

Draw, write and tell interview: Quality of life of children and adolescents with chronic condition

Desenhar, escrever e contar: qualidade de vida da criança e adolescente com condição crônica

Dibujar, escribir y contar: calidad de vida de niños y adolescentes con enfermedades crónicas

Livia Grazielle Benevides dos Santos¹, Thaís Rodriguez Pontes¹, Michelle Darezzo Rodrigues Nunes¹,
Fernanda Machado Silva-Rodrigues¹, Lilliane Faria da Silva¹, Sandra Teixeira Araújo Pacheco¹

¹Universidade do Estado do Rio de Janeiro. Rio de Janeiro, Brazil; ²Santa Casa de São Paulo. São Paulo, Brazil;

³Universidade Federal Fluminense. Niterói, Brazil

ABSTRACT

Objective: to understand, through the Draw, Write and Tell interview technique how chronic condition influences pediatric quality of life; To analyze the use of the technique in this population. **Method:** qualitative, descriptive, exploratory study. Eleven children and adolescents with chronic conditions between seven and seventeen years old participated. Data collection took place through semi-structured interviews, with the aid of the Draw, Write and Tell interview technique, in State University Hospital. For data analysis, thematic content analysis according to Bardin was used. **Results:** three categories emerged that show several changes in the quality of life of this clientele, with emphasis on the physical, emotional and social impairment that impact on the experiences that make up childhood and adolescence. The Draw, Write and Tell interview technique facilitated and enriched data collection. **Final considerations:** The chosen technique made it possible to identify the impaired quality of life of children and adolescents with chronic conditions.

Descriptors: Child; Adolescent; Pediatric Nursing; Chronic Disease; Quality of Life.

RESUMO

Objetivo: compreender por meio da técnica Desenhar, escrever e contar como a condição crônica influencia na qualidade de vida infantojuvenil; e analisar o uso da técnica nessa população. **Método:** estudo qualitativo, descritivo e exploratório. Participaram onze crianças e adolescentes com condição crônica entre sete e dezessete anos. A coleta de dados ocorreu mediante entrevista semiestruturada, com auxílio da técnica Desenhar, escrever e contar, em um Hospital público. Para análise dos dados utilizou-se a análise de conteúdo temática de Bardin. **Resultados:** emergiram três categorias que evidenciam diversas alterações na qualidade de vida dessa clientela, com destaque para o comprometimento físico, emocional e social que impacta nas de experiências que compõem a infância e a adolescência. A técnica Desenhar, escrever e contar foi um facilitador e enriqueceu a coleta de dados. **Considerações finais:** a técnica escolhida possibilitou identificar a qualidade de vida prejudicada da criança e adolescente com condição crônica.

Descritores: Criança; Adolescente; Enfermagem Pediátrica; Doença Crônica; Qualidade de vida.

RESUMEN

Objetivo: comprender, a través de la técnica de entrevista Dibujar, Escribir y Contar, cómo la condición crónica influye en la calidad de vida infantojuvenil; y analizar el uso de la técnica en esta población. **Método:** estudio cualitativo, descriptivo y exploratorio. Participaron once niños y adolescentes, con condiciones crónicas, de siete a diecisiete años. La recolección de datos ocurrió por medio de entrevistas semiestructuradas, con el auxilio de la técnica de entrevista Dibujar, Escribir y Contar, en un hospital público. En cuanto al análisis de datos, se utilizó el análisis de contenido temático de Bardin. **Resultados:** surgieron tres categorías que muestran varios cambios en la calidad de vida de esta clientela, con énfasis en el deterioro físico, emocional y social que tiene un gran impacto en las experiencias que componen la infancia y la adolescencia. La técnica Dibujar, Escribir y Contar facilitó y enriqueció la recolección de datos. **Consideraciones finales:** la técnica elegida permitió identificar la calidad de vida deteriorada de niños y adolescentes con condiciones crónicas.

Descriptores: Niño; Adolescente; Enfermería Pediátrica; Enfermedad Crónica; Calidad de Vida.

INTRODUCTION

Living with chronic conditions leads to various changes in the lifestyle of children, adolescents and their families, as they experience changes in their routines, fear of the unknown, vulnerability, pain, and loss of self-esteem. The need to go through varying periods of hospitalization causes suffering and separation from family members and pets, and social and school isolation, reducing their quality of life (QoL)¹. In addition, the decrease in QoL of children and adolescents with chronic conditions is directly linked to treatment and its adverse reactions such as nausea, vomiting, pain, weight loss or weight gain, alopecia, fatigue, fever and hypersensitivity reactions².

This study was financed in part by the Coordenação de Aperfeiçoamento de Pessoal de Nível Superior - Brasil (CAPES) - Finance Code 001.

Corresponding author: Michelle Darezzo Rodrigues Nunes. E-mail: mid13@hotmail.com

Editor in chief: Cristiane Helena Gallasch; Associate Editor: Magda Guimarães de Araujo Faria

Understanding so many transformations requires getting closer to this population in order to identify the expression of feelings, opinions, and thoughts in their realities. However, investigating the universe of children and adolescents is a challenging task that requires sensitivity on the part of researchers, since giving voice to this public means being immersed in their world of symbolism and meaning, and making them the protagonists in this process requires the use of specific techniques to facilitate the apprehension and translation of their experiences³.

