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FAMILY QUALITY OF LIFE: CONTENT VALIDITY OF A TOOL FOR FAMILIES OF ADULTS WITH INTELLECTUAL DISABILITIES IN BRAZIL

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ABSTRACT: On an international level, studies on the quality of life (QOL) are becoming more and more frequent, and few of them focus on the study of the quality of life of people with DI and their families. All of these studies identify a number of fields or areas that define the QoL, on both individual and family levels (Brown, MacAdam-Crisp, Wang, & Iarocci, 2006; Turnbull, Brown, & Turnbull, 2004; Schalock et al., 2002). In Brazil, legal guidelines exist that are moving relatively forward with respect to people with disabilities. However, in spite of all of the legislation and benefits, the insertion or inclusion of people with disabilities in the job market, schools and leisure centers is still low. The aim of the current research is to present the translation, adaptation and content validation of the Beach Center Family Quality of Life (Summers, Poston, Turnbull, Marquis, Hoffman, & Mannan, 2005) in the Brazilian context. To carry out the adaptation and standardization of the scale the seven steps proposed by Tassé and Craig (1999) and Beaton, Bombardier, Guillemin and Ferraz (2000) will be followed: (1) translation/adaptation to Portuguese; (2) consolidation of translation/adaptation; (3) preliminary normalization of translation; (4) review/adjustments; (5) pilot test of translation; (6) revision/adjustment of translation; (7) standardization the scale and obtaining index of validity and reliability. The research is currently on Step 4, review/adjustments, in which the content validity is implemented in order to achieve semantic, conceptual, idiomatic and experimental equivalence between the original tool and the final one (Tassé & Craig, 1999; Beaton et al., 2000). It is important to mention that the aim of the research is to understand the family quality of life, not only of the person with intellectual disabilities, but those of all of their family members.

Keywords: Family, quality of life, adults, intellectual disabilities, tool.

INTRODUCTION

There is historical evidence that disabilities have always been considered a differential mark, whether it was related to the idea of sin, supernatural powers or even as a kind of link with sainthood. According to studies carried out by Diniz (2007), Amiralian (1997), Belarmino (1997), Mazzota (2005) and Silva (2006), different historical moments show evidence of changes in the ways of understanding people with disabilities with relation to social, philosophical, religious, ethical and moral values. However, people with disabilities still face different social barriers and still experience denial of certain fundamental aspects of life, such as work, education, housing and leisure activities. In Brazil, legal guidelines exist that are moving relatively forward with respect to people with disabilities. However, in spite of all of the legislation and benefits, the insertion or inclusion of people with disabilities in the job market, schools and leisure centers is still low.

Among the laws that deal with various aspects of the quality of life, there are a few that stand out: the *Constituição da República Federativa do Brasil de 1988* and *Legislação de 7.853/89*, regarding fundamental rights and guarantees, *Decreto n° 914/93*, which establishes the *Política Nacional de Integração das Pessoas*

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com Deficiência (National Integration Policy for People with Deficiencies), and *Legislação nº 8.112/90*, which calls for the reservation of up to 20% of the spots in public contests for people with disabilities. Additionally, there are some benefits which can be applied for by people with intellectual disabilities, such as the *Benefício de Prestação Continuada (BPC-LOAS)*, which guarantees a minimum monthly salary (Brasil, 1993), free public transportation, and tax exemption for the purchase of a car. However, in spite of all of this legislation and these benefits, the insertion and inclusion of people with disabilities in the work force, schools and leisure centers remains low. This situation raises concerns about the quality of life for disabled people on the part of the government, reflected in some official documents; on the part of researchers, seen in academic research projects; and on the part of society, generally visible in the social context. The objectives of these official government documents focus on the promotion of improvements, such as the elimination of barriers and the design of services and programs, in addition to encouraging the general participation of disabled people in society (Brasil, 2009, 2013; Senac, 2006).

