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Journal of Hematology & Transfusion

Research Article

Agreement between Parents and Children with Sickle Cell Disease in Rating Children's Oral Health- Related Quality of Life

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Submitted: 09 March 2016

Accepted: 18 March 2016

Published: 20 May 2016

ISSN: 2333-6684

Keywords

- Sickle cell anemia
- Quality of life
- Parents
- Child
- Adolescent

Abstract

Objectives: To evaluate the agreement between parents and children with sickle cell disease (SCD) in rating children's oral health- related quality of life (OHRQoL).

Methods: A cross sectional study was conducted with children aged 8 to 14 years, from the referral center for hematology and transfusion services in Minas Gerais, Brazil, and their parents. OHRQoL were measured using the Child Perceptions Questionnaires at two ages, 8-10 and 11-14 years, and the Parent Child Perception Questionnaire. Wilcoxon signed Rank was used to calculate the Parent-child pair median difference. Also assessed were existing discrepancies between parent and child by using the mean of the directional differences. In order to determine the associations between child and parent OHRQoL scores, the Spearman Correlation Coefficient (rs) was used. When exploring the agreement proximity in relation to the characteristics of the children, the overall (rs) were calculated for individual characteristics, factors related to the disease, resources and oral conditions.

Results: The parents reported their children's OHRQoL better than the children did. The agreement between younger children and parents ranged from poor to moderate. The dimensions with poor agreements in that age group were oral symptoms (rs=0.26), emotional well-being (rs=0.22) and social well-being (rs=0.07). Teenagers and their parents had moderate agreements. Better agreements were observed in functional limitations (rs=0.57). Increased age, higher income, home ownership, car ownership, Caucasian and those with severe malocclusion ($p<0.001$) were factors that contributed to a higher level of agreement.

Conclusions: The parents under reported their children's OHRQoL. However, the parents are considered to be crucial participants in health care for children with SCD. Considering the viewpoints of both parties involved is essential when obtaining a comprehensive view of the impact of oral health on SCD and children`s quality of life.

ABBREVIATIONS

OHRQoL: Oral Health-Related Quality of Life; SCD: Sickle Cell Disease; HRQoL: Health-Related Quality of Life; QoL: Quality of Life; Hemominas: Center for Hematology and Transfusion Services in the State of Minas Gerais; CPQ: Child Perceptions Questionnaire; P-CPQ: Parent Child Perception Questionnaire; rs: Spearman correlation coefficient; DMFT: Decayed, Missing and Filled Teeth index; DAI: Dental Aesthetic index

INTRODUCTION

Children who are affected by sickle cell disease (SCD) are victims to serious and potentially life-threatening complications, which in turn affect their health and well-being. In the situation where a child is too young or too ill to self-report [1], parent-proxy reports have proven useful when determining the health-related quality of life (HRQoL) of the child. Evidence has suggested that the assessments of the Quality of life (QoL) of parents with children who have chronic health conditions are more discrepant when compared with parents of healthy children [2]. Furthermore, the caregiver of the child also has a tendency to report a more negative impact than the child does him or herself [3-8]. However, caregivers may over- or under-estimate the importance of factors like oral conditions [2]. Patients with SCD have peculiar musculoskeletal features such as delayed growth and puberty in children, bossy or prominent frontal bones, protruded anterior labial segment with increased over jet and deep overbite, which reflect their craniofacial complex and

influence their dental arrangement or occlusions [9]. Enamel hypo mineralization is often present in subjects with HbSS and could indicate that there is a hypo calcification of the enamel matrix, a result of metabolic and hormonal disturbances, would provide an increased risk of dental caries in these individuals [10]. The worst OHRQoL in children with SCD [11] is related to dental caries.

Parent-proxy reports of HRQoL have varying degrees of agreement with corresponding self-reports and have been shown to vary in function of the HRQoL domain, child's age, gender, severity of disease, family structure and socioeconomic status [12,13]. This overall finding suggests that it is important to examine how demographic and illness characteristics affect proxy ratings for specific disease states and for specific measures of HRQoL [8]. Not unlike other chronic diseases, it has been shown through studies of children with sickle cell disease, in order to comprehensively assess a child's HRQoL [7,13] both parent-reported and child-reported HRQoL are needed.