Thus, in order to be able to grasp and translate these experiences, techniques such as the use of therapeutic toys, free drawings, games, music, and storytelling are often used as facilitators in identifying the feelings, perceptions, and fantasies of children and adolescents on a given topic, considering that nurses play a decisive role in understanding the experiences surrounding chronic illness on the part of children and adolescents, to draw up care plans in line with each reality to improve quality of life⁴.

Therefore, recently, a group of Australian nurses developed a data collection technique called the Draw, Write, and Tell interview (DWT), with the aim of obtaining, in a more precise and active way, children's perspectives on situations they have experienced or are going through. Drawing and words written by the child themselves allow them to communicate their experiences through stories that emerge from their productions in response to interview questions⁵.

Thus, this study aimed to understand through the Draw, Write and Tell interview technique how chronic conditions influence the quality of life of children and adolescents, and analyze the use of the DWT interview technique in the child and adolescent population.

METHOD

This is a qualitative, descriptive and exploratory study⁶, carried out in the child and adolescent care wards of a state university hospital in Rio de Janeiro. Children and adolescents with chronic conditions who were cognitively able to answer the interview questions participated. Those who were in critical hospitalization situations or in the immediate post-operative period were excluded, due to the fragility of the moment and the possible influence of the clinical condition on their quality of life.

This study is part of a larger research project entitled: "Evaluation of signs and symptoms in children with chronic conditions and their relationship with quality of life from a qualitative perspective".

Data was collected by means of a semi-structured audio-recorded interview, using the Draw, Write and Tell interview technique. The technique involves formulating a triggering question so that the child knows the topic they are going to draw or write about. The audio recording is then started and includes the child's explanation of the drawings and textual elements⁵.

Participants were asked to draw a picture and/or write about the following topic: *"After being diagnosed with a chronic condition, some children/adolescents say that their lives have changed. We would like to know if this happened to you too. So, I am going to ask you to draw a picture or write about what has changed in your daily life since your diagnosis and the start of treatment. I will give you some time to draw and then we will talk about your drawing"*. Materials such as a drawing board, sheets of different colors, colored pencils, and colored pens were made available to the participants.

After being given some time, the participants were asked about the meaning of what they had written and/or drawn, and to answer some open-ended research questions, with the aim of deepening the data collection: *"Since you found out you were ill or started treatment, what has changed in your life?"*; *"When you are out of hospital (home, school, church), has anything changed in your day-to-day life?"*; *"How did you feel about these changes?"*; *"What makes you well despite this?"*. As these questions were answered, other questions were asked. Phrases such as: *"What do you mean?"*, *"Tell me more about this"*, were used to deepen the answers found.

The data was collected until it reached theoretical saturation⁷ and the data obtained was sufficient to answer the study's objectives. The data collected was transcribed and the content was subjected to thematic analysis according to Bardin⁸.

This study complied with the guidelines set out in National Health Council Resolutions 466/2012 and 580/2018, had its research protocol approved by the institution's Committee of Ethics and Research with Human Subjects and began only after obtaining the Free and Informed Consent of the legal guardian and Assent of the child or adolescent. No child/adolescent or legal guardian invited refused to participate^{9,10}.

RESULTS

Eleven children and adolescents with chronic conditions between the ages of seven and seventeen years old participated, with an average age of 13. They were mostly male (n= 7) and diagnosed with oncohematological (n= 6) and autoimmune (n= 3) diseases.

Three categories emerged from the analysis of the interviews: Experiencing constant hospitalizations; Living frequently with symptoms; and Changes in routine and its many limitations.

Experiencing constant hospitalizations

Through their statements and drawings, children and adolescents expressed the suffering caused by frequent hospitalizations, among them the need to undergo various painful and invasive procedures.

[...] In the ICU I got several punctures. [...] The nurses pierce me and put medicine in me...". (E1, 7 years old, LLA)

In addition to the procedures, hospitalization leads to being away from home for varying lengths of time, as described below:

I want to go home, I miss home [...] it's something I haven't done for a long time, because I'm stuck here doing nothing, just taking injections. (E7, 16 years old, LES)

In Figure 1, participant E6 represents the experience of being away from home.



Figure 1: Drawing made by participant E6, 16 years old, during the data collection stage. Rio de Janeiro, RJ, Brazil, 2019.

