



Family and Social Experiences in Children and Adolescents with Cancer expressed through their drawings

Experiencias familiares y sociales en niños y adolescentes con cáncer expresadas a través de sus dibujos

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ABSTRACT

Introduction: Assessing the family and social dimensions from the pediatric cancer patient's perspective encounters challenges, as children and adolescents often do not verbally express their needs and experiences related to family and interactions with others. Drawing emerges as a valuable method for psychological evaluation, offering access to the inner world of patients in an enjoyable and non-threatening manner.

Objective: To assess the family and social experiences of children and adolescents with cancer.

Material and Methods: A qualitative research design with inductive content analysis was utilized. The study included twenty children aged 6-17 years diagnosed with cancer from the Hospital de Especialidades Pediátricas in Maracaibo, Venezuela. Data collection involved drawings, observations, and interviews conducted over three individual sessions.

Results: Two main categories emerged from the analysis: (1) Family Dimension, encompassing aspects of the family dynamics from the patient's perspective, the patient's needs within the family context, significant figures for the patient, and the patient's perception of parental concerns; and (2) Social Dimension, which covers patients' appreciation for healthcare professionals and their social needs, such as the desire to be with friends, resume everyday life, and achieve goals in life.

Conclusions: Drawing is a valid and effective tool for evaluating family and social interactions and needs in children and adolescents with cancer.

Keywords:

Children, adolescents, drawing, cancer, family, social interaction.

RESUMEN

Introducción: La evaluación de las dimensiones familiar y social desde la perspectiva del paciente oncológico pediátrico posee desafíos, ya que los niños y adolescentes muchas veces no expresan verbalmente sus necesidades y experiencias relacionadas con la familia y las interacciones con los demás. El dibujo surge como un método valioso de evaluación psicológica, ofreciendo acceso al mundo interior de los pacientes de una manera amena y no amenazante.

Objetivo: Evaluar las experiencias familiares y sociales de niños y adolescentes con cáncer.

Material y Métodos: Se utilizó un diseño de investigación cualitativo con análisis de contenido inductivo. El estudio estuvo conformado por veinte pacientes de 6 a 17 años diagnosticados con cáncer del Hospital de Especialidades Pediátricas de Maracaibo, Venezuela. La recolección de datos incluyó dibujos, observaciones y entrevistas realizadas en tres sesiones individuales.

Resultados: Del análisis surgieron dos categorías principales: (1) Dimensión Familiar, que abarca aspectos de la dinámica familiar desde la perspectiva del paciente, las necesidades del paciente dentro del contexto familiar, las figuras significativas para el paciente y la percepción del paciente sobre las preocupaciones de sus padres; y (2) Dimensión Social, que comprende el aprecio de los pacientes hacia los profesionales de la salud y sus necesidades sociales, como el deseo de estar con los amigos, reanudar la vida cotidiana y alcanzar metas en la vida.

Conclusiones: El dibujo es una herramienta válida y eficaz para evaluar las interacciones y necesidades familiares y sociales en niños y adolescentes con cáncer.

Palabras Claves:

Niños, adolescentes, dibujo, cáncer, familia, interacción social.



INTRODUCTION

When assessing the factors that affect the adaptation of children and adolescents with cancer to the disease and treatment, it is critical to acknowledge the significant role of the family in shaping the patient's experience. This primary social nucleus can serve either as a support system for the patient or, on the contrary, as a potential barrier to their adjustment and emotional well-being.

A child's cancer diagnosis profoundly impacts all members of the family system. Cancer breaks dramatically into the life of the patient's family, defining a "before and after" of the disease. Parents are faced with overwhelming feelings, including fear, anxiety, loneliness, and sadness.^(1,2) In addition, they are tasked with striking a balance between caring for the sick child, managing treatment and work responsibilities, changes in the couple dynamic,^(1,3,4,5,6) and caring for other children.^(1,2,3,7)

On the other hand, patient relationships extend beyond their families, encompassing interactions with healthcare providers and peers. These social connections also play a role in influencing hospital adaptation, effective symptom management, and the patient's resilience in coping with the disease.⁽⁸⁾

Social interaction, communication, and friend acceptance hold particular significance for school-age children and adolescents dealing with cancer.⁽⁸⁾ Factors that may impact the social functioning of children and adolescents with cancer include changes in physical appearance,^(9,10) extended periods of absence from school,⁽¹¹⁾ physical limitations associated with pain and fatigue,^(10,12,13) and restrictions on participation in sports or extracurricular activities⁽¹¹⁾