To date, the agreement between parents and children with SCD concerning OHRQoL has not been examined. Therefore, this study aimed to assess the child's and parent's perceptions of quality of life related to oral health in patients with sickle cell anemia, checking existing agreements in CPQ questionnaire.

MATERIALS AND METHODS

This cross-sectional study was conducted in the Center for Hematology and Transfusion services in the state of Minas Gerais (Hemominas) in Brazil. The sample consisted of younger children and adolescents aged 8 to 14 years and their parents. The children were divided into two groups using the cut-off point of 11 years. This division allowed evaluating the quality of life using the questionnaires appropriate for each age group. OHRQoL was measured using child perceptions questionnaires for two ages: 8-10 and 11-14 years old. The study was approved by the Institutional Review Board of Hemominas, followed by obtaining informed consent from the parent and assent from the child.

Our calculation of the sample size originated from the expected standard deviations of the quality of life scales to evaluate the oral health-related quality of life (OHRQoL) CPQ_{8-10} (10.7) and CPQ_{11-14} (10.1) from a pilot study. The pilot study was conducted among a group age 8-10 (n=34), and a second group aged 11-14 years (n=35) with SCD in Hemominas-MG. The required sample size (n=51 younger children aged 8-10 years, and n=45 adolescents aged 11-14 years) was calculated based on our ability to detect a 5 points difference in quality of life scores assuming α=0.05 and β=0.10. Eligibility criteria of inclusion for participants with SCD were as follows: the diagnosis of SCD genotype HbSS in their medical records, not suffering from a painful crisis at the time of the survey, no medical conditions other than SCD, no emergency dental appointment in the past three months (a requirement of the instruments used to determine the oral quality of life), and did not have an intellectual disability.

The participants underwent of an oral exam for diagnosis of dental caries, malocclusion and gingival bleeding. The World Health Organization [14] standards were used to evaluate these oral conditions. The following indexes were used: Decayed, Missing and Filled Teeth index (DMFT), Dental Aesthetic index (DAI) and Gingival index. Dental Aesthetic Index (DAI) identifies clinical and aesthetic components and mathematically derives a single score. DAI scores have been found to be significantly associated with the perception of treatment needed by students and parents. A calibrated dentist performed an intra-oral exam on each patient using a disposable mirror, CPI probes and gauzes.

Prior to the fieldwork, the dentist underwent a calibration and training exercise for the diagnosis of dental caries, malocclusion and gingival bleeding. The test-retest to determine the inter-rater reliability of oral exams was kappa value =0.89 (inter examiner) and kappa value =0.92 (intra examiner). The correlation of responses to the interviews was also tested (kappa value=0.82). The recalibration of clinical exams carried out each 2 months consistently achieved a Kappa value of agreement ≥ 0.87. Scores between 0.61 and 0.80 are considered a good agreement and scores greater than 0.80 indicate excellent agreement values.

OHRQoL was measured using the child perceptions questionnaire (CPQ) at two ages, 8-10 and 11-14, and the Parent child perception questionnaire (P-CPQ). Both the CPQ and P-CPQ were translated and validated for the Brazilian population, and demonstrated to have good psychometric properties [15-17]. The CPQ_{8-10} contains 25 questions [15], the short version of the CPQ_{11-14} [16] contains 16 questions and the P-CPQ contains 33 questions [17]. The instruments encompass four health domains: oral symptoms, functional limitations, emotional well-being, and social well-being related to oral health conditions. All items consider the frequency of events in relation to the child's condition of teeth and mouth in the last three months. There were five different response option codes that were used for both the CPQ and P-CPQ: 0, never; 1, once or twice; 2, sometimes; 3, often; and 4, every day or almost every day. There was also a "don't know" response option in the P-CPQ questions that represented a score of 0 in the analysis [17]. The questionnaires also contain two single-item global ratings. The CPQ and P-CPQ sub-scale scores were calculated by summing responses. The overall CPQ_{8-10} score, which may range from zero to 100, the overall CPQ_{11-14} score, which may range from zero to 64, and the overall P-CPQ score, which may range from zero to 132, were the sum of all domain scores. Higher scores mean greater negative impact on OHRQoL. In order to compare the P-CPQ and CPQ and instruments, which have different number of questions en each subscale, the mean scores were considered in percentage.

