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Original Article

Artigo Original

Cultural Adaptation Quality of Family Life Scale for the Brazilian Portuguese

Adaptação Cultural da Escala de Qualidade de Vida Familiar (Family Quality of Life Scale) para o Português Brasileiro

Bianca Miguel Jorge[1]
Cilmara Cristina Alves da Costa Levy[2]
Lídio Granato[3]

Keywords

Quality of Life
Deafness
Family Relations
Hearing Aids
Hearing Loss

ABSTRACT

Purpose: To culturally adapt the Family Quality of Life Scale to the Brazilian Portuguese version and evaluate the instrument reliability and family quality of life of those who have children with hearing loss. **Methods**: The process of cultural adaptation of the scale followed the steps of the Guidelines for the Process of Cross-Cultural Adaptation of Self-Report Measure. It was conducted in three stages: translation, back translation, and application in a pilot sample, as a way to check the comprehension difficulties of the items. After it had been completed, it was administered to 41 families who have children with hearing loss and, with their results, the quality of life and reliability were analyzed based on the Cronbach's alpha statistical test. **Results**: In the first version (translation), among the 25 items, there were differences between the translators only in four items; after the corrections, the second version was done (back translation), in which other four more differences were found. Finally, after the final corrections, the last version was developed and used in the pilot sample without differences. Thus, it was applied to families with deaf children, who believe to be satisfied as to their quality of life. The Cronbach's alpha test found that the scale shows a satisfactory reliability. **Conclusion**: The Brazilian Portuguese version of the Family Quality of Life Scale is a tool of easy use and satisfactory reliability. The families are satisfied with their family quality of life.

Descritores

Qualidade de Vida
Surdez
Relações Familiares
Auxiliares de Audição
Perda Auditiva

RESUMO

Objetivo: Adaptar culturalmente a Escala de Qualidade de Vida Familiar (*Family Quality of Life Scale* — FQOLS) para a versão em Português Brasileiro (PB), avaliar a confiabilidade do instrumento e a qualidade de vida familiar (QVF) das famílias que possuem filhos com deficiência auditiva. **Métodos:** O processo de adaptação cultural da escala seguiu os passos do *Guidelines for the Process of Cross-Cultural Adaptation of Self-Report Measure.* Realizada em três momentos: tradução, retrotradução e aplicação na amostra piloto como forma de verificar dificuldades de compreensão dos itens. Quando finalizada foi aplicada em 41 famílias que possuem filhos com deficiência auditiva e, com os seus resultados, foram analisadas a qualidade de vida (QV) e a confiabilidade, a partir do teste estatístico alfa de Cronbach (α). **Resultados:** Na primeira versão (tradução), dentre os 25 itens presentes, apenas em 4 houve divergências entre as tradutoras; após as correções, houve a segunda versão (retrotradução), em que foram identificadas mais 4 divergências. Por fim, após as correções finais, a última versão foi elaborada e usada na amostra piloto sem divergências, e, dessa forma, foi aplicada nas famílias de filhos surdos, as quais se consideraram satisfeitas em relação à QV. Com o teste alfa de Cronbach (α) foi verificado que a escala tem confiabilidade satisfatória. **Conclusão:** A versão em PB da FQOLS é um instrumento de fácil aplicação e com confiabilidade satisfatória. As famílias estão satisfeitas com sua QVF.

Correspondence address:
Bianca Miguel Jorge
Rua Doutor Cesário Motta Jr., 61, Vila Buarque, São Paulo (SP), Brasil, CEP: 01221-020.
E-mail: biamigueljorge@gmail.com

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Study carried out at the Speech-Language Pathology and Audiology Course, Otolaryngology Department, School of Medical Sciences, Santa Casa de São Paulo – FCMSCSP – São Paulo (SP), Brazil.
(1) Graduate Program in Audiology, School of Medical Sciences, Santa Casa de São Paulo – FCMSCSP – São Paulo (SP), Brazil.
(2) Speech-Language Pathology and Audiology Course, School of Medical Sciences, Santa Casa de São Paulo – FCMSCSP – São Paulo (SP), Brazil.
(3) Course of Medicine, School of Medical Sciences, Santa Casa de São Paulo – FCMSCSP – São Paulo (SP), Brazil.
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INTRODUCTION

Recently, investigators have been focusing their studies on the quality of life (QL) theme(1,2), which, each year, is promoting not only its possibility but also being many people's purpose of life.