The social dimension also includes the interplay between the patients and healthcare providers, emphasizing the role of close and empathetic communication from healthcare professionals in promoting collaboration among pediatric patients during medical procedures. At the same time, elucidating age-appropriate information regarding treatment and medical procedures emerges as a determinant factor in empowering patients, engendering a sense of control, fostering active participation, and ensuring compliance with medical instructions.^(11,14,15)

Assessing the family and social dimensions from the pediatric patient's perspective encounters complexities, as children and adolescents often do not verbally express their needs and experiences related to family and interactions with others. To surmount this challenge, an alternative approach, transcending conventional verbal communication, is imperative. In this context, drawing emerges as a valid method of psychological evaluation, affording access to the inner world of pediatric patients in a manner that is both enjoyable and non-threatening.⁽¹⁶⁾

Research indicates that drawings effectively facilitate rapport establishment with pediatric patients and provide insightful observations of their interactions with healthcare professionals.^(17,16,18) Children's drawings encapsulate self-concept, interpersonal relationships, and the prevailing concerns and expectations of pediatric patients.⁽¹⁶⁾ Additionally, drawings serve as a medium to explore the experiences of disease in adolescents with cancer, encompassing familial and social interactions, extracurricular activities, and hospital experiences as data sources.^(17,19,20,21) Drawing acts as a form of initial communication for children, enabling the articulation of emotions while sharing the narrative embedded within the drawn expressions.^(17,21,22) This highlights the importance of comprehending patient experiences firsthand, mitigating the risk of misinterpretations by healthcare personnel.⁽²³⁾

Petzold & Razavi⁽²¹⁾ underscored the efficacy of art-based assessment as a valuable tool for comprehensively evaluating the experiences of children and adolescents grappling with cancer. Their initial findings highlighted the cognitive and emotional dimensions.⁽²¹⁾ Given the extent of the research project, the family and social dimensions were not developed in their initial publication despite being acknowledged as essential components of their research outcomes.

The current study sought to bridge this gap by delving into the family and social experiences of children and adolescents with cancer. This research has as objective to assess the family and social experiences of children and adolescents with cancer, thereby contributing to a more holistic approach to addressing the needs of this vulnerable patient population.

MATERIALS AND METHODS

A qualitative method with an inductive analysis was utilized to assess the family and social experiences of children and adolescents with cancer. It involved analyzing the content of the patients' verbal reports, observations of patient behavior and their drawings.

This research was conducted in 2019 as part of a broader project⁽²¹⁾ at the Pediatric Specialties Hospital in Maracaibo, Venezuela.

The pediatric oncology unit of the hospital comprises approximately 32 beds in the hospitalization area and 20 chairs in the ambulatory area. This study included a sample of 20 pediatric patients aged 6 to 17 years, diagnosed with cancer and at any stage of their cancer trajectory, including the diagnostic phase, treatment phase, relapse, and up to six months post-successful treatment completion. Selection criteria comprised a) cancer diagnosis; b) an age range between 6 and 17 years. This range was selected to capture the disease experiences across childhood (6-12 years) and adolescence (13-17 years); and c) proficiency in the Spanish language to ensure study participation. Patients were invited to participate, and all those who expressed willingness to take part in the study met the established

Data Collection

Interviews

Individual sessions, lasting approximately one hour, were conducted in the pediatric psycho-oncology office or the patient's room for hospitalized children. An assessment of family and social experiences through the drawing was carried out in each session, using an unstructured interview to encourage patients to elaborate on the images depicted in their drawings.^(24,25) All sessions were audio-recorded and later transcribed.

Observations

Throughout the sessions, the researcher discreetly recorded observations of patient behavior without disrupting the child's art activity. Field notes⁽²⁶⁾ were used, including the following information: 1. Medium chosen by the patient. 2. Duration and procedure involved in completing the art activity. 3. Comments made by the patient during the activity. 4. Behaviors, body language, and gestures during the patient's engagement in artistic expression. 5. Any additional remarks made by the patient.

Drawing

The drawing was utilized to explore children's family and social experiences, involving three sessions to capture drawing variability. Each drawing was photographed and added to the Atlas.ti 8 software along with patient identification data, completion date, and type of art project. The assessment was conducted by a clinical psychologist with specialized training in psycho-oncology and art therapy.

