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Comparison of rating scales in the development of patient-reported outcome measures for children with eye disorders

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Abstract

Background—A rating scale is a critical component of patient-reported outcome instrument design, but the optimal rating scale format for pediatric use has not been investigated. We compared rating scale performance when administering potential questionnaire items to children with eye disorders and their parents.

Methods—Three commonly used rating scales were evaluated: frequency (never, sometimes, often, always), severity (not at all, a little, some, a lot), and difficulty (not difficult, a little difficult, difficult, very difficult). 10 patient-derived items were formatted for each rating scale, and rating scale testing order was randomized. Both child and parent were asked to comment on any problems with, or a preference for, a particular scale. Any confusion about options, or inability to answer was recorded.

Results—21 children (aged 5–17 years) with strabismus, amblyopia, or refractive error were recruited, plus one of their parents. Of the first 10 children, 4 (40%) had problems using the difficulty scale, compared with 1 (10%) using frequency, and none using severity. The difficulty scale was modified, replacing the word “difficult” with “hard.” 11 additional children (plus parents) then completed all 3 questionnaires. No children had problems using any scale. 4 (36%) parents had problems using the difficulty (“hard”) scale and 1 (9%) with frequency. Regarding preference, 6 (55%) of 11 children and 5 (50%) of 10 parents preferred using the frequency scale.

Conclusions—Children and parents found the frequency scale and question format to be the most easily understood. Children and parents also expressed preference for the frequency scale, compared with the difficulty and severity scales. We recommend frequency rating scales for patient-reported outcome measures in pediatric populations.

Keywords

rating scale; response option; children; questionnaire; patient-reported outcome measure

INTRODUCTION

A rating scale is a critical component of patient-reported outcome instrument design (Khadka et al., 2012a, Khadka et al., 2012b). In pediatric questionnaire development, little attention has been given to the performance of different types of rating scales (Guyatt et al., 1987). Across existing questionnaires, a wide range of rating scales have been used, including frequency, severity, difficulty, ability, and agreement. As a critical step in optimizing patient-derived, vision-specific questionnaires for use across the spectrum of pediatric eye conditions, we evaluated the three most commonly used Likert-type rating scales. The aim was to determine which rating scale performed best when administering questionnaires to children with eye disorders and their parents.

MATERIALS AND METHODS

Ethics approval was obtained from the Institutional Review Board at Mayo Clinic, Rochester, Minnesota. All procedures and data collection were conducted in a manner compliant with the Health Insurance Portability and Accountability Act and all research procedures adhered to the tenets of the Declaration of Helsinki.

Parents of children were approached with information about the study and informed consent was obtained. In addition to parental consent, children aged 7 and older gave informed assent. Both the child and one of their parents were enrolled. Study participants were enrolled while attending pediatric ophthalmology outpatient clinics at Mayo Clinic, Rochester, Minnesota. None had participated in any previous phase of this study and both the child and their parent were required to be able to read and converse in English.

Patients

This present study was conducted as part of a broader project developing patient-reported outcome measures for pediatric eye care (Castaneda et al., 2016, Liebermann et al., 2016). For this present study evaluating rating scales, we enrolled children aged 5 to 17 years with a current primary diagnosis of strabismus, amblyopia, or refractive error. To provide a diverse and balanced cohort regarding age and eye disease we aimed to recruit approximately equal numbers of 5- to 7- and 8- to 17-year olds, and approximately equal numbers of children with a diagnosis of either strabismus, amblyopia or refractive error. For children in the strabismus group, any type of strabismus was allowed provided it measured 10 prism diopters (PD) or greater in primary position, at either distance or near, by simultaneous prism and cover test (SPCT). Co-existing diagnoses of amblyopia or refractive error were allowed for strabismus patients. For children in the amblyopia group, any type of unilateral amblyopia (strabismic, anisometropic, or combined mechanism) was included and an inter-ocular difference of a least 2 lines on visual acuity testing was required. Strabismus was allowed in the refractive error group if it measured less than 10 PD at both distance and near, by SPCT. Refractive error was also allowed. For children in the refractive error group, any type or degree of refractive error was allowed, but without amblyopia. Strabismus was allowed only if it measured less than 10 PD at both distance and near, by SPCT.