However, recent research has been approaching more than the personal/individual QL by focusing on families. The extension of individual QL for the family arose with the need of comprehending the family dynamics that directly influences on the life of each subject that contemplates it, especially when there is a person with a disability in the family, such as deafness(3,4).

The main characteristics found to concept and measure the subjects' QL include: general well-being feelings, feelings of positive social participation, and opportunities to reach personal potential(5,6). Nonetheless, these features point out the individual QL. For the family QL (FQL), the main idea depends on the fact if the special needs of each member are being fulfilled, as they spend time together and dedicate themselves to each other. There are also the influences of interaction between the aspects that represent family life areas, such as family interaction, care of parents with their children, emotional well-being, resources, and support(7-9).

The FQL becomes extremely important, especially when the services perform early intervention and the need to work directly with the family(10), such as at the moment of deafness diagnosis, because guidance and reception are the tools for family support.

Family support is also very important, because the family is in charge of supporting its members in physical, emotional, and social aspects and mainly in clarifying what is more appropriate to its growth; thus QL should be provided. Harmony and balance of people in the family environment are fundamental for its dynamics(11).

Family dynamics can be affected after the discovery of a child's deafness, which can cause a crisis and create conflicts among parents and/or other members of the family core, thus changing its FQL(3,4).

The way how families with deaf children show their dynamics is the main point for the child's development. Therefore, investigators started to be interested in this dynamic, in how they faced diagnosis and their adaptation to the new reality. Because there was not an instrument that evaluated families in general, interviewers applied it to parents or only to mothers in order to achieve these results, to check stress level, and enabling aspects that decrease stress and facilitate diagnosis confrontation, interfering directly in family and individual QL(12,13).

In order to fulfill the lack of instruments for evaluating the FQL, investigators(14) have developed a tool called Family Quality of Life Scale (FQOLS), with the aim of evaluating the QL in families that have children with several disabilities (such as intellectual disorder, autism, and hearing loss) and helping health professionals. Such development passed through modifications until resulting in 25 items, with 5 domains (family interaction, relationship between parents and children, emotional welfare, physical/material welfare and support related to disability, and with 5 kinds of satisfaction answers – 1=corresponds to very unsatisfied, 2=unsatisfied, 3=not satisfied nor unsatisfied, 4=satisfied, and 5=very satisfied).

There is not an tool in Brazil, which has such scope and measures the same aspects of this scale. Thus, the purpose of this study was to culturally adapt the FQOLS to the Brazilian Portuguese version, to evaluate the instrument reliability, to apply it for families with hearing-impaired children, and to evaluate the FQL of these families.

METHODS

This study was carried out at the Ambulatory of Educational Audiology of the Otorhinolaryngology Department of *Irmandade da Santa Casa de Misericórdia de São Paulo* (ISCMSP). It began after approval of the Ethics and Research Committee in Human Beings, Project number 333/09. All the subjects agreed in being a part of the study and signed the informed consent.

Participants

Forty-one parents of children with sensorineural hearing loss participated in this study. The inclusion criteria comprised parents whose children were aged until 10 years and whose level of sensorineural hearing impairment was severe or profound. Parents whose children were hearing-loss with multiple disabilities were excluded.

Instrument

The tool used in this study was a standardized scale called FQOLS(14). This was developed based on an investigation project conducted in the United States, focused on the search increase for QL of families whose children show general pathologies.

This scale is organized in 5 domains: family interaction (with 6 items), care of parents with their children (with 6 items), emotional well-being (with 4 items), physical/material well-being (with 5 items), and support to the disabled person (with 4 items), resulting in 25 items. The answers varied in five levels: 1=very unsatisfied; 2=unsatisfied; 3=not satisfied nor unsatisfied; 4=satisfied; and 5=very satisfied. The total score is obtained through the sum of all items, varying from 25 to 125.