The demographic data of the children and parents were collected through parental report and included individual characteristics: children age, gender, if the child is living with both biological parents; factors related to the disease: age of diagnostic of SCD (< 7 months old, from 7 months to 3 years old), disease severity (sum of points considering the following criteria: pain: 0 = absence, 1 = occurrence for over a month, occurrence less than a month; hospitalization: 0 = absence, 1= occurrence for over a month, occurrence less than a month; number of diseases associated with SCD, ulcerative lesions: 0- no, 1- yes, treatment with blood transfusion: 0 = Never, 1 = yes more than 3 months ago, yes less than 3 months ago); resources: family income (U$/month), home overcrowding (> 2 people/room), level of mother and father education (up to 8 years of schooling, more than 8 years of schooling), home ownership: (No/yes), car ownership: (No/yes).

SPSS software version 20.0 processed the data. Descriptive and univariate analyses were performed for SCD younger children and adolescents. The children with SCD were classified by age, forming two groups of pairs: younger children-parents and teens-parents. It has been shown that individuals, over time, alter the standards by which they rate their HQoL due to changes in circumstances or their physical and emotional development [1].

In the comparison analysis, two ways were computed: I. Wilcoxon signed Rank was used to calculate the parent-child pair median difference. II. Discrepancies between parent and child were also assessed by the mean of directional differences. It was done by subtracting the child's score from the parent's score and using the standard deviation of the differences between the 2 scores to rate concordance [2]. The scores had a similar rating when the difference between the scores was within 0.5 SD above or below a difference of zero [2]. If a difference greater than 0.5 SD below an overall difference of zero was present between the scores, it was considered that the child gave a higher score than the parent. If the scores had a difference greater than 0.5 SD above an overall difference of zero, it was considered that the parent gave a higher score than the child. Chi-square analysis was done to check the association of the distribution of concordance categories between the age groups. A comparison was made between the overall and domain scores. Spearman correlation coefficient (rs) was used to determine the agreement between child and parent OHRQoL scores and if those are significantly different than zero. A P-value of less than that of 0.05 proved a systematic difference between parental and child report. Correlation coefficients <0.3 were considered to have a poor level of agreement, between 0.3 and 0.5 moderate agreement and >0.5 strong agreement, as is accepted and standard practice for statistics in the social sciences [18]. In the correlation analysis, Spearman correlation coefficient (rs) for the overall and domain scores was calculated. When determining whether the agreement varied based on the characteristics of the children, the overall coefficients (rs) were calculated for individual characteristics, factors related to the disease, resources and oral conditions.

RESULTS AND DISCUSSION

A total of 106 pairs of children (56 younger children and 50 teenagers) and parents (85 mothers and 21 fathers/caregivers) completed both questionnaires. The mean age was 8.9 (SD=0.87) among children and 12 (SD=1.08) among teens. In both groups, the majority of participants were male (55.3% children, teens 60.0%) and mothers had schooling up to 8 years (children 57.0%, 58.0% teens). The disease was more severe between teens (mean 4.56 [SD 2.31]) compared com children (mean 3.7 [SD 2.02]). The oral conditions were similar, the mean DMFT/dmft was 1.3 (SD= 2.1) in the group of children (ages 8-10 years) and 1.5 (SD= 1.9) in the group of teenagers (ages 11-14 years), with an exception in the presence of gingival bleeding that was more frequent in teenagers (teens: 54%; children: 16.0%).