Questionnaire items

In a previous phase of this study, children and one of their parents were interviewed, concerns coded using NVivo 10 software (QSR International, Doncaster, Australia) and potential questionnaire items generated from the coded interview text (Castaneda et al., 2016, Liebermann et al., 2016). For this present study we selected 10 candidate questions from the area of concern coded Academic / Reading. We wanted to include questions that would be easily comprehended and applicable across the 5- to 17-year old age range, but apart from these concerns, the question content was considered secondary since the primary aim was simply to evaluate the performance of different rating scales. We were careful to select questions that could be answered using different types of rating scales.

Response options

Based on review of existing pediatric vision questionnaires (Angeles-Han et al., 2011, Borsting et al., 2003, Carlton, 2013a, Cochrane et al., 2011, Cole et al., 2001, Felius et al., 2004, Gothwal et al., 2012, Hatt et al., 2010, Holmes et al., 2006, Hrisos et al., 2004, Khadka et al., 2010, Sabri et al., 2006, Sacchetti et al., 2007, Tadic et al., 2013) and other data on response options, (Khadka et al., 2012a) we identified three commonly used Likert-type rating scales for evaluation: frequency (e.g., never, sometimes, often, always), severity (e.g., not at all, a little, some, a lot), and difficulty (e.g., not difficult, a little difficult, difficult, very difficult). These three scales were therefore selected for comparison in this present study. In adapting each rating scale for use in this study we applied the evidence-based guidelines reported by Khadka et al (Khadka et al., 2012a) which recommend using: 1) a maximum of five categories; 2) short descriptors; 3) non-overlapping categories; 4) a simple question format; 5) the same response options for each question. In our previous experience with both the Intermittent Exotropia Questionnaire (Leske et al., 2015) (for children and parents), and the Adult Strabismus-20 questionnaire, (Leske et al., 2012) we found, when performing Rasch analysis, that reducing five response options to four or three response options improved utilization of response option categories. Therefore we elected to use four response options across all age groups in this present study. Children were asked to choose a response based on their experience over the past week.

Final questionnaire format

The 10 questions regarding Academic / Reading concerns were articulated for the three different rating scales (Table 1 showing severity scale, phrased for child). The severity scale used the response options “not at all”, “a little”, “some”, “a lot”, the frequency scale used “never”, “sometimes”, “often”, “always” and the difficulty scale used “not difficult”, “a little difficult”, “difficult”, “very difficult.” Each set of 10 questions with its corresponding rating scale was formatted as a separate document, allowing questions with the same rating scale to be administered together and answered independently. The resulting questionnaire therefore consisted of 3 sets of questions (each with their own response options), and a total of 30 questionnaire items (10 questions asked three times each), for both the child and for the parent as proxy.

Questionnaire administration

For each child / parent the order of administration was randomized to avoid a fatigue effect for a particular rating scale. A three-way randomization assignment was produced in two blocks, one for 5- to 7-year olds and one for 8- to 17-year olds. All child questionnaires were administered by a trained investigator who read the questions and response options verbatim. The response option selected by the child was recorded by the examiner. Proxy questionnaires (completed by the parent), were self-administered in the same randomized order as the child questionnaires. Parents were asked to complete each set of questions without trying to recall the answers they had recorded previously. When one set of questions (with one set of response options) was completed, the second and third sets were administered in the same way.

Identifying problems with specific rating scales

For each set of questions (each with their own set of response options), the child was asked if they had any problems choosing a response and the investigator made a written note of any issues reported by the child. In addition the investigator made a written note regarding any apparent confusion the child demonstrated when choosing a response option, or if the child was unable to answer the question. By discussing with the child, it was possible to separate out any confusion regarding the response options from possible confusion regarding the question itself.