First, before the scale application, the Family Profile Form was used to characterize the family with questions about the responsible subject's age, educational level, occupation, salary, and family core living in the same house; child's educational level and age, kind of school, and if he/she wears hearing aid devices or cochlear implant.

Procedures

The study was developed in two phases: in the first one, which was pilot study, the cultural authorization, translation, and adaptation of the FQOLS were performed; and in the second one, the Family Profile Form and the FQOLS were applied.

First phase

Authorization

Adaptation and publication of the scale in the Portuguese spoken in Brazil were authorized by those in charge in the Beach Center (Jean Ann Summers, Kansas University).

Cultural adaptation

Cultural adaptation was performed based on the stages recommended by Beaton et al.(15) (Figure 1). Two translators worked independently — the investigator and the co-advisor of this article — and conducted the translation of the text to Portuguese. When both the versions (translation) were compared (T1 and T2), the necessary appropriations were done, and the result was version T3. In order to check if the terms were appropriate, version T3 was back translated to English by an American and a Brazilian, who were both bilingual and English teachers, with experience in speech-language pathology and audiology translations, who had not taken part of the previous phases. The result was once again evaluated by the investigators and, if necessary, sentences were rewritten in Portuguese, thus forming the final version T4 (Appendix 1).

Pilot study

The last version (T4) was applied (pilot study) to a group of five subjects in order to check compatibility of the sentences; hence, this version showed to be perfectly applicable.

Second phase

Scale application

The pilot study demonstrates that the last version is perfectly applicable. The research second phase was the application of the Family Profile Form and the scale to 41 parents of children with sensorineural hearing loss. The interviews were conducted with the investigator reading the items to the parents, while the children were undergoing the speech-language pathology and audiology therapy or during periodical follow-ups.

In order to check instrument reliability, in terms of internal consistence of the observed values, we applied the Cronbach alpha (α) statistical test, with variation between 0.000 and 1.000 and the reliability limits:

- 0.000 to 0.5000 (*exclusive*) – unsatisfactory;
- 0.5000 (*inclusive*) to 0.7000 (*exclusive*) – satisfactory;
- 0.7000 (*inclusive*) to 1.000 – high.

RESULTS

The scale was translated twice, resulting in the first version/adaptation, and then in the back translation and finally the second/final review.

In the first version, among the 25 items, differences among the translators were found in only 4 of them (Chart 1):

- if they would use the word *criança* [kid] or *filho* [child], choosing *filho;*
- if they would use the word *apoio* [aid] or *suporte* [support], choosing *apoio*;
- if they would use the word *atingir* [reach] or *buscar* [search], choosing *buscar;*

