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ORIGINAL ARTICLE

QUALITY OF LIFE OF CHILDREN SUBMITTED TO CYSTENTOPLASTY AND CAREGIVERS*

QUALIDADE DE VIDA DE CRIANÇAS SUBMETIDAS À CISTOENTEROPLASTIA E CUIDADORES

CALIDAD DE VIDA DE LOS NIÑOS SUJETOS A CISTENTEROPLASTIA Y CUIDADORES

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ABSTRACT

Objective: to evaluate the quality of life (QOL) of children with myelomeningocele who underwent cystenteroplasty in 2006-2016 and their caregivers. ***Method:*** this is a descriptive mixed study, conducted in a rehabilitation hospital, with a final sample of 16 participants, using the generic Pediatric Quality of Life Inventory instrument and a structured interview for the specific condition. The results were presented in tables and statements. ***Results:*** eight dyads participated in the study, being that "physical capacity" and "social aspect" were the domains with the most divergent perspective, whereas "emotional aspect" and "school activity" were more convergent. QoL was affected negatively in the immediate postoperative period due to prolonged fasting and the use of nasogastric tube and, in the late postoperative period, was positively attributed to the acquisition of social continence, lower frequency of urinary tract infection and greater independence of children. ***Conclusion:*** it is concluded that the perception of QOL of patients submitted to cystenteroplasty and their caregivers was improved after this surgery. ***Descriptors***: Child; Adolescent; Quality of Life; Pediatric Nursing; Neurogenic Urinary Bladder; Nursing.

RESUMO

Objetivo: avaliar a qualidade de vida (QV) de crianças com mielomeningocele submetidas à cistoenteroplastia, nos anos de 2006-2016, e de seus cuidadores. ***Método***: trata-se de um estudo misto, descritivo, realizado em um hospital de reabilitação, com uma amostra final composta por 16 participantes, utilizando-se o instrumento genérico *Pediatric Quality of Life Inventory* e uma entrevista estruturada para a condição específica. Apresentaram-se os resultados em forma tabelas e depoimentos. ***Resultados***: elencaram-se para participar do estudo oito díades, sendo que "capacidade física" e "aspecto social" foram os domínios com a perspectiva mais divergente, ao passo que "aspecto emocional" e "atividade escolar" foram mais convergentes. Afetou-se a QV no pós-operatório imediato negativamente devido ao jejum prolongado e ao uso de sonda nasogástrica e, no pós-operatório tardio, foi positivamente atribuída à aquisição da continência social, menor frequência de infecção do trato urinário e maior independência das crianças. ***Conclusão***: conclui-se que a percepção da QV de pacientes submetidos à cistoenteroplastia e seus cuidadores foi melhorada após a realização dessa cirurgia. ***Descritores***: Criança; Adolescente; Qualidade de Vida; Enfermagem Pediátrica; Bexiga Urinária Neurogênica; Enfermagem.

RESUMEN

Objetivo: evaluar la calidad de vida (CV) de los niños con mielomeningocele sometidos a cistenteroplastia en los años 2006-2016 y sus cuidadores. ***Método:*** este es un estudio descriptivo mixto, realizado en un hospital de rehabilitación, con una muestra final de 16 participantes, utilizando el instrumento genérico *Pediatric Quality of Life Inventory*e una entrevista estructurada para la condición específica. Los resultados se presentaron en tablas y declaraciones. ***Resultados:*** ocho díadas participaron en el estudio, ya que la "capacidad física" y el "aspecto social" fueron los dominios con la perspectiva más divergente, mientras que el "aspecto emocional" y la "actividad escolar" fueron más convergentes. La calidad de vida se vio afectada negativamente en el postoperatorio inmediato debido al ayuno prolongado y el uso de sonda nasogástrica y, en el postoperatorio tardío, se atribuyó positivamente a la adquisición de continencia social, una menor frecuencia de infección del tracto urinario y una mayor independencia de los niños. ***Conclusión:*** se concluye que la percepción de la calidad de vida de los pacientes sometidos a cistenteroplastia y sus cuidadores mejoró después de esta cirugía. ***Descriptores***: Niño; Adolescentes; Calidad de Vida; Enfermería Pediátrica; Vejiga Urinaria Neurogénica; Enfermería.