Similar to the process for the child, the parent was asked to make a written note on the questionnaire if they had a problem with the response options, including being confused, or finding it difficult to decide, or being unable to select a response at all. Care was taken to explain the difference between a problem with the question itself, and a problem with the response options. In addition to these initial instructions to the parent, once all questionnaires were completed the investigator asked the parent whether they had encountered any problems using any particular scale, and made a written note of their response.

Analysis

For each of the 3 response scales we calculated the proportion of patients reporting a problem. Any written comment that indicated either confusion regarding which option to choose, that the respondent didn't like the available options, or that they were unable to select a response, constituted a problem for that scale. A problem needed only to be mentioned once on a given scale for it to be counted. Also, for each question the pattern of responses across the three rating scales was assessed to determine whether or not the range of options was utilized similarly for each scale.

We planned to perform preliminary analysis of responses after the first 10 questionnaires in order to be aware early in the study of any problems with a particular scale. In the event that there were obvious problems with a particular rating scale we planned to modify the wording if appropriate and then continue to administer questionnaires using a modified format.

RESULTS

First cohort -initial questionnaire administration

Ten children, mean 8.6 (range 5–17) years of age were enrolled at the beginning of the study. Five were aged 5–7 years old and 5 were aged 8–17 years old. Seven (70%) were female and for 8 (80%) race was reported as White. Four had strabismus, 2 amblyopia, and 4 refractive error. On reviewing the 10 child questionnaires and the investigator's notes, 4 (40%) had problems using the difficulty scale, compared with only 1 (10%) using the frequency scale and none using the severity scale. Of the first 10 parents, 2 (20%) reported problems using the difficulty scale, 1 using the frequency scale and none using the severity scale. For children, it was evident from reviewing comments that the word “difficult” was not always understood, especially by younger children. Therefore the difficulty questionnaire was modified replacing the word “difficult” with the word “hard” for a second cohort of children.

Second cohort – modified questionnaire administration

Eleven children, mean 8.8 (range 5 to 17) years of age were enrolled to complete all 3 questionnaires, including the modified difficulty scale. Five were aged 5 to 7 years old and 6 were aged 8 to 17 years old. Six (55%) were female and for 10 (91%) race was reported as White. Five had strabismus, 2 amblyopia, 1 had amblyopia due to anisometropia and a visually insignificant cataract, and 3 refractive error. For this phase of the study, in addition to evaluating the number of patients reporting problems using a particular scale, we also asked both the child and their parent if they had a preference for any particular scale and recorded their responses.

No child reported any problems using any of the scales. Of the 11 parents, 4 (36%) reported problems using the difficulty scale, 1 using the frequency scale, but none had problems using the severity scale. When asked regarding which scale they preferred, 6 (55%) of 11 children and 5 (50%) of 10 parents said they preferred using the frequency scale, compared with 2 (18%) of children and 3 (30%) of parents preferring the severity scale. Three (27%) children and 1 (10%) parent preferred the difficulty scale and 1 (10%) parent had no preference.

DISCUSSION

When comparing three different types of rating scales, we found that the frequency scale was associated with very few problems in children and their parents, and was chosen by the majority as the scale they preferred to use. Overall, the difficulty scale was associated with more problems, and the severity scale was not preferred as often as the frequency scale.

We reviewed existing pediatric vision questionnaires as identified in a review by Khadka et al (Khadka et al., 2013) and in a PubMed search of pediatric vision instruments, and found that the majority use a frequency scale, (Bokhary et al., 2013, Borsting et al., 2003, Cochrane et al., 2011, Hatt et al., 2010, Holmes et al., 2006, Sabri et al., 2006) whereas others use difficulty scales, (Gothwal et al., 2003, Khadka et al., 2010, Tadic et al., 2013) agreement scales, (Cole et al., 2001, Rah et al., 2010) or severity scales (Carlton, 2013a). Some authors utilize a combination of different types of scales in a single questionnaire