[...] This is my house (drawing) that seems to be very far away, like right behind the ocean [...] it seems to be getting further and further away. (E6, 16 years old, Chronic osteomyelitis)

There was also a lack of activities offering some kind of recreation and distraction, which characterized the environment as tedious and unwelcoming, according to the following report:

[...] And boredom, boredom only gets worse with time [...] many days start, every time white room, white room, white room, soon I'll go crazy. [...] I have nothing to do [...] nothing can distract me. (E5, 14 years old, LES)

Figure 2 shows the representation of one of the participants about the need to remain in the hospital environment and carry out procedures related to treatment. Another participant wrote about this experience, as explained below:

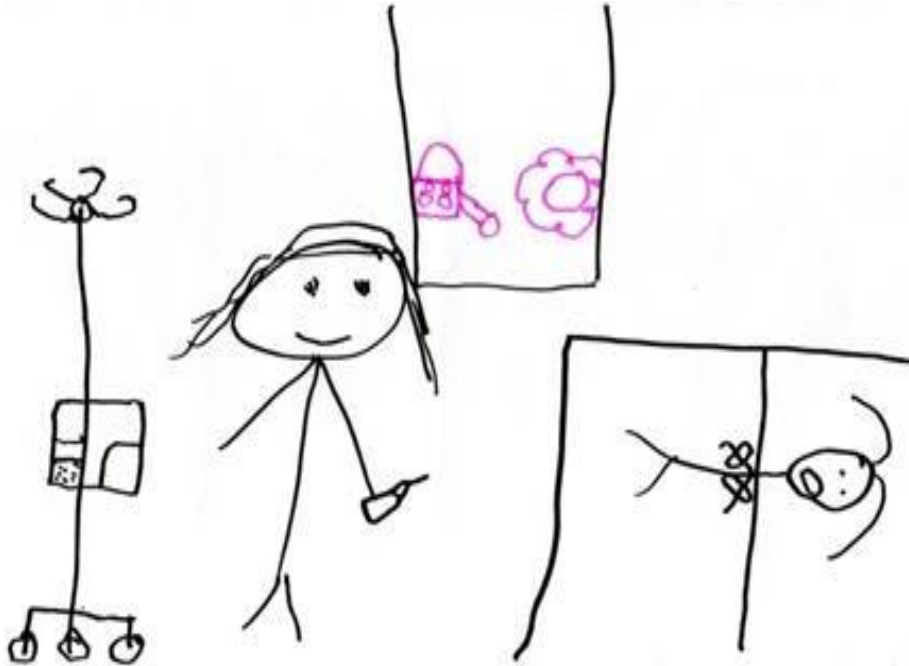


Figure 2: Drawing made by participant E7, 16 years old, during the data collection stage. Rio de Janeiro, RJ, Brazil, 2019.

In the image, the teenager depicted herself lying on a bed with a thermometer in one arm, an access in the other arm and a sad face, because she did not want to be punctured for the procedure. She also drew a nurse smiling with a syringe in her hand in the center of the page, and reported that she was happy to administer the drug invasively.

“One of the things that really marked me was the time I had hemodialysis, before I had it I had a dream, and in that dream I was having hemodialysis. I went through a process in which I had a seizure and had to undergo it, and I thought it was incredible, you know, because I dreamt it and it happened. I did HD for less than a month and my kidneys started working again. HD was also an experience in which I realized that we have to enjoy life even more, because we waste a lot of time there.” (E4, 17 years old, LES. Writes about their experience with treatment during hospitalization. Rio de Janeiro, Brazil, 2019)

They also reported that in these moments, religion and faith are important coping strategies for the difficult situations they experience in the hospital environment, giving them hope and optimism to deal with adversity:

[...] without God we can't live [...] I stayed calm, peaceful, because everything is in God's hands, right? God knows what he's doing, there's no point in complaining because he's the one who created us, he's the one who gave us this body. So I believe he's going to heal me, it's in his hands and life goes on. (E8, 15 years old, chronic kidney disease)

Living frequently with symptoms

Participants reported the multiple symptoms they experience and how these impact negatively their quality of life. Living with nausea, vomiting, fatigue, pain, and shortness of breath, limits them in carrying out daily activities, brings physical wear and tear, and can directly influence their quality of life.

We wake up wanting to vomit... [...] it makes me sick, I throw up [...] And... I feel tired more quickly. (E2, 14 years old, LLA)

I can't eat properly [...] sleep is also affecting me, my mood, I feel more tired, weaker and so on. [...] I don't feel like playing ball anymore, you know? [...] These bruises here that were appearing. (E11, 16 years old, LLA)

A lot of pain in my joints, I was weak, I was in bed, [...] I used to get sick, then after I started to stop being able to eat, I'd throw up everything I put in [...] I scratch myself all the time, it's getting dry [...] everything hurts because of the lupus. (E5, 14 years old, LES)

They also expressed symptoms that were not only physical, but also emotional and psychological, to the detriment of living with the chronic condition.

It was almost as if I was going to fall into depression, I would just lie on the sofa [...] I felt like nothing, as if I didn't even exist on Earth. (E4, 17 years old, LES)

[...] Discouragement, not wanting anything, everything was getting me down [...] I was really bad, I wasn't even smiling, I was sadder. I thought it wasn't going to get better. (E7, 16 years old, LES)

Changes in routine and its many limitations

From this category it is possible to identify changes in diet, school routine, daily activities, and lifestyle modifications, generating physical and social limitations and negative repercussions on the self-esteem and self-image of children and adolescents living with the chronic condition and its treatment, as evidenced by the following statements:

Burgers once a month, I can't have soft drinks, you know? I can't drink a lot of liquid, which I like. Then you go to a party, and you have to control it. (E8, 15 years old, chronic kidney disease)

I can't eat raw food because it has to be cooked and so on because of the risk of bacteria, germs. (E11, 16 years old, LLA)

When they are absent from school, they are subjected to the risk of failing the year, they are cut off from their friends and social environment, and they face difficulties in carrying out academic activities in the hospital environment, without the necessary support.