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INTRODUCTION

Myelomeningocele (MMC) is defined as one of the types of spina bifida (SB) manifested by an external protrusion of central nervous system (CNS) tissue. It is the most severe and prevalent form, representing about 75% of all SB[1] cases and, among the health problems presented by people with MMC, urinary incontinence (UI), related to the presence of neurogenic bladder (NB) is a problem with significant clinical relevance as it affects 48% to 76% of children with MMC.[2]

Conservative therapy is the first choice in the treatment of NB with the aim of increasing bladder capacity and / or reducing the high-pressure bladder, using anticholinergic medication, usually associated with the practice of clean intermittent catheterization (CIL). If this approach is unsuccessful, other options including procedures such as botulinum toxin injection, electrical stimulation therapy, and cystenteroplasty (augmentation cystoplasty) are recommended).[3]

It is noticed that young people with SB face multiple challenges in the adaptation and rehabilitation process, mainly affecting psychological and social well-being. It is understood that these young people are at risk of developing limited coping skills due to difficulties in problem solving and development of restricted social skills, in addition to challenges related to school performance, prejudice and delayed transition to independence.[4]

In this context, health-related quality of life assessments (HRQoL) and the use of patient-reported outcome measures are included. Patient reported-outcomes measures (PROMs) are used to analyze a range of outcomes that assess the impact of diseases or clinical interventions including health or functional status, HRQoL, well-being, satisfaction and perceived quality of health care, and there are numerous generic and disease-specific PROMs.[5]

There are generic PROMs, which are instruments for assessing patients 'perceptions, both those with and without a disease, and although they may allow the comparison of patients' perceptions with different diseases, they do not allow a description of perceptions of specific diseases, as opposed to those specific to a particular disease.[5]

HRQoL is known to be a multidimensional and subjective construct that captures life experience in the individual's physical, emotional, psychological and social aspects, as well as health perceptions that intersect with the World Health Organization's definition of health. Health (WHO) in its biopsychosocial aspects.[6,7] Such dimensions are believed to be profoundly affected in children with chronic diseases, especially those affecting the genitourinary tract (GUT).

Indeed, it is pointed out that the presence of congenital malformations of the GUT often requires numerous therapeutic interventions and / or reconstructive surgical procedures. These interventions result in prolonged hospitalizations, compromising the social interaction of children with UI symptoms, and may lead to psychosocial problems, which are brought about by the chronic character of the disease.[7]

Specific QOL measuring instruments are known to adapt to a particular condition or population, can help quantify disease symptoms and assess the impact on QOL. NB complications have been associated with lower QoL, especially in the physical, mental and social domains. Note, however, that there are only a few PROMs specifically designed for children with NB.[8] It is verified that the instruments used to measure HRQoL, when validated, are mostly generic, requiring complementation to investigate QOL related to the specific condition for the Brazilian population and such limitation led the researchers in this study to perform a mixed method study approach.

OBJECTIVE

- To evaluate the quality of life (QOL) of children with myelomeningocele who underwent cystenteroplasty in the years 2006-2016 and their caregivers.

METHOD

This is a descriptive mixed study, carried out in two units of the Rehabilitation Hospitals Network in Brasília-DF.

Inclusion criteria are children and / or adolescents (read children), of both sexes, from six to 16 years old, with primary diagnosis of MMC who underwent cystenteroplasty surgery, from 2006 to 2016. , and accompanied in one of the units of Brasilia-DF. The caregivers' inclusion criteria were: to be the main caregiver (ie, to be responsible or to be present most of the time during the care of the child); be present at the time of the interview and have legal custody of the child.

This work was submitted to the Research Ethics Committee (REC) under Opinion No. 2.170.105, approving it on 07/12/2017. Data were collected between August and October 2017 through interviews and all participants had at least six months of the surgery in question.

In the initial sample for the research, 15 children and 15 caregivers who met the inclusion criteria of the research were expected. Of these, five did not have any scheduled care at the institution during the period for data collection and, when they contacted by phone, inviting them to participate in the research, they refused due to the difficulty of attending the institution just for research, without scheduled professional care. In addition, most of these, although accompanied at the Brasília-DF unit, lived in nearby cities, but in another state of the federation (which made it impossible to collect data at home). Of the remaining ten, which would receive care during the data collection period, one agreed to participate in the research, but on the scheduled day, missed the attendance and, consequently, the participation of the research and another imposed condition to attend the institution provided it was given to the child's father, and the interviewed caregiver would be the mother, which also made data collection impossible. Thus, it is informed that the final sample consisted of 16 participants, eight children and eight caregivers who met the inclusion criteria and agreed to participate in the research.

