Development and Validation of a Gujarati Questionnaire for Evaluating Levels of Awareness, Acceptance, Socio-Economic Stress & Expectations from Physiotherapy Services in Parents of Children with Cerebral Palsy

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Abstract

Parents of children with cerebral palsy experience anxiety, depression, guilt and low self-esteem, frustration, low matrimonial and personal satisfaction etc. While planning interventions for the child with cerebral palsy, physiotherapist should consider physical and psychological health of caregivers, influence of social support, family functioning etc. This study gives an overview of the procedure for development and validation of a Gujarati questionnaire to evaluate levels of awareness, acceptance, stress & expectations from physiotherapy services through two-stage process. At the 1st stage domain determination, item generation and instrument formation was done. In the 2nd stage, face and content validation was done using consensus method by a group of 10 experts. As a result, questionnaire having 9 dimensions and 84 items with acceptable levels of validity was developed.

Keywords: *Cerebral palsy, parenting, parents, caregivers, physical therapy, questionnaire.*

Introduction

Parents having a child with cerebral palsy cope with their child's functional limitations along with their specific needs [1]. Parents who have children with CP are faced with many difficulties including issues with the personal relations, social problems, economic problems, personal physical problems, issues involving the sick child's care and education [2]. They frequently experience anxiety, depression, guilt and low self-esteem, frustration, low matrimonial and personal satisfaction due to feelings of inadequacy for not being able to have a normal child, and also have impaired sexual lives [3,4].

While a physiotherapist plans interventions for the child with CP, he should also consider parental awareness about various aspects; acceptance of the situation by parents, family and society; levels of stress due to parenting; experiences and expectations from physiotherapy services. To study such complex constructs, researchers require valid and reliable instrument [5].

CanChild Center for Childhood Disability Research has developed a conceptual framework of family-centered service and has defined it as follows:

"Family-centered service is made up of a set of values, attitudes, and approaches to services for children with special needs and their families. It recognizes that each family is unique; that the family is the constant in the child's life; and that they are the experts on the child's abilities and needs. The family works together with service providers to make informed decisions about the services and supports the child and family receive. In family-centered service, the strengths and needs of all family members are considered [6]". Lack of standard questionnaires or instruments to review and promote family-centeredness in paediatric rehabilitation has lead

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to a serious limitation in service provision capacities of country [7].

In the light of previous findings relevant to rehabilitation for CP in India, researchers have recommended that physiotherapists should focus on reviewing the difficulties of parents and provide education, guidance and support to them. This enables parents to cope better with the condition, thereby resulting in improved outcomes associated with treatment[2,4,8-10].

While reviewing available literature, it was found that only few instruments in English can provide comprehensive information about stress, acceptance, beliefs, expectations, utilization etc. [8,11-14]. Studies in India and Gujarat showed that, no valid and comprehensive questionnaire is yet available in Gujarati to help study these aspects.

When a new questionnaire is designed, measurement and report of its content validity have fundamental importance [15].It provides information on the representativeness and clarity of items and help improve a questionnaire through achieving recommendations from an expert panel[16,17]. Therefore, validity evidence should be obtained on each study for which a questionnaire is used [18].

Materials and Method

This exploratory mixed method research (qualitative-quantitative) study was carried out to design and validate the questionnaire measuring levels of awareness, acceptance, socio-economic stress & expectations from physiotherapy services in parents of children with CP.

Stage 1: Questionnaire Design

Process of questionnaire design follows 3 steps, including content domain determination, item generation and questionnaire construction [19,20].

Qualitative data was collected from the interviews with 21 parents of children with CP. Following the guidelines of Tilden et al. (1990) the data from interview was used as a resource to generate questionnaire items [21]. For item generation, Ridenour and Newman's deductive- inductive technique was applied [22]. In third step, questionnaire was constructed by refining and organizing items in a suitable format and sequence so that the finalized items are in a usable form [23].

Stage2: Judgment

This step included confirmation by a panel of experts, indicating that questionnaire items and the entire questionnaire have content validity. For this purpose, a panel with 10 experts having mean research or work experience of 23.1 + 8.47 years was appointed.

Experts were requested to provide their viewpoints on the relevance, clarity and comprehensiveness of the items [15,23]. In first round of judgement, few items were modified whereas some were eliminated based on the opinion of content experts about grammar, appropriate and correct words, correct and proper order of words and appropriate scoring [24]. For quantification purpose Content Validity Ratio (CVR) was used, where the experts were requested to score each item from 1 to 3, with a 3-degree range of "not necessary, useful but not essential, essential", and specify whether an item is necessary in a set of items or not. Values of CVR vary between 1 and -1. For this study 10 experts were included, therefore item with CVR value bigger than 0.62 was accepted [25].

Another widely reported approach for content validity for questionnaire development study is the content validity index (CVI) [23,26,27]. The expert panel members (n=10) were requested for to rate questionnaire items in terms of relevance and clarity on a 4-point ordinal scale [26]. A table like the one shown below (Table 1) was added to the cover letter to guide experts for scoring method. For relevance, CVI was calculated both for item level and the scale-level.

Table 1. The table added to the cover letter to guide experts for scoring method

Relevance	**Clarity**
1 – Not relevant	1 – Not clear
2 – Item needs some revision	2 – Item needs some revision
3 – Relevant but need minor revision	3 – Clear but need minor revision
4 – Very relevant	4 – Very clear

The I-CVI expresses the proportion of agreement on the relevance of each item, which is between 0 and 1 [18,23]. Minimum 80% agreement among experts was considered for the items to be appropriate for selection in the questionnaire [26]. Kappa statistic was undertaken to provide adjustment for chance agreement [28].The scale-level content validity index (S-CVI) is defined as "the proportion of items on an questionnaire that achieved a rating of 3 or 4 by the content experts" [29]. S-CVI was calculated using universal agreement method i.e. S-CVI/UA, as well as averages method i.e. S-CVI/Ave.

