

Information manual for the family of the child with leukemia: reception study

Manual informativo para a família da criança com leucemia: estudo de recepção

Manual informativo para familias de infantes con leucemia: estudio de recepción

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How to cite:

Santos LG, Mandetta MA. Information manual for the family of the child with leukemia: reception study. Acta Paul Enferm. 2024;37:eAPE02251.

DOI

<http://dx.doi.org/10.37689/acta-ape/2024A00022511>



Keywords

Information technology; Neoplasms; Family; Pediatric nursing; Child

Descritores

Tecnologia da informação; Neoplasias; Família; Enfermagem pediátrica; Criança

Descriptores

Tecnología de la información; Neoplasias; Familia; Enfermería pediátrica; Niño

Submitted

October 24, 2022

Accepted

July 20, 2023

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Associate Editor (Peer review process):

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Abstract

Objective: To understand the meaning attributed to the reception of a manual by families of children with acute leukemia.

Methods: Qualitative study based on the theoretical framework of the Reception Study. Online interviews were conducted with families of children undergoing treatment for acute leukemia at different stages of treatment and who used the manual 'My child has acute leukemia. How about now?' for thirty days. The WebQDA® software was used in the organization of data analyzed according to the inductive Qualitative Content Analysis.

Results: Participation of nine families represented by seven mothers, one father and one grandmother. From the analysis, emerged analytical categories related to the context experienced by the family when receiving the manual and to the evaluation of the language and illustrations. The meaning attributed by the family to receiving the manual, based on interactions with it, is 'Having the Hope of Healing Strengthened', which helps them to face the adversities of the treatment and keeps them optimistic about the best prognosis.

Conclusion: The use of informative materials facilitates communication with the team, promotes the family's health literacy and strengthens their hope for a cure.

Resumo

Objetivo: Compreender o sentido atribuído à recepção de um manual pelas famílias de crianças com leucemia aguda.

Métodos: Estudo qualitativo, embasado no referencial teórico do Estudo de Recepção. Foram realizadas entrevistas *on-line* com famílias de crianças em tratamento de leucemia aguda, em diferentes fases do tratamento e que utilizaram o manual 'Meu filho tem leucemia aguda. E agora?', por trinta dias. O software WebQDA® apoiou a organização dos dados que foram analisados de acordo com a Análise Qualitativa de Conteúdo indutiva.

Resultados: Participaram nove famílias, representadas por sete mães, um pai e uma avó. Da análise emergiram categorias analíticas relativas ao contexto vivenciado pela família ao receber o manual e a avaliação da linguagem e das ilustrações. O sentido atribuído pela família à recepção do manual, a partir das interações com o mesmo, é 'Ser Fortalecida na Esperança de Cura', que a ajuda a enfrentar as adversidades do tratamento e a mantém otimista em relação ao melhor prognóstico.

Conclusão: O uso de materiais informativos facilita a comunicação com a equipe, promove a literacia em saúde da família e fortalece sua esperança na cura.

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Conflicts of interest: none to declare.

Resumen

Objetivo: Comprender el sentido atribuido a la recepción de un manual por parte de familias de infantes con leucemia aguda.

Métodos: Estudio cualitativo, basado en el marco referencial teórico del estudio de recepción. Se realizaron entrevistas virtuales con familias de infantes en tratamiento de leucemia aguda, en diferentes fases del tratamiento, que utilizaron el manual "Mi hijo tiene leucemia aguda. ¿Y ahora?", durante 30 días. Se utilizó el software WebQDA® para organizar los datos, que fueron analizados de acuerdo con el análisis cualitativo de contenido inductivo.

Resultados: Participaron nueve familias, representadas por siete madres, un padre y una abuela. Del análisis, emergieron categorías analíticas relativas al contexto vivido por la familia al recibir el manual y a la evaluación del lenguaje y de las ilustraciones. A partir de las interacciones con el manual, el sentido atribuido por la familia al recibirlo es "fortalecerse en la esperanza de cura", que los ayuda a enfrentar las adversidades del tratamiento y los mantiene optimistas con relación al mejor pronóstico.

Conclusión: El uso de material informativo facilita la comunicación con el equipo, promueve la instrucción en salud de la familia y fortalece su esperanza en la cura.

