

Quality of life among children with cancer: agreement between child and parent reports

Qualidade de vida em crianças com câncer: concordância entre crianças e pais

Calidad de vida de niños con cáncer: concordancia entre niños y padres

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ABSTRACT

Objective: To describe the health-related quality of life (HRQoL) among children with cancer; assess agreement between self and proxy-report and identify influencing factors of the differences in self and proxy-report. **Methods:** A descriptive cross-sectional study was conducted in two pediatric oncology units of two Portuguese hospitals. The study involved hospitalized children with cancer (8-17 years old) and their parents. **Results:** The child's perception of their HRQoL was 66.0 ± 13.3 and parents' perception scored 60.3 ± 15.0 . The agreement between self and proxy-report was moderate (strong association). Variables related to the child's age, gender, type of tumor, time elapsed since diagnosis and number of hospitalizations did not influence the differences between self and proxy-report. **Conclusion:** An intervention with more support should be made in the resolution of concerns, management of pain and discomfort in children and reduce parental anxiety. It is necessary to clarify the influence of the factors that influence the differences between self and proxy-report.

Keywords: Child; Cancer; Nursing; Quality of life.

RESUMO

Objetivo: Descrever a qualidade de vida relacionada com a saúde (QVRS) de crianças com câncer; avaliar a concordância entre auto e heterorrelato; e identificar fatores influenciadores das divergências no auto e heterorrelato. **Métodos:** Estudo descritivo e transversal desenvolvido em dois serviços oncológicos pediátricos de dois hospitais Portugueses que envolveram crianças com cancro (8-17 anos) e seus pais. **Resultados:** A percepção da criança da sua QVRS foi de $66,0 \pm 13,3$ e a dos pais de $60,3 \pm 15,0$. A concordância entre auto e heterorrelato foi moderada, sendo a associação forte. Variáveis relacionadas com a idade da criança, sexo, tipo de tumor tempo de diagnóstico e número de internamentos não influenciaram as divergências entre o auto e heterorrelato. **Conclusão:** Uma intervenção com mais apoio deve ser realizada na resolução das preocupações, gestão da dor e desconforto da criança e redução da ansiedade dos pais. É necessário esclarecer a influência dos fatores que influenciam as divergências entre o auto e heterorrelato.

Palavras-chave: Criança; Câncer; Enfermagem; Qualidade de vida.

RESUMEN

Objetivo: Describir la calidad de vida relacionada con la salud (CVRS) de niños con cáncer; evaluar la concordancia entre el auto y el heterorrelato; identificar factores que influyen las diferencias en el auto y el heterorrelato. **Métodos:** Estudio descriptivo y transversal, realizado en servicios de oncología pediátrica de dos hospitales, que involucró a niños con cáncer (8-17 años) y sus padres. **Resultados:** La CVRS del niño fue $66,0 \pm 13,3$ y la de los padres $60,3 \pm 15,0$. La concordancia entre el auto y el heterorrelato fue moderada (asociación fuerte). La edad del niño, sexo, tipo de tumor, tiempo de diagnóstico y el número de hospitalizaciones no influyeron en las diferencias entre el auto y el heterorrelato. **Conclusión:** Una intervención con más apoyo debe ser realizada en la resolución de las preocupaciones, manejo del dolor y el malestar del niño y reducción de la ansiedad de los padres.

Palabras-clave: Niño; Câncer; Enfermería; Calidad de vida.

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INTRODUCTION

It is estimated that 165 new cases of cancer are diagnosed in the central and northern region of Portugal every year. Today, more than 79% of children with cancer survive¹ as a result of increasingly aggressive treatments. This poses serious challenges to ensuring a good health-related quality of life (HRQoL) for these children and their families who have to face an uncertain future, aggressive treatments, and repeated hospitalizations².

HRQoL assessment is essential for health care professionals to make a reliable and accurate diagnosis, capable of sustaining an effective intervention for its improvement. Despite self-report being the best method to assess personal experiences such as the HRQoL, the parents' perspective cannot be ignored as a key aspect in decision-making.