The interviews were linked to some service in the institution. It is explained that, in the case of two dyads (referring to the child and his caregiver), data collection took place during hospitalization, with one patient undergoing clinical treatment for pressure injury and the other in pre-operatory orthopedic correction surgery.

The interviews were conducted, firstly, applying the instrument validated for the Brazilian context PEDsQLTM4.0 (quantitative part), as a strategy to establish bond and facilitate the communication process with the interviewees. The PedsQL ™ 4.0 instrument is known to have been developed in two versions: a pediatric version to measure HRQoL in children aged five to 18 years and a version for parents of children two to 18 years old. It is noteworthy that it is a generic instrument for HRQoL assessment, which has been translated and validated for Brazilian culture. It is noted that this instrument assesses the overall QOL of the child / adolescent and is composed of 23 questions divided into four dimensions: physical functioning (five items), emotional functioning (five items), social functioning (five items) and school functioning (five items). The questions refer to the duration of a problem in the last month, being scored from zero (never a problem) to four (almost always a problem).[9]

Subsequently, the structured interview was carried out and recorded for later transcription of the speeches and in-depth analysis (qualitative part). It is described that in this structured instrument there were objective questions related to self-care practices and discursive questions related to how, when and what influenced self-care, as well as questions related to social and school life before and after the surgery in question.

Eight children were interviewed, five of whom did not do the interview individually due to lack of physical space, and of these five, three refused to respond to the interview away from their parents. In these cases, interviews were conducted with the children in the presence of their parents, and at no time did they interrupt their children's responses. It is noted that the average duration of the interviews (quantitative and qualitative) was about one hour and 30 minutes for each dyad.

Sociodemographic and clinical data were obtained through electronic medical records. The quantitative data obtained from the interviews were coded by inserting them into an Excel spreadsheet, Microsoft Office 2007 version.

Qualitative data were fully transcribed in a Word file, 2007 version, by the researcher, submitting them to Content Analysis in Bardin's proposition[10]. Initially, the material was explored with the exhaustive reading of the lines. Then, the answers obtained were grouped, synthesizing them according to the content of the speeches. Afterwards, the nuclei of meaning extracted from the interviewees' statements were identified, grouping them according to the thematic unit.

In this process, the thematic categories related to the meanings brought by the participants were obtained. The anonymity of the dyads was ensured through the use of an alphanumeric code to identify the interviews, with the letter P for pediatric patients and the letter C for caregivers, followed by their sequential number (P1, P2, ...P8 e C1, C2, ...C8).

RESULTS

Regarding the sociodemographic and clinical profile of the children, the ages ranged from 12 to 16 years, four (50%) female and four (50%) male.

It was found, considering the eight participants, that only two (25%) had no cognitive evaluation record in the medical records, since the children did not have any apparent lag; of the other six (75%), two (25%) had mild cognitive impairment according to the Wechsler Psychometric Intelligence Scale for Children - 4th edition (WISC-IV) or Raven's scale; two (25%) presented cognitive performance within the average age; one (12.5%) with extremely low global cognitive deficit and one (12.5%) in which the assessment was inconclusive, however, this did not hinder participation in the research, as the questions of the instruments used in the research were simple and straightforward.

The WISC-IV scale was used for children and adolescents from six years and zero months to 16 years and 11 months, which measures the intelligence construct, being of individual application and which aims to evaluate the intellectual capacity and the process.

troubleshooting. The scale is preferably administered in two sessions and, among its main applications, are cognitive estimation in psychological, neuropsychological and psychoeducational assessment; the differential diagnosis of neurological and psychiatric disorders and the planning of cognitive (neuro) rehabilitation programs.[11] This is the Raven Color Progressive Matrix Test, a nonverbal intelligence test that specifically assesses the "g" factor proposed by Spearman. It is preferable for children from five to 11 and a half years old, but can be used for the mentally handicapped and the elderly. It is also suggested for people with physical disabilities, aphasias, cerebral palsy and deafness, as well as those who do not speak the national language. The color scale is composed of three series (A, Ab and B), each with 12 problems. Basically, the evaluation involves two mental components, called eductive capacity and reproductive capacity. It is briefly explained that it would be the ability to extract meaning from a non-obvious situation, to develop new understandings, to establish constructs involving many mutually dependent variables. Progressive Matrix Testing is recommended for simpler and faster assessments and can be used in groups or individually.[12]