Introduction

The diagnosis of child cancer triggers feelings of sadness, pain, anger and impotence both in children and their family in relation to a situation that cannot be changed. It is a moment of suffering for everyone in the family, who must have their support needs met in order to cope.⁽¹⁻³⁾

A coping strategy of families is the search for information to acquire knowledge and reorganize themselves to deal with the situation. Health professionals are responsible for providing adequate information to the receiver's literacy, in this case, children and their family, in order to meet their information needs, improving communication with this population and their satisfaction with the care provided.⁽⁴⁾

Several types of informational materials are available in the literature, such as leaflets, manuals and booklets for use in patient and family education, considering the ease and complementarity with which they can be applied. It is relevant that they include clear, objective and didactic information.^(5,6)

In this sense, the authors of this article prepared the educational material on acute lymphoblastic leukemia (ALL) named 'My child has acute leukemia. How about now?'⁽⁷⁾, since this is the most common cancer in the pediatric population. Furthermore, based on the Patient and Family-Centered Care (PFCC) model, it is also aimed to guarantee the family's right to information in accordance with their perspective and needs.⁽⁸⁾

The manual construction process began in 2013, when the authors developed a methodological study⁽⁹⁾ to propose the items, content and format. The manual format was chosen as it provides guidance and information on a systematized man-

ner, with the function of a guide.⁽¹⁰⁾ In 2015, the manual underwent a Content Validation Study⁽¹¹⁾ by a group of judges composed of health professionals and pedagogues working in pediatric oncology. An agreement percentage of 80-100% was obtained in all items evaluated after three rounds. In 2018, a Semantic Validation Study⁽¹²⁾ was carried out with families of children with ALL at different stages of treatment with application of the Delphi technique. In the first round, 100% agreement was obtained in 163 out of the 171 items in the manual, and 85% in eight items after two rounds. The word lymphoblastic was removed from the title of the manual, as the group of judges understood that the content of the manual provides information and guidance to families of children affected by acute leukemia (lymphoblastic or myeloid).

The final version of the manual⁽⁷⁾ contains 25 pages and 53 illustrations, uses the question-answer style with simple and objective language that favors the reader's understanding. The illustrations were created exclusively by a graphic designer, respecting the Brazilian ethnic and racial diversity. The manual contains information on the definition and types of leukemia; etiology of the disease; its signs and symptoms; types of treatment; side effects of the treatment; warning signs during treatment; care related to food, home environment and personal hygiene; the most common tests during treatment; the prognosis; the rights of the child and the family; information about websites and telephone numbers of interest. A blank space was provided for the note making of possible doubts arising during the use of the manual by the family, and these can be reported to the multidisciplinary team in consultations and clinical visits.

The national literature has a diversity of studies addressing the construction of educational materials with a focus on the education of pediatric patients and their families, but there is a lack of studies on the meaning attributed by the reader to the reception of these materials.⁽¹³⁻¹⁶⁾

Reception studies have as a premise the relationship established between the subject reader and the content used by him/her. The characteristics analyzed from the perspective of reception allow the researcher to know the meaning attributed by the individual to the analyzed text and the possible relationships established between the text and the reader. This established relationship becomes a favorable space for the production of meanings, in which it is necessary to evaluate what people do with the message and what meaning they attribute to it.⁽¹⁷⁻¹⁹⁾

Thus, we set out to understand how the family receives and uses the aforementioned manual. We question if the use of the manual changes the family's experience; what is their perception about the use of this instrument and when they use it; what meaning is attributed to it and what is the impact of its use on the understanding of the child's disease by the family. Thus, the objective was to understand the meaning attributed by families of children with acute leukemia to the reception of the manual 'My child has acute leukemia. How about now?'⁽⁷⁾

Methods

This is a qualitative study based on the theoretical framework of the Reception Study, which is a conceptual framework of the Theory of Communication. Reception analyzes the meaning given by the reader to the text, as well as the relationship established with the content used. Thus, for the occurrence of reception, the receiver must be able to recreate the analyzed object at the time of its reading and assign a meaning.^(20,21)

The inductive Qualitative Content Analysis was the guiding axis of the collection and analysis of data applied to understand the subjectivity of the research problem.⁽²²⁾

The Convention on the Rights of the Child of the United Nations General Assembly, resolution

44/25 of November 20, 1989, defines a child as "any person under the age of 18 years",⁽²³⁾ so adolescents are already covered. In this study, this definition was adopted considering that acute leukemia is more prevalent in children aged between two and nine years old, and has a lower incidence among adolescents.⁽²⁴⁾

Inclusion criteria for the participation of families of children were: being a member of the family of a child diagnosed with ALL, both newly diagnosed and those experiencing different phases of chemotherapy treatment, and having used the manual for at least 30 days. Families of children who were hospitalized in an intensive care unit due to worsening clinical conditions or beyond the possibility of cure were not included out of respect for the moment of suffering they were experiencing.