LITERATURE REVIEW

Forty-eight studies were retrieved from the database of the *National Center for Biotechnology Information* (NCBI) using the keywords "PedsQL" and "cancer" and "Child" in the title and abstract and without any other restrictions. Among the studies that have been carried out in children with cancer and using the Pediatric Quality of Life Inventory™ (PedsQL™) 3.0 Cancer Module (self- and proxy-report), a study was found involving 339 families of children aged between 2 and 18 years in the United States. This study found a total mean of self-reported HRQoL of 73%, ranging between 68% and 82% for the subscales, and a mean of 74% in the proxy-report, ranging between 60% and 78%.³ In a study carried out in Libano⁴ with 85 children aged between 7 and 18 years, a mean HRQoL of 80% (64%-91%) was found. A study with 212 Japanese families of children aged between 5 and 18 years found self-report scores of 78% (67%-93%) and proxy-report scores of 75% (62% and 85%)⁵. In China⁶, a study with 359 families of children aged between 5 and 18 years followed on an outpatient basis found HRQoL scores of 84% (75%-94%) in children and 80% (68%-91%) in parents.

In the few studies that have examined the level of parent-child agreement on HRQoL⁷, no unanimous conclusions were reached^{2,8-10}. In all studies that found a level of agreement, that agreement was moderate¹¹. The factors that contributed to a higher level of agreement were related to the physical, emotional or social domains; chronically ill children, children undergoing active treatment and older children; and a lower parent-reported HRQoL (tendency to project their HRQoL onto their children's HRQoL)^{7,10}.

The assessment of children's HRQoL and parents' perceptions of their children's HRQoL, as well as the factors that might influence this relationship, enables and facilitates the implementation of interventions for improving HRQoL in children and their parents.

Thus, this study aimed to describe the HRQoL of children with cancer (child self-report and parent proxy-report), assess agreement between self- and proxy-report, and identify influencing factors of the differences in self- and proxy-report of the child's HRQoL.

METHOD

Study design and participants

A descriptive cross-sectional study was conducted in two pediatric oncology units of two Portuguese hospitals. The study involved hospitalized children with a diagnosis of cancer and their parents. Recruitment was consecutive between April 2013 and May 2014.

The sample was composed of 75 hospitalized children aged between eight and 17 years, with a median of 15 years and an interquartile range (IQR) of four years. Most of them were male 54 (72%), with seven or more years of education 51 (68.0%). At least half of them lived with a sibling, ranging between none and three. The mean time elapsed since diagnosis was four months (\pm 10 months), with at least half of them having received confirmation of diagnosis over the last month (IQR = 3 months).

The parents who participated in the study had a median age of 42 years (IQR = 8 years), ranging between 18 and 59 years. Most of them were married 49 (65.3%) and had 10 or more years of education 41 (52.7%). A total of 58 (78.7%) mothers participated in the study.

Instruments

The PedsQL™ 3.0 Cancer Module is an instrument for assessing HRQoL in children with cancer that includes a child self-report and a parent proxy-report.

The questionnaire is composed of 27 items divided into 8 subscales: "pain" (two items); "nausea" (five items); "procedural anxiety" (three items); "treatment anxiety" (three items); "worry" (three items); "cognitive problems" (five items); "perceived physical appearance" (three items); and "communication" (three items).

Parents assess how much of a problem each item has been during the past one month. A 5-point Likert scale is used: 0 = "never", 1 = "almost never", 2 = "sometimes", 3 = "often" and 4 = "almost always". These items are reverse scored and transformed to a 0-100 point scale (0 = 100, 1 = 75, 2 = 50, 3 = 25, and 4 = 0), in which higher scores indicate better HRQoL.

The Portuguese version of the PedsQL™ 3.0 Cancer Module (child self-report and parent proxy-report) was completed by the child and one of the parents separately, but simultaneously, in the hospital room.

Statistical treatment

Data were analyzed using the IBM SPSS Statistics 19 Software (IBM, Armonk, NY, USA).

The distributions were assessed using the Kolmogorov-Smirnov test for normality and histograms.

The mean and standard deviation were used to describe the summary statistics for total scale and subscales. Self- and proxy-reports were compared regarding: 1) the agreement using the intraclass correlation coefficient with a 95% confidence interval, considering a score \leq 0.40 as poor, \leq 0.60 as moderate, \leq 0.80 as good, and $>$ 0.80 as excellent¹², and using the percentage of agreement; 2) Spearman's correlation test, considering a score \leq 0.30 as a weak correlation, \leq 0.50 as moderate, and

> 0.50 as strong²; 3) the differences between self- and proxy-reports in the total scale and subscales using the Mann-Whitney U-test for independent samples according to age group (8-12 and 13-17 years), gender, and type of tumor (solid and liquid). The association with the time elapsed since diagnosis, number of previous hospitalizations, and number of siblings was assessed using Spearman's correlation coefficient.