Therefore, it is fundamental to carry out these studies on how to improve quality of life for these people and their families. The aim of the current research is to present the translation, adaptation and validation of the content of the Beach Center Family Quality of Life (Summers, Poston, Turnbull, Marquis, Hoffman, & Mannan, 2005) in the Brazilian context. It is part of a greater study, the objective of which is the validation of the Beach Center Family Quality of Life (Summers et al., 2005) in order to identify the quality of life of families with a member with intellectual disabilities over 18 years old in various states of Brazil. On an international level, studies on quality of life (QoL) are becoming more and more frequent, and few of them focus on the study of quality of life for people with DI and their families. All of these studies identify a number of fields or areas that define the QoL, on both individual and family levels (Brown, MacAdam-Crisp, Wang, & Iarocci, 2006; Turnbull, Brown, & Turnbull, 2004; Schalock et al., 2002).

Quality of Life

Quality of life refers to the degree of satisfaction that a person perceives from his/her surroundings in relation to having their needs met (Giné, 2004). As a result, it is a concept that is linked to a paradigm change with an ecological focus, centered on the person and considering that person's family, which should promote actions on individual, organizational and social levels (Verdugo, 2006). This also means that it is a multi-dimensional concept, with eight empirically determined dimensions: emotional well-being, interpersonal relationships, material well-being, personal development, physical well-being, self-determination, social inclusion and rights (Schalock et al., 2002).

In other words, quality of life touches on both subjective aspects, such as psychological indicators, and objective ones, such as social and ecological indicators. Studies on the quality of life help us to understand family in its broadest possible meaning (Brown et al., 2006) and drive us to consider the difficulties that can appear when a family has a member with an intellectual disability, such as the stress of chronic conditions, as in adult cases. The various ways of facing these situations are conditioned, on the one hand, by the individual characteristics of each family, which are unique in the moment in which their values, beliefs and expectations interact, and, on the other hand, by an organization and access to services and resources.

Family Quality of Life

According to Zuna, Summers, Turnbull, Hu, & Xu (2010, p. 10), family quality of life is the "dynamic sense of family well-being, defined in a subjective and collective manner by all of the members of the family, in which needs interact on an individual and a family level". This approach recognizes the singularity of the family as a unit and the context of development. It tells us that family quality of life is a critical area to study with the challenge of improving the skills of the family with relation to the intellectual disability of their family member, recognizing their strengths and providing service and support (Zuna, Seling, Summers, & Turnbull, 2009; Giné et al., 2013).

The findings of these studies on the quality of life for families of people with DI led the researchers to develop three instruments with which to measure family quality of life: (a) Beach Center Family Quality of Life, with elaboration and normalization carried out by the Beach Center on Disability (KU) and with adaptation and normalization in other countries such as China, Spain and Colombia (Summers et al., 2005), (b) Family Quality of Life Survey, carried out by the group Quality of Life Research Unit and applied in Canada, Australia, Israel, South Korea and Taiwan (Brown et al., 2006) and (c) Latin American Family Quality of Life Scale, constructed by Aznar and Castañón (2005), with the objective of being more accessible to intervention programs. In addition, in the Spanish context, two scales have been developed to measure the CdVF (CdVF-E) (Giné et al., 2013), one for families of people under 18 years of age with DI and one for families of people over 18 years of age with DI.

According to Brown et al. (2006), these studies on family quality of life offer useful information gathered with instruments used in the research and that promotes the construction of a model that could be useful in designing interventions. However, Zuna et al. (2009) expressed concern about the limited number of studies that deal with the applied aspects of family quality of life. There are many family quality of life scales, and much research has been done, but there are no studies that direct professionals on how to put to use the results of research on the measure of effective intervention. Zuna et al. (2009) defend the necessity to move on from the conceptualization and measure of the intervention. Therefore, they consider the need to currently analyze and synthesize the developed research in order to suggest a unified theory that describes the relationships among the variables that make up this model of family quality of life and the needs of the families.

Zuna et al. (2009) propose a theory on family quality of life that explains how some factors, such as the individuals and the family unit, influence the results understood as family quality of life. It is therefore necessary to have joint and reciprocal work involving professionals, researchers and the families in order to be able to positively influence the families. In other words, it is of utmost importance to incorporate the knowledge of professionals in developing the construct (Healy, 2005).

In accordance with the ideas stated in the previous paragraphs, the objective of this work consists of presenting the validation of the content of the scale Beach Center Family Quality of Life (Summers et al., 2005) as one of the first steps towards the normalization and adaptation of the scale to the Brazilian context.