Convenience sampling was adopted. Participants were recruited through referrals from health professionals specialized in pediatric oncology and invitations were through digital animation on social networks, websites and e-mail. Based on the interest demonstrated, each family was contacted by the main researcher via WhatsApp[®], the purpose of the study was clarified and in case of acceptance, the Informed Consent Form (IC) was sent via Google Forms[®] to obtain the participant's formal agreement. Subsequently, the manual was sent in Portable Document Format (PDF) by email to all families who agreed to participate in the study. However, three families also expressed interest in receiving the manual in printed version, which was delivered by the main researcher. Afterwards, the researcher made contact via WhatsApp[®] for confirmation of receipt, clarification of doubts and guidance for recording its use in a follow-up diary containing information about who used it at home, what was the usefulness of the manual, the results obtained and the reflections made. At that moment began the counting of the thirty-day period stipulated for its use. After the end of the period, was scheduled the date of the online interview using Zoom Cloud Meetings[®] or Skype[®] applications. All families who participated in the interviews lived in the city of São Paulo.

In order to bring the researchers closer to the family and know the context experienced during

the child’s diagnosis, the genogram and the ecomap were built together with the family in the first moment of the interview. These instruments are used to know the family structure and functioning.⁽²⁵⁾

Subsequently, a semi-structured interview was conducted by both researchers with each family individually. At that moment, the families could consult the follow-up diary records to answer the guiding questions: tell us about your experience using the manual. How did you use it? Was there anyone else in the family who also used it? What was it like to receive this material?

Families were identified by the letter indicating the degree of kinship with the child and a number indicating the order in which the interview was performed (Ex: MF1 - mother of family 1). The WebQDA® software, which has online access and confers more credibility due to the rigor and systematization applied in the process, was used in the organization of data.⁽²⁶⁾

Inductive analysis was applied to apprehend the latent meaning present in participants’ statements. The process of abstraction and continuous interpretation of data was reinforced to maintain the fidelity of the qualitative analysis. To this end, after transcribing the interviews, data were coded line by line to extract the most present perceptions in each statement. Then, the codes were grouped into categories by similarity. The final categories were compared in terms of similarities and differences in search of the meaning attributed by the family to the use of the manual. Data analysis was performed by the two researchers together.⁽²²⁾

The study was approved by the Research Ethics Committee linked to an Institute of Higher Education (Opinion: 3.903.558), (CAEE: 27346819.2.0000.5505) and the guidelines of the Consolidated Criteria for Reporting Qualitative Research (COREQ) were followed in its development.⁽²⁷⁾

Results

Nine families, represented by seven mothers, a father and a grandmother, participated. Next, we

present a summary of the characteristics of the participating families in chart 1.

Chart 1. Characterization of participating families

Identification and composition of the family of the child with ALL	Main caregiver/ education/ profession	Period when the family received the manual	Phase of the child's treatment when the family received the manual
Family 1 (MF1) Composition: father, mother and a 3-year-old daughter with ALL	Mother - postgraduate – pedagogue	Three months after diagnosis	Consolidation therapy
Family 2 (MF2) Composition: mother, 3 children, two 5-year-old girls (twins), one with ALL, and a boy, maternal aunt and maternal grandparents	Mother - completed higher education - nurse	Two months after diagnosis	Consolidation therapy
Family 3 (MF3) Composition: father, mother and a 4-year old daughter with ALL	Mother – complete high school - nanny	Seven months after diagnosis	Maintenance therapy
Family 4 (MF4) Composition: father, mother and a 6-year old daughter with ALL	Mother - complete high school – housewife	11 months after diagnosis	Maintenance therapy
Family 5 (MF5) Composition: father, mother and a 14-year-old daughter with ALL	Mother - complete higher education - publicist	Two years after diagnosis	Maintenance therapy, one month after the end of treatment
Family 6 (MF6) Composition: father, mother and three children; two girls, the oldest 9 years old with ALL, and a boy	Mother - complete higher education - pedagogue	One month after diagnosis	Induction therapy
Family 7 (FF7) Composition: father, mother and two children; a 5-year-old boy with ALL and a girl	Father - complete higher education - business administrator	Four days after diagnosis	Induction therapy
Family 8 (MF8) Composition: father, mother and three children; two 3-year-old girls (twins), one with ALL, and a boy	Mother - complete high school - hospital plaster technician	Seven days after diagnosis	Induction therapy
Family 9 (GF9) Composition: paternal grandmother, paternal aunt and a 6-year old girl with ALL (granddaughter)	Paternal grandmother (has custody of the child) – complete higher education - psychologist	Five months after diagnosis	Maintenance therapy

