

**Compassion as a Tool to Enhance
Communication between nurses and
children in the oncology pediatric ward.**

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This major research project (MRP) presents a communication tool designed through an experience-based co-design (EBCD) method that aims to increase empathy and establish an emotional connection between pediatric oncology patients and the nurses that care for them. We ask: What value can the personal experiences of participants bring to the design process of a tool intended for their use? We explore this question by first conducting a series of interviews with 4 pediatric oncology patients and 9 nurses of the pediatric oncology ward, focused on identifying and understanding the emotions they experience during the different procedures that take place during the patients' stay in the hospital. The data collected during these interviews was used to create emotional maps that informed the design of a mobile application, which allows users to collaborate by recording customized audios stating their feelings, and agreements between both parties, which they can later listen to during painful and emotionally tolling procedures. Participants then tested the prototype in a series of workshops where their feedback was collected and integrated into a second and final prototype. Our results show that 1) pediatric oncology patients and the nurses that care for them feel an emotional distance between each other, 2) both parties are open to and enthusiastic about using a tool to work together and empathize with one another, and 3) an EBCD method is helpful to understand and address abstract emotional conditions.

4 I dedicate to the children and nurses in the oncology ward all my efforts, thank you for letting me hear your stories which built this project, you have all my admiration.

And to one special child Lara, my daughter. Through you I understood the true meaning of creating. With you, my inspiration was born.

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Medical practitioners of all types face both professional and personal challenges in their day-to-day practices. Because medicine deals with human ailments, there is an emotional component that healthcare workers must take into consideration. Moral support is considered central to the practice of caregiving and care receiving (Kleinman, 2016). Children who suffer from cancer may experience significantly high-states of anxiety or depression (Patenaude & Kupst, 2005). At the same time, paediatric oncology nurses suffer from high burnout rates and are extremely vulnerable to its repercussions (Suzanne Waddill-Goad, 2016), including heightened stress, loss of sleep, and physical and emotional exhaustion. In the clinical encounter, an understanding for, and practice of, empathy, has the possibility to protect both the health professional, including nurses, and the patient, in this case paediatric oncology patients, from personal distress (Ekman & Krasner, 2017).

HOPi (Hemato Oncología Pediátrica Integral) is a group specialized in pediatric oncology and works primarily in a hospital in Mexico City, Mexico. This multidisciplinary team is made up of experts, including oncologists, bone marrow transplant experts, surgical oncologists, nutritionists and psychologists. HOPi team members acknowledge that one of the biggest challenges they face is the negative emotions displayed by patients after receiving their diagnosis, including shock, denial, distress, and uncertainty. During this time, patients deal primarily with nurses, who are tasked with ensuring they follow their established routine, as well as performing painful or uncomfortable procedures such as connecting their catheters or drawing blood samples. In healthcare centers, it is often the case that the stress experienced by patients and nurses make for an uncomfortable relationship between both parties (Suzanne Waddill-Goad, 2016).

The overarching goal of our research is to build a tool for the use of nurses and paediatric oncology patients of the pediatric oncology ward of a hospital in Mexico City, Mexico. Nine nurses and four paediatric oncology patients participated in the design of the prototype. The children were all between the ages of ten and twelve years old. The intention of the tool is to improve communication between pediatric oncology patients and nurses prior, during, and after uncomfortable but necessary medical procedures, such as catheterization, taking or receiving medication, and blood taking. The communication tool intended to meet the needs of both nurses and pediatric patients by taking into account their emotions

during these procedures. The tool was designed through an experience-based co-design process, which will be referred to as EBCD (Donetto, Pierri, Tsianakas, & Robert, 2015); a scheme supported by ethnographic-based methods (Bate & Robert, 2007). The research process allowed us to gain access to the users' experiences in order to address the perceived lack of trust and empathy between nurses and the pediatric oncology patients they care for. The final result of this EBCD method was a mobile application that allows users to record and listen to customized audio tapes through a playful and warm visual interface.

Through a series of in-depth interviews based on EBCD with the participants, we determined that the tool would function as a platform for recording and listening to audio material which focused on establishing a narrative to favor the psychological and emotional balance of the patient and nurse (Lyendo, 2017). The tool would thus function as a communication channel that the patient and nurse can relate through, and express and process the experiences they share during treatment in a more fluid and playful way (Gilljam, Arvidsson, Nygren, & Svedberg, 2016) than existing nurse-child patient clinical encounters.

An emotional map was created based on an initial workshop where participants identified the emotions they feel during different scenarios of their interactions with one another. Based on this data, a low-fidelity prototype (PT1) was designed and evaluated by participants during a second workshop. Finally, this evaluation led to the design and implementation of a high-fidelity final prototype (PT2) (E. B.-N. Sanders & Stappers, 2014).

In order to further understand the valuable role users can play in design, this paper contributes by designing a communication tool that is strongly based on the stated needs and desires of its final users. To the best of our knowledge, this is the first EBCD study focused on healthcare

to be carried out in Mexico. The remaining paper describes related literature that informed our work, our design methodology for prototyping, the results of the evaluations carried out through a series of workshops where users tested and reviewed the application, and conclusions.

2.1 Illness narratives

In addition to strictly professional responsibilities, healthcare workers face moral burdens. Acknowledging the personhood of sufferers is a basic moral act in human relationships of all types, including those between patients, physicians or caregivers (Kleinman, 2012). The concept of “presence” – moral support given even when nothing practical can be done – is considered central to the practice of caregiving and care receiving, because the interpersonal relationship formed resonates with both parties’ understanding of life, self, and dignity (Kleinman, 2012).

Children with cancer may experience poor psychosocial adjustments following their diagnosis or during the different stages of treatment, significantly high-state of anxiety or a depression score (Patenaude & Kupst, 2005). Children who lack emotional regulation abilities are more vulnerable to facing psychosocial difficulties during and after treatment, and behavioral interventions targeting emotion regulation skills are believed to reduce the internalization of symptoms in this population (Katz, Heleniak, Kawamura, & Jakubiak, 2015).

On the other hand, a study carried out in the US shows alarming rates of burnout levels among physicians. As such, 45.8% of physicians reported at least one symptom of burnout (Shanafelt et al., 2012). Burnout refers to overwhelming emotional exhaustion, depersonalization, and feelings of professional insufficiency. STS (Secondary Traumatic Stress) is a condition characterized by fatigue that can arise from witnessing or listening to accounts of disturbing experiences or traumatic events (Wagaman, Geiger, Shockley, & Segal, 2015). Emotionally charged and intensely demanding relations are the cause of this grave emotional crisis.

Physician burnout and mental distress not only affects the sufferer; it also affects the quality of care that they provide, since it leads to more medical errors (Shanafelt et al., 2010). Nursing is an inherently stressful profession because nurses are overly committed and deal with death and disease on an everyday basis, and they often play the role of peacemaker in an ambiguous hospital environment where uncertainty can cause chaos. Nurses suffer from high burnout and are extremely vulnerable to all of its repercussions (Suzanne Waddill-Goad, 2016).

Going deeper into demanding and intense relations, physicians, nurses and patients create one during a health crisis in a rapidly changing environment that includes constant suffering. Emotions run high, the work is intense and overwhelming, and the results can be stressful. This chain reaction has created an increase of burnout, emotional exhaustion and secondary traumatic stress in caregivers (Yuguero, Ramon Marsal, Esquerda, Vivanco, & Soler-González, 2017). This relationship between nurses, doctors and patients creates a complex system which can be easily harmed (Orlando, n.d.). Ida Jean Orlando, a renowned psychiatric nurse, theorist, consultant, and researcher, explained that this relationship is a dynamic “whole” and a very important ground for professional behavior that needs to be used to help the patient. Nurses who work in pediatric oncology become most distressed when they are unable to provide the high-quality compassionate care that they believe the child and family requires (Newman, Callahan, Lerret, Oswald, & Weiss, 2018).

2.2 Compassion training

Humans are emotional beings as well as thinking ones. According to Paul Ekman, “emotions are a process, a particular kind of automatic appraisal influenced by our evolutionary and personal past, in which we sense that something important to our welfare is occurring, and a set of psychological changes and emotional behaviors begins to deal with the situation” (“Universal Emotions | What are Emotions? | Paul Ekman Group,” n.d.). Emotions are a central part of the human experience. They determine how we understand the world and how we interpret the actions of others (“The Nature of Emotion - Andrew S. Fox; Regina C. Lapate; Alexander J. Shackman; Richard J. Davidson - Oxford University Press,” n.d.).

Dr. James Doty director of CCARE (The Center for Compassion and Altruism Research and Education, Stanford University) suggests that compassion, a multi-textured response to pain, sorrow,

and anguish including kindness, empathy, generosity, acceptance and the capacity to open to the reality of suffering and to aspire to its healing (Strauss et al., 2016) is what will save our species, and that this positive emotion is the core of our humanity. Humans are social, sentient beings – through language, we express and transmit information to each other. Some information is easy to express and deliver, and other information is more complex, such as emotions. It is not polemical to say that emotions are sometimes hard to identify in ourselves and in others and even more when we share them. Jean Decety defines empathy as “an inter-subjective induction process by which positive and negative emotions are shared, without losing sight of whose feelings belong to whom,” adding that “empathy can lead to personal distress or to empathic concern” (Decety & Meyer, 2008.). In other words, in the process of sharing emotions, the intensity of another’s negative emotions may lead us to experience pain ourselves.

Empathy in the clinical encounter has the possibility to examine how to enrich a therapeutic relation, benefit the health professional and patient, and protect both from personal distress (Ekman & Krasner, 2017). Neuroscientist Tania Singer states that there is a difference between empathy and compassion: “In contrast to empathy, compassion does not mean sharing the suffering of the other; rather, it is characterized by feelings of warmth, concern and care for the other, as well as a strong motivation to improve the other’s wellbeing. Compassion is feeling for and not feeling with the other.” (Singer & Klimecki, 2014). Understanding the nature of this important social emotion is crucial to identifying its positive impact in our human behavior (Yongey Mingyur, Swanson, & Goleman, 2007).

Neuroscientists and psychologists have recently shown interest in the study of compassion in an academic way, understanding it as the contemplative science that refers to interdisciplinary scientific approaches to the mind and mental training based in traditional Eastern contemplative

methods and philosophy (Kemeny et al., 2012). In the classic contemplative tradition of Buddhism, the study of mind, compassion, and meditation in compassion has been observed for centuries. Dharma, the teachings of Buddha, believes that the basic nature of all sentient beings is goodness. Compassion takes this capacity to look at another sentient being as equal to oneself and further. Since one of the current theories of modern physics holds that all matter was connected at a single point at the start of the Big Bang, it is theoretically possible – though as yet unproven – that whatever affects one particle in our universe also affects every other one (Yongey Mingyur et al., 2007). This entanglement creates connections we observe between individuals when sharing deep emotions.

The idea of being able to help others and share their emotions can become difficult when it comes to the sharing of suffering. When exposed to constant distress, the distinction between self and other becomes blurred, and managing this emotion becomes challenging, especially for professionals in healthcare institutions (Singer & Klimecki, 2014). Compassion is a convenient tool when handling a crisis (Wagaman et al., 2015).

Studies show that, when applied effectively, compassion can be used to prevent negative emotions that emerge during a crisis and mitigate constant exposure to the suffering of others (R. J. Davidson & Harrington, 2002). Many benefits have been found after cultivating compassion in the clinical encounter, such as that communication through empathy can improve patient outcomes (Neumann et al., 2009). Compassion can be taught; our brains can form new connections to produce new cells as well as sculpt existing connections. This is called neuroplasticity. When our brain faces a new challenge, it reorganizes and restructures to respond to that situation. In addition, our brain learns more established pathways and successful emotional regulation and creates a healthy habit (Davidson & Lutz, 2008). There is evidence that shows a change in neural responses to suffering in individuals who were

taught compassion training and a new coping strategy that fosters positive affect even when confronted with the distress of others (Klimecki, Leiberg, Lamm, & Singer, 2013). Furthermore, increased altruistic behavior after compassion training was associated with altered activation in brain regions implicated in social cognition and emotion regulation. These results suggest that compassion can be cultivated with training and that greater altruistic behavior may emerge by understanding the suffering of other people (Weng et al., 2013).