Regarding the CMM level, all of them had lumbar level, being six (75%) community walkers (CW) and two (25%) moved with the aid of wheelchair (WC); all had compensated hydrocephalus, four (50%) compensated with ventriculoperitoneal shunt (VPS) and four (50%) with third ventriculostomy.

The length of hospital stay for surgery ranged from 19 to 29 days, while postoperative time up to the time of the interview ranged from one year and five months to three years and ten months.

It was found that all participants performed self-CIL (clean intermittent self-catheterization) and five (62.5%) acquired continence and did not use diapers; two (25%) still had urinary leakage and one (12.5%) acquired continence, however, still reported feeling insecure and afraid of having urinary and / or fecal loss, and therefore, diaper users during all day long. These data are illustrated in table 1.

Table 1. Sociodemographic and clinical profile data of pediatric patients who underwent cystenteroplasty surgery, from 2006 to 2016, in a rehabilitation hospital. Brasilia (DF), Brazil, 2018.

ID	P1	P2	P3	P4	P5	P6	P7	P8
Age	16	16	13	12	13	15	12	13
Sex	M	M	M	F	F	M	F	F
Duration of hospitalization (days)	25	26	25	19	20	25	29	22
Post-Enlargement Time	2a and 7m	1a and 7m	1a and 5m	2a and 1m	3a and 7m	3a and 10m	2a and 7m	1a
Continence	UL and UD	UL and UD	UL and UD	C	C	C	C	C and UD

Key: PO: postoperative UL: urinary loss; UD: uses diapers; C: continent

Among the caregivers, only one (12.5%) was represented as the father and the others by the mothers, and the average age of the caregivers was 45 years old; In relation to education, the majority (62.5%) had at least the second level, being only one (12.5%) with higher education and one (12.5%) with technical level.

In the quantitative analysis, comparing the mean dyadic scores by domains of the PEDsQL^{TM}4.0 instrument, a proximity in the scores values, and this aspect points to a similarity of the answers, considering the perspective of each dyad component, when answering the interview. It was observed that the most striking difference is the averages in the "social aspect", comparing between the perceptions of the child and the caregiver, and the child presented a higher average in relation to the caregiver average, as shown table 2.

It was found, analyzing by domains, that there was a convergence of responses between the dyad scores for the domains "emotional aspect" and "school activity", ie, the dyad tends to score / agree in the same direction; On the other hand, there was no convergence between the scores for the domains "physical capacity" and "social aspect". In other words, children and caregivers tend to disagree and punctuate in opposite directions in these two domains.

Table 2. Comparison of mean domain scores of the PEDsQL^{TM}4.0 instrument of caregivers and pediatric patients who underwent cystenteroplasty surgery, from 2006 to 2016, in a rehabilitation hospital. Brasilia (DF), Brazil, 2018.

Domain	N	Pediatric patient		Caregiver	
		Average	Standard Deviation		
Physical capacity	8	50,3	18,5	53,9	23,3
Emotional aspect	8	65,6	18,6	66,9	27,0
Social aspect	8	69,4	21,8	62,5	17,5
School activity	8	49,4	18,0	48,1	20,2

In the qualitative analysis, the following three thematic categories were verified: urinary loss, surgery difficulties and independence for self-CIL. These thematic categories are presented and discussed below.

♦ **Thematic category 1: Urinary losses represented by "improvement", "continuing loss" and "acquiring continence".** According to the dyad, in this category, the perception of QOL, and according to three (37.5%) caregivers, after surgery, their children were "healthier" and had less urinary tract infection (UTI). (C4; C1; C2).

> *He continues with losses [...], but the surgery was valid because, thank God, his kidneys are preserved. (C1)*
>
> *98% improved his issue of infection [...] was greater blessing. (C2)*

There were reports such as a caregiver (C4), who mentioned that it was best to see his son no longer need to take medicine and be without diapers. Another caregiver (C5) reported that the length of stay was the most difficult. It was described by two caregivers (25%) that doing the CIL at 3 / 3h, inclusive, at dawn, was very difficult (C2 and C3). One caregiver (12.5%) reported that although she knew the kidneys were preserved, she was frustrated that her child continued to have urinary leakage (C6).