I just think it's really bad, because last year I failed and this year I'm due to fail again for absences [...] I was going to finish school this year, and I was also really sad I had to leave because the doctors asked me to. (E4, 17 years old, LES)

I just miss going to school [...] I miss my friends, they're nice to me. (E9, 8 years old, hemophilia A)

They report that activities they used to do are no longer part of their daily lives, as they are often unable to play or do exercises that require some physical effort or could compromise their health. As a result, they have been deprived of going out with friends or family and going to crowded places, distancing themselves from socializing with other people.

I stopped playing ball, this one (drawing) I stopped singing too... I used to sing in church. [...] the doctor said I can't stay in a closed place with lots of people. (E3, 11 years old, LLA)

In figure 3, E3 represents the activities they used to do before the diagnosis of the chronic condition and the start of treatment: playing ball, singing in church, and going to school.

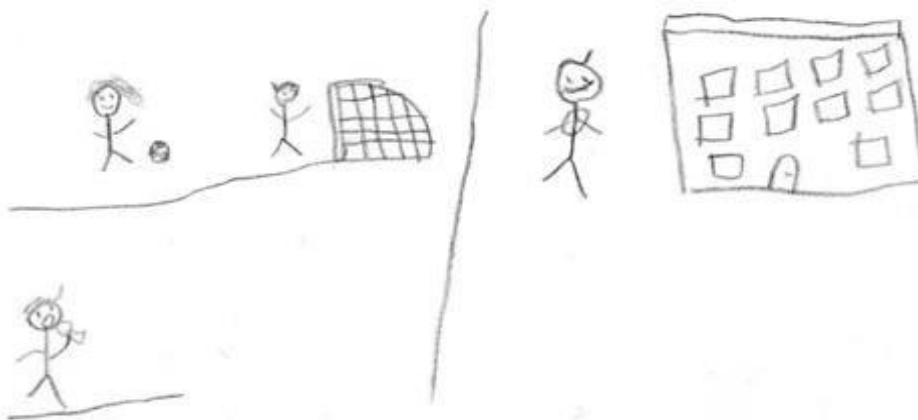


Figure 3: Drawing made by participant E3, aged 11, during the data collection stage. Rio de Janeiro, RJ, Brazil, 2019.

Every young person likes to go to the beach, play ball, eat and go to the pizzeria and stuff, have fun. At the moment I can't because I have the permcath, I can't [...] and that's shaken me up a bit because I saw my friends going, you know? to these places and I couldn't go. You feel a bit down, well, I could be doing that, but because of my illness, well, I can't. [...] Sad, right?... (E8, 15 years old, chronic kidney disease)

Concerning self-image, some drugs used in treatment can lead to alopecia, edema and weight gain, for example. These changes generate feelings of sadness, shame and discomfort with their appearance, damaging their self-esteem.

And the spots, everyone kept asking me "what's that?" and I'd throw my pillow at them so no one would notice. Sometimes everyone laughed at me because I was swollen [...] and when my hair fell out it bothered me a lot [...] I was sad, I was embarrassed to take a photo, because it was a bit faded here and here. (E4, 17 years old, LES)

As a vain person, I immediately thought of going bald [...] and it's making me ugly. Soon I'll be full of stretch marks. [...] my belly's ugly... before I could even do a little pout, now I'm getting fat, I'm getting stretch marks. (E5, 14 years old, LES)

Everyone looks at you like you're sick [...] I walked with a limp and everyone could tell I had something wrong [...] I don't know, everyone looked at me a bit strangely. I was a bit annoyed. (E6, 16 years old, Chronic osteomyelitis)

The interviews revealed that, although children and adolescents share common experiences in terms of symptoms, school, home and social distancing, and frequent invasive procedures, some expressions and feelings are elaborated differently by these groups.

Regarding adolescents, there was evidence of damage to their self-image, with a direct impact on their self-esteem, and greater vulnerability to emotional symptoms such as sadness and discouragement. In this sense, the hospital environment proved to be an aggravating factor in the presence of these emotions, being considered monotonous and with few recreational resources. However, as a way of coping with these difficulties, religion proved to be a strong foundation for this group.

For the children, the withdrawal from recreational and social activities such as playing, playing ball, and exercising their faith had the greatest impact when it came to breaking up their routines and the limitations they faced as a result of living with the chronic condition. They expressed greater difficulties in coping with physical symptoms, invasive procedures, and withdrawing from friends.

DISCUSSION

It was identified that children with chronic conditions suffer frequent hospitalizations and, as a result, their social activities, habits and practices are interrupted, concomitantly with their insertion into an unknown environment, which has specific restrictions and routines that interfere with their QoL¹¹.