In his research, neuroscientist Ezequiel Gleichgerrcht posits that for medical practitioners, it is important to understand where pain comes from in order to develop strategies that prevent them from having emotional burnout. Gleichgerrcht concludes that professional experience seems to desensitize physicians to the pain of others without necessarily helping them down-regulate their own personal distress. Minimum levels of empathy appear necessary to benefit from the positive aspects of professional quality of life in medicine (Gleichgerrcht & Decety, 2014).

Having understood that empathy and compassion can be useful in addressing the particular distress experienced by patients and healthcare professionals, this study aimed to design a communication tool that would improve the relationships between pediatric oncology patients and nurses working in the pediatric oncology ward of a hospital in Mexico City, Mexico. We decided to approach the design through a participation-based method.

Although a child’s right to participate in their own healthcare is an issue which has gained traction in research in recent years, their participation is unsatisfactorily applied in practice (Gilljam et al., 2016). Gaining a better understanding of a child’s perspective regarding their experiences in healthcare can inform the design of more appropriate care for child patients (Gilljam et al., 2016). By basing their design approach on constructivist grounded theory, a researcher can attempt to understand experience and its meaning in the same way as participants (Charmaz & McMullen, 2011).

The concept of experience-based co-design (EBCD) refers to the gathering of experiences from participants to identify key “touch points” – emotionally significant points – and assign positive or negative feelings to them (Bate & Robert, 2007). In addition to a focus on experience, EBCD aims to engage users in the design process through their active participation as co-designers (Donetto et al., 2015). Although the results of EBCD are mostly small-scale changes within one service area, they have been found to be immensely valuable to patients (Robertson, Simonsen, & Simonsen, 2012).

An example of the implementation of EBCD is the case of the UK-based User-Centered Healthcare

Design (UCHD), a team of researchers and practitioners from design and healthcare developing methodologies for healthcare service design. Their approach has a focus on people’s lived experiences and a commitment to participation in the process of design, as a means of ensuring that what is designed is relevant to the practices, needs and values of participants. Through Experience Based Design (EBD), the UCHD works together with patients, caregivers, and staff. Rather than being a single prescriptive method, EBD provides a range of techniques and tools within a four-phase structure where participants work together to capture and then understand their lived experiences of healthcare, improve a service based on this understanding, and measure the effects of change (Bowen et al., 2013).

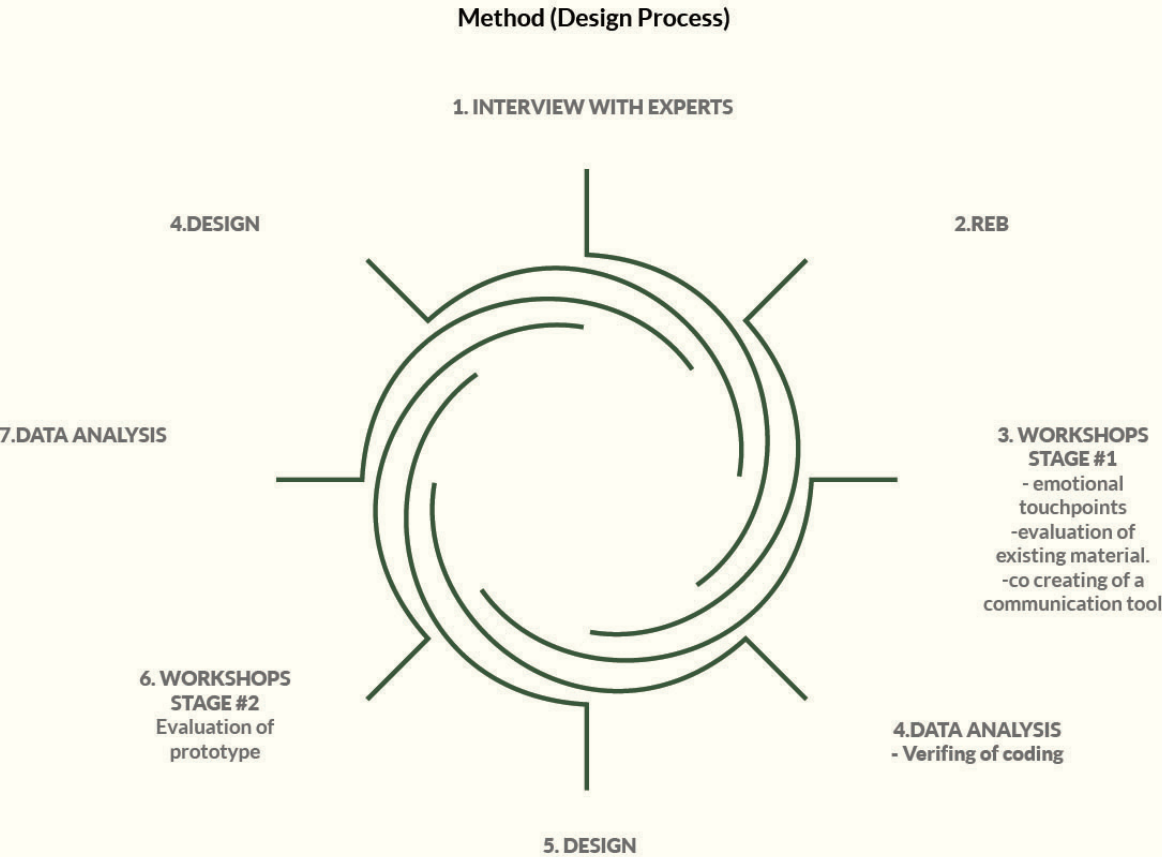


IMAGE 1 illustrates the EBCD methodology employed in our research, in chronological order.

The first step was to conduct a series of interviews with field experts, where we were able to discuss topics of emotions, the role and importance of compassion in the treatment of pediatric oncology patients, and all topics of interest in this paper (Sexton, 1980). Appendix 1 shows the full list of interview questions. The following experts were interviewed:

a. Mariana Campos, psychologist:

Mariana Campos – the psychologist working at the pediatric oncology ward of the hospital where this research was conducted – was interested in creating a communication tool that was comprehensive and effective for working with children during treatment. She was a key informant who introduced and inducted the researcher-designer into the hospital’s oncology pediatric ward by guiding a tour of the ward and sharing her insights on the average patient journeys in the hospital (Bate & Robert, 2007). Four semi-structured interviews to explore experiences in the pediatric oncology ward were held in the hospital (Pope, Van Royen, & Baker, 2002).

The questions where a combination of: Descriptive questions, Grand Tour questions, Typical questions, and Guided questions (“Asking descriptive questions - 26100 - UTS - StuDocu,” n.d.). Together during these interviews, we co-created the research design based on EBCD (Ledema et al., 2010) and emotional touchpoints (Dewar, Mackay, Smith, Pullin, & Tocher, 2010). In the final interview, we revised the feedback given by Emiliana Rodríguez Morales, and finalized the initial design.

b. Emiliana Rodriguez Morales

Emiliana Rodríguez has a Master’s in Mind, Brain and Education from Harvard University and a Bachelor’s degree in Physics from the National Autonomous University of Mexico. Rodríguez currently works at Atentamente, a civil organization specialized in mental and socio-emotional training. She was selected to be interviewed due to her expertise and knowledge on children and their emotions, and especially her experience with teaching emotional regulation to children. The question types asked were a combination of Descriptive questions and Example questions (“Asking descriptive questions - 26100 - UTS - StuDocu,” n.d.).

Rodríguez also participated in a second interview, where she evaluated the research design that had been previously created with psychologist Mariana Campos, and participated in a discussion on the nature of emotions (“The Nature of Emotion - Andrew S. Fox; Regina C. Lapate; Alexander J. Shackman; Richard J. Davidson - Oxford University Press,” n.d.). Together with another expert in emotions, Rodríguez suggested that we widen the emotional vocabulary employed (“Atlas of Emotions | Map of Emotions | Paul Ekman Group,” n.d.) (“Toolkit,” n.d.).

3.2 REB

The next stage in the design process consisted of obtaining written approval from the Research Ethics Board (REB). The application process was meticulous and relatively long because children and nurses – the key subjects of our research – are considered emotionally vulnerable.

In seeking REB approval, our main concern was not contributing to the stress of the children or nurses, as working with emotions can sometimes increase distress. Psychologist Mariana Campos, who works at the hospital and who had previously treated all patients involved in this research, was present during our work sessions with all parties, and was fully prepared to lead any necessary intervention. These ethical concerns led us to creating multiple workshop sessions for our research, in order to separate nurses and children, allowing children who felt indisposed to postpone the session, and nurses to be divided in groups to avoid heavily affecting their workload.

It was also decided that the researcher would not interact directly with the patients or nurses. The researcher acted as an observer, and psychologist Mariana Campos directed all sessions. To avoid overwhelming the participants, the duration of each work session was 60 minutes or less, as determined by the psychologist. Nurses participated voluntarily and were informed of the

research protocol through an informed consent form. The pediatric patients who participated were selected by the psychologist, and a consent form was signed by their parents.

When working with the pediatric patients, all questions and comments were made through play and words appropriate for their age, which they understood and which did not generate confusion or stress. The children were informed that they could stop the session at any moment. The workshops took place in an area of the hospital already familiar to the participants*. Only audio was recorded during the sessions; no video nor photographs were taken.

* Note: Due to the unexpected situation relating to the COVID-19 pandemic, some workshops were conducted virtually.

3.3 WORKSHOPS #1

After the REB approval was obtained, the first workshop was conducted with the aim of identifying and understanding the needs and emotions of all participants. This was the first stage of co-designing the communication tool. Appendix 2 shows the full workshop agenda.

Participants

Four nurses and four children were invited to participate in our Participatory Designing Workshop (Robertson et al., 2012) in the oncology ward of the hospital, located in the Observatorio neighborhood of Mexico City. The workshop was led by psychologist Mariana Campos and observed by the researcher designer. The nurses are all employed in the pediatric oncology ward. All four of them are females between the ages of twenty-five and sixty-five.

The pediatric oncology patient participants were three females, two of 10 and one of 12 years of age, and one male of 10 years of age. They have

all been diagnosed with cancer or are in need of a bone marrow transplant. The age range of the children was chosen for two main reasons. First, it was considered by the hospital staff to be an age range within which children will be most responsive to this play-workshop environment, and able to communicate their thoughts and express their preferences for communication tools. Second, because in this particular hospital the majority of the pediatric oncology patients are within this range, it is believed that new communication tools will have a positive impact on the highest number of children.

Originally, four workshops were planned, but due to the health situation the children were facing and the tight schedule the nurses work under, the workshops were divided. Three workshops were done with the children, one where two participants took part in an individual workshop, and another where two participants engaged

in the workshop together. With the nurses, we divided the workshops in two, where one was held with transplant pediatric oncology nurses and the other with pediatric oncology nurses.

Psychologist Mariana Campos invited nurses and pediatric oncology patients to participate by playing an active role in the creative process ("Making Emotional Connections Through Participatory Design - Boxes and Arrows," n.d.), through workshops aimed at developing a new communication tool intended to improve the nurse-patient interactions during painful oncology procedures. These workshops were held at the hospital. Psychologist Mariana Campos selected patients, considering that they were suitable to participate in the sessions based on her professional knowledge of the patients' states and fitting the strategies to the particular specific research participants (Charmaz, 2014).

