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Prijevod i kulturalna adaptacija upitnika ESSENCE-Q: iskustvo južnoslavenskih jezika

Anthropological and health psychology research suggest that health is "culture-bounded", which implies that culture prescribes views on what constitutes the current health status of an individual[1]. Values, traditions, and beliefs within communities of one culture or region interact with environmental conditions and opportunities to influence the health status of individuals at both the group and individual levels[2]. This observation is particularly relevant when a health problem occurs, because rates and patterns of disorders could be broadly similar across various culture groups, but still there are differences when the culture itself is taken into account. Inherently, health measures cannot be "culture-free" and they need to be evaluated in the context of the culture where these assessments are organized[3]. Therefore, health assessments are sensitive to the language and dialect, customs, beliefs and traditions of one culture and instruments developed in one language/culture are inherently sensitive to measuring specific health concepts only in one or a few, very similar cultures using the same language. Administering a health instrument in a new language/culture requires unavoidable translation and cultural adaptation into the new language to reach equivalence in measuring that construct between the source instrument and the target version[4]. The main requirement of the translation and cultural adaptation of one instrument is to ensure its cross-cultural measurement equivalence, what refers to "the possibility that interpretations of psychological measurements, assessments and observations are similar if not equal across different cultural groups"[5].

The ESSENCE is a newer concept that is rapidly shaping research and clinical views in the field of neurodevelopmental disorders. The acronym refers to Early Symptomatic Syndromes Eliciting Neurodevelopmental Clinical Examinations and it was introduce a few years ago by Christopher Gillberg[6]. The syndromes/disorders encompassed under the ESSENCE acronym are many, but some of the most common are autism spectrum disorder (ASD), attention-deficit/hyperactivity disorder (ADHD), oppositional defiant disorder (ODD), tic disorders, developmental coordination disorder (DCD), speech and/or language disorder (SLD), and intellectual disability/intellectual developmental disorder (IDD)[7]. The clinical reality with overlapping of problems encountered in the field of ESSENCE is moving experts towards

the standardized approach, which considers the implications of the other(s) diagnosis under the ESSENCE umbrella rather than focusing only on one compartmentalizing syndromes.

In order to speeding up the identifications process of a wide range of neurodevelopmental problems, the ESSENCE-Q, a brief (12 items) screening questionnaire, was developed[7]. The questions in the screener identify problematic developmental aspects, such as general development, speech and communication, social relationships, attention, activities, behavior, sleeping problems or nutrition. The ESSENCE-Q is easy to use and it is freely available at https://gillbergcentre.gu.se/english/research/screening-questionnaires/essence-q. The ESSENCE-Q was first validated in Japan[2] and the results of the study with this questionnaire suggested that almost all children scoring under cutoff would not have any problems/diagnoses from the ESSENCE[8].

The first conference dedicated to the ESSENCE and its comprehensive knowledge took place in Gothenburg in Sweden in April 2018, with around 1 500 participants from more than 20 countries. Among articles presented during the meeting, two posters made by an international group of practitioners led by the authors of this editorial were of particular importance, "Development and initial validation of the ESSENCE-Q South Slavic language versions" and "Screening for neurodevelopmental disorders in clinical settings with the ESSENCE-Q South Slavic language versions", which were presenting first psychometric the ESSENCE-Q screening instrument for neurodevelopmental disorders into South Slavic languages. Namely, during our first meeting with prof. Gillberg in December 2016, the first project which was identified was the process of translation and cultural adaptation of the ESSENCE-Q into the South Slavic group of languages, namely Bosnian, Bulgarian, Croatian, Macedonian, Montenegrin, Serbian and Slovenian. The short description of the process is described below.

A SHORT DESCRIPTION OF ALL THE STEPS

The translation process was conducted separately in each of the seventh countries, by members of research team. The teams consisted of a child psychiatrist, psychiatrist, pediatrician and/or psychologist, all in the field of neurodevelopmental disorders. The Principles of Good Practice for the Translation and Cultural Adaptation Process for Patient-Reported Outcomes (PRO) Measures by the ISPOR[9] were partially followed for the process of translation and cultural adaptation.

Forward translation

Initially, two independent forward translations were performed from English into the target language. Bilingual translators, with the target language being their mother tongue, produced two autonomous translations. At least one translator was familiar with the concept being measured by the questionnaire, while both were experienced in working with children and adolescents. During translation, maintaining the content of an item/response/instruction is the paramount aim (i.e. achieving conceptual and semantic equivalence, but minimizing construct bias). Taking into account the stated criteria, translators were requested to reason between literally altering the words in the items without conveying the sense of the original item, whereas on the other hand, removing, changing, adding, supplementing and/or modifying those items designed to measure behavior that may not generalize equivalently in our language. The two forward translations made from the English version of the questionnaire were synthesized into one single translation – the First translation, during a small panel meeting which has been lead out by the principal author in the team of each country. The translators' reports were carefully considered during this process, as well. The reconciliation resolved discrepancies between the original independent translations, and the single forward translation derived from the latter. However, in the case that the discrepancies could not be resolved, the specific item was left with all the possible translations.