The hospital environment represents the imminent possibility of undergoing procedures that generate pain, it is unwelcoming and monotonous, as they have little interaction with other patients and the space itself does not provide leisure alternatives, as elucidated by a qualitative study that dealt with the topic of pediatric hospitalization¹². The noise, temperature and even the color of the rooms also make the environment uncomfortable, as they consider it tiring and psychologically exhausting because of these factors¹³.

In addition, due to recurrent hospitalizations, being at home translates into occasional and special moments for this group of children and adolescents, transforming their homes into visitation environments. The home is considered a "therapeutic space" because it provides essential conditions for the continuity of children's development, minimizes stress and tension and promotes well-being since they feel part of the family again and find comfort in the environment in which they have developed¹⁴.

Physical and emotional symptoms were also identified when living with the chronic condition. The evolution of the clinical condition and the therapy, which uses various types of drugs, leads to the onset of nausea, vomiting, edema, pain, inappetence, vertigo, alopecia, body spots, among others. In the literature, pain, nausea, and vomiting were also the symptoms most cited by participants¹⁵⁻¹⁷. In addition to these, malaise, feeling unwell, lack of appetite, weight changes, alopecia, fatigue, and sleep changes were also found¹⁸⁻²⁰.

The symptoms and the health condition of these children and adolescents are often responsible for impairing their physical functions, which significantly limits the performance of activities that require physical effort²¹. These limitations drastically change the daily lives of these people, who have to deal with their diminished potential for activities such as playing games, playing ball, jumping, and exercising, making it necessary to suppress their recreational desires²²⁻²⁴.

Although we believe that chronic conditions impact the quality of life of children and adolescents more significantly than the characteristics of the life cycles themselves, making their experiences similar, we have found some particularities in the experiences of children and adolescents.

In adolescents, it was possible to see that living with a chronic condition has greater repercussions on their self-esteem and self-image, which makes coping with it even more challenging since they are already going through various physical and identity changes mediated by puberty²⁵. The diagnosis of a chronic condition involves the creation of stigmas that negatively affect people's lives by making them feel different from others, and generating a sense of exclusion. As a result, they feel misunderstood and are forced to deal with various barriers to social interaction²⁶.

Regarding children, the effect of living with the various changes in their lives was greater on the social aspects, as they had to break their school routine and move away from their friends and the environments they had previously enjoyed. It was clear that this population needs to reorganize themselves in the face of hospitalizations, manage their symptoms, and take time out to dedicate to treatment, which is why they need to be absent from school²⁷. This disruption has repercussions on the learning process and social interaction, as the child is separated from their friends and other people in the school environment, which is fundamental to their growth and development^{28,29}.

Studies report that living with a chronic condition during childhood and adolescence is a risk factor for emotional and behavioral disorders. The illness and treatment cause frequent psychological maladjustments, high levels of stress, depression, hopelessness, excessive worries about health, and limitations associated with the condition or disease. These factors may be related to poorer adherence to therapy³⁰⁻³².

As far as dietary aspects are concerned, in agreement with the findings of our study, a survey of ten adolescents with sickle cell disease points out that among the changes that occur due to the chronic condition are nutritional alterations, since following the therapeutic plan implies being subject to hydric and dietary restrictions³³. The effectiveness of treatment is influenced by following the diet proposed for each clinical condition, which takes into account the patient's health status, immunity and the possibility of unwanted reactions. These restrictions have an intimate effect on the daily lives of children and their families, making it difficult for them to adapt to new eating habits and limiting the consumption of foods they like³⁴.

Faced with these changes, children, adolescents and their families try to adapt to their new reality through coping strategies. By exercising their religion and faith, they are able to formulate more structured thoughts and more organized actions, favoring a global understanding of themselves and the situation they are experiencing³⁵. Their beliefs represent the possibility of restoring their health, the expectation of returning home and a reduction in worries, since faith gives them the optimism they need to face treatment and the evolution of their clinical condition.

Therefore, the findings obtained through this study indicate that, by influencing the physical, emotional, and social domains of quality of life, chronic conditions reflect in a lower QoL through so many repercussions that permeate the diagnosis, the stigma that surrounds the health condition, and the interruption of activities that for the child represent conviviality and socialization, similar to the findings in the literature³⁶.

Based on care centered on the children and their families, the nursing team must identify how these changes impact the needs of this group, acting with individualized interventions to provide them with satisfactory care. This requires an approach focused on planning, providing, and evaluating care based on the professional's scientific knowledge and that previously developed by the children and their families, making the children and adolescents active participants in their care and decision-making³⁷.

Professionals' knowledge of the changes in the dimensions of children's and adolescents' lives allows them to provide appropriate guidance on the best way to deal with the changes on a daily basis, minimizing emotional distress. This relationship creates bonds between the public and health professionals, contributing to quality and safe care³⁸.