All tests with a value of $p < 0.05$ were considered statistically significant.

Ethical considerations

Authorization was obtained from the MAPI Research Institute. The study was approved by the Ethics Committee of the Health Sciences Research Unit: Nursing of the Nursing School of Coimbra and the Ethics Committees of the Hospitals where the study was conducted (protocol number of the Ethics Committee 10-11/2010). Written parental consent and children's assent were obtained.

RESULTS

Overall, children reported better HRQoL (66.0 ± 13.3) than did their parents (60.3 ± 15.0). In the self-report, the highest scores were found in the subscales "perceived physical appearance" (79.0 ± 21.2) and "treatment anxiety" (79.0 ± 27.2). In the proxy-report, the highest scores were found in the subscales "communication" (78.6 ± 22.8) and "perceived physical appearance" (70.8 ± 24.8). The lowest score, both in self- and proxy-reports, was found in the subscale "worry" (39.2 ± 28.1 and 37.4 ± 29.1 , respectively) (table 1).

Table 1. Self- and proxy-report of HRQoL using the PedsQL™ 3.0 Cancer Module

PedsQL™ 3.0 Cancer Module	Self-report (Mean ± SD)	Proxy-report (Mean ± SD)
Total	66.0 ± 13.3	60.3 ± 15.0
Pain	65.8 ± 25.9	57.2 ± 28.3
Nausea	53.8 ± 22.2	56.7 ± 24.0
Procedural anxiety	67.8 ± 26.9	54.8 ± 30.3
Treatment anxiety	79.0 ± 27.2	60.3 ± 28.9
Worry	39.2 ± 28.1	37.4 ± 29.1
Cognitive problems	69.6 ± 20.7	64.9 ± 21.9
Perceived physical appearance	79.0 ± 21.2	70.8 ± 24.8
Communication	76.6 ± 25.26	78.6 ± 22.8

The percentage of agreement between self- and proxy-reports was 41.0%, being higher in the subscale "communication" (50.2%) and lower in the subscale "treatment anxiety" (34.2%). Overall, the agreement was moderate 0.53 (0.32-0.69), with a strong ($r_s = 0.56$) and statistically significant ($p < 0.01$) association. The best agreement (0.71; 0.58-0.81) and correlation

($r_s = 0.70$) were found in the subscale "nausea", while the worst were found in the subscale "treatment anxiety", 0.38 (0.01-0.59) and $r_s = 0.37$, respectively (table 2).

No statistically significant differences were found in the self- and proxy-reports regarding the child's age, gender, and type of tumor, as well as no statistically significant association with the time elapsed since diagnosis, number of previous hospitalizations, and number of siblings.

DISCUSSION

The results describe the HRQoL of parents and children with cancer aged between eight and 17 years who were hospitalized in two of the four Portuguese pediatric oncology units.

Children reported better HRQoL than did their parents. This evidence is found in several other studies^{2,7,10} and justified by the parents' tendency to project their HRQoL onto their children. Although they reported a better HRQoL than their parents, it is lower than that found in other studies^{3,6,7}. This aspect should receive special attention from those who care for these children and families. However, the time elapsed since diagnosis is very low in our study, which may explain an impaired HRQoL, as the experience of the different stages along the course of the disease allows for a progressive adaptation of the child and parents to the situation and, consequently, an improvement of HRQoL¹⁰.

When comparing the means of the subscales between the studies, a coincidence was found in the subscale "treatment anxiety", which was perceived as the best score in our study and in that of Varni et al.³ This evidence seems to reflect that children and parents cope with the situation by keeping their hope and belief in a cure through treatments¹³.

Both children and parents reported lowest HRQoL in the subscale "worry", which indicates that both of them are concerned about the possible side effects of treatments, their effectiveness and disease recurrence. This is common in children with cancer from other parts of the world⁴ and reinforces both the urgent need for an effective, targeted and planned intervention, with more information and support for a good management of this problem that affects children and their parents, and the importance of both children and parents being cared for.

As in the study developed in Libano⁴, the subscale "nausea" was one of the subscales in which both children and parents reported the lowest scores. The subscale "pain" was another subscale in which children and parents had low scores of HRQoL, suggesting a clear and urgent investment in alleviating the child's pain and discomfort. New pharmacological and non-pharmacological strategies of undeniable value have been developed to prevent intravenous and procedural pain¹⁴. Their use will help to improve the children's HRQoL in this dimension, as well as in the dimension related to "procedural anxiety".