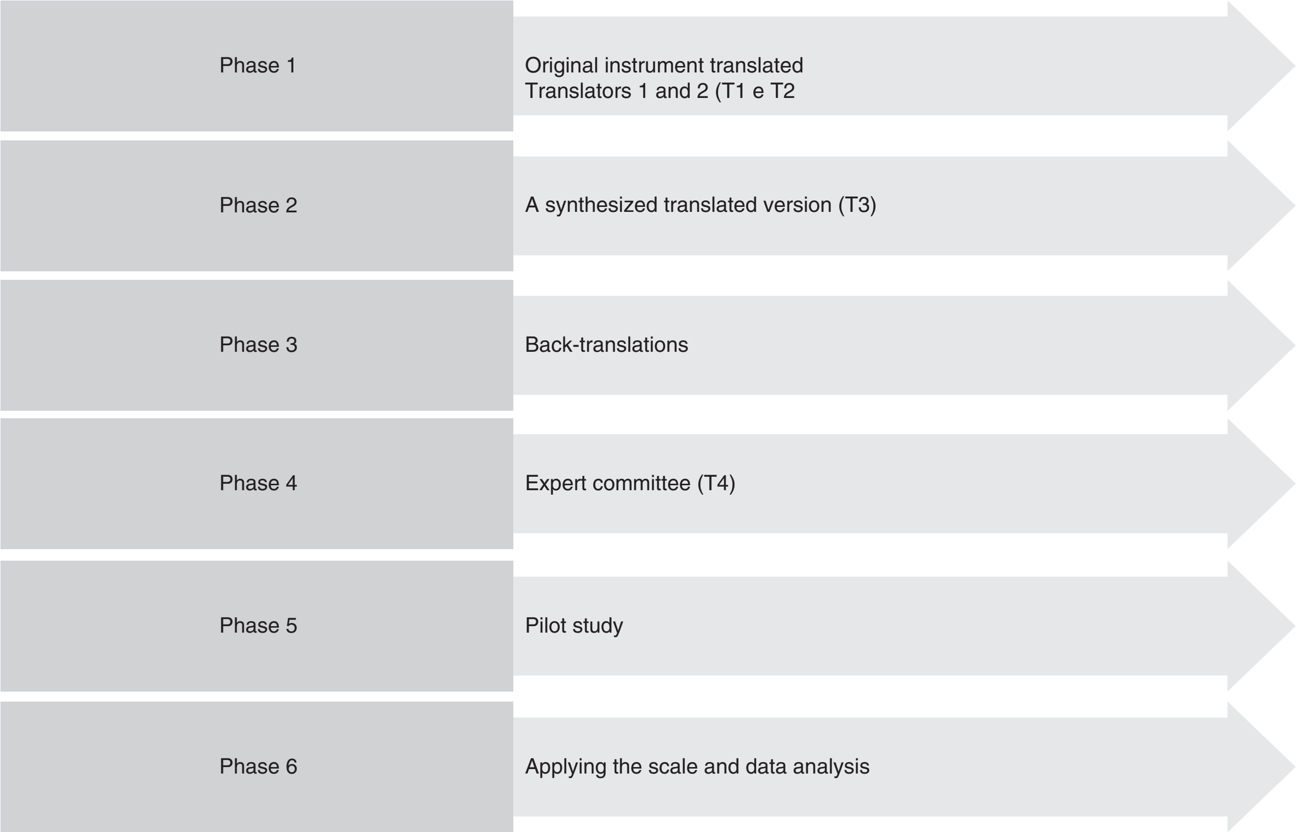

Figure 1. Graphical representation of cultural adaptation and validation stages (Beaton et al.(15))

Chart 1. Differences on the adaptation formation

Question	Translation 1	Translation 2	Adaptation 1
2. My family members help the children learn to be independent.	2. Os membros da minha família ajudam os *filhos* a aprender a ser independente.	2. Os membros da minha família ajudam *as crianças* a aprender a ser independente.	2. Os membros da minha família ajudam os *filhos* a aprender a ser independente.
3. My family has the support we need to relieve stress.	3. A minha família tem o *apoio* necessário para aliviar o estresse.	3. A minha família tem o *suporte* necessário para aliviar o estresse.	3. A minha família tem o *apoio* necessário para aliviar o estresse.
5. My family members help the children with schoolwork and activities.	5. Os membros da minha família ajudam os *filhos* com trabalhos escolares e atividades.	5. Os membros da minha família ajudam as crianças com trabalhos escolares e atividades.	5. Os membros da minha família ajudam os *filhos* com trabalhos escolares e atividades.
8. My family members teach the children how to get along with others.	8. Os membros da minha família ensinam os *filhos* a conviver com os outros.	8. Os membros da minha família ensinam as crianças a conviver com os outros.	Os membros da minha família ensinam os *filhos* a conviver com os outros.
9. My family members have some time to pursue our own interests.	9. Os membros da minha família têm tempo para *atingir* seus interesses.	9. Os membros da minha família têm tempo para *buscar* seus interesses.	9. Os membros da minha família têm tempo para *buscar* seus interesses.
12. My family members show that they love and care for each other.	12. Os membros da minha família *mostram* amor e carinho um pelo outro.	12. Os membros da minha família *demonstram* amor e carinho um pelo outro.	12. Os membros da minha família *mostram* amor e carinho um pelo outro.
23. My family member with a disability has support to accomplish goals at home.	23. O membro familiar com necessidades especiais tem apoio para fazer progressos no *ambiente familiar.*	23. O membro familiar com necessidades especiais tem apoio para fazer progressos *em casa*.	23. O membro familiar com necessidades especiais tem apoio para fazer progressos no *ambiente familiar.*

- if they would use the word *casa* [home] or *ambiente familiar* [family environment], choosing family environment.

