Chapter 37

Design thinking: the illustrated book as a strategy for psycho-educational intervention with children under oncological treatment

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ABSTRACT

illions of cancer cases are diagnosed each year, including in children. The success of treatment depends on adherence and one of the strategies for adherence is the use of books or manuals. The present work aims to present Design Thinking and show how this method can contribute to the creation of an imagetic material to support psychoeducation. Bibliographic research and interviews with the author of the book "I'm sick, now what? Guidelines for children with cancer", with a psychologist from the Hospital do Câncer de Londrina, and with mothers of cancer patients. The methodology used was Design Thinking, which facilitated the generation of ideas, project direction and working together with professionals from various areas of knowledge, resulting in a collection of children's books for children, parents and professionals.

Keywords: children, cancer, psychoeducation, image, design thinking.

1 INTRODUCTION

Cancer treatment imposes an abrupt change in daily life as a result of constant medical consultations and usually invasive therapeutic interventions. When it comes to childhood cancer, the child with the disease ends up suspending a series of practices that are necessary and important for their development phase. Furthermore, the drastic change in routine or the imposition of social isolation can lead to fear, frustration and anxiety. Therefore, the patient needs to develop some skills during treatment: how to face complex and difficult situations, how to undergo invasive procedures and face physical changes (scars, hair loss, etc.).

As for the emotional aspect, the context of cancer treatment should favor an environment that facilitates development, learning and autonomy. It is essential to expose the repertoire about the disease and coping with it. The information and provision of guidelines contribute to adherence to treatment.

Therefore, psychoeducation is a strategy that aims to provide information to help in the development of behavioral coping repertoire, helping to adhere to treatment. In addition, psychoeducation facilitates

decision-making, facilitates therapeutic support and reduces insecurity (Guimarães, 2012). Interventions aimed at children need to be direct and objective, and can be provided with books and recreational activities (Amaral, 2010).

In this situation, it is essential to encourage the child's learning. The images inside the books make the content more attractive to children and allow for a better understanding. Therefore, Design Thinking is a method that allows you to assist in the production of graphic projects, obtaining tools that allow collaborative work, covering different areas of knowledge, and always thinking about the target audience. The objective of the article is to present Design Thinking, and how this method can contribute to the construction of imagery material to support psychoeducation.

PSYCHOEDUCATION

Psychoeducation uses resources from the field of Psychology with the aim of encouraging the learning of concepts, obtaining a repertoire to analyze the context and identify important behaviors to act in the situation. Psychoeducation is "the act of teaching the individual aspects related to their diagnosis, the principles of behavior control, the function of feelings and their life history" (Santos et al., 2018).

Intervention is important, because during cancer treatment there is a sudden change in daily life, in addition to the side effects that emotionally impact the patient and their family members. This sudden change in routine increases the child's symptoms of anxiety and depression (Martins, 2017). The psychoeducational intervention favors the understanding of the situation, development of a collection of coping with the situation, increased adherence and a decrease in symptoms of stress and anxiety.

ILLUSTRATED BOOK CHARACTERISTICS

One of the most used resources for early childhood education is the illustrated book. The picture book has a narrative in which text and image are equally important for understanding the content (Nikolajeva & Scott, 2011). This type of material, combined with instructional activities and accompanied by guidance from professionals or guardians, are effective for the child's understanding. To make a picture book, one must understand the physical and structural aspects. Some physical elements of the book are the cover, type of material, format and size. These directly influence the structure and layout, where it is important to understand the concepts of framing, grid, hierarchy. The integration between all parts allows efficient communication.

Of the physical elements of the book, the cover is the person's first contact with the material. It must be consistent with its content, as it serves as a sample. In addition, it must be attractive to the target audience, creating anticipation for the reader. It should also be taken into account that the material will be constantly consulted by a children's audience, so it must have a resistant material and finishes (Van Der Linden, 2011). In addition to the material, it is necessary to choose the size and format of the book. A large size for books can be more attractive and easier for children to handle (Nikolajeva & Scott, 2011).