One patient (12.5%) was reported to have stopped sports after cystenteroplasty because she was afraid of being injured (P5), and her caregiver (C5) made clear in her speech that discontinuing sports was a self-preservation strategy.

> *Continues to participate in sports activities within limitations. One thing we always put to her is self-preservation. Ball activities, we always spoke to be careful [...] she always had this notion of preserving herself. (C5)*

Two patients (25%) were reported as having difficulty waking up at dawn to perform the 3 / 3h CIL (P2 and P5).

♦ **Thematic category 2: Surgery difficulties represented by the use of the "nasogastric tube" (NGT) and "mediate postoperative fasting"**

Pain was reported as a postoperative discomfort, as reported by two dyads (C1 / P1 and C3 / P3); however, all children reported that the major discomfort was fasting and the use of postoperative NGT.

> *The most difficult was the nose tube, which was very annoying [...]. And the fast. At home, it was just joy [...] not even the cat at dawn bothered me [...] I was so happy with the result that it was cute. (C1)*
>
> *The most difficult, at the time of surgery, the tube and fasting. At home it was all quiet. The surgery was very worthwhile because I stopped wearing a diaper, I don't lose so much pee [...] even at school friends said: "She wet her clothes, look, she peed"; now it doesn't happen. (P3)*

● **Thematic category 3: Independence for auto-CIL with subcategories "acquired", "facilitated" and "no difference"**

One patient (P8) testified, becoming more independent in the practice of auto-CIL after enlargement surgery and placement of the Mitrofanoff conduit. Previously, it was difficult to position during catheterization, requiring its mother to perform the procedure and, postoperatively, there was the possibility of self-CIL practice, promoting greater independence in the management of urinary elimination, besides the acquisition of social continence.

DISCUSSION

Almost normal IQ is present in patients born with SB, and the presence of significant delay is observed in less than 20% of cases, and most of them have low back MMC and are CD (55%).[13]

Hydrocephalus is mentioned as one of the most frequent complications arising from MMC, being present in 73% of young people with MMC and, among these youngsters, 97% used the ventricular bypass valve (VB) .13 Another study reported 54% of children with MMC were CD with or without assistance and 63% were using CR.[14]

These results are similar to those found in the literature, since most participants in this study had no relevant cognitive impairment that prevented the interviews, and all had low back MMC and were CD.

Regarding the operative period, the length of hospitalization for this surgery, mentioned by other studies, ranged from seven to 9.7 days, [3,15,17] which approached the temporality found in the results of this research.

It is known that young people living with a chronic illness remain between wanting to be independent and still needing self-care support. In fact, chronic illness often increases dependence on others, challenges one's self-image and identity,[4] and approximately 85% of children with MMC who have CIL can socialize in relation to urinary continence.[16]

In view of the above, the caregiver of children with NB who performs the CIL has an overload due to the demands and care derived from this practice.

Thus, it is evident the importance of health professionals, which lies in the fact that they can provide and encourage the pursuit of independence in the practice of self-care by young people, as well as encourage and support caregivers to let their children perform this care. It is allowed, by relieving this burden of the caregiver, that they can resume their professional and / or personal activities at the time they would devote to providing this care to their children.[18]

In this study, it is pointed out that the dyads reported a similarity of perception in the domains “physical capacity” and “school activity”. On the other hand, it is understood that there was no strong correlation between the scores for the domains “emotional aspect” and “social aspect” and this fact may be related to an overprotection of parents in relation to their children or even underestimate the children's developmental skills.

It is also observed that most of the sample consisted of adolescents and the divergences in the PEDsQL responses may be related to the characteristics of this phase of development, that is, the search for identity and independence. It is believed that some parents may be reluctant to give adolescents autonomy in managing their condition, and the literature indicates that parental overprotection is common in young people born with some kind of disability.[19]

In the case of young people with SB, even though they are in a family that provides support and values their emotional growth, they still reported the family's difficulty in coping with the chronic disease. In these cases, what begins as concern and care becomes isolation and adolescent.[4]

It is evident that augmentation cystoplasty can promote social continence in up to 95% of cases, [17,20] which corroborates the results of this study, since most participants reported the acquisition of social continence.