METHODS

Participants

The participants were three researchers, four translators and four experts. All of them had a high level of both Portuguese and English. The table below briefly explains their profiles.

Table 1: Table Participants

Participants	Roles	Profile
Translator 1	Translation of the original version in English to Portuguese	Portuguese native speaker and trained in English
Translator 2	Translation of the original version in English to Portuguese	Portuguese native speaker y certified Portuguese-English translator
Translator 3	Translation of the Portuguese version for English	English native speaker and trained in Portuguese
Translator 4	Translation of the Portuguese version for English	English native speaker and certified English-Portuguese translator
Expert 1	Analysis translations	Portuguese native speaker and trained in English
Expert 2	Analysis translations	Portuguese native speaker and trained in English
Expert 3	Analysis translations	Portuguese native speaker and trained in English
Expert 4	Analysis translations	Portuguese native speaker and trained in English

INSTRUMENT

The Beach Center Family Quality of Life is composed of twenty-five items grouped into different areas: family interaction, parental roles, emotional well-being, physical well-being, material well-being and support for the disabled (Summers et al., 2005). It offers five response options: no need, low need, need, elevated need and highly elevated need.

PROCESS

To carry out the adaptation and standardization of the scale the seven steps proposed by Tassé and Craig (1999) and Beaton, Bombardier, Guillemin and Ferraz (2000) will be followed: (1) translation/adaptation to Portuguese; (2) consolidation of translation/adaptation; (3) preliminary normalization of translation; (4) review/adjustments; (5) pilot test of translation; (6) revision/adjustment of translation; (7) standardizing the scale obtaining validation and reliability.

The research is currently on Step 4, review/adjustments, in which the validation of the content is implemented in order to achieve a semantic, conceptual, idiomatic and experimental balance between the original questionnaire and the end one (Tassé & Craig, 1999; Beaton et al., 2000).

(1) Translation/Adaptation to Portuguese

Committee 1 was composed of three researchers together with professional translators (English/Portuguese) with expert knowledge of the subject matter, in addition to being native Portuguese speakers. Two translators were asked to do the translation/adaptation independently; that is to say, they were asked to go beyond a literal translation to Portuguese and to consider the cultural characteristics of Brazilians. Both translators were native Brazilians. The translators had different profiles: one of them had expert knowledge of the subject matter in the questionnaire, while the other was not familiar with the topic (Beaton et al., 2000).

(2) Consolidation of Translation/Adaptation

The consolidation of the translation/adaptation was done in a meeting of Committee 1 (three researchers and professional translators, English/Portuguese, with expert knowledge of the subject matter and native Portuguese speakers), during which they compared the translations/adaptations, identified the discrepancies, and then combined the two documents into one single document through a discussion between the translators (Beaton et al., 2000). The scale was later exhaustively analyzed, an agreement was reached by all of the members of Committee 1, and a report was written in which the process of synthesis was carefully documented, each of the questions was addressed and the resolution of the differences was recorded. This phase ended with the first version of the scale, which we call here the preliminary translation.

(3) Preliminary normalization of translation

This first version was submitted to an inverse translation carried out by a second committee, Committee 2, consisting of two people who were not familiar with the scale and were asked to translate it back to its original language; in other words, to translate it from Portuguese to English. The translators were people with a high level in Portuguese, and both were native English speakers. At the end of this phase, we had a second version of the Beach Center Family Quality of Life in English. Adjustments were made to the first version after studying the discrepancies identified between the inverse translation and the original version. The translation, grammatical structure and adaptation to cultural context were confirmed at this time. A third version of the scale was obtained at the end of this process.

(4) Review/Adjustments

In order to validate the content of the scale, two people who were not involved in the translation process were invited to participate as experts. Experts allow for the verification of questions that originated with the normalization of the preliminary translation in order to reach a consensus (Tassé & Craig, 1999; Beaton et al., 2000). The role of these participants, considered experts in both languages, was to review all versions of the questionnaire—the original version and the translated versions—as well as the written reports explaining the decisions made in the previous phases. These experts reviewed the authentic meaning of the items and their semantic, conceptual, idiomatic and experimental equivalence between the original questionnaire and the final translation (Tassé & Craig, 1999; Beaton et al., 2000).

