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Examining a Developmental Approach to Health-related Quality of Life Assessment:
Psychometric Analysis of DISABKIDS Generic Module in a Portuguese Sample

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Abstract

The aim of this study was to assess the properties of a generic instrument for paediatric health-related quality of life (HRQL) assessment – DISABKIDS-37 – in a sample of Portuguese children and adolescents with chronic health conditions. Participants were 349 children/adolescents with asthma or epilepsy and their parents/caregivers, who reported on children/adolescents' HRQL, along with generic quality of life and psychological adjustment measures in self and proxy-report formats. Using classical statistic validation procedures, reliability, scale inter-correlations, and convergent, divergent and discriminant validities were analysed. Results were reported using age group stratifications, attesting the developmental appropriateness of DISABKIDS-37 questionnaire to assess HRQL in children, adolescents and mixed samples.

Keywords: health-related quality of life – children and adolescents – Disabkids – psychometrics

The changing epidemiology and clinical understanding of childhood health and disease, promoted in paediatric settings over last decades, demands a continuous improvement on the conceptual and measurement issues of quality of life (QL) assessment. Even if self-limiting acute illness still accounts for most childhood morbidity, the increasing number of children and adolescents suffering from chronic health conditions (Blum, 1992; Perrin & Shonkoff, 2000; Varni, Limbers & Burwinkle, 2007) argue for a refinement of the existing measures for the assessment of the disease impact on the child's QL (Eiser & Morse, 2001). Research in medical settings, including the paediatric one, has recently focused on assessing patients' reported outcomes, such as health-related quality of life (HRQL) (Patrick, 2003). HRQL is defined as a multidimensional construct covering physical, emotional, mental, social and behavioural components of well-being and function as perceived by patients or proxies (Bullinger, 1997), and is considered a component of the more general construct of QL (The WHOQOL Group, 1998). Although some criticisms have been made to the concept of HRQL, such as being considered a mere disease impact marker (Wallander, Schmidt, & Koot, 2001), the aforementioned definition assumes an intermediate conceptual position between those specific disease-related markers and the overarching general QL concept.

Despite the increasing number of QL and HRQL measures for paediatric populations, children and adolescents are usually taken as a single, unified developmental group. However, a substantial body of knowledge from interrelated disciplines, such as developmental psychopathology, developmental and paediatric psychology, shows that children and adolescents face specific developmental tasks and maturation issues, have distinct cognitive abilities, and use different coping strategies (Achenbach & Rescorla, 2006; Lerner, 1982; Spirito, Stark, Grace, & Stamoulis, 1991). Thus, an important research gap in this field is to

examine whether HRQL instruments that cover a wide age range, adequately and reliably assess the same construct in those two developmental groups.

The Need of Refining a Developmental Approach to HRQL Assessment

Due to a number of conceptual and methodological questions, QL assessment in children and adolescents has been a neglected topic for decades, comparatively to the amount of research published on the same issue for adults (Drotar, 1998). Following the work with the International Association for Child and Adolescent Psychiatry and Allied Professions, the Division of Mental Health of the World Health Organization (WHO, 1993) presented general guidelines to foster a consistent development of QL assessment instruments for children, stating that these should be child centred; employ subjective self-reports whenever possible; be age-related (or at least developmentally appropriate); enable cross-cultural comparisons; include a generic core and specific modules; and put an emphasis on health promotion aspects of QL, rather than solely on negative aspects (i.e. to avoid negative wording and the exclusion of positive dimensions of functioning).

Within a developmental approach to QL and HRQL, adult measures are inappropriate for use with children because of the level of abstraction required for decision making, the lack of developmental considerations, and the inclusion of certain areas that may be irrelevant, or exclusion of other areas which may be greatly valued (Spieth & Harris, 1996). However, these same considerations may be pertinently raised when administering the same instrument to children and adolescents. In fact, the lack of attention to these developmental issues may raise the question if children are sometimes considered to be “small adolescents” or if, on the other hand, adolescents tend to be merely seen as “grown up children”. A way to endorse this developmental approach is to systematically test the psychometric performance of the existing measures for children and adolescents, in joint and separate samples, as the majority of

studies to date cover a wide range of ages without presenting a stratification of the results by age group (Gerharz, Eiser, & Woodhouse, 2003).