The psychologist conducted the workshops while the researcher took field notes, recorded the sessions, and collected the materials created by the children and nurses. As observed in the Dewar (2010) research on the use of emotional touchpoints as a method of tapping into the experience of receiving compassionate care in a hospital setting, the use of emotional touch points helps people to get in touch with their own experience. It also enables the development of relationships with patients, families and staff (Dewar et al., 2010). Participants were therefore invited to engage with emotional touchpoints, pairing emotions with touchpoints or experiences during hospitalization, such as surgeries, chemotherapies, consumption of medication, canalization, among others (Dewar et al., 2010), as well as activities that involved evaluating the existing didactic material tools and designing, drawing, or otherwise explaining their ideal toy or tool (E. B. N. Sanders, Brandt, & Binder, 2010). The analysis of the workshop led to exploring more profound issues during the following session (Charmaz, 2014).

Findings

In their work, Simon Bowen, Kerry McSeveny, Eleanor Lockley, Daniel Wolstenholme, Mark Cobb & Andy Dearden (Bowen et al., 2013) reported initial concerns about activities being "daunting" from participants of their study. After their workshop, participants agreed that sharing their experiences "helped to build empathy and cohesion in the project group." Also, as in their research implementing patient-centred cancer care: "using experience-based co-design to improve patient experience in breast and lung cancer services, the majority of our participants nurses and children felt vulnerable at certain points in the pathway" (Tsianakas et al., n.d.). Our workshops yielded similar results.

Below, we have divided our findings into three categories. First, we present the conclusions of Mariana Campos and the researcher. Second, we present the children's responses to the activities. Third, we present the conclusions of the nurses after participating in the activities.

Analysis

Our analysis involved different steps. First, a read-through of collected field notes and open discussion sessions with psychologist Mariana Campos (Pope et al., 2002). Second, a session of coding systematic code through content analysis took place (Sexton, 1980). The session involved a categorization of themes that led to the first findings of the nature of the prototype (Emerson, Fretz, & Shaw, n.d.). The material created by children and nurses was analyzed, grouped by themes, and categorized to identify the relation between the emotions presented by the children and the nurses during the same experience or touch point. After coding was finalized for the purpose of triangulation and verification of the coding, a session with Emiliana Rodriguez took place to analyze the focus of the research and the nature of the prototype (Emerson et al., n.d. Bowen et al., 2013 Iledema et al., 2010). We report on these findings below.

a. Psychologist Mariana Campos and researcher

The aim of the first activity was to identify and understand the emotions presented by both children and nurses during the children's hospitalization ("Toolkit," n.d.). Concluding on this activity, psychologist Mariana Campos stated that "children feel happy during hospitalization when they are playing; when they are able to receive visitors, especially visitors they don't often receive such as their siblings; when they are leaving, and when they receive good news regarding their progress".

The aim of the second activity was to analyze the pre-existing didactic material available to the children. Psychologist Mariana Campos observes that she believes "that most of the time the psychologist is the one who gives them toys and the parents are the ones who give them love... But then the nurses are the ones that give them shots."

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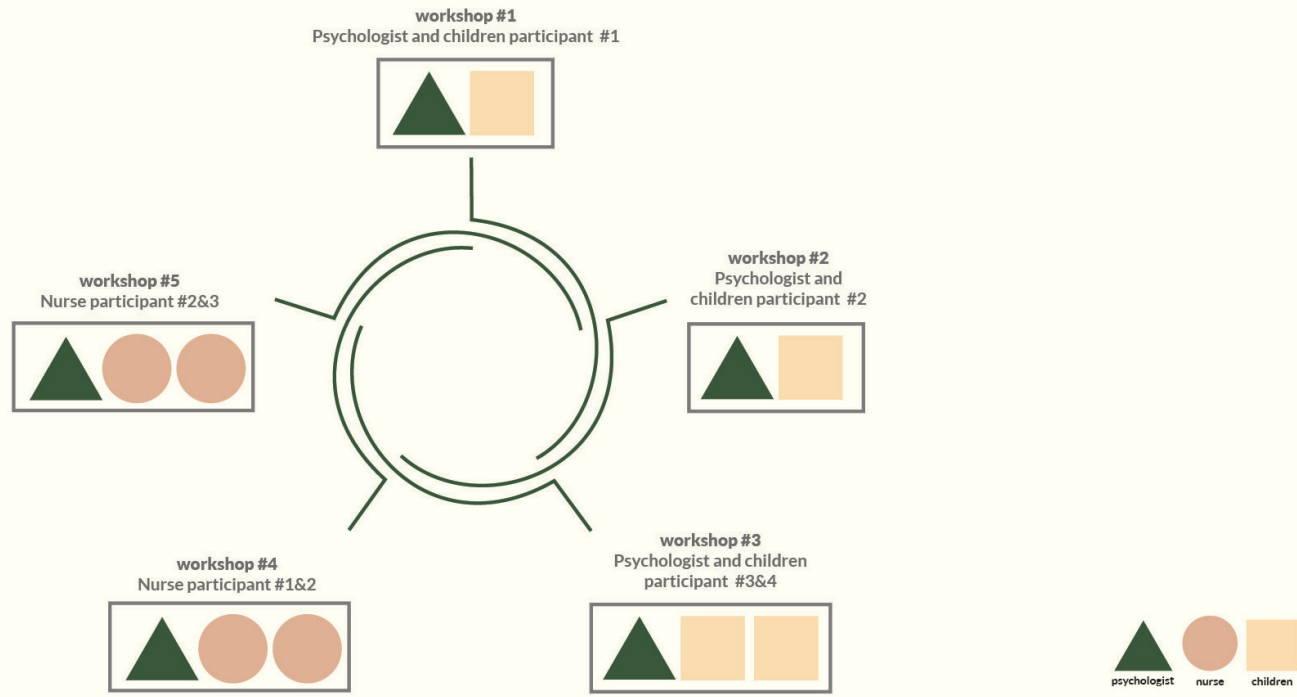


IMAGE 2 shows the structure of the first round of workshops.

The first category of didactic material analyzed was toys with medical content. For Mariana Campos, the positive aspect of these toys is that pediatric oncology patients can easily identify themselves with the toys to then refer them to their experience. Psychologists refer to this process as “projecting.” Mariana Campos explains that these toys allow the child to elaborate on the experiences they have had while they are in the hospital. She identifies them as a sort of free therapy, as playing like this allows the child to talk about the experience and assimilate everything they have lived. As for these toys’ negative aspects, Mariana Campos points out that they are not always made with suitable materials for hospitals. Sometimes they’re made with materials that can’t be used in bone marrow transplant or other treatment areas. Also, the images are not always the best; she believes they should be warmer so that the children can identify themselves with them. It’s easier for a child to project his feelings when the images don’t involve any distress.

The second category of didactic material analyzed was illustrated children’s “feel better” books. Based on Mariana Campos’ experience working in the hospital, we learned that often, children and even parents don’t read informational books or material. However, she believes this category of illustrated children’s books are good because children can identify with the characters and project their own experiences onto them. Though interactive stories are better, we don’t have many aimed at the age group we are focusing on in this research. The negative aspects of this category of didactic material is that some illustrated books available in the hospital show images of sick children, which can cause the patients distress if they identify themselves with the image. Additionally, as with the previous category analyzed, some of these books are made of materials which cannot be brought into the transplant area.

The third category analyzed comprised of games with no medical content, which are reinterpreted

by inventing new rules aimed to talk with the children about their emotions. For Mariana Campos, this category of game is especially well suited for distracting the children. She states that “while you are playing together, the child can tell you many things without realizing they are broaching subjects that are normally uncomfortable, such as pain.” These games, however, are made from unauthorized materials and take a lot of time to play, so they are not well suited for interactions between nurses and children because of the limited free time the nurses have.

The aim of the third activity was to co-design (E. B.-N. Sanders & Stappers, 2014) the new communication tool. For this, we understood from the workshops that the communication tool should reduce stress experienced by both the nurses and the children during painful procedures. It should empower the nurses and children; the child should feel that they are in control of something during this stressful moment, because the sense of powerlessness is identified as one of the key factors that cause stress in a child. Consequently, when the child loses control, the nurse’s stress level rises. It should improve communication between children and nurses. It should communicate to the child that the nurse is not inflicting the pain or situation, as it is common for the child to project his anger onto the nurse. The tool, in conclusion, should connect the child and the nurse on an emotional level, humanizing them both to each other.

b. Children

The aim of the first activity was to identify and understand the emotions presented by children during the children’s hospitalizations (“Toolkit,” n.d.). This emotional mapping exercise was used to invite the patients to reflect on the emotional impact of the touch points along the pathway (Bate & Robert, 2007)(Dewar et al., 2010). The most common emotions shown by children during hospitalization processes are fear and worry. 50% of pediatric oncology patient

participants feel worried and sad when they receive the news that they will be hospitalized, and mostly all emotions they say they feel are negative. When they are canalized or in a catheter process, 3 out of 4 children feel fear. One participant expressed that she feels secure because she feels safe, but the rest of the emotions are negative, like worry and desperation. During hospitalization, 3 out of 4 children feel sadness. Other feelings expressed are anger, discouragement, and confusion. One participant says she feels safe in the hospital but, at the same time, stressed and with fear. While taking labs, 3 out of 4 children feel fear and 2 out of 4 feel nervousness. During surgeries, chemotherapy and radiation, 2 out of 4 participants feel fear and confusion. The emotions the children feel while taking medication were different for each one. 3 out of 4 of the children associated taking medicine with strong negative emotions such as anger, desperation and discouragement. 2 out of 4 children said they feel at peace, especially when they finish taking them all. 1 participant expressed only positive emotions, like a sense of security and peacefulness. When given bad news, all four children felt strong negative emotions such as sadness, fear, concern, frustration and desperation. 2 out of 4 felt sadness.

The aim of the second activity was to analyze the pre-existing didactic material available to the children within the hospital (E. B.-N. Sanders & Stappers, 2014). Reflecting on this, the four children who participated in this study stated that they enjoy playing with toys during hospitalization. All four had brought some of their favorite toys from their homes to the hospital. Some mentioned that they faced problems bringing them into the hospital due to safety concerns. They stated that this personal object serves for relief. The participants did not show deep interest for reading or looking at illustrated books during hospitalization. They don’t talk much about technology, though participant #2 mentioned that what is most enjoyable for her is playing online games with her friends.

In 1958, Donald Winnicott introduced the concept of the Transitional Object (TO) – a blanket,

stuffed animal, or other object chosen by the child to serve a soothing and comforting function and lessen the stress of separation from the child’s mother or primary caregiver (Rudnytsky, 1993). Children display a capacity to create and maintain relationships with transitional objects (Borenstein, 2019). Because children ascribe individual meaning to their chosen TOs, it was established that the prototype that would be designed in conjunction with the children and nurses after analyzing the results would not attempt to function as a TO, but rather as a complementary tool that establishes touch points between the nurse, the child, and their family members and loved ones.

The aim of the third activity was to co-design the new communication tool (E. B.-N. Sanders & Stappers, 2014). All four pediatric oncology patient participants said that what helped the most during painful and complicated procedures was being close to their mother, with some mentioning their father as well. They also mentioned that the saddest moment is being separated from their parents and their siblings, friends, and grandparents. One participant also mentioned her pet. They all drew toys and security objects such as stuffed animals and blankets they had during their hospitalization. All of these objects were brought from home by the pediatric oncology patients. One girl drew a pizza because “it was the only dish that never changed flavor,” so we associate this with comfort of something she knew or relied on. When one participant drew her family, she drew hugs and holding her mother’s hand while in pain. Participant #2 states: “in fact, every time I’m punctured, I lean on mom, I hug her and close my eyes.”

c. Nurses

The aim of the first activity was to identify and understand the emotions presented by both children and nurses during the children’s hospitalizations (Bate & Robert, 2007) (Dewar et al., 2010) and to involve them in a collaborative

identification of areas of opportunities and possible solutions (Ledema et al., 2010). When the nurses have their first contact with a new patient, 3 out of 4 nurses report feeling positive emotions such as happiness and excitement. 3 out of 4 feel excited by the idea of meeting a new patient and look forward to it. One nurse experiences only negative emotions since she does not like working in the pediatric ward and prefers working with adults.

