



Translation of the Broad Autism Phenotype Questionnaire to an Indian language: A description of the process



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ABSTRACT

The Broad Autism Phenotype Questionnaire (BAPQ) which is a reliable, efficient and easy to administer instrument is used to assess the Broad Autism Phenotype (BAP). In order to understand cross cultural perspectives using this instrument, a key process is translation of the instrument. The process of translation is often overlooked and hence the quality of the translated instrument may suffer. This paper highlights the robust process adopted for translating the BAPQ into one of the Indian languages – Kannada, using the International Society for Pharmacoeconomics and Outcomes Research (ISPOR) and World Health Organisation (WHO) guidelines. The translated instrument was tested on a pilot sample of parents of 10 children with ASD and parents of 11 typically developing children. The results are in congruence with the published literature.

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1. Introduction

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder characterized by impairments in social communication and interaction, and restricted repetitive patterns of behaviour. It is now well known that ASD has a strong genetic component and that relatives of ASD are at a higher risk for the disorder. Twin and family studies conducted by many research groups have indicated hereditary factors in ASD (Bailey et al., 1995; Bolton et al., 1994; Folstein and Rutter, 1977; Piven et al., 1997a). The core features of ASD that are also present in other family members of individuals with ASD, albeit in much milder forms, but not meeting diagnostic criteria for ASD, is called the “Broad Autism Phenotype” (BAP). It has been reported that 20–50% of family members of individuals with ASD exhibit at least one BAP feature (Bolton et al., 1994; Dawson et al., 2007).

Assessment of BAP traits is a challenge and various research groups have employed different assessment methods such as direct measures, measuring the BAP domains separately e.g.

Pragmatic Rating Scale (PRS) (Landa et al., 1992) and the Modified Pragmatic Rating Scale (MPRS; Ruser et al., 2007) or interview-based family history data, e.g., Family History Interview (Bolton et al., 1994) and Family History Schedule, (Piven et al., 1997b). Some of the newer instruments to assess the BAP include, the Broader Phenotype Autism Symptoms Scale: BPASS (Dawson et al., 2007) Social Responsiveness Scale: SRS (Constantino and Todd, 2005), Autism Spectrum Quotient: ASQ (Baron-Cohen et al., 2001) and the Broad Autism Phenotype Questionnaire: BAPQ (Hurley et al., 2007)

The BAPQ has been reported to be an efficient, reliable, easy to administer questionnaire with a good replicable proposed factor structure in comparison with the other tools like the ASQ and SRS, within the general population (Ingersoll et al., 2011). The BAPQ has been specifically designed as a self and informant measure of the BAP, unlike many other questionnaires which were originally developed to identify individuals with ASD and later on used to evaluate the BAP also. For efficient implementation of this instrument across different linguistic cultures, it has to be translated to a language specific to the test population/region. The BAPQ has now been adapted from English to six other languages viz., Chinese, Japanese, Croatian, Portuguese, Turkish and Hebrew. For the first time the BAPQ has been translated to an Indian language – Kannada, a language that is spoken in the state of

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Karnataka, Southern India, one of the several principal languages spoken in the country. The purpose of reporting the development of the Kannada version of the BAPQ is to document the process adopted for the translation process. Additionally and more importantly, a description of the process may perhaps become a basis for translation of the tool into many other languages in India for research and clinical applications. Thus, the aim of the current study was to develop a Kannada version of the BAPQ and pilot test it on parents of children with ASD.

2. Materials and method

2.1. Description of the BAPQ

The BAPQ assesses an individual's personality traits and language characteristics in three domains namely; aloof personality, pragmatic language and rigid personality. The three domains are parallel to the three cardinal areas of impairment in autism. Moreover, these areas are considered as key features of the BAP in parents of individuals with autism (Losh et al., 2008; Piven et al., 1997a,b). The aloof personality domain is characterized by a lack of interest in social interaction; the pragmatic language domain is described as difficulties in maintaining a conversational use of language; rigid personality domain is characterized by difficulty in adapting to change and need to follow routines. It consists of 36 statements, where each statement is rated on a 6-point Likert scale (1 = very rarely, 6 = very often). Scores in the three subscales (Aloof, Pragmatic Language, and Rigid) are analyzed separately as domain scores. Each statement is rated by both the individual (self-scores) and the spouse (informant scores). An average of the two is taken to arrive at the best estimate score. Finally a total score is arrived at by summing the score an individual gets on all the three domains as a Total Self (TS) score, Total Informant (TI) score and Total Best estimate score (TB). Higher scores are indicative of possible presence of the BAP feature. The BAPQ has cut off scores originally proposed in 2007 (Hurley et al., 2007) and later revised in 2013 (Sasson et al., 2013). These scores allow an individual to be placed categorically as BAP+ and BAP-, which correlates well with the M-PAS-R/PRS (Hurley et al., 2007).