There is not yet a consensual answer for what is age appropriate in QL and HRQL assessment, with the expression sometimes being used without the definition of its intended meaning (e.g. Clarke & Eiser, 2004). Regarding instrument development and psychometric testing, different approaches have been adopted: some authors proposed to include specific dimensions for adolescents in a common questionnaire (Eiser & Morse, 2001); others developed a specific QL conceptual and measurement model for adolescents (Edwards, Huebner, Connell, & Patrick, 2002; Patrick, Edwards, & Topolski, 2002); a third group still, designed different age versions of the same instrument, such as the QL questionnaire KINDL (“KINDER Lebensqualitätsfragebogen”, German QL questionnaire for children) and its three forms: KINDL-Kiddy (4-7 years); KINDL-Kid (8-12 years) and KINDL-Kiddo (13-18 years) (Ravens-Sieberer & Bullinger, 1998); finally, these last authors also successfully developed and tested the same HRQL instruments for both children and adolescents (e.g. Ravens-Sieberer et al., 2007). In the next section, we specifically describe and reflect on the contributions made by the DISABKIDS project, in applying the outlined developmental approach.

The Contribution of DISABKIDS Project

The DISABKIDS project was originally funded by the programme “Quality of Life and Management of Living Resources” (Fifth Framework of the European Union), with its main goal being the development and promotion of the use of standardized instruments to assess HRQL in children and adolescents with chronic conditions (Bullinger, Schmidt, Petersen, & The Disabkids Group, 2002). This project enabled the construction and testing of a battery of instruments, which is now generally called “The DISABKIDS Questionnaires”. All these questionnaires have self and proxy-report forms, and include: a chronic generic

module (long and short versions); seven condition specific modules, and a measure of Smileys (for younger children aged between 4 and 7 years old). Since its original implementation, the main distinctive features of this project remain its cross-cultural perspective; the modular system for combining generic and condition-specific aspects; the inclusion of a wide age range, and the assessment of both parents and their children's views (The European DISABKIDS Group, 2006). For the purpose of the present study, the DISABKIDS Chronic Generic Module (known as DISABKIDS-37) is described next.

The DISABKIDS-37 was originally developed from a simultaneous approach (i.e. different countries participating at the same time in the construction of a new instrument) (Simeoni et al., 2007), and revealed sound psychometric properties (Petersen, Schmidt, Power, Bullinger, & The Disabkids Group, 2005; Simeoni et al., 2007; The European Disabkids Group, 2006). The instrument clearly accomplished all the requirements to paediatric QL measures proposed by the WHO (1993), and complied with most suggested criteria to assess instrument developmental adequacy (Bruil & Detmar, 2005; Bullinger & Ravens-Sieberer, 1995; Wallander, Schmitt, & Koot, 2001).

The DISABKIDS-37 questionnaires were designed to be administered to both children and adolescents, thus adopting a conceptual and methodological perspective based on age universal markers, which is open to criticism regarding the exclusion of important age specific information (Wallander, Schmitt, & Koot, 2001). Nevertheless, the DISABKIDS project adopted a number of methodological procedures which, in the light of the main cluster of research conducted so far, may be seen as relevant contributions to the refinement of a developmental approach to HRQL assessment. First, it emphasised the perceptions of children and adolescents themselves for conceptualizing HRQL and defining items accordingly, in a way that has been described as the most desirable approach (Petersen-Ewert, Erhart, & Ravens-Sieberer, 2011); second, several items addressed the notion of age-relevant contexts,

such as family (e.g. “Are you able to do things without your parents?”), friends (e.g. “Do you go out with your friends?”), leisure activities (e.g. “Are you able to play or do things with other children/adolescents (like sports)?”), and school (e.g. “Do you have problems concentrating at school because of your condition?”); third, the authors pursued a valuable and consistent strategy for psychometric data analysis, by systematically reporting a stratification of results by age groups (Petersen, Schmidt, Power, Bullinger, & The Disabkids Group, 2005; Schmidt et al., 2006; The European Disabkids Group, 2006).