Analytical categories related to the context experienced by the family when receiving the manual, the evaluation of the language, illustrations and their usefulness, and the meaning attributed by the family to the reception emerged from the analysis of data.

The unknown context to the family

The family reveals that receiving a diagnosis of cancer in one of its members is something totally unknown to them and causes an impact, es-

pecially in this study, as it was developed during the pandemic caused by the SARS-CoV-2 Coronavirus, which imposed changes in human relationships across society. The imposed social isolation brought a series of restrictions, causing the separation between members of the nuclear family and the extended family and friends. In the hospital environment, the family was prevented from knowing and sharing their experiences with other families who experienced similar situations.

“[...] After the pandemic started, my brothers only see her from the door, they stay in the apartment hallway and we open it for them [...] people took a shower before coming to see her, nobody came straight from the street, we are very careful with that.” (MF5)

“At the hospital we don’t have contact with other children, I guess because of the pandemic, we go into our room and stay inside, so I don’t have contact.” (MF6)

At the moment of diagnosis, because of the pandemic, the family has more difficulty in accessing information that can answer their doubts, which creates uncertainties, especially about the diagnosis. Thus, when the family receive the manual sent by a specialist nurse and know it is a scientific study linked to a university, they feel stimulated to get information about the disease. In this context, family members infer that the child’s diagnosis is real and it is necessary to prepare themselves by acquiring information, such as that offered in the manual, in order to cope with the situation. In this way, the family perceive the meaning and value of the manual and begin to use it.

“[...] and then when you also come and hand me the manual, it carries a burden, in the sense of ‘go get information [about the disease], because it is necessary’... And, if the nurse is giving it to me, it’s because he has leukemia.... it’s because he really has. That’s why I started to read and use the manual to inform myself” (FF7)

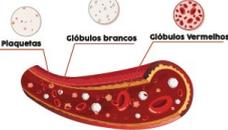
Use of embracing language

In the family’s assessment, the language used in the manual is sensitive and embracing, capable of enhancing their strengths at a time when they are weakened by the child’s disease and the pandemic. The family reveal that the manual allows them to acquire knowledge about the disease and child care, which were unknown. In this way, reading about a topic that causes intense suffering in family members becomes lighter precisely because of the way it is offered, with the use of careful language that facilitates understanding, favoring changes in the way of caring for the child, as they assimilate the information and feel motivated to put it into practice. As for illustrations, the families mention that viewing the pictures in the text breaks its rigidity and helps to better understand what is being said. When looking at the drawn images, the families bring up the changes caused by the disease and treatment in the child’s body, such as hair loss, weight loss, among others, so they have the opportunity to reflect on the acceptance process, when thinking about the child from the images. In table 2, we present a summary of families’ evaluation of the language and illustrations together with the meaning attributed by them.