Session 1: Family Test

The Family Drawing Test, as proposed by Corman,⁽²⁷⁾ was administered to assess the subjective perceptions of familial relationships among children and adolescents. This test emphasizes emotional aspects of adaptation within the family environment, facilitating exploration of the child's communication with family members and interpersonal dynamics within the familial system. Patients were instructed to "Draw a family that you imagine." The media included colored crayons and pencils, and no time limit was given.

Session 2: My Hospital Story

This activity evaluated the child's hospital experience by inviting them to create a narrative describing their life in the hospital using a booklet of folded A4 paper sheets. Patients were instructed, "You are going to make your own story about your days in the hospital; you can use both words and drawings." No limited time was indicated, and the media were colored crayons and pencils.

Session 3: Free Drawing

Patients were encouraged to freely express themselves through drawing on standard drawing paper (29.8 x 2.5cm) using their preferred media. The objective of this activity was to stimulate creativity and free expression. Patients were instructed "You can make any drawing you want, in any way you want, with the materials you like the most." Media included using colored pencils, crayons, and pencils without a limited time.

Data Analysis Procedures

Each session was transcribed and analyzed using content analysis, that included the interviews, observations, and drawings. A total of sixty documents (sessions' transcriptions, projective test, and drawings) were analyzed using Atlas.ti 8 software. Each drawing was digitized using the mentioned software, and specific characteristics and relevant words, phrases, or paragraphs (units of meaning) relevant to the study were identified by the researcher. Subsequently, codes were assigned to these units of meaning, leading to the establishment of categories upon which this study is grounded: (1) the family dimension, and (2) the social dimension. See Table 1 for categories, themes, and variables conceptualization.

Table 1: Categories, themes, and variables conceptualization			
Category	Theme	Definition	Art attributes/Artwork characteristics
Family Dimension	Family dynamics	Considers parental conflicts and aspects related to the parents' activities	<ul style="list-style-type: none"> • parents carry out their activities
	Patients' needs regarding their family	Need of the patients associated with parental and family bonding, and the desire to be with the family	<ul style="list-style-type: none"> • parental block drawing • family holding hands • illustrations of the united family
	Figures of importance to the patient	Those figures that are vital for the patient within the family	<ul style="list-style-type: none"> • drawings representing their mother, grandmother, father, and siblings
	Perception of parental concern	Patient' meaning given to parental concerns about the patient's health	<ul style="list-style-type: none"> • parents' presence in the drawings of the hospital scenes
Social Dimension	Appreciation for health professionals	Recognition of the attention, care, and support offered by health care providers	<ul style="list-style-type: none"> • representations of health care providers, especially nurses, and physicians
	Social Needs	Desires to resume their life, to achieve goals and be with friends	<ul style="list-style-type: none"> • drawings of friends • graphic representations of patients' aspirations • drawings of daily life activities before cancer

The study followed the International Ethical Guidelines for Biomedical Research Involving Human Subjects⁽²⁸⁾ and it was approved by the Bioethics Committee of the Pediatric Specialties Hospital.

RESULTS

Participants

The mean age of the patients was 12 ± 3.5 years (mean ± SD), with the majority being girls (75 %) and most of the participants (95 %) belonging to a low socioeconomic status. The predominant diagnosis among patients (70 %) was acute lymphoblastic leukemia, and most of them were undergoing chemotherapy treatment (95 %) at the time of the study. For patients' socioeconomic and clinical characteristics, see Table 2 and Table 3.

Table 2: Sociodemographic characteristics of patients (n = 20)		
Sociodemographic characteristics	No.	%
Age (years)		
Average	12	-
Standard Deviation	3.5	-
Median	12	-
Range	6-17	
Children (6-12)	11	55
Adolescents (13-17)	9	45
Sex		
Female	15	75
Male	5	25
Socioeconomic Level		
Low	19	95
Middle	1	5
Residence		
Urban	17	85
Rural	3	15
Place of residence		
Single mother's home	11	55
Family Home (presence of both parents)	9	45
Siblings		
At least one sibling	15	75
No siblings	5	25
Education Level		
Primary school	13	65
Secondary school	7	35

Table 3.- Clinical characteristics of patients (n = 20)		
Clinical characteristics	No.	%
Diagnosis		
Acute lymphoblastic leukemia	14	70
Hodgkin's lymphoma	1	5
Osteosarcoma	2	10
Other solid tumors	3	15
Stage of cancer trajectory		
Diagnosis	3	75
Treatment	15	15
Relapse	1	75
6 months following successful treatment	1	5
Treatment		
Chemotherapy	17	85
Chemotherapy & Surgery	2	10
Completed treatment (6 months following successful treatment)	1	5

Family Dimension

This dimension reflected the most important aspects of the family environment from the patient's perspective, including family dynamics, the patient's needs within the family context, significant figures for the patient, and the patient's perception of parental concerns.