DATA ANALYSIS

The analysis of the data of the translations was carried out in a qualitative manner, making comparisons between the different translations and suggesting a new version for some items based on the established criteria, such as making it a priority to keep the language simple, accessible and clear. It is important to point out that the root of the key word of the item was taken into account during the revision in order not to lose any meaning. In other words, analysis of equivalences (semantic, idiomatic, experimental and conceptual) was carried out in order not to lose the essence of the items.

In order to validate the content, the agreements of the experts were calculated using the Holsti coefficient (1969, quoted by Stemler, Steve, 2001) and the degree of concordance by the Kappa de Kyalseth coefficient (1989 quoted by Stemler, Steve, 2001). This coefficient was calculated for each of the dimensions analyzed by the experts: (a) semantic equivalence, (b) idiomatic equivalence, (c) experimental equivalence, (d) conceptual equivalence (e) other errors.

RESULTS and FINDINGS

This section will be divided into three parts. The first and the second will present a qualitative discussion of the analysis carried out during the process of translation from English to Portuguese and the inverse translation. The third will present the degrees of agreement among the four experts in relation to: (a) semantic equivalence, (b) idiomatic equivalence, (c) experimental equivalence, (d) conceptual equivalence and (e) other errors.

(1) Translation/Adaptation to Portuguese and Consolidation of Translation/Adaptation

The different profiles of the translators contributed to the elaboration of a translation that was adjusted to the content and the Brazilian culture. The first translator was familiar with the material and could be more sensitive to the vocabulary and semantic aspects of the specific topic. In contrast, the second one was not familiar with the topic, and their reading and revision was closer to that of a normal person answering the questions on the scale without a lot of knowledge of the topic (Beaton et al., 2000).

The two translators used different Portuguese words to refer to the same items in doing the translation. Therefore, Committee 1 had to establish criteria for making a choice, which consisted in choosing the easier word in order to make the language more accessible to the general population. These criteria have to do with the intended population of the study, families of people with disabilities, who usually belong to a lower socio-economic level and have possibly had less access to education. At the same time, the translation that maintained the closest meaning to the key words of the item, so that the item did not lose the meaning of the original version, was considered to be the best translation.

Of the twenty-five items composing the scale, sixteen were by Translator 2, one was by Translator 1, five were translated the same way and three items were written after a consensus between the translations of the two was reached.

Table 2: Consolidation of Translation/Adaptation

Original version (English)	Translator 1 (Portuguese/English)	Translator 2 (Portuguese/English)	Version 1 (Portuguese)
<i>Item 1</i> My family enjoys spending time together.	<i>Minha família</i> gosta de passar tempo junta	<i>Os membros da minha família</i> gostam de passar tempo juntos	<i>Os membros da minha família</i> gostam de passar tempo juntos
<i>Item 6</i> My family members have transportation to get to the places they need to be.	<i>Membros da minha família têm transporte para ir aos lugares que precisam estar</i>	<i>Os membros da minha família têm transporte para ir onde precisam</i>	<i>Os membros da minha família têm transporte para ir onde precisam</i>
<i>Item 12</i> My family members show that they love and care for each other.	<i>Os membros da minha família mostram que se amam e se importam uns com os outros.</i>	<i>Os membros da minha família demonstram que eles se amam e se importam com o outro</i>	<i>Os membros da minha família mostram que eles amam e cuidam uns dos outros.</i>
<i>Item 14</i> Adults in our family teach the children to make good decisions.	<i>Adultos em minha família ensinam as crianças a tomar boas decisões.</i>	<i>Os adultos na minha família ensinam às crianças a tomarem decisões sensatas</i>	<i>Os adultos na minha família ensinam seus filhos a tomarem boas decisões</i>
<i>Item 17</i> Adults in my family know other people in the children's lives (friends, teachers, etc.).	<i>Adultos em minha família conhecem outras pessoas nas vidas das crianças, ou seja, amigos, professores</i>	<i>Os adultos da minha família conhecem outras pessoas que fazem parte da vida das crianças (amigos, professores)</i>	<i>Os adultos da minha família conhecem outras pessoas que fazem parte da vida dos seus filhos (amigos, professores)</i>
<i>Item 19</i> Adults in my family have time to take care of the individual needs of every child.	<i>Adultos em minha família têm tempo para cuidar das necessidades individuais de cada criança.</i>	<i>Os adultos da minha família têm tempo para cuidar das necessidades individuais de todas as crianças</i>	<i>Os adultos da minha família têm tempo para cuidar das necessidades individuais de todos os filhos</i>

