to the elliptical construction in English.³³ Hence, pre-testing added benefit in the cross-cultural adaptation process.

In general, most respondents had difficulty in addressing questions that were related to the expression of emotions. They would prefer a neutral response, and they were also reluctant to elaborate further on questions that asked about emotions, particularly the negative ones. This might be due to the fact that most people do not feel comfortable in sharing their emotions with people they have just met (interviewers), and probably because mental health is still a sensitive issue in the community. There was no simple solution identified within STRiDE about how best to resolve this. In some instances (e.g., elder abuse questions) the decision was made to remove them from the toolkit.

All of the respondents in pre-testing survey spoke Bahasa Indonesia as their first language and in daily conversation. Most of the respondents belonged to Batak ethnic group, others were Malay and Javanese. When considering the relationship between culture and language, it should be noted that language need not represent a culture. It may be possible that speakers of the same or of very similar languages belong to cultures that are so different that the validity of a test that works well in one group would be compromised in the other group without adaptation.⁸ However, this is not to say that language, culture and thought processes are independent from one another.³⁴

This study aimed highlight the importance of cross-cultural adaptation and pre-testing of measures in new settings such as North Sumatra. However, there are several limitations to consider. First, the findings reflect the experiences as reported from a small group of respondents derived from a single region in North Sumatra (Medan). As such, there may be additional cultural differences that exist in rural regions that may not have been detected. Second, we did not perform any formal analysis on the field notes and as such the findings presented here may be subject to error. Third, the number of issues identified in the testing may vary dramatically dependent on who was involved in the translation process, what the questionnaires are about and the level of engagement from respondents. Finally, the findings and experiences reported here do not necessarily guarantee validity of the toolkit. This needs to be confirmed in subsequent analysis.

Conclusion

When using a questionnaire developed in a different language or setting, it is important to ensure that it measures and is interpreted as it was originally intended. Pre-testing plays an important role to achieve this goal as it highlights issues arising from translation and may give options for replacement of items translated. The STRiDE toolkit was generally accepted and understood, although without the pre-testing the utilization of the toolkit in the field would have been problematic.

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