What set this study apart was the use of a new technique for collecting data with children and adolescents, which proved to be a facilitator and promoted more in-depth responses from the child and adolescent participants. We noticed that through the semi-structured interview together with the DWT interview strategy, children and adolescents were able to express the changes that had taken place in their lives more easily, allowing them to express their feelings, create bonds, and favor an understanding of the moment they were experiencing.

Drawing is considered a therapeutic activity capable of holding the children's attention and helping them to explore communication by stimulating their imagination, offering them the opportunity to express experiences that may be less conscious or difficult to say using words alone. The association of drawing and writing is a method that has already been used in the fields of psychology and education, and has recently been incorporated into health research as a way of understanding children's and adolescents' views on issues related to this field⁵.

Study limitations

The limitations of the study include the use of participants with different chronic conditions and the collection of data in only one location, which may disregard the specific experiences of each disease and compromise the generalization of the results.

FINAL CONSIDERATIONS

Children with chronic conditions live with various symptoms, treatments, and experience recurrent hospitalizations and limitations. These have repercussions that go beyond a break in routine, and can cause emotional and social changes, resulting in damage to their quality of life.

The use of the DWT technique together with the semi-structured interview proved to be a facilitating tool in the expression of their experience with the chronic condition, making it possible to delve deeper into the subjective dimension of the health-disease process experienced by this population, entering the world of meanings.

In addition to the contributions of the strategy for obtaining data with pediatric patients, we believe that these findings can contribute to nursing care for hospitalized children in the planning of interventions, giving a voice to children and adolescents facing illness, as well as incorporating into their practices measures that take into account the objective and subjective dimensions, considering that care must take place in a participatory and collaborative manner.

REFERENCES

1. França JRFS, Costa SFG, Lopes MEL, Nóbrega MML, Batista PSS, Oliveira RC. Experiência existencial de crianças com câncer sob cuidados paliativos. *Rev. Bras. Enferm.* 2018 [cited 2022 Oct 15]; 71(Suppl 3):1320-7. DOI: <http://dx.doi.org/10.1590/0034-7167-2016-0493>.
2. Morais GSN, Costa SFG, França JRS, Duarte MCS, Lopes MEL, Batista PSS. Experiência existencial de crianças em tratamento quimioterápico sobre a importância do brincar. *Rev Rene.* 2018 [cited 2019 Jun 15]; 19:e3359. DOI: <http://dx.doi.org/10.15253/2175-6783.2018193359>.
3. De Paula GK, Góes FGB, Silva ACSS, Moraes JRMM, Silva LF, Silva MA. Play strategies in nursing care for the hospitalized child. *J Nurs UFPE on line.* 2019 [cited 2019 Dec 10]; 13:e238979. DOI: <https://doi.org/10.5205/1981-8963.2019.238979>.
4. Alves LRB, Moura AS, Melo MC, Moura FC, Brito PD, Moura LC. A criança hospitalizada e a ludicidade. *Rev Min Enferm.* 2018 [cited 2019 Dec 10]; 23:e-1193. DOI: <http://dx.doi.org/10.5935/1415-2762.20190041>.
5. Pope N, Tallon M, Leslie GD, Wilson S. Using 'draw, write and tell' to understand children's health-related experiences. *Nurse Res.* 2019 [cited 2019 Jun 15]; 26(2):42-5. DOI: <http://dx.doi.org/10.7748/nr.2018.e1594>.
6. Minayo MC, Costa AP. Fundamentos teóricos das técnicas de investigação qualitativa. *Revista Lusófona de Educação.* 2018 [cited 2019 Jun 15]; 40(40):11-20. Available from: <https://www.redalyc.org/journal/349/34958005002/34958005002.pdf>.
7. Minayo MC de S. Amostragem e saturação em pesquisa qualitativa: consensos e controvérsias. *Rev. Pesq. Qual.* 2017 [cited 2019 Jun 15]; 5(7):1-12. Available from: <https://editora.sepq.org.br/rpq/article/view/82>.
8. Bardin L. *Análise de conteúdo.* Lisboa, Portugal; Edições 70; 2018.
9. Brasil. Conselho Nacional de Saúde. Resolução nº 466, de 12 de dezembro de 2012. Aprova normas regulamentadoras de pesquisas envolvendo seres humanos. *Diário Oficial da União,* 2012 [cited 2019 Oct 08]. Available from: <https://conselho.saude.gov.br/resolucoes/2012/Reso466.pdf>.
10. Brasil. Conselho Nacional de Saúde. Resolução nº 580, de 22 de março de 2018. Aprova normas regulamentadoras de pesquisas em hospitais do SUS. *Diário Oficial da União,* 2018 [cited 2019 Oct 08]. Available from: <https://conselho.saude.gov.br/resolucoes/2018/Reso580.pdf>.
11. Budzyn CS, Oliveira VZ. Illness, Treatment and the Patient-Doctor-Caregiver Relationship According to the Hospitalized Child. *Rev. Interinst. Psicol.* 2020 [cited 2021 Jul 15]; 13(3):e15166. DOI: <http://dx.doi.org/10.36298/gerais202013e15166>.
12. Coelho HP, Souza GSD, Freitas VHS, Santos IRA, Ribeiro CA, Sales JKD et. al. Perception of the hospitalized child about the instructional therapeutic play in intravenous therapy. *Esc Anna Nery.* 2021 [cited 2022 Jan 05]; 25(3):e20200353. DOI: <https://doi.org/10.1590/2177-9465-EAN-2020-0353>.
13. Silva MKCO, Ferraz LCC, Farias MB, Januário JKC, Vieira ACS, Moreira RTF, et al. A utilização do lúdico no cenário da hospitalização pediátrica. *Rev enferm UFPE online.* 2019 [cited 2021 Jul 15]; 13:e238585. DOI: <https://doi.org/10.5205/1981-8963.2019.238585>.
14. Rockembach J, Espinosa T, Cecagno D, Thumé E, Soares DC. Insertion of play as facilitator of hospitalization in childhood: parental perception. *J Nurs Health.* 2017 [cited 2019 Dec 10]; 7(2):117-26. DOI: <http://dx.doi.org/10.15210/jonah.v7i2.7646>.
15. Pinheiro LC, McFatrigh M, Lucas N, Walker JS, Withycombe JS, Hinds PS, et al. Child and adolescent self-report symptom measurement in pediatric oncology research: a systematic literature review. *Qual Life Res.* 2018 [cited 2021 Jul 15]; 27(2):291-319. DOI: <http://dx.doi.org/10.1007/s11136-017-1692-4>.
16. Linder LA, Bratton H, Nguyen A, Parker K, Wawrzynski S. Symptoms and self-management strategies identified by children with cancer using draw-and-tell interviews. *Oncol Nurs Forum.* 2018 [cited 2021 Jul 15]; 45 (3), 290-300. DOI: <http://dx.doi.org/10.1188/18.ONF.290-300>.
17. Linder LA, Al-Qaaydeh S, Donaldson G. Symptom characteristics among hospitalized children and adolescents with cancer. *Cancer Nurs.* 2018 [cited 2021 Jul 15]; 41(1):23-32. DOI: <http://dx.doi.org/10.1097/NCC.0000000000000469>.