The percentage of agreement between self- and proxy-reports reached no more than 50% of the answers, being higher in the subscale "communication" and lower in the subscale "treatment anxiety".

Table 2. Correlation between self- and proxy-report

PedsQL™ 3.0 Cancer Module	Intraclass correlation (95% confidence interval)	Spearman's correlation (r_s)	Agreement (%)
Total	0.53 (0.32-0.69)	0.56*	41.0
Pain	0.56 (0.37-0.70)	0.59*	43.3
Nausea	0.71 (0.58-0.81)	0.70*	39.7
Procedural anxiety	0.57 (0.32-0.73)	0.64*	44.0
Treatment anxiety	0.38 (0.01-0.59)	0.37*	34.2
Worry	0.49 (0.30-0.65)	0.48*	36.9
Cognitive problems	0.53 (0.35-0.68)	0.42*	38.7
Perceived physical appearance	0.41 (0.20-0.58)	0.39*	44.0
Communication	0.46 (0.27-0.63)	0.49*	50.2

* $p < 0.01$.

Overall, the agreement assessed by intraclass correlation coefficient was moderate¹², with a strong association (Spearman's correlation)² in all subscales, but lower than the values found by Matziou et al.⁷ The highest agreement was identified in the subscale “nausea” and the lowest in the subscale “treatment anxiety”. Both children and parents can easily and objectively identify problems (signs and symptoms such as nausea) related to an activity of daily living, such as feeding. Treatment anxiety (anxiety about visiting the doctor, going to the hospital or in the waiting room) is related to a feeling of threat that precedes moments of danger or tension of unknown cause, whose assessment relies on cognitive maturity, which is quite different between a child and an adult. On the other hand, it is an intimate and personal experience with very different manifestations. In addition, parents have a tendency to associate cancer with poor prognosis and uncertainty about the future, even more than children⁷, which may explain this greater divergence between children and parents. This evidence, together with the low scores of proxy-reports in this dimension, should lead to the implementation of interventions aimed at reducing anxiety, particularly in parents, who are often forgotten. Parents are key members of the healthcare team for their child's recovery, which will only be effective if they feel at peace and safe.

No statistically significant differences were found in the HRQoL of children and parents regarding child-related variables such as age, gender, and type of tumor, as well as no statistically significant association with the time elapsed since diagnosis, number of previous hospitalizations, and number of siblings. Other studies have reached these same conclusions^{4,15}.

Although the differences were not statistically significant, younger children, male children, children with a diagnosis of liquid tumor, children with less time elapsed since diagnosis and children with less hospitalizations showed better HRQoL. However, further studies are needed to clarify the influence of these factors.

Implications for clinical practice and research

The results suggest that the health care professionals, and particularly the nurses, should be more proactive and effective during hospitalization in the search for the best way to implement a life project with quality, specifically in the dimensions “worry”, “nausea” and “pain”. The work method with a primary nursing in Portugal (model of work organization in which the nurse is responsible for total care of assigned clients on a 24-hour basis), a reality that has not yet been implemented in Portugal, can give a major contribution to the establishment of a helping relationship which will allow children and parents to cope better with their concerns about the disease and the treatments. It is necessary to translate the scientific evidence on management of procedural anxiety and pain into practice in order to improve these HRQoL dimensions.

A cross-sectional analysis of HRQoL in children with cancer was performed in this study. We recognize that a longitudinal study at various moments during the course of the oncologic disease may provide additional information on the evolution of the children' and parents' perception of HRQoL and the influencing factors.

CONCLUSION

The children and parents who participated in this study reported a lower HRQoL than that found in other studies. The highest score was found in the subscales “perceived physical appearance” and “treatment anxiety”, which seems to indicate the level of care provided to help children and parents cope with the situation and keep their hope and belief in a cure. However, more information and support is needed to help children and parents deal with their concerns and better manage pain and discomfort (areas with lower HRQoL).

In general, the child-parent agreement is moderate and has a strong association, which suggests that, in children who are

not able to self-report, the parent proxy-report is a valid method to assess HRQoL.

As key members of the healthcare team in their child's recovery, parent-focused interventions should be implemented to reduce their anxiety and enable their effective and efficient participation in care.

No differences were found in HRQoL (self- and proxy-report) regarding the child's age, gender, type of tumor, time elapsed since diagnosis, and number of hospitalizations. However, further studies are needed to explain the influence of these factors on the divergence between child self-report and parent proxy-report.

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