Family Dynamics

Parental conflicts emerged as a notable stress factor for the patients, as directly reported by them. Instances of parental separation were expressed by the patients, illustrating the emotional toll such conflicts impose on them.

“The separation and problems between my parents generate high stress” (Girl 11-year-old); “They (referring to the parents on the drawing) have big problems, they are arguing in front of me and that affects me” (Boy, 10-year-old)

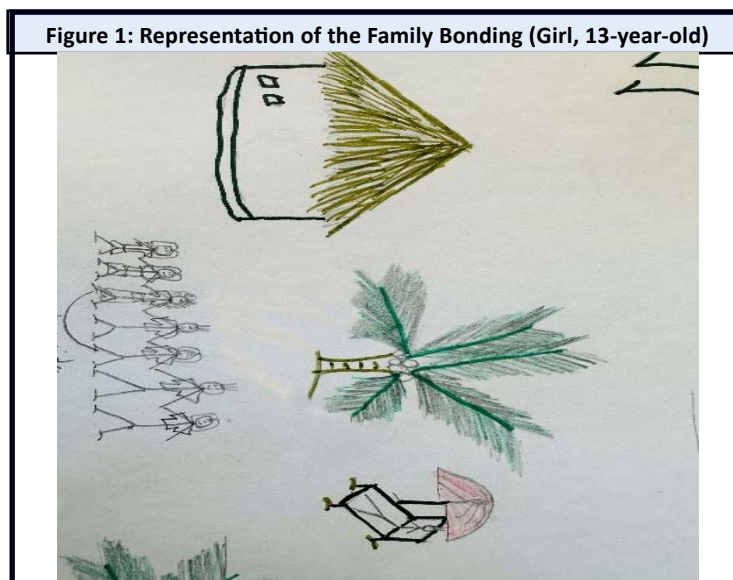
Furthermore, the involvement of parents in everyday activities, as depicted in drawings and verbal expressions, offered insights into their roles within the family structure. They were expressed through phrases such as:

“Here (pointing to the drawing) are my parents, cooking” (Boy, 7-year-old); “My dad couldn't work yesterday; he couldn't fish in the lake” (Girl, 14-year-old); “My mom is going to work” (Girl, 8-year-old).

Patients' Needs Regarding Their Family

Parental and family bonding

The patients' needs for parental and family bonding were evident through both drawings and verbal expressions. The desire for parental bonding was exemplified by depictions of family togetherness, such as parental block drawing and holding hands⁽²⁷⁾ and verbal expressions longing for the presence of both parents during challenging times.



Figures of Importance to the Patient

Significant figures within the family hierarchy, including mothers, grandmothers, fathers, and siblings, were discerned through drawings and verbalizations. The maternal figure emerged as particularly influential, often depicted first and closest to the patient in drawings.⁽²⁷⁾ Some patients requested the presence of the maternal figure to carry out activities they could do independently. Similarly, the presence and importance of grandmothers, fathers, and siblings were conveyed through drawings and verbal reports, shedding light on their roles and significance within the familial context.

“Mom, can you help me?” (asking for her mother’s help to make the drawing, Girl, 16-year-old; “The other day he (referring to his younger brother) made me cry, he asked me for my blessing, I miss him, I want to be with him” (Boy, 6-year-old).

Perception of Parental Concern

The patients' perception of parental concern for their health was highlighted through parents' presence in drawings depicting hospital scenes, underscoring the importance of parental support and involvement in the patients' healthcare journey.

“Mom is here (referring to the drawing) ...outside the operating room” (Boy, 11-year-old).

Social Dimension

The social dimension encompasses patients' appreciation for healthcare professionals and their social needs.