Testimony:

Nurse #4: I feel peaceful because I haven’t had any contact with them yet so it doesn’t cause me... I feel concerned because I don’t know what I’m going to face, what parents I’m going to face, what kind of parents. If they are cooperative and help, that is great. And I feel happy because I would be able to do something different or something else for that little person, right?

During catheter and canalization processes, all four nurses feel negative emotions such as stress, guilt, insecurity, and frustration. 3 out of 4 feel stressed and insecure.

Testimonies:

Nurse #1: I tend to get stressed; I feel a little insecure depending on the patient. If they are pediatric patients and they do not cooperate, then it is a little worrying because you have to hold them hard, and you have to try not to hurt them. So yes, I feel that way.

Nurse #2: There are children who get very difficult, they don’t like needles. Sometimes when their pulse is stressed, it gets ugly, because when they are very small and stressed, they move a lot. Yes, I’ve had to see a lot of that, a lot of struggle, not even the parents can control them. We feel bad because for many years they have been in different hospitals so they have seen many needles. They feel quite scared. I have had cases where you have to hold them by one hand and one foot. That makes things more difficult, since

because they receive chemo their skin becomes more sensitive.

During hospitalization, 2 out of 4 nurses feel sad, 2 out of 4 feel astonished, and 2 out of 4 feel worried.

Testimonies:

Nurse #1: In hospitalization, we have to face all kinds of situations. We feel happy when we know that the graft has been successful, and that everything is going well. It is sad when we get bad news, because the patient doesn’t feel good. You feel worried when you have to face things that are not very positive.

Nurse #2: And well, the hospitalization part is sometimes sad because they stay for many days. They feel, I don’t know, like locked up. It sometimes is very difficult for them to have contact with me because they do not see me due to my mask and medical gear. It is very difficult to show your emotions through your eyes. Well, that part has caught my attention a lot. Because they don’t know that I am smiling at them or that you are doing something even though they don’t look at you. I don’t know. I feel that communication is broken and the relationship with the patient is cut. Because you don’t see each other well. You only see the other person’s eyes.

Nurse#4: Hospitalization scares me, because I don’t know what I’m going to face. I’d be afraid because I wouldn’t know what would happen to that patient. And I’d be broken hearted if something happened to him. Also, during hospitalization you get attached to this kind of patients. Even if it’s a difficult child, you always have contact with him and you get attached. Even if the kid is rude or has tantrums. And that will always cause a mix of emotions.

When they take labs or medical screenings such as blood samples, 2 out of 4 nurses feel worried. Other emotions mentioned where insecurity, stress and confusion.

Testimonies:

Nurse#1: I tend to feel worried when I have a big workload and I must go with a pediatric patient. I feel worried because, well, you still have other patients to look after or you have more things to do. So, you don’t know if they are going to arrive and be screened, or how long it is going to take.

Nurse #2: It adds a little to the workload, right? You tend to feel a little stressed, and sometimes the children do not cooperate. We have talked about taking their samples very early in the morning. It is something that bothers them because we wake them up.

Nurse #4: As for the catheter and the IV, I feel confident because I know how to do it. That is one of my abilities. That gives me confidence. But I’d also feel frustrated if I couldn’t do it. I’d feel stressed because if the parents were pressuring me and they only told me to do something but wouldn’t help, we couldn’t do much. And guilty if something happens, because maybe I had something to do with that. I know what that entails. I am concerned about lab works, because they determine if the patient stays longer or not.

During procedures like surgery, chemotherapy, and radiation, 2 out of 4 of the participating nurses feel worried. Other emotions stated were stress, broken-heartedness, and confusion.

Testimonies:

Nurse #1: The main concern is how the patient’s body will react. You have to be careful not to ignore anything, right? To be able to react immediately.

Nurse #2: They are very anxious or very frustrated. That also worries you: “Ah, poor thing”. They are very sad or very frustrated because they are going to the operating room to have a catheter placed or taken out. That is also difficult for them.

Nurse #4: I feel happy about procedures because if everything goes well during surgery and the chemo works, then the child will be okay.

As for giving medicine to the children, all four nurses feel angry. 2 out of 4 nurses felt positive

emotions in addition to negative emotions. The positive emotions reported were gratefulness and safety. Other emotions reported were frustration, guilt, astonishment, concern, and discouragement.

Testimonies:

Nurse #2: As for medication, well, I tend to feel confident, right? Because I know that what I am doing has a therapeutic reason to cover their needs. However, it is sometimes stressful and kind of worrisome when they do not cooperate at all. When medications are semi-oral and they vomit or spit them out. Well, it is stressful because I cannot scold them, right? Or tell them to behave, because if you do, you are kind of the bad guy.

Nurse #1: And as for medications, well, yes, there might be some frustration or anger when they don’t want to take them. Besides, well, I feel that the responsibility falls on us. I mean, if they didn’t take the medication, it’s as if it was our fault.

Nurse #4: I have mixed feelings about medication. One, I’m grateful if parents cooperate. If they help us. It is easier, less traumatic, and less complicated for the child. But also, angry because children are the reflection of adults. If the child has tantrums and does not cooperate, we still have to make them take the medicine. That’s when the nurse becomes rude and ugly, when she doesn’t speak nicely, when she doesn’t know, when she can’t... And that leads us to many medical errors too.

When the children are given bad news, 3 out of 4 nurses feel sad, 2 out of 4 feel frustrated and astonished, and all feel negative emotions such as concern, broken-heartedness, guilt and discouragement.

The aim of the second activity was to analyze the pre-existing didactic material available to the children. In open interview questions, we showed the nurses the existing materials, and they agreed that distraction was useful, and that for them, it’s important that the children cooperate in the daily routine.

Testimonies:

Nurse #1: However, what I have noticed here is that, for example, children who exceed the average stay for transplants are the ones who become more difficult. Yes. They get tired of the routine; they don't want to do things anymore. And if they do, they do them in a bad mood, or they even start fighting with their relatives for the same reason they don't want to be here anymore. That's when there are difficulties. We still have to give them their medicine, follow the routine, but they don't want to.

Nurse #3: So, I say that they don't enjoy books much... Not books. No... They like toys. They do. But that's when you have already approached them. Because I think contact is the critical aspect. That's first.

The aim of the third activity was to co-design the new communication tool. In response to the question: What should this communication tool solve and communicate? nurses stated the following:

- 1. Resolve attitude
- 2. Security
- 3. Interpretations
- 4. Availability
- 5. Resolve doubts
- 6. Communicate education and information among staff
- 7. Effective communication
- 8. Resolve honesty
- 9. Resolve conflict between us

In response to the question: What affordances should it have? nurses stated the following:

- 1. Attitude
- 2. Companionship
- 3. Emotional help
- 4. Teamwork
- 5. Flexibility; not so many limits
- 6. Empathy
- 7. Consistency and communication between interdisciplinary team
- 8. Knowledge and education

In response to the question: What should the tool avoid? nurses stated the following:

- 1. Representation of angry or stressed nurses
- 2. Representation of needles
- 3. Representation of nurses who don't know
- 4. Crying children
- 5. Closed rooms

Conclusion

The children and the nurses trust that the hospital, health professionals and the treatment prescribed are adequate and helpful, and that their stays in the hospital are necessary. But the children don't feel an emotional connection with the nurses. They don't feel they are a team. Among the many emotions mentioned by the children, isolation and loneliness are deep emotions that

indicate their need and longing for human contact (Fox, Lapate, Shackman, & Davidson, n.d.). We observe that the emotions come from both the physical pain and the emotional pain (Weissbourd, 2009).

Psychologist Mariana Campos, expert in emotional education Emiliana Rodríguez Morales, and the researcher concluded, as a team, that it is not wise to over-stimulate the children's senses, and to avoid incorporating the sense of smell into any activities designed. In addition, visual stimulation should be very subtle and abstract, and avoid concentrating on graphic stimulation. The nurses were concerned with the isolation kids experienced and said that, in their experience, video games disconnect them further, causing them to neglect their every-day routines during hospitalization.

While discussing the coding with expert in emotional education Emiliana Rodríguez Morales, we were impressed by the powerful and elaborate minds these children have, perhaps because of the process they are living and the work they have done in therapy. They are extremely sensitive and aware of their emotions. This is a good opportunity to take advantage of: The power of their mind. Another good opportunity is the trust they feel or communicate about the processes they are submitted to and the medication they are prescribed.

3.4 DESIGN OF PROTOTYPE #1

A prototype can change the world, because in interventions it allows people to experience a situation that did not exist before. Prototypes allow testing of a hypothesis (E. B.-N. Sanders & Stappers, 2014).

The design process for this prototype involved the four stages described by Sanders and Strap-pers in their work. These include probes, toolkits,

prototypes, and three approaches: pre-design, generative, evaluative, and post-design. Within this process, nurses and pediatric oncology patients are active participants of the generative and evaluative stages through a series of interviews and trials of the prototype (Bate & Robert, 2007).

Research has been conducted on the subject of the use of music and sound therapy to alleviate stress and improve immune system function. It has been widely documented that stress can be suppressive of various aspects of the immune response (Brennan & Charnetski, 2000). In modern times, music is used in many facilities such as hospitals, nursing homes, schools, and clinics to help combat a variety of problems, including anxiety. Relaxing music helps slow down heart rates, breathing, thinking, and enables a person to reach a deeper level of rest and tranquility. It therefore can become a key tool to help relieve stress and calm the mind (Clements-Cortés, n.d.).

Additionally, the strengths and limitations of the available didactic materials were determined in the workshops. Materials such as books and toys worked well as complements to psychological therapy, however, the nurses don't have access to these materials. The objective was to design a tool that facilitates an emotional connection being formed between the children and nurses. Books and toys do not engage both parties, therefore they do not serve that purpose. Additionally, the accessibility of these materials is limited, as they are prohibited from certain areas of the oncology ward for hygiene purposes.

On the other hand, the nurses stated that their main task is to ensure their patients cooperate with them and abide by their routines, and that this becomes difficult to accomplish when pediatric oncology patients do not trust or feel an emotional connection to them. However, the nurses have little free time to devote to devising activities that enable them to bond with their patients.

In response to these findings, it was determined that the prototype would be an application, accessible from smartphones, and based on sounds rather than images (Iyendo, 2017) . The nature of the app would be based on establishing emotional connections between the participants (nurses and their pediatric oncology patients), allowing them to discover the touch points in which they often feel the same emotions. Smartphones were found to be possessed by the parents of even the most underprivileged pediatric oncology patients, as well as by all of the nurses of the oncology ward. All parents and nurses interviewed were familiar with smartphone applications and able to operate them. Therefore, they were determined to be an accessible tool that does not require additional time spent on specialized training.

During interviews, pediatric oncology patients stated that they feel good when they seek contact with the people they love or when they are in contact with positive objects they are familiar with. It was therefore determined that the application would be used prior, during and after painful and stressful procedures that the nurses administered to the children, such as vaccines or the taking of blood samples. The application would allow the nurse and the patient to connect on an emotional level before these procedures, establishing touch points of compassion and empathy between them. It is through design that we can add spirit and aesthetic to the equation of good engineering ("Programmers, designers, and the Brooklyn bridge | Scott Berkun," n.d.).

Mobile applications for meditation or music listening, such as Headspace or Spotify, are widely available. This prototype is instead focused on establishing and nurturing a personal relationship of trust and an emotional connection between the nurses and the pediatric patients of the hospital's oncology ward, through customizable voice messages that can be recorded by both parties. The shapes and colors displayed in the user interface were muted to avoid overstimulating the users.