The meaning attributed by the family to receiving the manual: To have the hope of healing strengthened

Having the hope of healing strengthened is the analytical category that represents the meaning attributed by the family to the reception of the manual as they interact with it. The family understand that despite the complexity of the disease and treatment, it is possible to face it with resources and knowledge acquired through careful reading. This helps them feel more confident to fight for a life-friendly outcome. Thus, families assume the central role in the care of the child, ensuring the maintenance of his/her health, doing everything in their reach, with gratitude for the message of hope contained in the manual, which makes them learn about the disease, the treatment and above all, helps them believe that all their efforts have a great chance of being rewarded with the child’s cure. The subcategories forming

Table 2. Summary of the analysis regarding the embracing language of the manual “My child has acute leukemia. How about now?”⁽⁷⁾

Representative picture of the analytical category - Evaluation of the manual from the family's perspective: use of embracing language	Primary caregiver speech	What did it represent to the family?
<p>É uma desorganização da medula óssea, que é a responsável por produzir as células do sangue para nosso corpo.</p> <p>Os três tipos de células sanguíneas são:</p> <p>Glóbulos vermelhos são responsáveis pelo transporte de oxigênio para nutrir todas as células do corpo e por carregar ferro;</p> <p>Glóbulos brancos são como os soldados do nosso corpo, sua função é protegê-lo contra os agressores (infecções).</p> <p>Plaquetas protegem o corpo de sangramentos</p>  <p>Na leucemia, a medula óssea passa a produzir de forma descontrolada os linfoblastos (tipo de glóbulo branco). O acúmulo dessas células bloqueia a produção dos glóbulos vermelhos, brancos e as plaquetas, levando a criança/adolescente a ficar mais predisposta a ter anemia, infecções e sangramentos.</p> <p>Definition of leukemia</p>	<p>"[...] there is this part where it says there is no reason for Priscila to have had this, right... and there is someone who told me that I must have let her get anemia. [...] the manual was good because I could see things clearly. The right research I was doing and the wrong research, right, and what that person said had nothing to do...." (MF6)</p>	<p>Understanding the etiology of leukemia, clarifying possible doubts and even misconceptions that could be contributing to intensify their suffering.</p>
 <p>Aparecimento de manchas, bolhas ou feridinhas pelo corpo</p> <p>Representation of a warning sign (adverse effect) during treatment</p>	<p>"[...] and then, I was even able to ask the physicians about some things that I had not yet been warned of, until one day, I even told you about the wounds on the skin and then I just started using the moisturizing cream "x" because I saw in the manual that these wounds could occur." (FF7)</p>	<p>Family see themselves as capable of anticipating child care and learn to question the team, as reading the manual awakens them to aspects that had not yet been warned of.</p>
 <p>Representation of the bald child in the treatment phase</p>	<p>"[...]because there was a fear, on our part, on the issue of hair loss, and then, this little child in the manual itself, there is an illustrative image, right [...]. In fact, illustrations are very important in the manual! I think it's fundamental because it makes us see ourselves or else you see your child in those illustrations and this is part of this acceptance process we are going through [...]" (FF7)</p>	<p>The child with alopecia is represented at different times in the manual. When seeing the illustrations, the family can think of their own child who is experiencing the disease. This helps in accepting the changes that occur in the child's body.</p>
 <p>Representation of the symptoms of acute lymphoblastic leukemia (ALL)</p>	<p>"Laura has always had a throat infection, always, since she was a little girl... I remember this could be a symptom, but for me, who didn't know, I had no idea that it could be [...] she got a lot of throat infections, so I imagine that this was already a symptom of leukemia, because I saw in the manual that infections are one of the symptoms, right." (MF3)</p>	<p>Learn about early signs that may indicate a possible leukemia diagnosis, such as repeated infections.</p>

this category are: understanding the complexity of the disease and treatment; having a protagonist role in the care of the child; and gratitude for the message of hope.

Understanding the complexity of the disease and treatment

The family can understand that the disease is complex and the aggressive treatment can contribute to worsen the child's clinical condition. Aspects that previously were not part of the child's and family's life, such as the need to receive a blood transfusion, become present. With the careful reading of the way this topic is addressed in the manual, the family begins to better understand the reasons and the way this treatment is carried out, which helps to calm them down and maintain hope in the child's recovery.

"[...] because I didn't know that a person undergoing leukemia treatment needed blood bags, I didn't know... Very lay, really, I was scared the first time she needed it because we really don't know." (MF4)

As families understand the child's treatment, they realize that the course of the disease and treatment does not always follow as initially planned. Changes in therapeutic plans may occur, delaying treatment or even interrupting it. The family wants to know about all these possibilities so they can have a little more control over the situation. They do not want to be taken by surprise. Therefore, they request the inclusion of a text in the manual on the possible situations in which the treatment may undergo changes in plan and a deepening on the phases after induction therapy. Families understand that even after discharge from treatment, care actions cannot stop.