It is pointed out that urinary continence probably benefits social participation, allowing better performance and independence of daily activities. Additional procedures for the acquisition of social continence are required in some cases, for example the creation of a catheterizable canal (ostomy continent by Mitrofanoff technique) as a means to provide more convenient access when urethral catheterization it's hard or impossible.[3] In this study, it was found that only one child needed the construction of the Mitrofanoff conduit in order to facilitate auto-CIL. Such surgical intervention was positively associated with improved QOL, as it provided the patient with the independence to empty their own bladder.

It is known that after surgery, the presence of pain is predictable, since surgical procedures were directed to GUT problems,[21] but in this study, only two dyads reported postoperative pain.

Self-preservation may be related to the aspects of parents' overprotection towards their chronically ill children, as they do not always perceive their children's difficulties in expressing their own limitations, nor the difficulties in coping with socialization, since that many do not believe in their children's independence in activities of daily living. Thus, it is noteworthy that the anti-socialization providers of the children end up being the parents themselves because, in an attempt to “protect” them, they promote the removal of the children from the positive social relations generated by socializing.[22] One patient reported having stopped sports after surgery for fear of injury and her caregiver reported this as a self-preservation strategy.

It has been found that cystenteroplasty is still the basis for urinary tract reconstruction for patients with low bladder capacity who do not respond well to conservative treatment with CIL and / or anticholinergic drug therapy. The main objective of this reconstruction is known to improve bladder function by maintaining low intravesical pressure in order to preserve the kidneys as well as to achieve continence.[23]

It is evident that children with NB represent one of the largest pediatric populations that need continuous and complex urological management as they transition to adult care. Although a complex relationship exists, a qualitative study with young people and parents reiterated the effect of continence on QOL through greater independence and opportunities for social participation.[18]

It is noticeable that, in the past, little thought was given to the HRQoL aspect of the infant and juvenile population with NB since survival was low, around 10% of live births with MMC, but nowadays, with medical advances. , survival to adulthood is greater than 50%. In the last decade, there has been an increase in published research on QOL linked to this public, but there are still few validated instruments in Brazil to assess HRQoL in their specific condition.[23-4]

It is evident that, with the change in care paradigms, the assessment of QOL in the perception of children and not only caregivers has been taken into consideration. Thus, it is evident that interest in this field has increased, but studies for this age group are scarce due to the absence of specific and validated questionnaires for the Brazilian culture capable of determining HRQoL in pediatric patients with chronic disease.[23-4]

The importance of the rehabilitation process in children with NB focusing on stimulating their functional abilities, facilitating the transition to adulthood and generating a positive reflection on the QOL of all involved, both caregivers and children.[24]

It is mentioned that the main limitations of this study were related to the small sample size due to the clinical characteristics of the research participants and the amount of eligible sample during the data collection period, besides the use of a generic QoL evaluation questionnaire. However, it is believed that the use of PEDsQL^{TM}4.0 was useful because, although generic, it was easy to apply and is validated for the Brazilian pediatric context. Finally, another limitation is listed, which was the methodological design adopted in the quantitative part of the research, as it was a cross-sectional study. Thus, the results can be influenced by two main aspects: the recollection of the events and the relationship with traumatic events, since the participants who underwent surgery more recently can remember more and better the events that occurred.

Therefore, future studies with prospective designs are suggested and further studies on HRQoL are recommended, including the creation and validation of specific condition instruments to assess the QOL of children with NB in the national context.

CONCLUSION

It was concluded that the perception of QOL of patients undergoing cystenteroplasty surgery and their caregivers was improved after this surgery, especially in their health status, with lower incidence of UTI and better social conditions, based on reports of lower frequency of urinary leakage between CIL intervals. Thus, it is associated with surgical treatment based on reconstructive techniques, such as cystenteroplasty surgery to preserve renal function and improve bladder capacity, to improve HRQoL indices in the late postoperative period.

It contributed to a better understanding of the surgical situation of cystenteroplasty in the context of the dyad, allowing us to rethink and qualify health care during the process of rehabilitation of the child with NB submitted to this surgery, with a look at the most significant dimensions of HRQoL, specific condition of this population.

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