The need of developing new language versions led the research group to standardize additional translation and validation procedures to ensure the cross-cultural adequacy of those new versions to be developed along a sequential approach, such as the Mexican (Medina-Castro, 2007), the Brazilian (Fegadolli, Reis, Martins, Bullinger, & Santos, 2010), the Swedish (Chaplin, Hallman, Nilsson, & Lindblad, 2011) and the Portuguese (Carona, Canavarro, & Bullinger, 2011) ones. Those procedures were based on updated guidelines for cross-cultural instrument adaptation (Schmidt & Bullinger, 2003), and included the phases of (1) translation (with the assessment of conceptual equivalence by international harmonization of items); (2) semantic validation; (3) pilot study, and (4) field study (The DISABKIDS Group, 2004). The results from semantic validation and pilot study of the Portuguese version of DISABKIDS-37 have been published elsewhere (Carona, Canavarro, & Bullinger, 2011), and attested the comprehensibility, relevance and adequacy of items and response scales for both children and adolescents. As regards the cross-cultural adaptations of DISABKIDS-37 conducted so far, the abovementioned research gap remains pertinent: although the psychometric properties of these latest versions have been assessed in samples covering a wide age range (from 8 to 18 years old), those studies considered the differentiation of age subgroups only for the analysis of test-retest reliability (Chaplin et al., 2011) or did not consider it at all (Fegadolli et al., 2010; Medina-Castro, 2007). Thus, the main research goal

for the present study was to examine the psychometric performance of the Portuguese (self and proxy-report) versions of DISABKIDS-37 in a global sample and age-stratified subsamples, in order to verify the instrument adequacy for both children (8-12 years old) and adolescents (13-18 years old). Accordingly, the study aimed at assessing instrument reliability (internal consistency and parent-child agreement) and different types of validity (convergent, divergent and discriminant), using age group stratifications.

Method

Participants

Participants for this cross-sectional psychometric study were recruited at the Immunoallergology and Neurology/Neuropaediatric outpatient services of Coimbra University Hospitals, Paediatric Hospital of Coimbra Central Hospital, Garcia de Orta Hospital (Almada) and Leiria Santo Andre Hospital, between March 2009 and December 2011. The convenience sample included subjects who met the following criteria: (1) age between 8 and 18 years old; (2) clinical diagnosis of asthma and epilepsy according to ICD-10, established by a physician; (3) minimum disease duration of 12 months; (4) regular medication intake. Subjects who presented comorbidity of asthma and epilepsy, or had major difficulties in understanding and answering questions (as indicated by doctors, following gross assessment of their cognitive abilities during clinical interviews), were excluded from the study. Parents or caregivers (adults accompanying the child/adolescent to the hospital) who consented their child's participation, were also asked to participate in the study as proxies, with no additional inclusion criteria required for their participation. The diagnoses of asthma and epilepsy were chosen as inclusion criteria, in agreement with the previous work of semantic validation and pilot study of the Portuguese versions of DISABKIDS-37 (Carona, Bullinger, & Canavaro, 2011). Besides, asthma was required as the common condition to be

tested across all countries participating in the original DISABKIDS project (Simeoni et al., 2007) and subsequent instrument cross-cultural adaptations.

Measures

A similar assessment protocol was administered to children/adolescents and their parents, in self and proxy-report versions, which included the measures described next.

DISABKIDS-37. The Disabkids Chronic Generic Module (Carona, Bullinger, & Canavarro, 2011; The European Disabkids Group, 2006) assesses HRQL in children (8-12 years old) and adolescents (13-18 years old) with any chronic health condition, and is available in self and proxy report forms. The instrument consists of 37 questions comprised along the following facets (examples are taken from self and proxy forms): Independence (e.g. “Are you able to do everything you want to do even though you have your condition?”; “Does your child feel able to do things without you?”); Emotion (e.g. “Does your condition make you feel bad about yourself?”; “Does it bother your child that his/her life has to be planned?”); Social Inclusion (e.g. “Do other children/adolescents understand your condition?”; “Does your child go out with his/her friends?”); Social Exclusion (“Do you feel lonely because of your condition?”; “Does your child feel different from other children/adolescents?”); Physical Limitation (e.g. “Does your condition bother you when you play or do other things?”; Does your child feel able to run and move as he/she likes?) and Treatment (e.g. Does taking medication disrupt everyday life?, Does taking medication bother your child?). DISABKIDS-37 is a Likert-scaled (1-5) questionnaire that provides standardized values (0-100) for each one of the facets and total score, with lower values indicating a more impaired HRQL. The standardized scale results from the calculation of the scoring algorithms of the instrument, with missing values being substituted if all but one of the items within a facet was responded to (Sandeberg, Johansson, Hagell, & Wettergren, 2010; The European Disabkids Group, 2006). In order to assess symptom severity and thus