18. Silva LTL, Freitas BHBM, Deus JC, Bortolini J. Qualidade de vida de crianças e adolescentes com fibrose cística. *Rev enferm UFPE online*. 2019 [cited 2021 Jul 15]; 13(3):551-9. DOI: <https://doi.org/10.5205/1981-8963-v13i3a236410p551-559-2019>.
19. Gomes RA, Coelho ACO, Moura DCA, Cruz JS, Santos KB. Avaliação da qualidade de vida de pacientes com doença oncohematológica em quimioterapia. *Rev enferm UFPE online*. 2018 [cited 2021 Jul 15]; 12(5):1200-5. DOI: <https://doi.org/10.5205/1981-8963-v12i5a231413p1200-1205-2018>.
20. Votto M, Castagnoli R, Filippo M, Brambilla I, Cuppari C, Marseglia GL, et al. Behavioral issues and quality of life in children with eosinophilic esophagitis. *Min Pediatr*. 2020 [cited 2022 Apr 20]; 72(5):424-32. DOI: <http://dx.doi.org/10.23736/S0026-4946.20.05913-7>.
21. Nentwich J, Ruf K, Girschick H, Wieden AH, Morbach H, Hebestreit H. Physical activity and health-related quality of life in chronic non-bacterial osteomyelitis. *Pediatr Rheumatol Online J*. 2019 [cited 2022 Apr 20]; 17(1):45. DOI: <http://dx.doi.org/10.1186/s12969-019-0351-4>.
22. Gabatzl RIB, Marten VM, Bório TC, Specht AL, Bazzan JS, Motta MGC. Difficulties and facilitating interactions in chronic health conditions: perceptions of children and adolescents. *Rev Atenção Saúde*. 2021 [cited 2022 Apr 20]; 19(70):173-86. DOI: <https://dx.doi.org/10.13037/ras.vol19n70.8086>.
23. Niemitiz M, Gunst DCM, Hovels-Gurich HH, Hofbeck M, Kaulitz R, Galm C, et al. Predictors of health-related quality of life in children with chronic heart disease. *Cardiol Young*. 2017 [cited 2019 Dec 10]; 27(8):1455-64. DOI: <http://dx.doi.org/10.1017/S1047951117000440>.
24. Yuwen W, Lewis FM, Walker AJ, Ward TM. Struggling in the dark to help my child: parents' experience in caring for a young child with juvenile idiopathic arthritis. *J Pediatr Nurs*. 2017 [cited 2019 Dec 10]; 37:e23-9. DOI: <http://dx.doi.org/10.1016/j.pedn.2017.07.007>.
25. Bozzini AB, Neder L, Silva CA, Porta G. Decreased health-related quality of life in children and adolescents with autoimmune hepatitis. *J Pediatr*. 2019 [cited 2022 Apr 20]; 95:87-93. DOI: <https://doi.org/10.1016/j.jpeds.2017.10.013>.
26. Guo L, Rohde J, Farraye FA. Stigma and disclosure in patients with inflammatory bowel disease. *Inflamm Bowel Dis*. 2020 [cited 2022 Apr 20]; 26(7):1010-6. DOI: <http://dx.doi.org/10.1093/ibd/izz260>.
27. Pinquart M. Health-related quality of life of young people with and without chronic conditions. *Journal of Pediatric Psychology*. 2020 [cited 2022 Nov 12]; 45(7):780-92. DOI: <http://doi.org/10.1093/jpepsy/jsaa052>.
28. Gomez KSR, Gutiérrez LFH. Impact of chronic kidney disease on health-related quality of life in the pediatric population: meta-analysis. *Jornal de Pediatria*. 2021 [cited 2022 Nov 12]; 97(5):478-89. DOI: <https://doi.org/10.1016/j.jpeds.2020.10.013>.
29. Vaz JC, Milbrath VM, Gabatz RIB, Motta MGC, Nunes NJS, Bório TC. Situation of vulnerability perceived by the family in school inclusion of children with chronic condition. *Rev Enferm Atual In Derme*. 2022 [cited 2022 Nov 12]; 96(38):e-021232. DOI: <https://doi.org/10.31011/reaid-2022-v.96-n.38-art.1205>.