Appreciation for Health Professionals

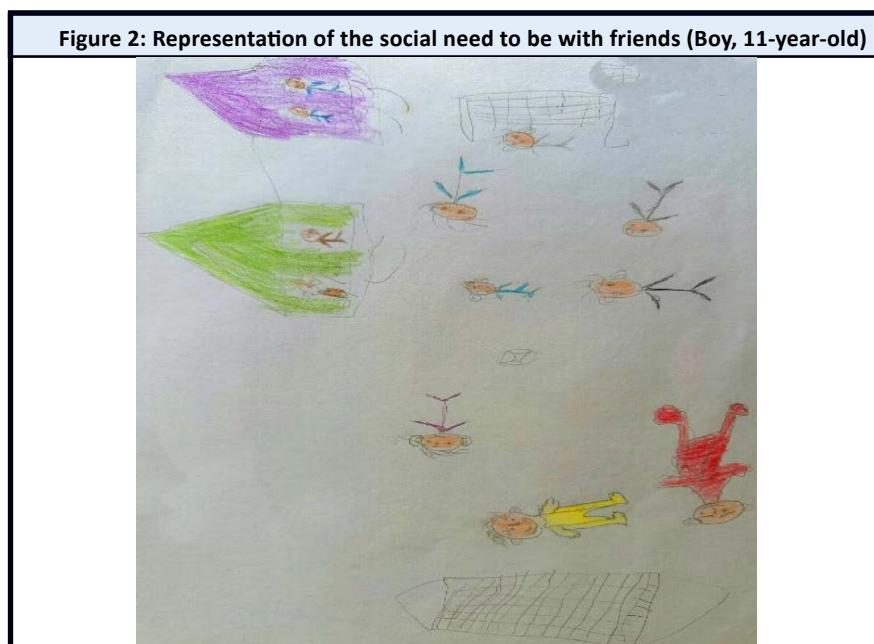
Patients expressed gratitude for the care and support provided by healthcare professionals through both drawings and positive remarks. Their acknowledgment of the efforts and compassion exhibited by healthcare providers show the crucial role of these people in the patients' care and treatment journey.

“The doctor is the one who assesses me, she does everything with love” (Girl, 13-year-old); “...the nurse Claudia, always does her job with love, I like the way she explains everything to me...” (Girl, 11-year-old”).

Social Needs

The patients' social needs were articulated through drawings and verbalizations, reflecting their desire to be in the company of friends, resume everyday life, and achieve goals in life. These expressions reflect the patients' longing for social connections, reintegration into social areas, and pursuit of personal aspirations beyond the realm of their illness.

“I was at the foundation since I left, I played with my friend Santiago there”; “I am going on a trip with all the oncology children to Machiques, where I can play soccer” (Boy, 11-year-old). (Figure 2).



“I am going to enroll at law school, this is what I want to study” (Girl, 17-year-old). (Figure 3).

Figure 3. Representation of the social need to achieve goals in life (Girl, 17-year-old)



DISCUSSION

Family Dimension

Family dynamics emerged as a central aspect, showcasing the balance parents navigate between caregiving responsibilities and daily activities. This finding aligns with existing literature highlighting parents' challenges in managing their child's illness while attending to work and familial obligations.^(1,3) Moreover, the study found how pre-existing conflicts between parents are exacerbated by a child's cancer diagnosis, thereby adversely impacting the child's well-being and family cohesion.^(1,3)

A second aspect, the need for parental bonding, was identified within the family dimension. That means having both parents together and having a non-conflictual, healthy relationship, even in those cases where the parents were separated or in the process of separation. Children's perception of dual parenting as an ideal construct that exercises caring, and protective functions could thus explain this need for parental bonding.⁽³⁾ Other studies have determined that in times of danger, the attachment behavior is reinforced; that is, children want to have their parents with them as a resource that instills security and support to face the threatening situation of being in the hospital.^(2,14,15) Indeed, being able to have their parents close by during the disease and its treatment has been reported by children as the most valuable resource to help them face this experience.⁽¹¹⁾

A third aspect, the need for a united family, reflected the importance of familial togetherness for the patient, which serves as a support to resume daily life. This is consistent with previous research indicating that when a family member is sick, togetherness among their members is considered an element that promotes health since it helps maintain the daily routines that restore the patient's stability, reinforces the sense of belonging, and provides a sense of unconditional support.^(14,17,15)