improve sample characterization, three questions from the asthma and epilepsy DISABKIDS specific modules (“When was the last time your child had an asthma attack/a seizure?”; “How many asthma attacks/seizures did your child have during the last year?”; “How severe was your child’s condition during the last year?”) were added to DISABKIDS-37 proxy-report questionnaire. Finally, the Portuguese versions of DISABKIDS-37 also included several questions on basic socio-demographic data; parents/caregivers’ job and educational level were used to determine the socioeconomic status (SES), according to the classification system developed for the Portuguese context (Simões, 1994).

KIDSCREEN-10. The shortest version of Kidscreen questionnaires (Gaspar & Matos, 2008; Ravens-Sieberer et al., 2010), is a unidimensional measure composed of 10 questions regarding physical (e.g. “Have you felt fit and well?”), psychological (e.g. “Have you felt sad?”) and social (e.g. “Have you had fun with your friends?”) aspects of children and adolescents’ QL. Kidscreen-10 was designed for individuals aged between 8 and 18, and includes both child and parent proxy reports. Each item is answered on a 5-point Likert scale, and the instrument provides an overall score (ranging between 5 and 50), where the lowest values reflect feelings of unhappiness, dissatisfaction and inadequacy towards different contexts of children and adolescents’ lives (i.e. family, peers and school). Adequate Cronbach’s internal consistency values were observed within our sample, for both self ($\alpha=.77$) and proxy-report ($\alpha=.79$) versions.

Strengths and Difficulties Questionnaire (SDQ). The SDQ (Fleitlich, Loureiro, Fonseca, & Gaspar, 2005; Goodman, 1997) assesses adjustment difficulties in children and adolescents, along four dimensions: emotional symptoms (e.g. “I worry a lot), conduct problems (e.g. “I fight a lot”), hyperactivity/inattention (e.g. “I am constantly fidgeting or squirming) and peer relationship problems (e.g. “Other children or young people pick on me or bully me”). SDQ is available in self and proxy report forms, with 3-point Likert response

scales: 0 (“not true”); 1 (“somewhat true”) and 2 (“certainly true”). The overall score originated by the sum of the aforementioned sub-scales ranges between 0 and 40, with higher scores implying the existence of more psychological adjustment difficulties. Good internal consistency coefficients were obtained in this study for self ($\alpha=.77$) and proxy ($\alpha=.83$) versions of the instrument.

Procedure

Formal authorizations were obtained from the Ethical Committees of the aforementioned four public hospitals in Portugal. A brief description of the project’s aims, methods and expected results was presented to the coordinators of the medical teams working in the departments where the sample was to be collected. Clinical cases who met the sampling criteria were identified by the responsible physician. A trained research assistant, acquainted to the project development and methodology, approached the children/adolescents, as well as their parents/caregivers, for briefly outlining the details of participation in the study. Signed informed consents were obtained from parents regarding their own and their child’s participation when under 14 years old; these young children were not to be included even if the parents had previously allowed their participation, but they refused it themselves afterwards. In case of individuals aged 14 or older, informed consents were obtained from the adolescents and informed assents from their parents. Children/adolescents and their parents filled in the questionnaires in a room available at the outpatient services in the presence of a research assistant, who answered the questions posed by the participants regarding the clarification of item content, assisted children/adolescents or parents with reading difficulties while filling in the questionnaires, and prevented information exchange between child and parent, so that the concordance between raters could be accurately assessed. In the few cases when the parent was unable to finish the questionnaire a stamped envelope was provided so that the parent could return it to the research team.