Backward translation

After the First translation was created, it was back translated into English, by an independent bilingual translator, who has not been included in the forward translation. This translator was also

instructed to weigh between the literal and conceptual back-translation of items. Once more, a "pool of possible translations" could have been provided, including all the possible back-translation options for a particular item, as well as the grades – easy, difficult, or impossible to translate back into the original language.

Harmonization

The harmonization of the questionnaire was conducted in two phases. In the first step of the process, the research team in each country, along with the principal project leader (D. Stevanovic), revised the First translation and Back-translation, and then suggested a pre-final language version. In addition, the part of the harmonization was also conducted by one of the project leaders (R. Knez) who has been working as a psychiatrist working at a department of child and adolescent psychiatry for the past two and a half years, and has obtained a C1 language degree in Swedish, with Croatian as the mother tongue. Specifically, the suggested pre-final version was compared to the original Swedish version, as well as the English translated versions and minor changes have been made on specific items. Apart from the principal project leader, in the third phase of the translation, a group of professionals (a psychiatrist, pediatrician, psychologist or medical doctor) from the majority of the aforementioned Slavic countries (Bosnia and Hercegovina, Bulgaria, Croatia, Serbia and Slovenia), currently living and residing in Sweden for over two year, and with a proficient knowledge in Swedish, as well as English, and with understanding of the cultural context of the specific Slavic countries from which they come from, were included. Unfortunately, the last phase of harmonization was not conducted for the Macedonian or Montenegrin version, since there was no referent professional that would match the above described criteria; so the suggested and accepted pre-final version made by the research team was adopted, after certain revisions regarding problematic items in the harmonization of the latter described questionnaires were made. The described process was carried so as to avoid too much aberration of all the seven questionnaires created, and to make the questionnaires most possibly similar to the original.

Throughout the whole harmonization process, notes about concordance were made, and lastly, the final version of the questionnaire for each country was suggested to the country project leaders[4]. After adopting the final versions, all the questionnaires were graphically uniformed and transformed into a pdf file, in order to preserve the original format.

Summary of translation report

For all the created versions of the instrument, all the instructions and eleven translated items were estimated as comprehensive, precise, and relevant for assessing development and emotional/behavioral difficulties in young children, thus they remained unchanged and no terms were added, replaced or omitted in the developed versions. However, the slang "funny spells", referring to an epileptic seizure, was not possible to translate; so in some versions the translation was made mostly literally, with the proverb being translated as "looking weird for short" or "atypical behavior". On the other side, "absence" was translated into "periods of absence" which would back-translated as "periods when one is absent".

Pre-testing phase

The pre-testing process served to assess the level of comprehensibility of items, to test any translation alternatives that might not be resolved in the previous steps, to highlight any items that might be inappropriate and to test the operational properties of the translation, such as its format, layout, instructions and other. The pre-testing of the questionnaire therefore included several independent semi-structured interviews with parents of children with neurodevelopmental disabilities in each country. The items were read one-by-one and parents were asked the following: (a) to explain what exactly is the item measuring or what the instruction is about; (b) to respond to the item in a way that it applied to him/her; (c) how he/she formulated the response; (d) whether the item is relevant; (e) whether the item is appropriate; (f) whether the response format is appropriate; and (g) wheth-

er format, layout, and mode of administration are convenient.

This procedure allowed testing for precision, clarity, effectiveness, relevance and appropriateness. Special attention was given to those items left with more translation options, or unresolved discrepancies in their meanings, during the previous phases. The applied procedure revealed difficulties with the term "milestones" as related to motor functioning, so an alternative was proposed – "motoric development". Only after the procedure described above was conducted, the final language version was created.

Developing clear regulations for the translation and cross-cultural adaptation, as a complex process involving different steps, it would be possible to better guide the translation, cultural adaptation, and psychometric validation of health instruments in order to have reliable instruments for cross-cultural comparisons.

We hope that this editorial published in Medicina Fluminensis will not only rise interests for the ESSENCE concept in the readers, but also encourage them to use the ESSENCE-Q and in their everyday praxis, and maybe motivated them to publish their results here in some future numbers. Early ESSENCE-problems can be found at approximately 10 % of all schoolchildren (around 13 % boys and 7 % in girls)[6,10]. Moreover, poor mental health later in life can be predicted by major problems in at least one ESSENCE domain before 5 years of age[10]. With that in mind early screening on neurodevelopmental disorders is recommended and the ESSENCE-Q as a screening-tool can be administered by doctors, psychologist and others health professionals, as a reliable standardized routine procedure in the child health service.

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