30. Rohan JM, Verma T. Psychological considerations in pediatric chronic illness: case examples. *Int J Environ Res Public Health*. 2020 [cited 2022 Apr 20]; 17(5):1644. DOI: <http://dx.doi.org/10.3390/ijerph17051644>.
31. Alioto AG, Gomez R, Moses J, Paternostro J, Packman S, Packman W. Quality of life and psychological functioning of pediatric and Young adults patients with gaucher disease, type 1. *Am J Med Genet A*. 2020 [cited 2020 Oct 18]; 182(5):1130-42. DOI: <http://doi.org/10.1002/ajmg.a.61533>.
32. Zheng K, Abraham C, Bruzzese JM, Smaldone A. Longitudinal relationships between depression and chronic illness in adolescents: na integrative review. *J Pediatr Health Care*. 2020 [cited 2020 Oct 18]; 34(4):333-45. DOI: <http://doi.org/10.1016/j.pedhc.2020.01.008>.
33. Santos LM, Silva TNP, Brito LS, Passos SSS, Jenerette MC, Carvalho ESS et al. Ser adolescente apesar das restrições e da discriminação impostas pela doença falciforme. *Acta paul. Enferm*. 2022 [cited 2022 Nov 12]; 35:eAPE0243345. DOI: <https://doi.org/10.37689/acta-ape/2022AO0243345>.
34. Souto SGT, Lima GS, Silva PLN, Oliveira RS, Gonçalves RPF. Chronic renal failure patients' perceptions of the everyday implications of hemodialysis therapy. *Rev enferm UERJ*. 2017 [cited 2022 Nov 12]; 25:e8093. DOI: <http://dx.doi.org/10.12957/reuerj.2017.8093>.
35. Silva MEA, Moura FM, Albuquerque TM, Reichert APS, Collet N. Network and social support in children with chronic diseases: understanding the child's perception. *Texto Contexto Enferm*. 2017 [cited 2022 Feb 06]; 26(1):e6980015. DOI: <http://dx.doi.org/10.1590/0104-07072017006980015>.
36. Barthel D, Sieberer UR, Nolte S, Thyen U, Klein M, Walter O, et al. Predictors of health-related quality of life in chronically ill children and adolescents over time. *J Psychosom Res*. 2018 [cited 2022 Feb 06]; 109:63-70. DOI: <http://dx.doi.org/10.1016/j.jpsychores.2018.03.005>.
37. Nunes MDR, Jacob E, Lopes-Júnior LC, Leite ACAB, Lima RAG, Nascimento LC. Quality of life of cancer children-adolescents with and without fatigue. *Acta paul. enferm*. 2022 [cited 2023 Set 12]; 35:eAPE0288345. DOI: <http://dx.doi.org/10.37689/acta-ape/2022ao0288345>.
38. Fassarella LG, Macedo IF, Nunes MDR, Rocha LS, Amantéa ML, Maciel RO. Nursing's understanding of shared care for hospitalized children with a chronic condition. *Rev enferm UERJ*. 2022; [cited 2023 Set 12]; 30:e65617. DOI: <http://dx.doi.org/10.12957/reuerj.2022.65617>.

Author's contributions:

Conceptualization, LGBS, TRP and MDRN; methodology, LGBS, TRP and MDRN; validation, LGBS, TRP, MDRN and STAP; formal analysis, LGBS, TRP, MDRN and STAP; investigation, LGBS, TRP and MDRN; resources, LGBS, TRP and MDRN; data curation, LGBS, TRP and MDRN; manuscript writing, LGBS, TRP, MDRN, STAP and LFS; manuscript review and editing, LGBS, TRP, MDRN, STAP, LFS and FMS; visualization, LGBS, TRP, MDRN, STAP and LFS; supervision, MDRN, STAP and LFS; project administration, LGBS, TRP and MDRN. All authors have read and agreed to the published version of the manuscript.