(Angeles-Han et al., 2015, Feliuss et al., 2004, Hrisos et al., 2004). In the 2013 review by Khadka et al, (Khadka et al., 2013) difficulty and frequency scales were again the most frequently utilized, although severity, agreement, and bothered scales were also used. Nevertheless, in reports describing the development of these existing instruments, it is often unclear why a certain type of rating scale was chosen. Carlton (Carlton, 2013a) incorporated the terminology used by the child in the interview to inform response options. However we decided to objectively compare the performance of three different types of scales in a new cohort of patients, because even if a high proportion of children and or parents used a particular form of expression when describing their concerns, if others did not readily relate to that form of expression, then using that terminology in the final instrument would not be optimal. We chose to compare not only the commonly used frequency and difficulty rating scales, but also the lesser-used severity scale. A severity scale was chosen over an agreement scale because we suspected that the concept of how bad something is might be easier for younger children to grasp than the concept of agreement. In addition, a severity scale is utilized in younger children using the CAT-QoL (administered to 4 – 7 year olds) (Carlton, 2013a). Although two existing pediatric vision questionnaires use agreement scales one (Cole et al., 2001) was designed as a proxy / parent questionnaire (no child component) and the other (Rah et al., 2010) was designed for older children, aged 8 to 11 years. Therefore we did not select an agreement scale for comparison.

The words used to describe each category in a rating scale can differ according to personal preference or experience. For example in existing pediatric vision questionnaires, frequency rating scale response options have been worded “Never, Rarely, Sometimes, Often, Always”, (Hatt et al., 2010) or “Never, Infrequently, Sometimes, Fairly often, Always” (Borsting et al., 2003) or “Rarely, Occasionally, Sometimes, Mostly, Almost always” (Bokhary et al., 2013). There are currently few data on how the specific wording of an option influences how a patient responds. In this present study we chose to use the wording “Never, Sometimes, Often, Always,” similar to our previous questionnaires (Hatt et al., 2009, Hatt et al., 2010). Nevertheless, in subsequent testing, following the completion of this present study, we found that some children did not seem to use or understand the “Often” response option. Therefore the frequency scale responses were modified and are now worded “Never, Sometimes, Most of the time, All the time.” We have found excellent acceptability of this wording of response options in subsequent pilot testing.

Across the spectrum of medical sub-specialties, the development and utilization of patient-reported outcome measures continues to increase. Nevertheless, few studies have attempted to evaluate the performance of different rating scales in pediatric populations, and none that we are aware of in pediatric ophthalmic populations. Outside ophthalmic literature, Van Laerhoven et al (van Laerhoven et al., 2004) administered seven general questions regarding simple activities, feelings and opinions to 6- to 18-year old children, and provided three different types of scales for recording responses: a Likert-type scale, a visual analogue scale and a numeric analogue scale. They found that the Likert-type scale was the easiest to complete, and was preferred by most children. In the present study we chose to compare different Likert-type scales, rather than compare Likert-type scales with other types of rating scales. The findings reported by Van Laerhoven et al (van Laerhoven et al., 2004) confirm

that the Likert-type scale is preferable to other types of scales when administering patient-reported outcome measures in pediatric populations.

We are aware of only one previous study comparing different types of rating scales in ophthalmic questionnaires, conducted in an adult population. Khadka et al (Khadka et al., 2012a) performed Rasch analysis on 17 existing cataract-related patient-reported outcome measures, to determine how four different scales (difficulty, severity, frequency and global) performed. Rasch analysis provides a rigorous assessment of rating scale performance and, in an ideal world, would be the method of choice when comparing different rating scales. Khadka et al (Khadka et al., 2012a) found that performance of each scale varied depending on the parameter assessed (ordering of thresholds, measurement range, category utilization). Overall, difficulty scales performed well, providing ordered thresholds, and a wider measurement range and more even category utilization than frequency scales. Nevertheless, frequency scales were also found to have properly ordered thresholds, with the choices in the scale following the expected hierarchical order. This strength of frequency rating scales reported by Khadka et al, (Khadka et al., 2012a) combined with the problems we encountered in the present study using the difficulty scale, lead us to conclude that frequency scales may be preferred for pediatric ophthalmic populations.