2.2. Translation of the BAPQ instrument

The translation guidelines of the International Society for Pharmacoeconomics and Outcomes Research: ISPOR (Wild et al., 2005) and the World Health Organisation (WHO) were used for the translation work. Though the ISPOR guidelines essentially highlight principles of good practice for the Translation and Cultural Adaptation Process for Patient-Reported Outcomes (PRO) measures, this was adopted for the translation process since it has rigorous and detailed guidelines. While the WHO provides a framework with four steps viz., Forward translation, Expert panel back-translation, Pre-testing and cognitive interviewing and Final version, the ISPOR guidelines define many more steps viz., Preparation, Forward Translation, Reconciliation, Back Translation, Back Translation Review, Harmonization, Cognitive Debriefing, Review of Cognitive Debriefing Results and Finalization, Proof-reading and Final Report. Though the ISPOR has more steps, the WHO describes the crucial steps (e.g. back translation) in greater detail. Therefore, the guidelines from ISPOR and WHO were adopted and the steps, from both, which were appropriate for the current study were employed and have been described in the Table 1.

To maintain conceptual equivalence of a word/phrase/sentence and not a word-for-word translation between English and Kannada, a back-translation was conducted. First, the BAPQ was translated into Kannada by two independent forward translators

who were native Kannada speakers, one being an author of this paper (NS). A third independent translator and the author (NS) worked in unison to finalize a single forward translation. The back translation step was carried out by three individuals well-versed in English and Kannada. All were native speakers of Kannada and studied English as their first language and medium of instruction in school and college for over 12 years. The three versions of the back translation were compiled and reviewed by one of the authors (SSM). All the three versions were similar in the meaning they conveyed though they were worded differently. For example, to the original statement "People have to talk me into trying something new", the three back translated versions were; (i) "Others have to push me to try something new", (ii) "Others have to coax me to try out new things", (iii) "I need others to push me or encourage me to try anything new". The compiled version was sent to the authors of the English BAPQ instrument (JP & MP) for independent review and expert comments. Authors identified six of the 36 statements as not matching with the original version. For example, to the original statement "I like to closely follow a routine while working" the back translated version was "I stick to routine". The authors of the original instrument asked for a word in Kannada to be added that would give a meaning of "I stick to routine in my work/in work". Suggestions received from these authors were incorporated and the above mentioned process was repeated from the first step-forward translation. Cognitive debriefing [i.e. testing the instrument on a small group of relevant patients or lay people (with an informed consent) in order to test alternative wording and to check the understandability, interpretation, and cultural relevance of the translation] was carried out on 20 spousal pairs representing upper, middle and upper lower SES (10 parents of children with Autism Spectrum Disorders, 10 parents of Typically Developing children). These participants were asked to explain what they understood when they read each statement/question. For example to the original statement "I like being around other people", one of the participant (also called a pre-test respondent) interpreted this as "I like mixing with other people/I like to move with other people". The Conceptual equivalence of this is "I like being around people". These participants were also asked to rate the instrument on a three-point scale; easy, ambiguous and difficult to understand. All participants (100%) rated the instructions as well as the questions/statements easy to understand. Finally, two independent judges who were well versed in Kannada literature proofread the questionnaire and the final version was printed.

2.3. Administration of Kannada BAPQ

Parents of 10 children with ASD (20 participants) and parents of 11 typically developing children (22 participants) were recruited for the study, after obtaining a written consent from each participant as per the guidelines of the IRB. Detailed clinical evaluation and diagnosis of ASD based on the *Diagnostic and Statistical Manual of Mental Disorders (2013)* criteria was made by the Child Psychiatrist (CP) who had a minimum of 25 years of clinical experience in working with children with ASD. Parents of typically developing children who volunteered to participate were recruited only if their child had no history of delayed developmental milestones or scholastic difficulties, or no serious complaints from the school regarding the child's behaviour and had satisfactory overall performance, which was comparable to children of his/her age. Both parents had to agree to participate and possess a minimum of 10 years of education and also be capable of speaking, reading and writing in Kannada to enable them to answer the questionnaire. Parents diagnosed with developmental disorders during their childhood or having known neurological or psychiatric illnesses were excluded from the study.

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