Description of Prototype #1

The application features a Welcome page that displays two options: Instructions (which can be skipped) and Start. By clicking Start, the user is taken to the Home page, which is divided in three sections: Create, Listen, and Reflect. Instructions are available for all three sections, and there is an option to skip the instructions.

The first section, Create, is divided into two sections: One that enables the user to record with or without background sounds, and another that records agreements, where the pediatric oncology patient and nurse can record themselves stating mutually beneficial agreements. Once the user has recorded something, they are automatically taken to the Listen section. The Listen section allows the user to play the different recordings they have saved, organize their order, and create playlists. The final section, Reflect, allows the user to evaluate the recordings, reflect on where and when the application was used, and whether or not they found it useful.

3.5 WORKSHOPS #2

After the data collected from workshop #1 was transcribed and analyzed, and the first prototype (PT1) was created, a second workshop subdivided into six sessions was conducted to test the P1. Appendix 4 shows the full workshop 2 agenda.

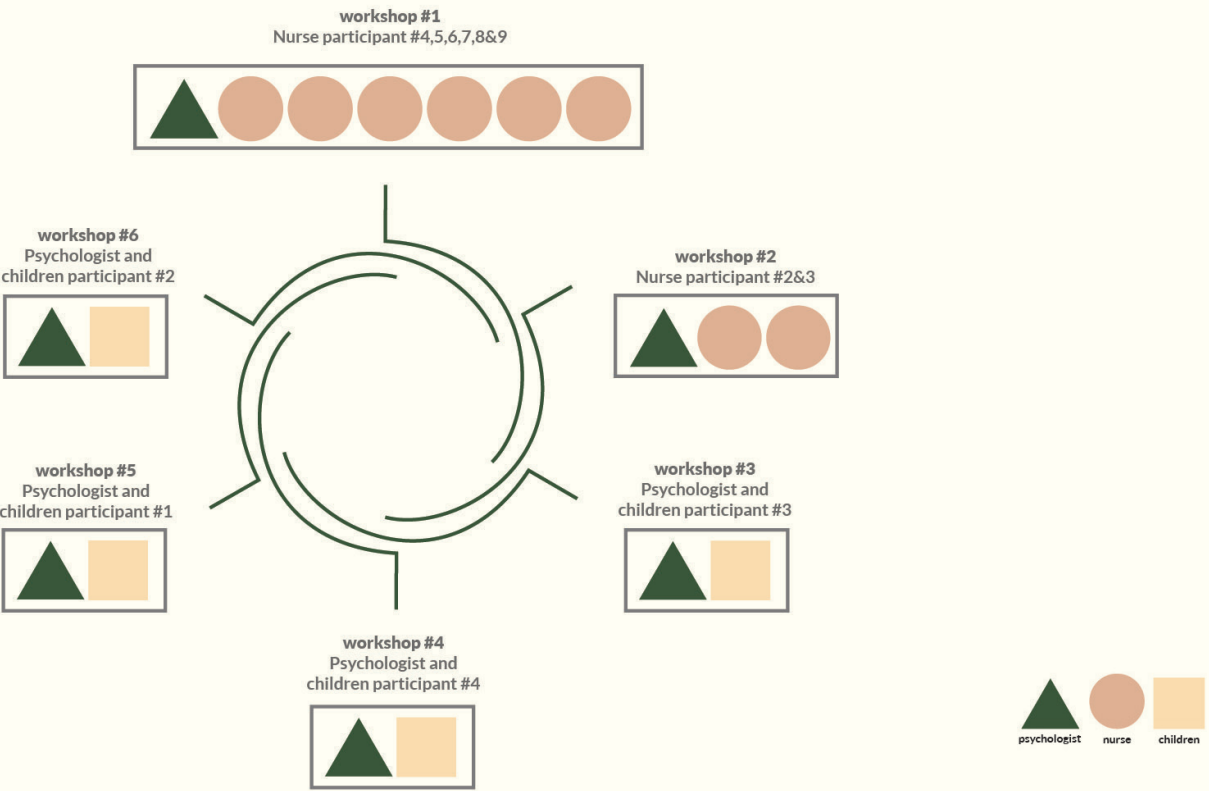


Image 3 shows the structure of the second round of workshops.

The questions we asked the nurses and children that were invited to engage virtually with the prototype were based on the three elements of good design by Essays on Design Engineering and Project Management ("Programmers, designers, and the Brooklyn bridge | Scott Berkun," n.d).

The following are the most relevant takeaways from the interviews. Appendix 2.

Workshop #1 and #2

For the first workshop, six nurses were gathered and presented with the results from previous workshops. They were invited to engage with the prototype and later interviewed on their opinion ("Toolkit," n.d."EBCD: Experience-based co-design toolkit | Point of Care Foundation," n.d.). The second workshop repeated this dynamic, with two nurse participants. The questions were asked openly, and the participants were invited to answer freely as a discussion.

As a group, all six nurses interviewed agreed they liked the idea of an application using personalized sound recordings to help them connect with their patients, though some concerns were raised about presenting themselves as vulnerable to the children, as well as about time constraints in their tight schedules. The group agreed that the prototype's user interface was legible and easy to navigate. Regarding the prototype's graphic design, all six nurses agreed that they would like the colors to be brighter, and for the general design to be more child-friendly by integrating illustrations or animations. Regarding the integration of pre-recorded meditations and breathing exercises to the prototype, the majority of the nurses interviewed agreed that they are interested in using an application to relax and be in touch with their emotions.

Testimony:

Nurse #2: I am interested in using this app on my way home so I don't arrive stressed with my family; so I don't yell at my own children and get angry.

Through this interview, it was determined that an introduction on the topic of compassion should be added to the application. This could take the form of an animation to motivate the nurses and children to establish a connection between them and with their own emotions. It was also determined that following interviews should focus on collecting more personal stories from the nurses to analyze.

A second workshop comprising of an interview involving only two nurses was conducted. The feedback was similar to the answers recorded in the first workshop. Both nurses agreed that the tool would be useful to them, and that establishing an emotional connection with their patients would help them carry out their work. They agreed that the prototype was simple to navigate and suggested the word "Reflect" be changed to something more child-friendly. Both nurses suggested more colorful shapes for the design.

Workshops #3, #4, #5, and #6

For workshops #3 - #6, four children were invited to engage with the prototype and later interviewed on their opinion, individually. Each workshop interviewed a different pediatric oncology patient. The interview questions were the same as those asked in workshops #1 and #2.

All four children generally agreed that they liked the idea of the prototype. The two children in remission stage liked the initial design's muted color scheme: the other two stated they would prefer livelier colors and shapes. All participants

agreed that they found the application easy to use; one child stated there were words they did not understand, but that they would ask their parent or guardian to explain.

Testimonies:

Child Participant #4: I think it is a good idea because it could help me to relax and not be so scared before procedures in the hospital.

Child Participant #3: I would like a character with colorful features. I like the colors, but I would like them to be a little stronger or livelier. I like the colors but not the tone so much. I would like them more intense.

Child Participant #2: I would like to hear the voice of someone from my family, especially my mother. They often take my mom out of the room.

3.6 FINAL DESIGN PROTOTYPE #2

In response to the findings of the evaluation of Prototype #1, the color palette and the script were modified, and illustrations were added.

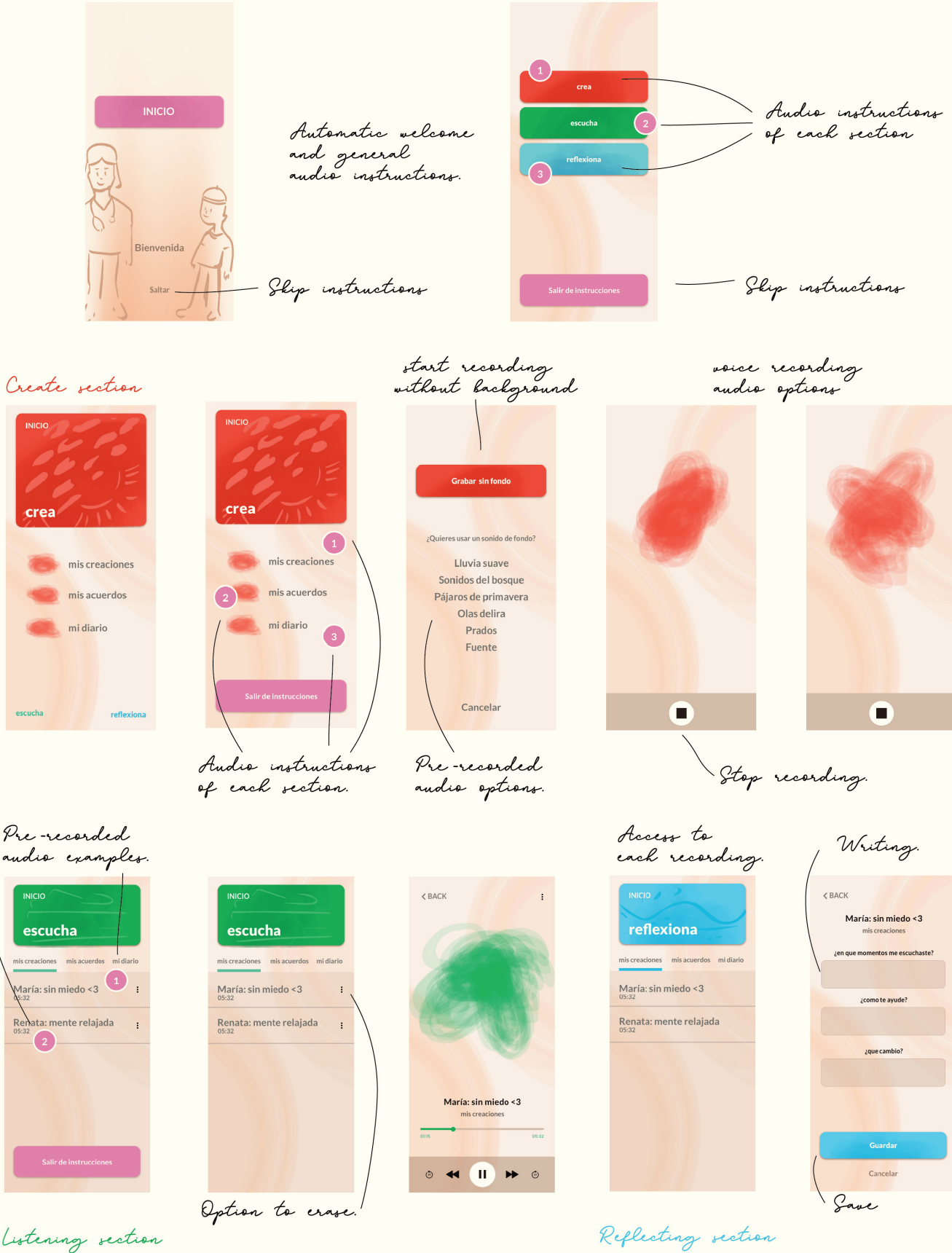


IMAGE 4 shows the final prototype.



Description of improvements:

Color palette

The first color palette was chosen in a low intensity hue based on psychologist Mariana Campos' expertise and experience with didactic material to induce a calm mental state and to invite the participant to partake in the action of interiorizing. Taking into account the evaluation of the first prototype, we made the colors less mild and more attractive based on the nurses and children's descriptions of what color palette they would like (De, Rivas, Luisa, & Rodríguez, 2018).

Script

Taking into account the results of the evaluation of the prototype and the suggestions given, we made changes to the script. We summarized the instructions based on the understanding that both children and nurses found the app intuitive while interacting with it, and the excess of instructions were not needed. See appendix #4 for full script of audio instructions.

Illustrations

In response to the suggestions to make the prototype more user-friendly, we created some illustrations of a nurse and a child and added more texture to the backgrounded (De et al., 2018). The interaction and structure of the app stayed the same, since they were able to interact and understand it easily.