Data Analysis

Data were analyzed with SPSS 20.0 for Windows. Internal reliability was determined by calculating Cronbach's coefficient α . Pearson coefficients were computed to evaluate intercorrelation between facets and convergent and divergent validity. Following the suggestions of Nunnally & Bernstein (1994), alpha values $\geq .70$ were considered acceptable, and $\geq .80$ optimal; correlation coefficients between 0.1 and 0.3, 0.31 and 0.5, and those superior to 0.5, were classified as indicators of weak, moderate and strong associations, respectively. In addition, if the alpha value of a facet was higher than its correlation to the other facets, it was assumed that facet scores represented distinct aspects of HRQL (Sandeberg et al., 2010). This analysis was performed as a preliminary assessment of construct validity, because when the correlation between two subscales is less than their reliability coefficients, there is some evidence of a distinctive reliable variance measured by each subscale (Ware & Gandek, 1998). Discriminant validity was assessed through one-way between-groups multivariate analyses of covariance (MANCOVAs), examining diagnosis, age and gender differences in HRQL, separately for each factor and controlling for the remaining two factors by their inclusion as covariates. When the multivariate effect was significant we used univariate analyses (ANCOVAs) to further explore which facets of HRQL significantly differed across groups. Effect-size measures (partial Eta squared) are presented for the comparison analyses, considering $\eta_p^2 \geq .01$ as a small effect, $\eta_p^2 \geq .06$ as a medium effect and $\eta_p^2 \geq .14$ as a large effect (Cohen, 1988). Intraclass correlation coefficients (ICC) and Pearson coefficients were computed to assess the level of concordance between self and proxy-reports. All results were considered to be significant for a minimum confidence interval of 95%.

Results

Sample Characteristics

Participants were 349 children/adolescents with chronic conditions and their parents/caregivers, with a balanced distribution of the target group across age categories: children (group between 8 and 12 years old) were 56.2%. Frequencies in socio-demographic and clinical characteristics are shown in Table 1.

Table 1 about here

Reliability

Acceptable and optimal internal consistency values were observed for the Disabkids' total score and each facet separately, for both age groups, with the exception of Independence ($\alpha=.68$), Inclusion ($\alpha=.66$) and Limitation ($\alpha=.68$) facets in children's self-reports, where Cronbach's alphas were slightly below the threshold for the acceptable values (see Table 2).

Table 2 about here

Intercorrelations between Facets and Total Score

Moderate to strong positive associations were verified for the correlations among facets and between facets and total HRQL scores, except for the Treatment sub-scale which correlated weakly, but still significantly, with the remaining facets (see Table 3). Across all samples, the correlation of a given facet with the other facets was always lower than the alpha value obtained for that same facet.

Table 3 about here

Convergent and Divergent Validities

Table 4 shows the results for the analyses of convergent and divergent validities. Moderate to strong associations with the expected direction were observed for the correlations between DISABKIDS-37 facets and total score, and QL (Kidscreen-10) and psychological adjustment difficulties (SDQ).

Table 4 about here

Discriminant Validity

For self-reported version of DISABKIDS-37, results presented statistically significant multivariate effects between chronic conditions (asthma vs. epilepsy), controlling for gender and age, and between age groups (children vs. adolescents), controlling for diagnosis and gender. While controlling for diagnosis and age, no multivariate effects were found for gender. Multivariate effects of diagnosis, after controlling for children's gender and age, were also statistically significant for the proxy-report version measure of paediatric HRQL. The proxy-report version of DISABKIDS-37 also demonstrated discriminant validity between children's gender, controlling for age and diagnosis, but not between age groups when diagnosis and gender effects were controlled. For both self and proxy report versions, univariate effects for each facet and global score of HRQL are presented on Table 5.

Table 5 about here

Parent-child Agreement

Moderate levels of agreement between child/adolescent and parent-proxy reports did not differ across the total and separate age-group samples (Table 6).

Table 6 about here

Discussion

The present paper is, to our knowledge, the first to report comprehensive results from a validation field study of DISABKIDS-37 according to the procedures outlined by the original Disabkids European project (The DISABKIDS Group, 2004), while differentiating its psychometric analyses for children and adolescents age groups. Following the development of the Portuguese versions of DISABKIDS-37 according to the latest guidelines in cross-cultural instrument adaptation (Carona, Bullinger, & Canavarro, 2011), the main aim of this study was to assess the developmental adequacy of DISABKIDS-37 for children and adolescents with chronic health conditions, by systematically testing its psychometric properties in age-stratified samples. Key findings from this study indicate that the Portuguese versions of DISABKIDS-37 are reliable and valid measures for the assessment of HRQL in children, adolescents and mixed paediatric samples, and highlight the ability of these questionnaires for mapping differences in the HRQL of children and adolescents with chronic health conditions.