To diagram a book, one must understand about grid and hierarchy. The hierarchy allows you to define the most important elements of your work, and guide the reader's eye in a defined sequence. Without hierarchy, visual communication is confusing. The grid is a geometric mesh that allows organizing the content, allowing the alignment of texts and images, creating a harmonic composition on the page (Lupton & Phillips, 2008).

To design a picture book, in addition to knowing the physical and structural aspects, it is essential to know the target audience of the material and know how to design the product effectively.

DESIGN THINKING IN THE ILLUSTRATED BOOK PROJECT

To design a material, it is important to use a methodology that serves as a guide during the process. Therefore, Design Thinking was chosen, as it is a tool used in the period of product creation, aiming to identify problems and generate creative solutions.

One of the characteristics of Design Thinking is always having the target audience as the focus throughout the product creation process. Thus, it is essential to understand the context, problems and needs of the people involved, in this case patients, family members and professionals. In addition to the ability to visualize problems and develop scenarios based on people, Design Thinking allows for interdisciplinary work. This method allows bringing together professionals from different areas of knowledge to work cooperatively (Brown, 2009).

Some of the techniques of this methodology are: immersion framework, personas, empathy map and prototype. The immersion framework consists of putting together ideas, written or drawn information, important information acquired throughout the project. This information placed on the board are the insights, and they are arranged by content proximity, helping to reveal possible implicit ideas and allowing the construction of new insights. The board also helps in communication between all parties involved in the project, constituting an area where everyone can express their ideas (Kumar, 2013).

After completing the immersion frame, the personas will be created. Personas aim to understand your target audience and provide direction. These are archetypes, a fictional character that portrays this audience. Names, age, profession, behavior patterns and needs are created. This step aims to bring empathy and always remember your target audience, prioritizing their problems and guiding them in decision making.

The empathy map is generated after the persona. He seeks to better understand the needs of his target audience. It has the following questions to be completed: What do you think and feel? What you see? What are your pains? What are your needs? What do you say and do? And what do you hear?

The prototype is the first model that aims to simulate the product. This step allows for closer contact with the final version of the material, and also allows for the application of tests (Demarchi, 2011).

This project consists of analyzing and making changes and updates to the book "I'm sick, what now?" (Casanova & Soares, 2009) according to the Design Thinking methodology.

2 METHODOLOGICAL PROCEDURE

The project was developed with the participation of professors and students from the State University of Londrina (UEL) and with the help of the Cancer Hospital of Londrina (HCL), in the sector of child oncology. The Londrina Cancer Hospital is a philanthropic entity, with the title of CACON (Center for High Complexity in Oncology). The institution is a reference for 220 municipalities in Paraná and had more than 908 thousand attendances in 2018 (SYMPLA, 2019).

Aiming for flexibility, the research had an exploratory character, thus providing the improvement of ideas and the discovery of intuitions. For the design, the indirect and direct approach was used. The indirect approach allowed a study with bibliographical research. The direct approach provided data and information at the hospital itself.

For this, a field study was carried out. This study consists of obtaining information directly from the place where the phenomena occur. Interviews or observations can be made to achieve the objective (Gil, 2007). Interviews were conducted with the HCL psychologist; in addition to interviews with four mothers of children with cancer, with the aim of understanding their difficulties and needs for child care.

In addition, the Design Thinking methodology was used to assist in the integration of the multidisciplinary team and facilitate the construction of the product. The team consisted of: a student from the Graphic Design course at UEL and a professor from the same course; a master's student from the Graduate Program in Behavior Analysis at UEL and a professor from the same program; a psychologist from the child oncology sector at HCL.

3 RESULTS AND ANALYSIS

Firstly, there was an interview with one of the authors of the book "I'm sick, what now?", to learn more about the book in depth. In this way, positive points and elements to be improved about the publication were recorded. It was understood that initially the content was separated into cards, so the child received the information as needed. For ease of editing, all this information had been collated into a book. One of the questions addressed was: if the complete content is delivered at once to the child, could this cause anxiety unnecessarily?

Some changes in the material were also suggested. Regarding the physical aspects, the recommendations were to separate the content into different sections and increase the weight of the paper to facilitate carrying out the activities. From the content, it was suggested the inclusion of some metaphors that are frequently used to explain cancer to children, but that were not being used in the current story. In addition, it was thought of adding other content, such as returning home after treatment in the hospital and more content for parents and professionals.