On average, younger children reported a lower level of OHRQoL than their parents, as indicated by the mean CPQ_{8-10} 14.61 (SD=11.97) versus P-CPQ 11.58(SD=9.98). The same was observed in the teen's dyad. The CPQ_{11-14} was 25.09 (SD=18.2) versus P-CPQ 17.23 (SD=13.62). The median difference was statistically significant in parent-child pair (p<.05) and parent-teen pair (p<.001). This indicates that there was a systematic under-reporting in parents' assessments (Tables 1-3). The younger children's scores were also higher in almost all subscales, except for functional limitation. However, systematic under reporting was observed in the subscales 'oral symptoms' and 'emotional well-being' (p<.01). The highest agreement between parents and young children in relation to functional limitations can be justified by the more easily understood by the parents, the difficulties encountered by his son to feed, for example, compared to problems like irritation or frustration with oral conditions and impact on emotional well-being.

The teen's responses presented higher scores in all subscales. Comparing teen and parent scores, the median difference parent-teen pair was significantly different on subscales oral symptoms and functional limitation (p<.01). These results were confirmed in the correlations test. According to this test, the degree of agreement between the parents and children was moderate and strong between teen and parent reports of functional limitation, a moderate correlation of overall and emotional well-being subscale, and a weak correlation of oral symptoms and social well-being. These results are also similar in higher levels of agreement for domain functional limitations than domains related to emotional and social wellbeing found in previously mentioned studies in healthy populations [5] and children with SCD [3]. This better correlation between parents and teenager group may be explained pela greater verbal skills may improve a child's ability to describe his/her experiences and emotions [19].

Analysis of individual characteristics, factors related to the disease, resources, and oral conditions specific data suggested that the level of parents-child agreement (poor, moderate, or strong) might vary according to these variables. The overall correlation rs were 0.41 (p<0.001) for younger children and 0.58 (p<0.001) for teenagers. For the factors related to the disease, the correlations (rs) were: 0.610 (p<0.001) for the white race, 0.539 (P<0.001) for black and 0.456 (p<0.01) for mix. A higher disease severity rs was 0.503 (p<0.001) and 0.41 (p<0.05) for a lower severity of the disease. Considering resources, the correlations were: 0.605 (p<0.001) for higher income and 0.41 (p<0.01) for lower income. The rs was 0.895 (p<0.05) for owning a car and 0.537 (p<0.001) for not having a car. The rs was 0.678 for owning house and 0.224 for not have own house. In terms of oral conditions, the correlations (rs) were: 0.693 (p<0.001) for severe or moderate malocclusion and 0.36 (p<0.001) for light malocclusion. (data not showed). The variations in agreement between each characteristic previously mentioned was statically different (P<0.001), eliminating overlap effects (data not shown in table). This results are consistent with those observed in previous studies [12,13]. Among the factors investigated, there is the lower income may be associated with lower health literacy (concerning oral hygiene practices) as well as lower access to preventive health care information [20]. These results agree with previous studies showing that higher income and wealth can be considered co-factors in the relationship between SCD and oral health [21-23]. White race was explained as a factor related to higher levels of income in our study sample. Finally, severe malocclusion is a visible oral condition, and it is expected to be more concordant between parents-children.

Table 1: Oral health-related quality of life in younger children with SCD (aged 8 to 10 years): comparison of child and parent scores.

	Parent reported	Child reported	Parent-child pair	Parent-child pair
Scale	**P-CPQ mean score[1] (SD)**	**CPQ_{8-10} mean score[1] (SD)**	**Median difference[2]D)**	**Correlation coefficient[3])**
Overall	11.58 (9.9)	14.61 (11.9)	2.79*	0.41**
Oral symptoms	20.09 (16.3)	27.68 (17.8)	7.50**	0.26*
Functional limitation	18.53 (17.6)	14.11 (15.7)	-3.12	0.42***
Emotional Well Being	6.91 (9.4)	16.79 (22.5)	6.87**	0.22
Social Well Being	5.39 (9.4)	7.23 (8.95)	2.08	0.07

[1]Mean scores in (%) because the questionnaires have different number of questions in each subscale.
[2]Wilcoxon signed Rank. [3]Spearman correlation coefficient (rs); **p<.05; **p<.01; ***p<.001*

Table 2: Oral health-related quality of life in teenagers with SCD (aged 11 to 14 years): comparison of teen and parent scores.