The observed results in terms of internal consistency, parent-child agreement and construct validity are similar to the originally published by the European research group (The European DISABKIDS Group, 2006), thus highlighting the importance of adopting structured instrument adaptation protocols, in order to ensure its cross-cultural validity and quality of psychometric performance. Reliability values for DISABKIDS-37 items and facets were generally very good, although scores in children-reported Independence, Inclusion and Limitation facets, and self-reported Inclusion facet, were below the commonly established value of .70.

The fact that every facet's internal consistency was always higher than its correlation to the other facets suggests that facet scores depict distinct aspects of paediatric HRQL; however, the suggested factorial structure is to be tested in further studies since the ones

conducted so far reported inconsistent findings (Sandeberg, Johansson, Hagell, & Wettergren, 2010; Schmidt et al., 2006). Regarding convergent validity, the fact that moderate to strong associations were observed between generic QL and HRQL instruments underlines the pertinence of assuming those two concepts as complementary in their applications, but somehow distinct in nature (Wallander, Schmitt, & Koot, 2001). The same tenet is valid for understanding the similar strength of associations between HRQL and psychological difficulties, since mental health status has been described as a foremost determinant of QL outcomes (Bovier, Chamot, & Perneger, 2004). These psychometric properties were systematically tested and observed in this study for children and adolescents mixed and separate samples, thus reaffirming the developmental adequacy and reliability of DISABKIDS-37 for both age groups. Despite the fact the instrument discriminated between gender (proxy version) and age (self version) groups, effect sizes were larger for discrimination between conditions. These findings have been observed in previous studies (Sandeberg, Johansson, Hagell, & Wettergren, 2010), and emphasize the adequacy of DISABKIDS-37 to discriminate between diagnoses (the original main purpose of the instrument), without rejecting its sensitivity to age specificities.

Levels of agreement between parent/caregiver and child/adolescent reports were only moderate in our study, besides the fact that evidence on the discriminant validity of the questionnaires was differently observed in each report form. These results indicate that child/adolescent and parent/caregiver reports are valid and complementary to each other, and support the recommendation for “hearing the voices” of both information sources (and not just substituting one for another), depending on the specific aims of a given HRQL assessment (Theunissen et al., 1998).

Limitations and Strengths

The interpretation of results from the present study must take into account its major limitations: first, the obtained convenience clinical sample mainly included individuals with moderate to severe health conditions and from lower economic backgrounds, demonstrating discrepancies in frequency distribution for clinical (severity) and socio-demographic (SES) variables, which have been extensively reported to influence paediatric adaptation outcomes (Bullinger, Schmidt, Petersen, & The Disabkids Group, 2002); second, interaction effects between clinical and demographic variables were not explored, even if that analysis was not among this study aims; third, the stratification of analyses for two age groups suited the sample size, but it could be further refined by testing, for instance, three groups of children (8-11), preadolescents (12-14) and adolescents (15-18).

Despite these limitations, this study validates the pertinence of using DISABKIDS-37 as a single measure to assess paediatric HRQL in different age groups: if on the one hand some age-relevant information is likely to be missed, on the other hand, depending on the specific purpose of a given assessment, that restraint might be a relatively small cost for the sake of allowing between- and within-group comparisons. Besides the quality of psychometric performance observed in our study, DISABKIDS questionnaires operationalize the unique importance of context for the refinement of paediatric health outcomes assessment (Barros, Matos, & Batista-Foguet, 2008; Christakis, Johnston, & Connell, 2001; Matza et al., 2004), by including different items with a clear reference to common age relevant contexts such as family, friends and school environment.

Conclusion

Overall, results from the present study support the use of DISABKIDS as a reliable and useful assessment tool for assessing, in a developmental appropriate way, HRQL for children and adolescents with chronic conditions. Future research aiming at a comprehensive

and contextual paediatric HRQL assessment could benefit from the use of both quantitative and qualitative methods, as it has been suggested for other constructs in paediatric psychology (Spirito, 1996). The combination of the use of DISABKIDS-37 with qualitative methodologies, the analysis of its performance in relatively understudied samples (e.g. cerebral palsy, obesity), and the examination of its factorial structure with exploratory and/or confirmatory factor analyses, are promising venues for future research in this field.

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