The fourth topic comprises identifying key familial figures, including mothers, grandmothers, fathers, and siblings, which sheds light on the unique roles each individual plays in the patient's support network. The maternal figure emerges as a primary source of care, comfort, and security, aligning with previous studies highlighting the maternal role in alleviating distress during illness.^(1,29) The importance that the patient gives to the mother, the typical caregiver, could also be a consequence of the prolonged time adolescents spend with their mother due to treatment thus reinforcing the attachment towards her. The mother's constant presence could be problematic when children get used to her help and rely on her even for actions that they could do for themselves, making the transition to autonomy challenging.^(3,30) Similarly, the significance was given to the grandmothers. In Venezuela, the figure of the grandmother has a vital role in the care and attention of grandchildren. Frequently, she assumes the role of the child's mother, fulfilling her duties as she works or carries on other activities. This agrees with past research that indicates that grandparents assume parental roles, helping and taking care of their grandchildren and filling the absence of the parents throughout the treatment.⁽³⁾ It has also been reported that grandparents become widely involved during a child's cancer treatment, becoming a support resource that promotes closeness among the family.⁽²⁾ The paternal figure also assumes prominence, symbolizing protection and providing support to patients throughout their illness journey, assuming the tasks of caring for, and accompanying the patient in cases where the mother was not present. Additionally, the role of siblings related to enjoyment, well-being, affection, support, and returning to life as it was before the illness. In this regard, and paralleling previous findings, needs identified in the patients included missing their siblings during hospital stays and the desire to share with them daily activities and play with them at home.⁽²⁹⁾

Lastly, the study highlights the perception of parental concern among pediatric cancer patients, emphasizing children's awareness of parental distress regarding their health, treatment, and prognosis.^(29,13) Children can perceive when their parents feel stressed, anxious, or sad about their child's suffering, even when the parents do not openly express it. In turn, evidence indicates that children are worried about the well-being of their parents while they are accompanying them in the hospital and acknowledge the suffering, they experience due to their child's illness.^(29,13)

Social Dimension

The study illuminated the affection and consideration expressed by pediatric cancer patients towards health professionals involved in their care. This agrees with previous studies about the appreciation, care, and consideration expressed by children towards health personnel.^(29,15) In the same way, this study aligns with preceding findings that described that factors that contribute to a better adaptation to the disease in the child are a health staff that cares for and listens to the patient, models tolerance to uncertainty, can effectively explain aspects of the disease and its treatment, is friendly, and show competence in administering procedures.^(11,14,15)

On the other hand, the social dimension includes several needs. Patients articulated a compelling need to be with friends to recapture the essence of pre-diagnosis experiences. This longing for social connection resonates with previous research highlighting the profound impact of illness on children's social lives^(11,13) and the therapeutic value of friendships in promoting well-being since it is associated with positive emotions and having someone with whom share their cancer story.⁽³¹⁾ The study also highlights the role of peer relationships as a support resource, fostering resilience associated with cancer diagnosis and treatment.⁽³²⁾

A second aspect patients expressed was a need to resume normalcy and reclaim aspects of life disrupted by the disease. This aspiration to return to the pre-diagnosis routine, including school-related activities and family dynamics, shows the impact of cancer on patients' sense of their daily experiences.^(2,11,13) The study reaffirms the need for school resuming and social reintegration; this has also been reported as a factor in facilitating patient adjustment and promoting overall well-being.⁽³²⁾ Lastly, patients manifested a need to achieve life goals, illustrating the intrinsic link between hope, coping, and goal setting.⁽³³⁾ This aspiration to fulfill postponed goals, such as graduating from school or starting university, came to light as factors that could act as motivating agents that give meaning to life and contribute to coping with the disease.

The study's primary limitation is the small sample size, which restricts the generalizability of our findings to other populations.

CONCLUSIONS

Drawing serves as a valid assessment tool for portraying the familial and social dimensions of pediatric patients studied. Through this modality, access to the patient's inner world is facilitated via a visual representation, which, on the one hand, allows for the expression of the patient's familial and social perspective and, on the other hand, opens a channel of communication between patient-researcher/healthcare provider thereby eliciting firsthand insights into the depicted needs and experiences. Such an approach fosters the development of interventions tailored to address the reported needs of this vulnerable population.

RECOMMENDATIONS

Replicate the study with a larger sample size to generalize the findings. Additionally, further research about the use of drawing as an intervention tool and its potential impact on both physical and psychological variables.

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Authors' contributions

Olimpia Petzold: Study design, processing of information, analysis and discussion of the results, writing-original draft.

Darius Razavi: Analysis and discussion of the results, critical review of the manuscript.

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