Determining face validity of a questionnaire

Face validity is related to the appearance and apparent attractiveness of a questionnaire, which may affect the questionnaire acceptability by respondents [19]. To determine face validity 10 parents of children with CP (lay experts) was requested to judge on the importance, simplicity and understandability of items[27]. They were asked to grade importance of all items on a 5-point Likert scale i.e. very important, important, relatively important, slightly important, and unimportant. The items were revised to make them more meaningful and understandable as per the suggestions from respondents.

Final questionnaire was constructed at the end of this designing and validation process. The final version of questionnaire included 9 sections and 84 questions.

Results

Results of Stage 1

Qualitative content analysis of the data collected through semi-structured in-depth interview of 21 parents of children with CP was done. The results led to identification of content domain within 4 dimensions and 16 sub-dimensions (Table 2).

Table 2. The Content Domains identified during qualitative content analysis

Sr. No.	Domain	Sub-domain
1	Awareness in the parents	1. Cerebral palsy: causes & prognosis 2. 2.Available treatment options 3. Role & importance of pt 4. Support & aid
2	Problems experienced by parents	1. Social problems 2. Physical problems 3. Psychological problems 4. Financial problems 5. Other problems
3	Acceptance of the child	1. By parents 2. By family 3. By society
4	Expectations of the parents	1. Availability of rehab services 2. Quality of rehab services 3. Response to rehab measures 4. Other support services

During the process 117 questions were generated from the data derived out of the interviews. 22 questions were added from relevant literature and related questionnaires. 41 questions were removed due to duplication and overlapping of concept. At the end of item generation process, preliminary questionnaire was developed having 98 items within 9 sections. The sections and the variables covered by them are enlisted below:

Section 0: Interview related variables
Section 1: Child related variables
Section 2: Child’s difficulties and associated variables
Section 3: Caregiver related variables
Section 4: Child’s family related variables
Section 5: Caregiver’s awareness and associated variables
Section 6: Child’s acceptance and associated variables
Section 7: Parental stress and associated variables
Section 8: Expectations from Physiotherapy and associated variables

Results of stage 2:

Results for estimation of Content Validity

In the second stage the panel of 10 content experts were requested to judge the content of questionnaire qualitatively and quantitatively using prescribed formats in three rounds.

In the first round of judgment, 10 items having CVR lower than 0.62 were eliminated. The remaining items were modified according to the recommendations of panel members.

In the second round, the proportion of agreement among panel members on the relevance and clarity of 88 remaining items of the first round of judgment was calculated. In this round, among the 88 questionnaire items, 5 items with a CVI score lower than 0.70 were eliminated. 7 items with a CVI between 0.70 and 0.79 were modified (according to the recommendation of panel members and research group forums). According to experts’ suggestions, an item about advice regarding the neonatal follow up was added in this round. After modification, the questionnaire containing 84 items was sent to the panel members for the third time to judge on the relevance, clarity and comprehensiveness.

The probability of chance agreement was first calculated for each item and then kappa (K) was computed by using the numerical values of Pc and I-CVI. All 84 items had K values >0.74 and were accepted for face validation.

Results for estimation of Face validity

A panel of 10 parents of children with CP (lay experts) was requested to judge face validity of all 84 questions. According to their opinions, to make some items more understandable, objective examples were included. For instance,

“બાળકની ફિઝીયોથેરાપી અને અન્ય સારવાર માટે આશરે કુલ માસિક ખર્ચ કેટલો થાય છે?”

was changed to,

“બાળકની ફિઝીયોથેરાપી અને અન્ય સારવાર માટે આશરે કુલ માસિક ખર્ચ કેટલો થાય છે? (દા.ત. વાહનમાં આવવા-જવાનો, નાસ્તો-પાણી, કેસ ફી, સારવાર ફી, દવાઓ વગેરે.)”

All 84 items were found satisfactory and accepted for the final questionnaire. Finally, at the end of the content validity and face validity process, our questionnaire was prepared with 9 sections and 84 items for the next steps and doing the rest of psychometric testing.

Discussion

Present paper demonstrates quantitative indices for content validity of a new questionnaire and outlines the process of design and psychometric analysis of Gujarati questionnaire for evaluating levels of awareness, acceptance, socio-economic stress & expectations from physiotherapy services in parents of children with CP.

It should be said that validation is a lengthy and complicated process involving many people including experts and subjects from the population of interest. The first-step of validation, the content validity, should be studied in extensive manner. Meanwhile, this study showed that although content validity is a subjective process, it is possible to objectify it through various statistical procedures. The further analyses of psychometrics should be directed towards reliability evaluation (through internal consistency and test-retest), construct validity (through factor analysis) and criterion-related validity [27].

Clinicians and researchers should realize if the questionnaires they use for their studies are suitable for the construct, population under study, and socio-cultural background in which the study is carried out, or there is a need for new or modified questionnaires. Training on content validity study helps students, researchers, and clinical staffs better understand, use and criticize research questionnaires with a more accurate approach.

Main limitation of this study is, as experts' feedback is subjective, the study is subjected to bias that may exist among the experts.

Conclusion

This was a systematic content validity study conducted through two stage process. In the first stage, questionnaire design was carried out and in the second stage; judgment on questionnaire items was performed. Such process should lead the development of a valid and reliable questionnaire in terms of content. In general, this content validity study revealed that this questionnaire enjoys a satisfactory level of content validity.

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