Subsequently, the team visited the child oncology sector of the Londrina Cancer Hospital to contact the psychologist. In the interview, it was understood that the age range of the patients treated was wide, ranging from babies to 17-year-old adolescents. Patients' recurrent doubts were also understood. Children

usually ask about alopecia (hair loss), length of stay, presence of mucositis (mouth sores caused by the treatment) and the possibility of death. Parents' doubts are similar, but there are also insecurities and questions about their children's behavior (aggressiveness, irritation, disobedience).

The psychologist emphasizes the importance of the role of parents for the child's adherence to cancer treatment. Parents are often references for children, so their behavior in the face of the situation can direct the child's performance in the treatment.

It was mentioned that the psychologist uses the book "I'm sick, what now?" (Casanova & Soares, 2009) with some adaptations. Furthermore, she suggested some content changes and additions. One of them was the addition of topics on the two most common types of catheter: the port-a-cath and the PICC (peripherally inserted central venous catheter). It was also requested that the order of the presented information be changed to a sequence that would facilitate the psychologist. In addition, he asked to insert that it is necessary for the patient to replace blood components frequently (for example, platelets), add clarification on the different types of chemotherapy administration (outpatient, inpatient and medication) and information on mucositis, which are sores in the mouth caused by treatment. It was also seen that it would be interesting to ask post-treatment questions, such as returning home and school.

Another proposed adaptation was about the activities. She made copies of the activities in the books, as the group of children who used it was large. A material designed to facilitate these copies would be ideal.

After the visit and interview with the psychologist at Hospital do Câncer de Londrina, four individual interviews were conducted with mothers of children undergoing cancer treatment. The scope was the identification of changes in behavior presented in this period and changes in routine. The data obtained indicate that the decrease in immunity led to a reduction in interaction with friends and a reduction in contact with family members. An increase in the frequency of behaviors related to hygiene and restrictions on certain foods and contact with pets was found. Mothers verbalized that their children had increased symptoms of irritability, tiredness and isolation.

During the interview, it was reported that both mothers and children sought to resolve their doubts on professional websites available on the internet. It was reported that both consider reading an interesting activity and that they do not have difficulties in carrying it out. However, the mothers expressed the lack of time, which makes it difficult to read books. Children, on the other hand, have more time to carry out this activity, being interested in adventure themes and comic books.

Based on the interviews, it was seen that the target audience would engage more if the reading had accessible language and the material was brief, with the inclusion of indication of websites aimed at parents and guardians. For children, it would be relevant to develop creative skills that generate decision-making.

After collecting information, the mental model of Design Thinking was used to analyze the material. The following tools were used: immersion chart, personas, empathy map and prototype.

In the immersion frame, the essential information regarding the bibliographical research, observations and interviews were placed. Kumar (2013) names this information synthesized by insights,

which are ideas formed or facts studied during development. Insights were organized by approximation of content, allowing a better visualization of the project, helping to create new ideas.

Subsequently, the understanding space began, where the personas were created. Aiming to increase empathy, these fictional characters are created with names, ages, professions, behaviors and needs. This step helps by always directing attention to the defined target audience, thus also helping in decision-making (Kumar, 2013).

Three personas were developed for this project: Augusto, portraying the child with the disease; Patrícia, the mother and guardian of the child; and Sarah, corresponding to the psychologist for these two patients (Figure 1). The selection of the three personas comes from the target audience: the book is aimed at children with cancer, but will be instructed and mediated by psychologists. It is intended to have a session for parents and guardians, which will provide content for the child's return to school and home routine. Furthermore, this project intends to create activities that will facilitate the perception of psychologists about possible demands.
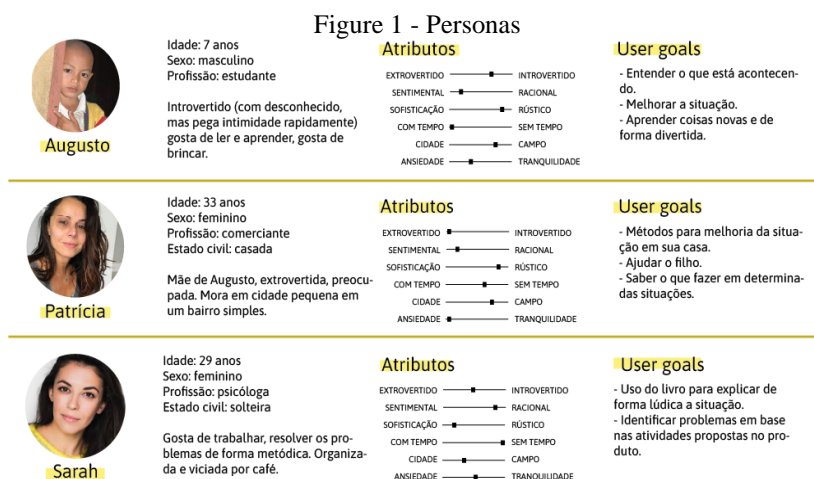
Figure 1 - Personas