After the first version, two translators conducted the back translation, and did not agree only in one item: if they would use the term *aprender* [learn] or *se tornar* [become], choosing *se tornar*.

After such alterations, the final version was developed, and a pilot study was conducted with five mothers to check if the sentences were comprehensible.

In the pilot study, families whose children were listeners and did not have any associated pathology were interviewed. During the interviews, the mothers did not have any doubts as to the items; thus, the study continued by applying the scale to families whose children are deaf.

In order to evaluate the reliability of the studied instrument, the Cronbach alpha (α) statistical test was applied and α=0.663 was found. Therefore, the scale reliability is satisfactory.

The final version of the scale was applied to 41 parents of children with hearing loss, and the parents did not have any doubts about the items and mentioned being very satisfied with each item.

From the interviewed parents (41), 83% were mothers and 17% fathers; 56% did not work, whereas 44% worked; 17.1% did not conclude or were coursing elementary school, and 22% had finished it; 9.8% did not conclude or were coursing high school, and 41.5% had completed it; and 4.9% were coursing or did not finish higher school and 4.9% had finished it.

With regard to family income, it was a heterogeneous sample with a great concentration of one-and-a half minimum wages, followed by one and three minimum wages

As to the family core, the following structures and concentrations were found: mother, father, and child in 14 families (34%); mother, father, and children in 13 families (32%); mother, father, child/children, and relatives in 9 families (22%); mother and child in 5 families (12%).

Most of the children studied in a regular school (51%), with 22% of them in a special school, 20% did not go to school, because they were aged younger than 3 years, and 7% were in a nursery.

Differences were found in the measurement of the FQL level in each domain of the scale and the general one, in which the lowest level of satisfaction belongs to the emotional welfare domain, followed, respectively, by support related to the disabled subject, physical/material welfare, and relationship of parents with their children; and the highest satisfaction was seen in the family interaction domain (Table 1).

DISCUSSION

The first aspect to be emphasized in the study is choice and adaptation of the tool. The FQL, of holistic scope, is a theme

Table 1. Quality of life level by domain and total

Domain	Min–Max	Median (Mean±SD)
Family interaction	8–29	24 (22±3.5)
Parent–children parenting	16–30	22 (22±2.3)
Emotional well-being	7–16	12 (11±2.26)
Physical/material well-being	10–20	12 (11±2.26)
Support to the disability-related support	12–20	15 (15±1.5)
Total quality of life	72–108	15 (15±1.5)

Caption: Min = minimum; Max = maximum; SD = standard deviation that has not been very studied, yet, owing to its complexity, especially in the attempt of comprehending the dynamics and subjectivity of each family(16). Because family is essential in the process of hearing rehabilitation, it is extremely important our deepening in this theme through the use of an instrument that provide us a basis to where we should follow after our reception.

Cultural translation and adaptation of the scale to Brazilian Portuguese were not hard tasks, because the original items seemed very pertinent and, during translations, there were few doubtful interpretations (four), which were mainly associated with synonyms.

Because the scale has general items about families with disabled children, it can be used for multiple deficiencies, and because the items are very specific about family interaction, parent–children relationship, emotional, physical, and material welfares, and family relationship with service providers, it was highly acceptable for hearing-impaired subjects.

The second aspect is how the instrument was applied. The original version was mailed to the families. This research consisted of the investigator interviewing parents individually by reading each item to them loudly, while children were being cared in the service (all the items were answered, thus, there were no omissions).