In most of the cases, the choice was made based on what the translator suggested, because two of them had to do with expressions like “my family” and “my family members”, which were mostly changed to “my family members” by Translator 2. In addition, the article “os” was added to the beginning of sentences, changing the expression to “os membros da minha família”. We believe this modification to be relevant in order to highlight the objective of the scale, which is to measure family quality of life. Additionally, Translator 2 had a more accessible Portuguese, except in Item 12, where the version by Translator 1 was chosen.

Items 14, 17 and 19 were rewritten based on the criteria of the two translations. In Item 14, the word suggested by both translators was used. In Items 14, 17 and 19, Committee 1 decided to change the word “criança”, which means children in a general sense, to “filhos,” which means sons and daughters. This decision had to do with the general proposal of the study, which is to work with families of adults with disabilities. Therefore, the choice of sons and daughters expresses the best possible meaning.

(2) Preliminary Normalization of Translation

The two native English-speaking translators carried out the inverse translation, which was the most adequate time to evaluate the qualitative manner of the translation of the scale and to confirm the validity of the translation, ensuring that the translated version reflected the same content of the items (Tassé & Craig, 1999; Beaton et al., 2000). The people participating as experts were crucial in achieving transcultural equivalence (Beaton et al., 2000).

Of the twenty-five items that make up the scale, thirteen were suggested by Translator 4, five were written by Translator 3, five were translated the same way by both and two items were rewritten based on the synthesis of the proposals of the two translators and the considerations of Committee 4 to adjust the meaning of the item.

Table 3: Consolidation of Translation/Adaptation

Version 1 (Portuguese)	Translator 3 (Portuguese/English)	Translator 4 (Portuguese/English)	Version 2 (English)
Item 22 O membro da minha família com deficiência tem apoio para progredir na escola ou no trabalho	The member of my family with disability has support to make progress at school or at work	The disabled member of my family has support to progress at school or at work.	My family member with a disability has support to accomplish goals at school or at workplace
Item 23 O membro da minha família com deficiência tem apoio para progredir na escola ou no trabalho	The member of my family with disability has support to make progress at school or at work	The disabled member of my family has support to progress at school or at work.	My family member with a disability has support to accomplish goals at home.

After obtaining the two version of the scale, the two committees met and compared the version to the original one to find possible discrepancies and/or incongruences. Nineteen items of the version remained the same and six changed. Of these items, numbers 5, 10, 11, and 25 were re-written because of discrepancies among the translators, and items 22 and 23 were re-written because it was considered that Version 3 did not convey the same idea as the original version.

Table 4: Consolidation of Translation/Adaptation

Version 2 (English)	Original version (English)	Version 1 (Portuguese)	Version 3 (Portuguese)
Item 5 The members of my family help the children with their homework and other school activities	My family members help the children with school work and activities.	Os membros da minha família ajudam as crianças com os deveres de casa e outras atividades da escola	Os membros da minha família ajudam as crianças com as tarefas da escola e atividades
Item 10	Our family solves	Os membros da minha	Os membros da minha

The members of my family solve problems together.	problems together.	família resolvem os problemas juntos	família resolvem problemas juntos
Item 11 The members of my family support each other to achieve goals.	My family members support each other to accomplish goals.	Os membros da minha família apoiam um ao outro para atingir metas	Os membros da minha família apoiam uns aos outros para atingir metas
Item 22 My family member with a disability has support to accomplish goals at school or at workplace	My family member with a disability has support to accomplish goals at school or at workplace.	O membro da minha família com deficiência tem apoio para progredir na escola ou no trabalho	O membro da minha família com deficiência tem apoio para conseguir a suas metas na escola ou no trabalho
Item 23 My family member with a disability has support to accomplish goals at home.	My family member with a disability has support to accomplish goals at home.	O membro da minha família com deficiência tem apoio para progredir na escola ou no trabalho	O membro da minha família com deficiência tem apoio para conseguir as suas metas em casa
Item 25 My family has a good relationship with the service providers who work with the disabled family member.	My family has good relationships with the service providers who provide services and support to our family member with a disability.	Minha família tem um bom relacionamento com os prestadores de serviços que trabalham com o membro com deficiência	Minha família tem um bom relacionamento com os prestadores de serviços que trabalham e prestam apoio ao membro com deficiência