"If possible...if you can add that there might be some disagreements at some point, that's good. Like, it can happen, not that it will happen, if the child gets sick, the chemotherapy has to be stopped, the treatment is delayed. Things that can happen and not that will happen, you know? I guess that's cool, that's the only thing I didn't see there." (MF3)

"As this manual has the information, I received, I used, I can say that I used it, yes, I still use it nowadays, the physician even said that it will take six months to fully recover." [MF5]

"[...] because for a manual itself, which is the objective, it is super valid and helps a lot. My issue today is about the protocols and what will come after [...]. My proposal is that the manual has a continuation, that is, when I say that it has a sequel, it is in the sense that it's something more specific." (FF7)

Having a protagonist role in the care of the child

Understanding the complexity of the disease and treatment reinforces the importance of the family taking over the protagonist role in the care of the child for coping. Thus, when reading about child care during treatment, the family attributes a sense of importance to changing eating and hygiene habits so that the child's clinical conditions are reinforced and he/she can better face the disease and recover, and consequently, the family assumes this care.

"Look, in terms of hygiene, I used it a lot (the manual), in terms of diet suggestions too, especially now that she has entered maintenance [...] so it's all already there, we read it and it is expected, we become a little more familiar with this manual and it is already a little more familiar when we are in contact with this disease face-to-face, live and in color." (GF9)

The food issue is a critical point for the family, which strives to provide the best care for children, making them stronger to avoid infections. This aspect is valued by the family because it makes them feel important.

"So, I try to be very careful with her diet. We look for it and here (in the manual) it says a lot and teaches how to clean everything, I think it's a very important thing so that she doesn't get any infection." (MF2)

With the knowledge acquired, families become familiar with the conduction of treatment. It helps

in understanding what happens to the child. When feeling safe with the knowledge obtained, the family share the information contained in the manual both with members of the family and others.

“So, through the manual, I had more peace of mind to give her (grandmother of another child) this information. I was much happier by helping her through a reliable source, through a manual that you developed, you, who are qualified, you know what I mean?” (MF3)

“[...] I sent it to my niece, because she had many doubts and she is pregnant, then she said ‘oh I was scared, because I thought it ran in the family’ [...] so she (the niece) thought that because they were twins, she could have it too.” (MF8)

Gratitude for the message of hope

Families reveal gratitude for the knowledge acquired by reading and interacting with the manual, which calms them down and brings a sense of security and hope, knowing that the disease can be treated and there are great chances of recovering the child's health and life. In this way, the family renew their faith and have their hope of healing strengthened.

“Oh, I find it very gratifying because it adds something that helps, something that when you have a doubt you go there and take a look again, being available on the cell phone makes it even easier.” (GF9)

“Even with the physicians being available for us to ask, it gives a sense of security to have a manual like this with us, you know? So, I say again that it's very important to have a manual like this from the beginning, because it gives the family more security [...] I guess it brought this sense of security, that it will work and for us to be strong.” (MF6)

Discussion

The development of this study made it possible to expand knowledge about the potential of informa-

tion for the family, providing them with tools to better cope with the child's disease condition. Hope in the meaning attributed by the family to receiving the manual, built from information obtained from the family's interactions with the manual and with professionals of the team that help them to interpret it.

Reception studies are valuable to understand how families use the information materials offered to them, apprehend the knowledge made available and assign meaning to it.⁽¹⁷⁻²¹⁾

In this study, the richness of how families report their experience with reading and using the manual, the reasons that make them use it and the attitudes they take based on the knowledge apprehended proved to be fundamental to broaden our perception of the importance to establish communication with the family, in which their rights are respected, as well as their health literacy. When we hear from the family about the changes that the knowledge obtained from readings and rereadings throughout the child's disease experience generated in their family nucleus and even in the extended family, we advance in the understanding that it is necessary to go further. Not only by bringing information about a certain disease, but by helping the family to understand the diagnosis, treatment and prognosis, supporting them with explanations that promote their health literacy and make them correlate with their child's situation. In this way, families learn to handle child care and become aware of the complexity of leukemia. Positive language, which uses linguistic resources that make it lighter, considering it is a disease with a stigma associated with death, helps to strengthen the hope of a cure in the family.