Source: Suzuki (2019)

The empathy map is another technique in the understanding space, designed to facilitate the process, better interpreting the personas (Figure 2).

Figure 2 - Empathy map

Source: Suzuki (2019)

During the creation process, several "dolls" were printed to simulate the books. Through the prototypes, several people from different areas of knowledge could suggest ideas to improve the product.

About the illustrations, the first versions were presented to the group, which discussed the exchange of some questions: the explanation of the bone marrow, red blood cells, platelets and leukocytes, which at first consisted of a gray factory and warriors.

In analysis, the professionals considered the analogy of the marrow as a blood factory positive, however they judged the factory too hard and gray to be part of the human body. The explanation of red blood cells, white blood cells and platelets have also been changed, so that there is no content with "violent" elements such as weapons and shields. Based on feedback and conversations, the designer reworked the illustration.

In the amendments, the three elements of blood explained in the book were characterized in the form of "little balls". The leukocytes (the body's defense cells) were represented as blue "balls" that face weeds/weeds (which are the metaphor for the cell with cancer). The platelets, on the other hand, are symbolized as yellow "little balls" that divide to fix the broken wall, interpreting people's injuries and the protection process exercised by the body. The red blood cells, whose representation was of a train due to their function of transporting oxygen and carbon dioxide, kept their red color and were transformed into a flatter "ball" (as they are often represented). These red blood cells are represented in movement in pipes that will pass through the "city". All of them start from the bone marrow, now represented by a rounded plant with light shades, resembling a bone. In Figure 3, the before and after are represented.

Figure 3 - Bone marrow analogy

Source: Suzuki (2019)
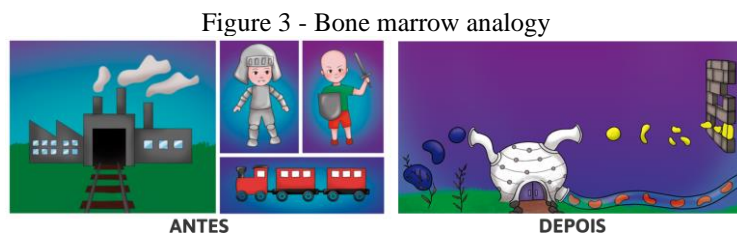
The version was shown to the team and to a designer specializing in children's illustrations, and they pointed out the need to generate more contrasts between the colors, since it is possible for children to lose visual acuity during treatment. One more page was included for the explanation of blood cells, as the content was too long for a single double page. The illustrations with the changes were shown below in Figure 4.

Figure 4 - Illustration of blood cells

Source: Suzuki (2019)
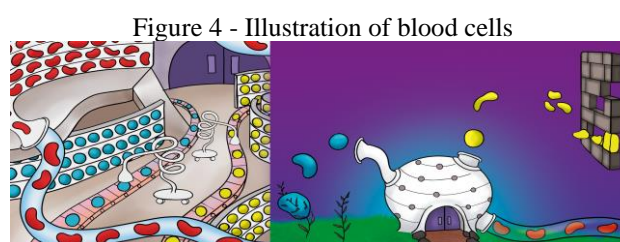
You can see how important communication using Design Thinking is. All feedback is considered and the polishing of the proposal is evident.