IMAGE 5 shows a comparative between Prototype #1 and #2

Through their work, Freshwater and Stickley argue that emotion plays a crucial role in the development of effective and meaningful relationships between patients and healthcare professionals (Freshwater and Sickley, 2004). Their claim is supported by others who believe that moral support is essential to the practice of caregiving (Kleinman, 2012). Jean Decety, a neuroscientist specializing in developmental, affective, and social neuroscience, defines empathy as a process by which positive and negative emotions are shared (Decety and Meyer, n.d.). Applied in the clinical encounter, empathy has shown to yield myriad positive results, including the possibility to examine how to protect patients and healthcare professionals from experiencing distress. Despite this, empathy in medicine remains an undervalued and understudied topic (Riess, 2010; Schattner, 2012).

Experience-based co-design (EBCD) engages users by gathering their experiences and taking them into account, thus making them active participants in the design process (Donetto et al., 2015). Our study aimed to create a communication tool that would improve the relationship between child cancer patients and nurses working in the pediatric oncology ward of a hospital in Mexico City, Mexico.

As stated in the Methods section, we interviewed field experts who helped outline two workshops. In the first workshop, participants were able to provide key insights on their experiences and needs, from which we built an emotional map that elucidated the main concerns that the communication tool would address. The findings of our study can be divided into two sections. The first section focuses on the process of building and testing our prototype. The second section reflects broadly on the reach and limitation of this study, specifically in the context of Mexico. We expand on these sections below.

1. The emotional states of nurses and children

Though the pediatric oncology patients that participated in this study appear to understand that the treatment given by nurses is necessary, they feel that the nurses are distant or in a hurry, and don't understand their relationship to the nurses as that of a team. On the other hand, nurses appear aware of an emotional disconnection between them and their pediatric oncology patients, despite reporting that they feel empathy and attachment towards them. Nurses also

report feelings of exasperation when they face difficulties with making the children cooperate with treatments. Nurses are interested in building a relationship based on trust and compassion with their patients.

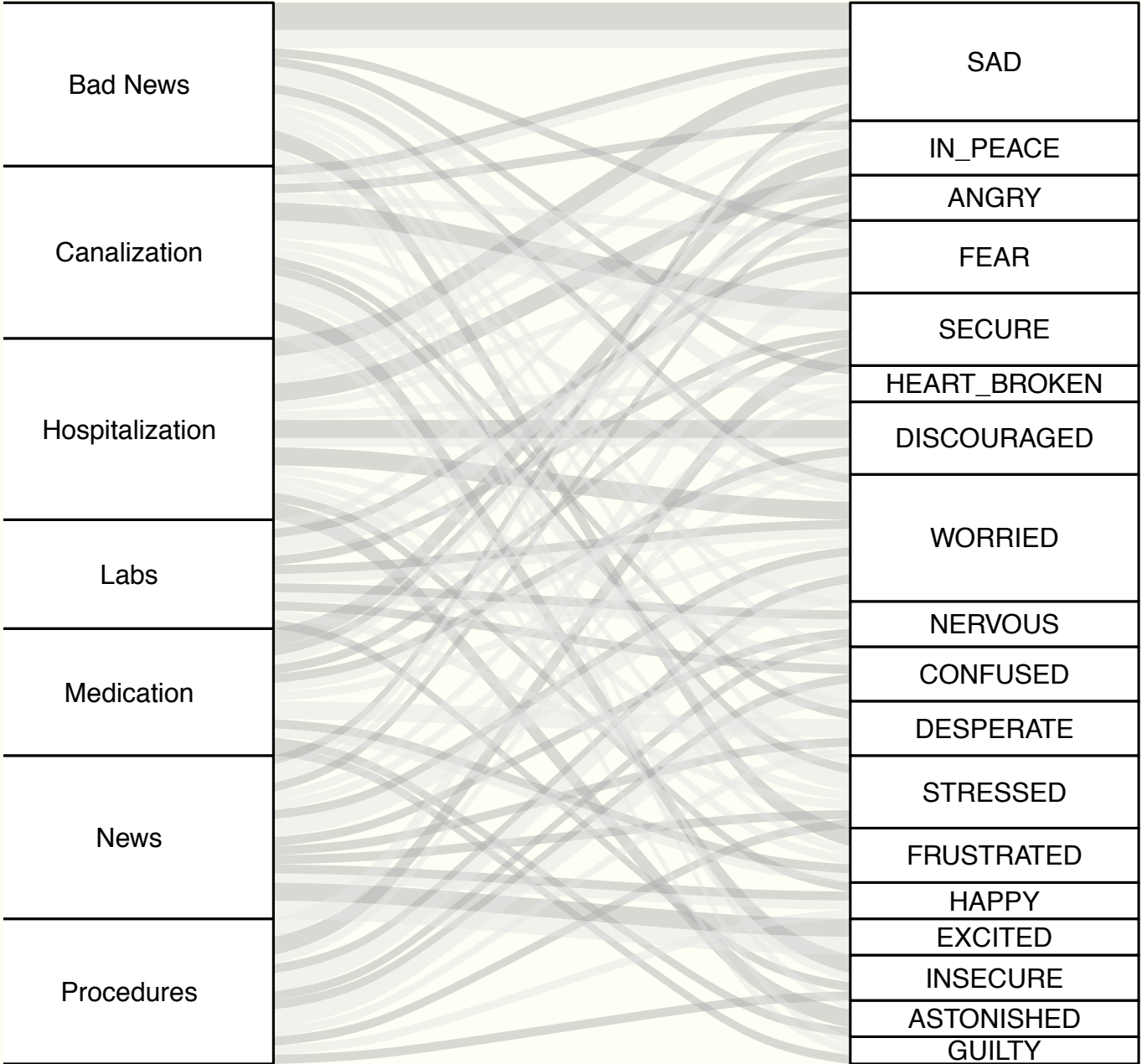
In the emotional map, we can observe that, for the nurses, the process of meeting a new patient is generally pleasant and accompanied by positive emotions such as excitement. As the clinical encounter evolves, however, these emotions transform and give place to negative emotions like fear, despair and anger. Nurses shared that they feel stress when facing a patient's lack of cooperation in taking their medicine or engaging in treatments, or when the patient is distracted by activities such as video games. As they mention, these scenarios make their daily tasks take longer, and hinder other procedures. We observed that nurses lack the tools to manage these situations, which generate an emotional disconnection between both parties.

Psychologist Mariana Campos mentions that during hospitalization, children tend to have regressions, which means that they regress to previous stages of their development. They seek protection, yearning for the most basic care experienced in their earlier ages. Therefore, it is to be expected that children look for their primary caregivers, a blanket, or something warm, which we observed in the interviews.

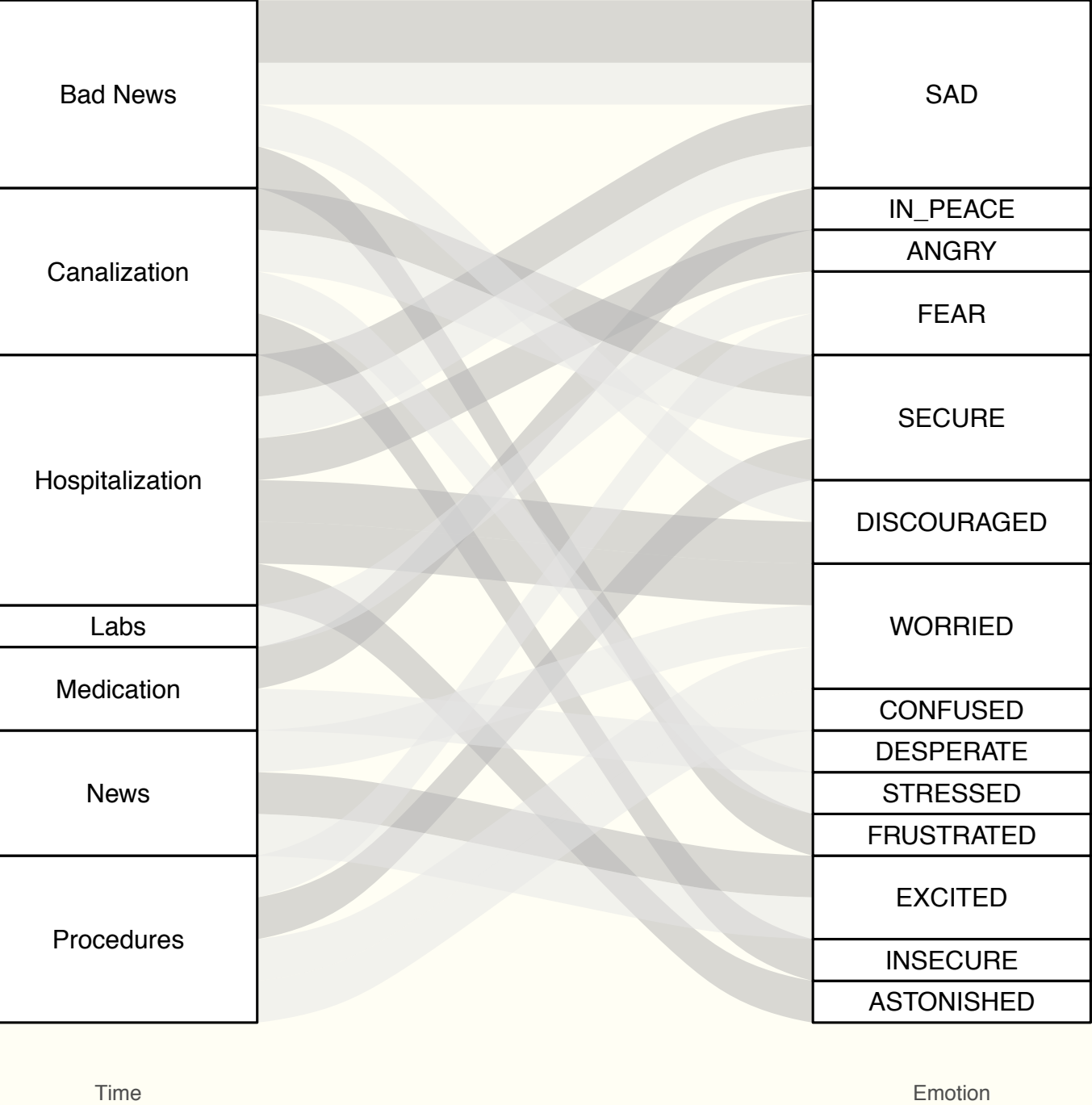
An important finding during the interview and workshop processes was that the child participants have an acute emotional awareness, perhaps due to their constant therapy work with expert psychologists. They are accustomed to identifying and communicating their emotions. One common thread between the children is a feeling of isolation, and of missing their homes and loved ones. Nurse participants in this study, however, do not receive therapy, and they report difficulty with handling their emotions. Nurse participant # 6 reported feeling insecure about showing vulnerability when displaying emotions.

Below, Image 6 displays the emotional map that was drawn as a result of the interviews and workshops. Through it, we identify the emotions reported by the participants and the moment in which these emotions arise. This emotional map was a crucial part of the design process because it determined what the prompts given by the application prototype would be.

The lines show the connections between emotions and touchpoints. The thickness of the lines illustrates the number of participants that mentioned a particular emotion during the workshop. The size of the box of the emotion represents the amount of times this emotion was mentioned during the workshop.



36



Child

Nurse

In Image 7, the emotional map was streamlined to reflect only the most prevalent emotions presented. Emotions that were mentioned by only one participant were removed.

The emotions that we visualize in the emotional map are predominantly negative. This leads us to conclude that emotional relationships are complicated, and they do not create a productive environment for nurses and children to connect and cooperate.