If we compare the scale used in this research with the original one, we can find satisfactory and high(14) reliability (evaluated through the Cronbach alpha), respectively. This difference can be attributed to the sample size applied to the scale, smaller than the original one, and to the heterogeneity of parents' answers, because they were not sure about their level of satisfaction.

Thus, if we analyze the alpha values of both versions of the scale, we can conclude that the coefficient obtained in the translated version was similar to the original one when we mention that they present satisfactory values; therefore, they have good reliability for their reproducibility.

The third aspect to be mentioned is the study family profile. Families that took part in the study were those who wanted to be cared in a hospital from the Health Unified System (SUS, acronym in Portuguese) owing to financial reasons or because it is a renowned hospital in the area. Therefore, the profile designed for these families is that most of them have a monthly income of one-and-a-half minimum wage, ended high school, and did not work. These findings are different from another study(17), in which most of the participants had completed higher education, worked, and had a considerably higher income.

Most of the families also had a mother, a father, and child/children in the family structure, demonstrating the traditional structure for a family and the existence of role separation, such as mothers who stop working to take care of their children, in this case with hearing loss, and fathers who work.

The fourth aspect to be discussed is the level of satisfaction for each domain of the scale, which registers that the greatest satisfaction is family interaction, and the lowest level of satisfaction is associated with emotional well-being(12,17-19).

The family interaction domain comprises items about support that each family member provides to the other, the items include the time the family spends together, the opening they have to talk to each other, the solution of problems in groups, family support to reach personal goals, demonstration of affection, and the way how they deal with the highs and lows of life. We believe this domain showed the greatest index of satisfaction owing to the presence of a deaf child, because it may be associated with communication among family members. Thus, in this issue, the desire of being able to communicate with a child, of being understood and understanding the desire of the other are extremely important, which favor communication among the family themselves and family members and child.

At the time of the interview, when we were applying the FQOLS, we noticed, especially when we were discussing about emotional well-being items, that the participants told us some things of their lives that they did not tell their therapists. So, we assumed that this was the moment when they could stop to analyze what had been going on in their lives.

Following emotional well-being, the lowest satisfaction index was registered to the disability-related support, which is a very commonly discussed theme among experts(17-19), because this is the domain that discusses how parents deal with their children's deafness every day. When they do not have the opportunity of going to a parents' group, they do not receive counseling or reception or they even do not have anyone to talk to in order to clarify their doubts; so, these parents exhibit isolated thoughts, increasing false beliefs, with difficulties both in the child and family's development(17,19-23).

Data from this domain (support to the disability-related support) show that parents are not completely involved with their child's routine, and it includes items of: school stimulation, over which the mothers report their dissatisfaction, because they mention that schools do not give the proper attention to their children such as teaching literacy in the right time; stimulation in the family environment, over which part of the mothers also express dissatisfaction, because they do not have enough time to give the proper attention to their child when they arrive home; family stimulating the child in making new friends, because some parents are not used to going out with their children; involvement of parents with service providers, which is the only item where good satisfaction is unanimous.

During the instrument application, we found families that did not take part in/adhered to the treatment, whether because they were not involved (regardless the felt emotional stage), whether because of occupational reasons (work), and in such cases, satisfaction also decreases with an even lower FQL; the more the family is involved, the more the FQL, which is in agreement with the results of other authors(20).

In this study, despite the particularities of domain dissatisfactions and a different family profile, families reported being satisfied with all areas of family life when the general FQL was computed, as seen in other investigations(17,18).

Thus, we believe that choosing this scale to evaluate FQL with deaf children showed us the process of role transformation within the family structure owing to the discovery of a deaf child.

In the current globalized world, it may seem difficult to measure FQL, but knowledge of information created through instruments such as the one used in this study can compete so that, collectively, we, professionals, can map the main problems of these families and favor their process of emotional adaptation and, at the same time, map new therapeutic models for families and children.

Although the answers to a QL scale seem subjective, and each family provides them in different moments of their process, they help us to impartially consider the singularities of each case, and the results are important tools for our intervention work.