	Parent reported	Teen reported	Parent-teen pair	Parent-teen pair
Scale	**P-CPQ mean score[1] (SD)**	**CPQ_{11-14} mean score[1] (SD)**	**Median difference[2] nan)**	**correlation coefficient[3])**
Overall	17.23 (13.6)	25.09 (18.2)	6.51***	0.58**
Oral symptons	23.49 (17.0)	33.63 (21.2)	10.13**	0.31*
Functional limitation	21.27 (18.5)	29.25 (22.6)	7.29**	0.57***
Emotional Well Being	15.34 (16.6)	20.13 (20.1)	3.57	0.46**
Social Well Being	12.44 (15.5)	17.38 (21.8)	2.81	0.38**

[1] Mean scores in (%) because the questionnaires have different number of questions in each subscale.
[2] Wilcoxon signed Rank; [3] Spearman correlation coefficient (rs). **p<.05; **p<.01; ***p<.001*

Table 3: Percentage of dyads on overall OHRQoL and each subscale in the three concordance categories.

	Dyad younger children n(%)	Dyad teens n(%)	X^2 *value*
Overall			
Parents > children	13 (23%)	7 (14%)	
Parents = children	21 (38%)	24 (48%)	1.89
Parents < children	22 (39%)	19 (38%)	
Oral symptoms			
Parents > children	8 (14%)	7 (14%)	
Parents = children	25 (45%)	20 (40%)	0.28
Parents < children	23 (41%)	23 (46%)	
Functional limitation			
Parents > children	19 (34%)	8 (16%)	
Parents = children	24 (43%)	22 (44%)	5.73*
Parents < children	13 (23%)	20 (40%)	
Emotional well being			
Parents > children	7 (13%)	8 (16%)	
Parents = children	31 (55%)	25 (50%)	0.40
Parents < children	18 (32%)	17 (34%)	
Social well being			
Parents > children	10 (18%)	6 (12%)	
Parents = children	29 (52%)	28 (56%)	0.71
Parents < children	17 (30%)	16 (32%)	

Chi-square test (X^2): association between younger children and teens. **p<.05*

This is the first study that assesses the agreement in OHRQoL of Brazilian SCD children and their parents. The evaluation of OHRQoL, combined with clinical data, it is useful in the formulation of models of care for oral health. Knowledge of the perception of children, adolescents and parents allows the construction of a more comprehensive care model, considering beyond the clinical aspects, the impact of oral abnormalities in the development of routine activities and social life. This fact becomes even more relevant considering patients with SCD, since these can be neglected oral health concern due to the higher parent of general health. Thus, knowledge of the perception of children and adolescents themselves can better guide decision-making about the need for treatment or preventive measures aimed at oral health.

Our findings were limited by the small sample size involved and regarded as a suggestion and not as a definitive result. Further research of parents and their children from different locations using larger samples could be done. The findings could be compared with the agreement parent-child of healthy children, as well longitudinal follow-up studies. Moreover, the fact that the sample was composed of patients regularly treated at an institution limited to generalize the results to other populations with SCD.

The parents underreport in OHRQoL, and the low agreement for some subscales imply that parents should be not be used as a proxy of oral symptoms, emotional wellbeing and social wellbeing for younger children, and in oral symptoms, and social well-being for teenagers. However, the parents are considered to be very important participants in health care for children with SCD. Therefore, the views of both parties should be considered to obtain a comprehensive view of the impact of oral health on SCD children`s quality of life.

CONCLUSION

In conclusion, the results this study demonstrated that children with SCD aged 8-14 years can provide valid and reliable reports of their oral health-related quality of life. Therefore, it is important considering the assessment of children on the impact of oral changes in quality of life when making decisions about the need for dental treatment.

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Cite this article

da Matta Felisberto Fernandes ML, Corrêa-Faria P, de Oliveira VSF, Paiva SM, Pordeus IA, et al. (2016) Agreement between Parents and Children with Sickle Cell Disease in Rating Children's Oral Health- Related Quality of Life. J Hematol Transfus 4(1): 1044.