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The next stage involved analyzing the data collected from the first workshop and designing the initial prototype (PT1). In this stage, it was determined that the PT1 would be a mobile application based on sounds, to avoid over-stimulating the participants' visual senses, which Psychologist Mariana has found in her work in the hospital to trigger emotional responses more easily than other senses. Based on psychologist Mariana Campos' observation that children can enter a melancholic emotional state after a visually stimulating video call with their loved ones, we ensured that the interface of PT1 maintained their awareness of their hospital surroundings. By only incorporating sounds into the PT1, we grant participants control over what to record, manipulate, or erase, enabling them to choose what relaxes them. Nurse participants mentioned that children appear isolated after they spend prolonged time interacting with screens, and that this makes it difficult for the nurses to connect with them. For this reason, PT1 is intended to be low interaction in front of the screen.

The nature of the P1 application is intended to help establish an emotional connection between pediatric oncology patients and nurses of the pediatric oncology ward; to generate an affective bridge of communication between patient and nurse by using technology – which is something that children currently value and are familiar with it – and to support the nurses in the daily procedures they are tasked with by creating communication strategies. An example of these strategies is the possibility of recording verbal agreements through the application. In order to cooperate and form a healthy relationship, first both parties should avoid being in a state of alert or stress. Connection is very difficult to accomplish in a state of alertness, stress, worry, or anger (Fox, Lapate, Shackman, & Davidson, n.d.). By accessing relaxing sounds or the sound of a family member through this application, we hope to lower this state of anxiety in participants, so they can then begin making agreements and forming an interpersonal connection.

Later, the second workshop consisted of allowing participants to test the prototype, and then collecting their feedback. Finally, the data was analyzed and employed to create a second prototype (PT2). From the participants' feedback, we concluded that:

- The PT1 responded to the children's feelings of isolation and nostalgia by allowing them to record custom audios of their loved ones and reminders of joyous memories.
- It allowed children and nurses to have a moment in which, together, they established and recorded agreements through negotiations, to listen back to them during painful or difficult procedures. In this way, the nurse and patient had a space for connection that was mediated by a concrete tool which was used equally by both participants, because the interface is the same for children and nurses.

2. An EBCD method is helpful to address abstract emotional conditions, and is innovative in Mexico

To the best of our knowledge, there is no literature in Mexico that addresses emotional processes through an EBCD methodology. Our findings showed that all participants recognized the necessity for a communication tool, were eager to participate in the design process, and found the resulting prototype to be engaging and helpful. This leads us to conclude that there is an area of opportunity in exploring an EBCD methodology and design thinking to address abstract and complex problems such as those that are linked to emotions.

Due to the vulnerable health situation of the child cancer patients who participated in this study, as well as the hectic and ever-changing schedules that the nurses work under, many of the workshops had to be rescheduled. Furthermore, all contact with participants was mediated by Mariana Campos, the hospital's psychologist, which represented an additional constraint.

In March of 2020, while this study was being carried out, the COVID-19 pandemic struck Mexico. Participants of this study were transferred to a different hospital, and access to them was further complicated due to understandable concerns of public health. It is worth noting that though the children appeared to remain in stable psychological conditions, the nurses reported feeling more stress than usual.

This paper has contributed to the understanding of how incorporating participants in the design process of a tool intended for their use can be beneficial by drawing from their experiences. The prototype that resulted from our work at the pediatric oncology ward of the hospital in which this research was carried out shows that the needs, desires and experiences of end-users can serve as the guiding design principles of a tool aimed at helping them navigate highly stressful situations.

Adding the voices and testimonies of participants remains pending, as this would require permission from the REB, and the process was understandably halted due to the COVID-19 pandemic. In the future, we would aim to record more feedback from participants to further our understanding of the prototype's reach and limitations. Additionally, Child Participant #4 suggested customizing the prototype. We agree that this could be an added stage of the design process. Finally, in the future we would like to include children of different age ranges to test their responses.

It is important to continue generating tools that facilitate assertive communication between the members of a healthcare circle, including patients, family, physicians and all other medical personnel, since the different complex situations that may arise during treatment are evident.

Rinpoche, Y. M. (2007). The joy of living: Unlocking the secret and science of happiness: Yongey Mingyur Rinpoche with Eric Swanson.

Asking descriptive questions - 26100 - UTS - StuDocu. (n.d.). Retrieved April 18, 2020, from <https://www.studocu.com/en-au/document/university-of-technology-sydney/integrating-business-perspectives/other/asking-descriptive-questions/4992905/view>

Atlas of Emotions | Map of Emotions | Paul Ekman Group. (n.d.). Retrieved April 15, 2020, from <https://www.paulekman.com/blog/atlas-of-emotions/>

Bate, P., & Robert, G. (2007). Bringing user experience to healthcare improvement : the concepts, methods and practices of experience-based design. Radcliffe Pub.

Borenstein, L. (2019). When More “We” Becomes More “Me”: Transitional Objects and Forward Movement in Child Psychotherapy. *Journal of Infant, Child, and Adolescent Psychotherapy*, 18(3), 223–233. <https://doi.org/10.1080/15289168.2019.1615273>

Bowen, S., McSeveny, K., Lockley, E., Wolstenholme, D., Cobb, M., & Dearden, A. (2013). How was it for you? Experiences of participatory design in the UK health service. *CoDesign*, 9(4), 230–246. <https://doi.org/10.1080/15710882.2013.846384>

Brennan, F. X., & Charnetski, C. J. (2000). STRESS AND IMMUNE SYSTEM FUNCTION IN A NEWSPAPER’S NEWSROOM '. *O Psychological Reports* (Vol. 87).

Charmaz, K. (2014). Grounded Theory in Global Perspective. *Qualitative Inquiry*, 20(9), 1074–1084. <https://doi.org/10.1177/1077800414545235>

Clements-Cortés, A. (n.d.). Music to Reduce Stress - ProQuest. Retrieved from <https://search-proquest-com.ocadu.idm.oclc.org/docview/878608221?pq-origsite=summon>

Davidson, R., & Lutz, A. (2008). Buddha’s Brain: Neuroplasticity and Meditation [In the Spotlight]. *IEEE Signal Processing Magazine*, 25(1), 176–174. <https://doi.org/10.1109/MSP.2008.4431873>

Decety, J., & Meyer, M. (2008.). From emotion resonance to empathic understanding: A social developmental neuroscience account. <https://doi.org/10.1017/S0954579408000503>

Dewar, B., Mackay, R., Smith, S., Pullin, S., & Tocher, R. (2010). Use of emotional touchpoints as a method of tapping into the experience of receiving compassionate care in a hospital setting. *Journal of Research in Nursing*, 15(1), 29–41. <https://doi.org/10.1177/1744987109352932>

Doing Research Inclusively – Doing Research Well? (n.d.). Retrieved April 2, 2020, from [http://www.doingresearchinclusively.org./](http://www.doingresearchinclusively.org/)

Donetto, S., Pierri, P., Tsianakas, V., & Robert, G. (2015). Experiencebased co-design and healthcare improvement: Realizing participatory design in the public sector. *Design Journal*, 18(2), 227–248. <https://doi.org/10.2752/175630615X14212498964312>

EBCD: Experience-based co-design toolkit | Point of Care Foundation. (n.d.). Retrieved April 17, 2020, from <https://www.pointofcarefoundation.org.uk/resource/experience-based-co-design-ebcd-toolkit/>

Ekman, E., & Krasner, M. (2017). Empathy in medicine: Neuroscience, education and challenges. *Medical Teacher*, 39(2), 164–173. <https://doi.org/10.1080/0142159X.2016.1248925>

Emerson, R. M., Fretz, R. I., & Shaw, L. L. (n.d.). Writing ethnographic fieldnotes.

Fox, A. S., Lapate, R. C., Shackman, A. J., & Davidson, R. J. (n.d.). The nature of emotion : fundamental questions.

Gilljam, B.-M., Arvidsson, S., Nygren, J. M., & Svedberg, P. (2016). Promoting participation in healthcare situations for children with JIA: a grounded theory study. *International Journal of Qualitative Studies on Health and Well-Being*, 11(1), 30518. <https://doi.org/10.3402/qhw.v11.30518>

Gleichgerrcht, E., & Decety, J. (2014). The relationship between different facets of empathy, pain perception and compassion fatigue among physicians. *Frontiers in Behavioral Neuroscience*, 8(JULY). <https://doi.org/10.3389/fnbeh.2014.00243>

Iedema, R., Merrick, E., Piper, D., Britton, K., Gray, J., Verma, R., & Manning, N. (2010). Codesigning as a Discursive Practice in Emergency Health Services: The Architecture of Deliberation. *The Journal of Applied Behavioral Science*, 46(1), 73–91. <https://doi.org/10.1177/0021886309357544>

Iyendo, T. O. (2017, November 1). Sound as a supportive design intervention for improving health care experience in the clinical ecosystem: A qualitative study. *Complementary Therapies in Clinical Practice*. Churchill Livingstone. <https://doi.org/10.1016/j.ctcp.2017.08.004>

Katz, L. F., Heleniak, C., Kawamura, J., & Jakubiak, J. (2015). Emotion regulation, internalizing symptoms and somatic complaints in pediatric survivors of acute lymphoblastic leukemia. *Psycho-Oncology*, 24(11), 1536–1544. <https://doi.org/10.1002/pon.3762>

Kemeny, M. E., Foltz, C., Cavanagh, J. F., Cullen, M., Giese-Davis, J., Jennings, P., ... Ekman, P. (2012). Contemplative/emotion training reduces negative emotional behavior and promotes prosocial responses. *Emotion* (Washington, D.C.), 12(2), 338–350. <https://doi.org/10.1037/a0026118>

Kleinman, A. (2012, November 3). Caregiving as moral experience. *The Lancet*. Elsevier. [https://doi.org/10.1016/S0140-6736\(12\)61870-4](https://doi.org/10.1016/S0140-6736(12)61870-4)

Klimecki, O. M., Leiberg, S., Lamm, C., & Singer, T. (2013). Functional Neural Plasticity and Associated Changes in Positive Affect After Compassion Training. *Cerebral Cortex*, 23(7), 1552–1561. <https://doi.org/10.1093/cercor/bhs142>

Making Emotional Connections Through Participatory Design - Boxes and Arrows. (n.d.). Retrieved April 8, 2020, from <http://boxesandarrows.com/making-emotional-connections-through-participatory-design/>

Neumann, M. A., Bensing, J. B., Mercer, S. C., Ernstmann, N. A., Ommen, O. A., & Pfaff, H. A. (2009). H. Analyzing the “nature” and “specific effectiveness” of clinical empathy: a theoretical overview and contribution towards a theory-based research agenda. *Patient Education and Counseling Analyzing the “nature” and “specific effectiveness”*, 74(3), 339–346. <https://doi.org/10.1016/j.pec.2008.11.013>

Newman, A. R., Callahan, M. F., Lerret, S. M., Oswald, D. L., & Weiss, M. E. (2018). Pediatric oncology nurses’ experiences with prognosis-Related communication. *Oncology Nursing Forum*, 45(3), 327–337. <https://doi.org/10.1188/18.ONF.327-337>

Orlando, I. J. (n.d.). The Dynamic Nurse-Patient Relationship: Function, Process, and Principles. Eweb:93981. Retrieved from <https://repository.library.georgetown.edu/handle/10822/835380>

Patenaude, A. F., & Kupst, M. J. (2005). Psychosocial Functioning in Pediatric Cancer. *Journal of Pediatric Psychology*, 30(1), 9–27. <https://doi.org/10.1093/jpepsy/jsi012>

Pope, C., Van Royen, P., & Baker, R. (2002). Qualitative methods in research on healthcare quality. *Quality and Safety in Health Care*, 11(2), 148–152. <https://doi.org/10.1136/qhc.11.2.148>

Programmers, designers, and the Brooklyn bridge | Scott Berkun. (n.d.). Retrieved April 6, 2020, from <https://scottberkun.com/essays/30-programmers-designers-and-the-brooklyn-bridge/>

Robertson, T., Simonsen, J., & Simonsen, J. (2012). Participatory Design: an introduction, 21–38. <https://doi.org/10.4324/9780203108543-7>

Rudnytsky, P. L. (1993). Transitional objects and potential spaces : literary uses of D.W. Winnicott. Columbia University Press.