We are aware that evaluating QL is hard, especially, because the aspects associated with social and emotional questions can vary according to the day or even the moment when the instrument is applied. However, QL is a primordial factor and ignoring it would be neglecting the child's development stages; therefore, we believe that the family is fundamental for the child's psychosocioemotional and language development. Among different instruments that are able of measuring the QL, we have chosen this scale owing to the multiple aspects that it gathers.

The use of FQOLS as a FQL evaluation tool with deaf children was advantageous and of great benefit, mainly because it guided us to reception of each family and to understand their decisions.

QL is a theme that has been increasingly studied, and this investigation is only the beginning for families with deaf children in Brazil. Understanding criteria associated with QL is fundamental for the development not only of deaf children but also of families. It is up to us, professionals, to continue studying in order to better understand all issues by analyzing deeply to improve family support and increase our knowledge on the indicators that facilitate the acceptance of a child's deafness.

CONCLUSION

The Brazilian Portuguese version of the FQOLS scale has proved to be an instrument of easy use and satisfactory reliability.

The families are satisfied with their FQL.

The instrument helps health professionals to better understand family dynamics, fragilities, and singularities of each family.

BMJ, adapted the Scale, selected sample, wronte dissertation and manuscript; LG was the advisor research, dissertation and manuscript review CCACL was the co-advisor the research and contributed to adapted the Scale, selected sample, dissertation and manuscript review.

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APPENDIX 1 - FAMILY QUALITY OF LIFE SCALE
BEACH CENTER

Hoffman L, Marquis J, Poston D, Summers JA, Turnbull A. Assessing family outcomes: Psychometric evaluation of the Beach Center Family Quality of Life Scale. J Marriage and Family. 2006;(4):1069-83.

Nome: ____
Idade:______________Grau de Escolaridade:______________Profissão:______________
Grau de Parentesco: ______________________________Salário (por mínimo):______________
Núcleo Familiar:____
Nome da criança: ____
Escolaridade: ____________Idade: ______________________AASI ou I.C? ______________________

Quanto eu estou satisfeito referente à...

	Muito satisfeito	Satisfeito	Indiferente	Insatisfeito	Muito insatisfeito
1. A minha família gosta de passar tempo junta					
2. Os membros da minha família ajudam os filhos a se tornar independentes					
3. A minha família tem o apoio necessário para aliviar o estresse.					
4. Os membros da minha família têm amigos ou outras pessoas que fornecem apoio.					
5. Os membros da minha família ajudam os filhos com trabalhos escolares e atividades.					
6. Os membros da minha família têm transporte para ir aos lugares que necessitam.					
7. Os membros da minha família falam abertamente uns com os outros.					
8. Os membros da minha família ensinam os filhos a conviver com os outros.					
9. Os membros da minha família têm tempo para atingir seus interesses pessoais					
10. Nossa família resolve os problemas junta.					
11. Os membros da minha família apoiam uns aos outros para atingir objetivo.					
12. Os membros da minha família mostram amor e carinho um pelo outro.					
13. Minha família tem ajuda externa à sua disposição para cuidar de necessidades especiais de todos os membros d*a família.*					
14. Os adultos da minha família ajudam os filhos a tomar boas decisões.					
15. Minha família recebe atendimento médico quando necessário.					
16. Minha família tem condições de cuidar das despesas de casa.					
17. Os adultos da minha família conhecem outras pessoas na vida dos filhos (isto é, amigos, professores).					
18. Minha família é capaz de lidar com altos *e baixos da vida.*					
19. Os adultos da minha família têm tempo para cuidar das necessidades individuais *de cada filho.*					
20. Minha família recebe atendimento odontológico, quando necessário.					
21. Minha família se sente segura em casa, no trabalho, na escola e no *bairro.*					
22. O membro da família com necessidades especiais tem apoio para progredir na escola ou no trabalho					
23. O membro familiar com necessidades especiais tem apoio para fazer progressos no ambiente familiar					
24. O membro familiar com necessidades especiais tem apoio para fazer amigos					
25. Sua família tem um bom relacionamento com os prestadores de serviços que trabalham com o membro com necessidades es*peciais*					