(3) Expert judgment

Version 3 is the result of the expert judgment by four native Portuguese speakers, all with a high level of English. In this phase, they all reviewed the process of translation and adaptation between the original questionnaire and the final version, while considering the five categories of analysis: a) semantic equivalence, b) conceptual equivalence, c) idiomatic equivalence, d) experimental equivalence and e) other errors (Beaton et al., 2000). They did so with the intention of maintaining the authentic meaning of the item from the original version and suggested some changes for Version 4.

Semantic Equivalence

With relation to semantic equivalence, the concordance between the results was calculated using the Kappa statistic, and the result was $Kappa = -0,140873$, $p = 0.0845$, which demonstrates that the degree of concordance among the experts was low.

The discrepancy among them was due to the fact that some of them considered the use of synonyms correct, and others considered it incorrect and suggested a modification in the Portuguese word because it was a literal translation from English. For example, in Item 20, “*cuidado dentário*” and “*assistência dentaria*” mean the same thing in Portuguese, but “*cuidado dentario*” is a more accessible term. The same thing occurred in Items 22 and 23, where the words “*conseguir*” and “*alcançar*”, which mean the same thing, yet “*conseguir*” is more accessible and, therefore, was used.

In Item 1, one of the experts suggested that the expression “os membros da minha família gosta” be changed for “minha família gosta”; in Items 14, 17 and 19, they suggested changing the word “filhos” for “criança”. However, both issues have to do with decisions made previously which will not be taken into consideration in the interest of achieving the end goal of the research: to introduce a scale able to reach families from various social classes, with varying levels of education and with adult sons and daughters who do not fit the word “children”.

Other issues related to semantic equivalence considered pertinent were: i) nuances with relation to missing words in adjusting the translation of an item, such as, in Item 5, instead of the word “atividades”, they suggested “atividades escolares”; ii) changes with relation to pronouns, such as “seus” instead of “nossos” in Item 9 and “minha” instead of “nossa” in Item 13, which changes the meaning of the sentence; iii) the mistaken use of the word “junto”, which one of the experts suggested changing to “unida”; and, iv) the change of the word “mostra” for “demonstran”, which totally changes the meaning of the item.

Conceptual Equivalence/Idiomatic Equivalence/Experimental Equivalence

With relation to conceptual, idiomatic and experimental equivalence, the general concordance generated a Kappa=1 among the experts, signifying perfect agreement among the evaluators.

Other Errors

With relation to other errors, the dependability among the experts registered -0,020408, $p=0.08026$ on the Kappa index. The discrepancies were related to errors identified by two of the experts with relation to verb tenses, such as changing “relacionarem” to “relacionar” in Item 8.

CONCLUSION

This study has presented the process of the translation, adaptation and validation of the content of the scale Beach Center Family Quality of Life (Summers et al., 2005) to a Brazilian context. For this transcultural adaptation, we considered the phases presented in this article to be important because they are the base for achieving cultural equivalence. Therefore, it needed not only to be translated, but it was also necessary to adapt the items in order to incorporate cultural aspects of Brazilian society. All of the participants in the study had a fundamental role, especially the experts, as their evaluation regarding the different equivalences contributed to the most adequate translation for the Brazilian reality.

It is important to point out that, in addition to the validation the content of the scale Beach Center Family Quality of Life (Summers et al., 2005) by experts of both languages, another validation of the content will be carried out by other experts. In this case, the experts will be mothers of disabled adults and professionals in order to verify that there is a good understanding of the scale. Finally, there will be a pilot study and the normalization of the scale in order to be used for the Brazilian population.

RECOMMENDATIONS

In general, a high index of agreement was reached among the experts for most of the established criteria. In addition, we believe that further modifications to the scale will be made in the next phases, such as the pilot study and the normalization of the research in order to adjust the adequacy of the scale to the Brazilian context.

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