The interaction of professionals and the establishment of communication with the family based on the principles of PFCC, with respect, sharing of information, offering opportunities for patient and family participation in care in a proactive way, assuming their protagonist role, was fundamental. Thus, the manual was conceived and made available for use by the family using sensitive, empathetic and embracing language. A dense theme such as cancer in children and adolescents is offered in the lightest and most positive way possible so that the family

can read, despite the suffering imposed by the situation, learning about the disease and treatment and sustaining their hope in the child's cure.

When the family acquire knowledge and feel safe to understand the disease and the treatment, they can realize that although the cancer diagnosis brings an impact, it is a curable disease. This evidence corroborates the importance of sharing information with the family and facilitating coping with the treatment.⁽²⁸⁻³⁰⁾

Furthermore, it is important to emphasize that the manual was offered when the pandemic caused by COVID-19 was declared. The changes in the routines of services aimed at patient safety, contributed to social distancing, impairing contact between the families of hospitalized children and preventing the exchange of experiences, bringing more doubts and information needs. All that was left for the family was the internet access, but it generated more anguish and did not meet their demands. In meetings with the team, the family had the opportunity to clarify their doubts, but even so, it was not enough. The offer of the manual happened in this context, meeting the needs of the family, who yearned for materials of this nature.

The Institute for Patient-And-Family-Centered Care (IPFCC) reinforced in its publications the importance of maintaining effective communication with families in times of a pandemic to ensure the sharing of information. Strategies are focused on three aspects: communicating with the family; promoting bonding between patient and family; and offering support to patient, family and everyone involved in care. One of the recommendations is to offer information through materials written in the most positive way, in appropriate language for the community, following the best health literacy practices.^(31,32)

In this sense, the manual is a strategy that can mitigate the lack of information imposed on the child and family in this context. It also contributes to promote a connection between family members, from the moment of information exchange between family members and explanations obtained from the team.

The family's ability to make decisions and anticipate the necessary care for the child with cancer,

based on the information acquired and the meaning attributed to the use of the manual was evidenced in this study. It revealed the importance of investing in knowledge to promote the strengthening of the family, who takes over a protagonist role and participates in the care provided by the multidisciplinary team. Families became able to question this team of possible adverse effects of treatment that they became aware of after using the manual, also developing their autonomy.

The importance of strengthening health literacy of the family is highlighted, i.e., one's ability to understand and use information with the aim to promote healthy care. Families strengthened by knowledge become more active, have favored critical thinking and are able to make assertive decisions and solve health problems.⁽³³⁻³⁷⁾

Another relevant aspect of the manual is that it was prepared and validated with deep respect for the information needs of the family of children with acute leukemia, with adjustments to assist them in their health literacy, using inclusive and adapted language that was considered adequate by the participating families. Note that the manual was used only after the moment the families recognized themselves and their children in the various figures and texts presented.

It is difficult to use any tool when the language is not adapted to lay people, compromising readability and ease of understanding. It is important that health professionals understand the constant changes occurring in health literacy, therefore, nurses must share information through materials designed according to the information needs of the family.⁽³⁵⁻³⁹⁾

Furthermore, by ensuring the family's access to information, nurses reaffirm their ethical role as a moral agent that defends families in vulnerable conditions, especially their right to access information during the child's oncological treatment.^(40,41)

A limitation of the study was its conduction with families from a homogeneous social group, from middle to upper class, with a similar level of education. In this regard, it does not portray the Brazilian population as a whole, therefore it should be expanded.

Conclusion

The view from the perspective of the Reception Study made it possible to understand the meaning attributed by the family to using the manual 'My child has acute leukemia. How about now?' From the clarifications about the child's treatment and prognosis, families strengthened their protagonist role as caregivers and were able to modify beliefs and build new habits, which gave rise to a feeling of gratitude for the information received. Families were able to make assertive and mature decisions, revealing that the process of receiving, using and assigning meaning to the manual favored their strengthening. The use of informational materials facilitates communication with the team, promotes the family's health literacy and strengthens their hope for the cure.

Acknowledgements

We thank Dr. Carla Renata Pacheco Donato Macedo and her team for their support in the search for the families participating in the study and for their brilliant performance in pediatric oncology.

Collaborations

Santos LG and Mandetta MA declare that they contributed to the design of the study, analysis and interpretation of data, writing of the article, relevant critical review of the intellectual content and approval of the final version to be published.

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