The use of Rasch analysis to directly compare rating scale performance is preferred by many authors, but is not always possible. Rasch analysis requires a large study population, which we were unable to utilize at this early stage in the development of pediatric vision questionnaires. Instead we chose to perform a more qualitative analysis on a smaller number of patients, comparing the frequency of problems encountered, as well as the preferences of children and their parents. Using this approach we found the frequency scale was associated with few problems and was preferred by most children and parents. Although findings from small study populations such as ours may be subject to selection bias, we believe there is still value in this first attempt at understanding how these scales perform in children. As we progress towards the development of pediatric vision questionnaires, we plan to perform Rasch analysis in larger populations of children.

It has been recommended that the same response category format be used for all items within a domain (Khadka et al., 2012a). Nevertheless, using the methodology we adopted in developing our patient-reported outcome measures, the specific domains would not be apparent until factor analysis or principal component analysis has been performed, and such analysis of patient responses requires a prior commitment to a particular rating scale. This creates a challenge in that a rating scale must be chosen in order to collect data on which to perform factor analysis or principal component analysis, and then collect additional data (using different rating scales) in order to determine whether or not the choice was optimal. This time-consuming process may partly explain why such studies have not yet been conducted, and in the absence of these more rigorously derived data, the approach used in this present study may be helpful. Alternative methodological approaches to developing patient-reported outcome measures, such as developing a conceptual framework, enable selection of a specific rating scale early in the development process, but such an approach requires assumptions be made regarding the robustness of specific domains.

There are some limitations to our study. We were only able to recruit a small number of patients and the results may have been different had we recruited more subjects. Nevertheless, we attempted to recruit a diverse cohort by enrolling a range of ages and diagnoses. Also, due to the limited number of subjects, we did not perform Rasch analysis, an approach often used for evaluating rating scale performance because it provides a robust assessment of response categories. Nevertheless, as we have described, there are considerable challenges to acquiring the large amount of data required for such an analysis. Although less rigorous than Rasch analysis, the present study still provides valuable initial data on rating scale performance in children and their parents. In addition, at the time of planning this present study we did not consider the type of question to be of primary importance since we were simply aiming to compare different rating scales. Of the 10 included questions, seven address functional vision concerns, two symptoms (#7, #8, Table 1) and one health-related quality of life (#9, Table 1). It is possible that the preponderance of questions addressing functional vision concerns influenced our findings. Future studies might evaluate the potential for differential performance of rating scales, depending on the type of question.

When comparing different types of rating scales among children with eye disorders and their parents, we found the frequency rating scale was preferred over difficulty, and severity rating scales, and was associated with few problems. Frequency rating scales may be the best choice when developing and administering patient-reported outcome measures for pediatric populations.

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Table 1

Child questions phrased for the severity rating scale. *

1) Is it hard to learn because of your eyes?				
Not at all	A little	Some	A lot	Comment _____
2) Is it hard to concentrate at school because of your eyes?				
Not at all	A little	Some	A lot	Comment _____
3) Is it hard to read close up because of your eyes?				
Not at all	A little	Some	A lot	Comment _____
4) Is it hard to see the board at school because of your eyes?				
Not at all	A little	Some	A lot	Comment _____
5) Is it hard because you have to miss school because of your eyes?				
Not at all	A little	Some	A lot	Comment _____
6) Is it hard to participate in class because of your eyes?				
Not at all	A little	Some	A lot	Comment _____
7) Do your eyes give you headaches?				
Not at all	A little	Some	A lot	Comment _____
8) Are your eyes painful?				
Not at all	A little	Some	A lot	Comment _____
9) Is it hard because your eyes get tired easily?				
Not at all	A little	Some	A lot	Comment _____
10) Is it hard because you have to get extra close to see things?				
Not at all	A little	Some	A lot	Comment _____

* The same 10 questions were repeated but phrased for the frequency rating scale and for the difficulty rating scale.