Finally, the content of the book "I'm sick, what now?" it was subdivided into 5 different booklets: "Understanding Cancer", it is an introductory explanation about cancer, cells and exams;" It's time for treatment! What to do?", will be addressed on issues of catheter, chemotherapy, hospitalization; "The return home", has content on fundamental care in routine; "Activities" and; "Glossary". In addition to the illustrated booklets dedicated to children, a separate issue was created, aimed at parents and guardians, offering information on how to use the collection and how to mediate the process with the child.

With the separation of contents, five different colors were established to represent each of the booklets. Purple/lilac was chosen for the introductory book, as it means spirituality, knowledge and changes (understanding the body, cancer, types of cancer). For the second, the color chosen was blue, as it represents seriousness and confidence in a systematic moment such as treatment. The predominant color of the third book was green, as it symbolizes hope and tranquility (from the comfort of the house, from an interval of calm). The Glossary has as its main color orange, because it is happy, stimulating the children's search for the meaning of words. In the Activities book, it has a predominance of yellow on the cover, representing the energy and being active regarding the book's content. The inside was printed in black and white, with just a colored band demarcating which booklet the activity was announced from (if it is in the homecoming book, there will be a band in green, located in the bottom corner of the page). The book printed in this way allows children to paint, stimulating creativity, in addition to making it more affordable. The book for parents and guardians is more neutral and serious, with a predominance of light tones, facing white (the combination of all colors) (Figure 5).

Figure 5 - Covers

Source: Suzuki (2019)

A change was made to the Glossary with the addition of images to explain the terms. The use of images and infographics to explain the content seeks to contribute to the understanding not only of the child, but also of the parents.

The Activities booklet incorporates all the dynamics related to the other booklets. It was recommended to use thicker paper, with black and white printing for the child to color, with only a colored band, indicating the original booklet by color and writing. This category of coloring book, in addition to being widely used in schools, boosts the user's creativity. The black and white pages will also make copying

easier to do the dynamic with a large group of children. This is very important, considering that the target audience includes both children and professionals at Hospital do Câncer de Londrina.

A style was also defined for the entire collection: a more "childish" style (in which the proportion of the character's height is equivalent to two and a half heads in the drawing). The adult characters were portrayed with a 5-head ratio. Contours and strong colors were used to provide better contrast, thus being more ergonomic for children with low vision.

Finally, it is important that the material is inclusive, portraying people from diverse ethnic groups. The collection was created considering this ethnic diversity and paying attention to the different types of family structures, avoiding the representation of the traditional family ("father, mother, brothers"). In this way, it is open to the reader to interpret what the protagonist's family is like. In addition, a playful narrative was developed (with familiar concepts, such as superheroes and the factory, for example) to explain the complex contents.

4 FINAL CONSIDERATIONS

The research shows the importance of images and information in understanding new content and in adhering to the treatment of a disease as aggressive as cancer. Cancer is still treated with great stigma, and thus it often makes it difficult to adhere to treatment, especially in the early stages. Through research, it was found that information is essential as it helps in understanding the situation. This succeeds in reducing anxiety and insecurity. The material was designed in such a way that its manipulation occurs from the beginning, so that it can be followed from the diagnosis and beginning of the treatment.

This stigma that cancer means death must also be demystified for parents and guardians, as they are the main points of reference for cooperation. It is important for them to understand what the disease is and the treatments available.

Given the context, the role of design and its social contribution is notorious. The design allows you to convey the necessary information in a way that attracts the target audience. In this case, it allows informing in a playful way, in the format of stories and activities, so that the child is interested, wants to learn and adhere to the treatment. Furthermore, the method applied by the designers allows multidisciplinary integration. Therefore, professionals and the target public collaborate to build the product and its evaluation.

Lately, Design Thinking has been applied in numerous areas. In the health area, it has favored the construction of projects that provide information for different age groups and cultural levels, guaranteeing knowledge and better conditions to face the disease. The skills used by the designer for the project are: empathy, Visual Thinking (ability to express oneself non-verbally), experimental thinking (building prototypes that help understanding), collaboration, working in an interdisciplinary way, cross-pollination (looking for solutions in other areas) and the use of iteration. The great collaboration of this model is in the creation and sharing of ideas among all participants.

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