Sanders, E. B.-N., & Stappers, P. J. (2014). Probes, toolkits and prototypes: three approaches to making in codesigning. *CoDesign*, 10(1), 5–14. <https://doi.org/10.1080/15710882.2014.888183>

Sanders, E. B. N., Brandt, E., & Binder, T. (2010). A framework for organizing the tools and techniques of Participatory Design. In *ACM International Conference Proceeding Series* (pp. 195–198). New York, New York, USA: ACM Press. <https://doi.org/10.1145/1900441.1900476>

Sexton, J. D. (1980). : The Ethnographic Interview . James P. Spradley.

American Anthropologist, 82(4), 937–938. <https://doi.org/10.1525/aa.1980.82.4.02a00790>

Shanafelt, T. D., Balch, C. M., Bechamps, G., Russell, T., Dyrbye, L., Satele, D., ... Freischlag, J. (2010). Burnout and Medical Errors Among American Surgeons. *Annals of Surgery*, 251(6), 995–1000. <https://doi.org/10.1097/SLA.0b013e3181bfdab3>

Shanafelt, T. D., Boone, S., Tan, L., Dyrbye, L. N., Sotile, W., Satele, D., ... Oreskovich, M. R. (2012). Burnout and satisfaction with work-life balance among US physicians relative to the general US population. *Archives of Internal Medicine*, 172(18), 1377–1385. <https://doi.org/10.1001/archinternmed.2012.3199>

Singer, T., & Klimecki, O. M. (2014). Empathy and compassion. *Current Biology*, 24(18), R875–R878. <https://doi.org/10.1016/j.cub.2014.06.054>

Strauss, C., Lever Taylor, B., Gu, J., Kuyken, W., Baer, R., Jones, F., & Cavanagh, K. (2016). What is compassion and how can we measure it? A review of definitions and measures. *Clinical Psychology Review*, 47, 15–27. <https://doi.org/10.1016/J.CPR.2016.05.004>

Suzanne Waddill-Goad. (2016). Nurse Burnout: Overcoming Stress in Nursing. Indianapolis, IN : Sigma Theta Tau International. 2016. Retrieved from <http://eds.b.ebscohost.com/eds/detail/detail?vid=7&sid=3fe0da4f-a66a-49c3-80b3-bf6a41e98113%40pdc-v-sessmgr05&bdata=Jmxhbmc9ZXMMc2l0ZT1lZHMtb-Gl2ZQ%3D%3D#db=nlebk&AN=1151365>

The Nature of Emotion - Andrew S. Fox; Regina C. Lapate; Alexander J. Shackman; Richard J. Davidson - Oxford University Press. (n.d.). Retrieved April 16, 2020, from <https://global.oup.com/academic/product/the-nature-of-emotion-9780190612573?cc=mx&lang=en>

Toolkit. (n.d.). Retrieved April 18, 2020, from <http://test7.scottparker.co.uk/step3.html>

Tsianakas, V., Robert, G., Maben, J., Richardson, A., Dale, C., & Wiseman, T. (n.d.). Implementing patient-centred cancer care: using experience-based co-design to improve patient experience in breast and lung cancer services. <https://doi.org/10.1007/s00520-012-1470-3>

Universal Emotions | What are Emotions? | Paul Ekman Group. (n.d.). Retrieved April 15, 2020, from <https://www.paulekman.com/universal-emotions/>

Wagaman, M. A., Geiger, J. M., Shockley, C., & Segal, E. A. (2015). The Role of Empathy in Burnout, Compassion Satisfaction, and Secondary Traumatic Stress among Social Workers. *Social Work*, 60(3), 201–209. <https://doi.org/10.1093/sw/swv014>

Weissbourd, R. (2009). The parents we mean to be : how well-intentioned adults undermine children’s moral and emotional development. Houghton Mifflin Harcourt.

Weng, H. Y., Fox, A. S., Shackman, A. J., Stodola, D. E., Caldwell, J. Z. K.,

Olson, M. C., ... Davidson, R. J. (2013). Compassion Training Alters Altruism and Neural Responses to Suffering. *Psychological Science*, 24(7), 1171–1180. <https://doi.org/10.1177/0956797612469537>

Yongey Mingyur, R., Swanson, E., & Goleman, D. (2007). *The joy of living : unlocking the secret and science of happiness*. Harmony Books.

Yuguero, O., Ramon Marsal, J., Esquerda, M., Vivanco, L., & Soler-González, J. (2017). Association between low empathy and high burnout among primary care physicians and nurses in Lleida, Spain. *European Journal of General Practice*, 23(1), 4–10. <https://doi.org/10.1080/13814788.2016.1233173>

48	APPENDIX 1	
	Mariana Campos	
	Interview 1	
	1.Tour of oncology ward.	during their treatment. For the nurses it starts when meeting a new patient.
	Psychologist Mariana Campos gave a tour of the oncology pediatric ward	-Hospitalization: daily hospital routines.
	2. Explanation of HOPI group specialized in pediatric oncology.	- Catheter or canalization process.
	Psychologist Mariana Campos gave a profile of HOPI: HOPI is a group specialized in pediatric oncology and works primarily in the Centro Médico ABC hospital in Mexico City, Mexico. This multidisciplinary team is made up of experts including oncologists, bone marrow transplant experts, surgical oncologists, nutritionists and psychologists.	- Laboratory exams
	3. Can you describe a treatment journey of a pediatric child in this oncology ward.	- Medication
	. Description of the most common patient journey inside it. She gave a general profile of the patients and their treatments.	- Procedures: chemotherapy, radiation, surgical procedures.
	4. Can you show me the didactic materials you have and how you used them.	- Bad news
	Existing materials where categorize in three: Category #1 didactic toy that has medical content (like a memory card with illustrations of sick children, doctors, medical tools, etc) Category #2 Illustrated children’s ‘feel better’ books that have questions, exercises and drawing material (all of them have cancer related topics). Category #3 common bored games.	Interview 3
	Interview 2	The researcher presented the proposal for the research design to Mariana to evaluate:
	The researcher designer shared information on Participatory design and touchpoints to co create a research design.	Open discussion on the Research Design.
	1.What are the most important touchpoints that a nurse and a child share?	The workshops where divided in three sections.
	-The journey for the children starts prior to hospitalization, it all begins when their parents tell them that they have to go to the hospital and stay for indefinite time. They will come and go	-Pairing emotions with touchpoints or experiences during hospitalization,
		-Evaluating the existing didactic material tools.
		-Designing, drawing, or otherwise explaining their ideal toy or tool.
		Interview 4
		- Revision of final research design to present to REB.
		Emiliana Rodriguez
		Interview 1
		1.Explanation of project and research design
		2.Comments on Research design.
		Interview 2
		Verifying of the coding.
		-It is important to pay attention and understand through coding the negative emotions that arise in children and nurses during treatment and the methods they use to calm themselves.
		-In the nature of the security object may lay the nature of the communication tool.
		-An emotional state that is not mentioned as such but is very evident is the feeling of isolation.
BETWEEN NURSES AND CHILDREN IN THE ONCOLOGY PEDIATRIC WARD.		

-In children: There a need or yearning for human contact and a need for going back to what they know and love.

APPENDIX 2

PAEDIATRIC ONCOLOGY PATIENTS

Introduction (5-10 Minutes)

Category #1

Category #2

Category #3

Activity 1

(25 Minutes)

The objective of this activity is to answer the questions:

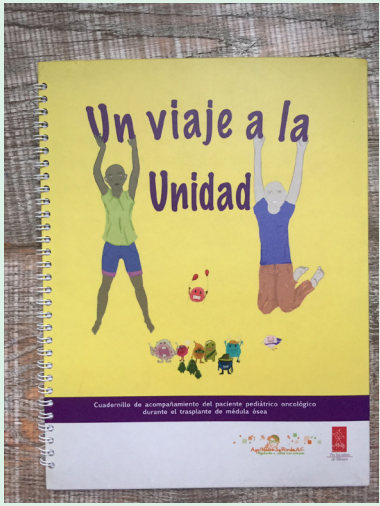
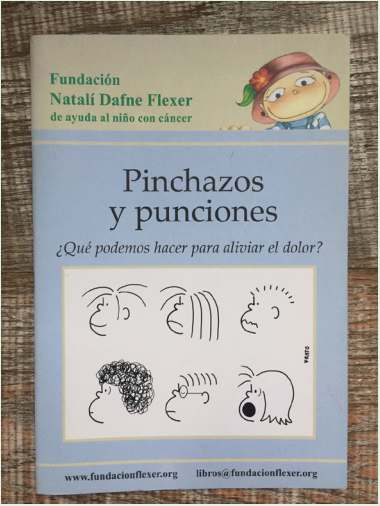
What didactic tools they have been presented in the past that have been useful and which ones haven't and why? What characteristics do they believe are key to create a successful communication tool?

The children will be presented with 3 different types of materials that have been used in the past to discuss. This will be discussed using age appropriate language.

Examples of the material that were presented to the children:

Examples of the material that were presented to the children:

Examples of the material that were presented to the children:



Activity 2 (15 Minutes)

Create your journey in the Oncology Pediatric Ward.

What are the critical processes of communication where compassion is required as a tool? What are the most common emotions during each procedure? These questions will be discussed using age appropriate language. The patients will be presented with a timeline of their hospitalization process with an emotional vocabulary to pair with crucial moments.

This are the elements that the timeline will include:

- a. The news. You will have to go to the hospital.
- b. Arriving to the hospital.
- c. Catheter or canalization
- d. Studies: lab, blood, Xray, etc
- e. Procedures (operations, chemo, radiation, etc)
- f. Hospitalization - eating - sleeping - routine everyday procedures.

Emotional vocabulary:

sadness, excited, exasperated, distressed confused, insecure, loved, safe, guilty, grateful, relieved, happy, frustrated, heartbroken, at peace, worried, astonished, discouraged, among others.

Instructions:

- 1.Please add to each stage of your timeline and emotion. It can be more than one.
- 2.Please answer this question: In case the experience was negative: Is there something or someone that help you through this stage. In case the experience was positive: what or who enhance it?

Activity 3 (15 Minutes)

Please answer the following question?

What kind of toy do you like to play with the nurses and the psychologist when you are in the hospital? The psychologist will ask all of them to create a description with drawings and/or with words of the toy. How will they do it? colors, pencils, crayon, markers and papers.

Conclusion

NURSES OF THE ONCOLOGY PEDIATRIC WARD

INTRODUCTION

(15-20Minutes)

Presentation of the workshop to the nurses:

1.Understanding the affordances on compassion as a communication tool.

The psychologist will do an introduction of what is compassion, empathy, compassionate communication and its affordances. Definition that will be presented: Compassion is characterized by feelings of warmth, concern and care for the others, as well as a strong motivation to improve the other’s wellbeing, this tool is very convenient when handling a crisis. Singer and Klimecki . (Singer, T., & Klimecki, O. M. (2014). Empathy and compassion.)

After defining compassion the psychologists will explain the difference between empathy and compassion: “In contrast to empathy, compassion does not mean sharing the suffering of the other: rather, it is characterized by feelings of warmth, concern and care for the other, as well as a strong motivation to improve the other’s wellbeing. Compassion is feeling for and not feeling with the other.” Singer and Klimecki . (Singer, T., & Klimecki, O. M. (2014). Empathy and compassion.)

2.The psychologist will explain why they are invited to this workshop:

We need your help in codesigning a new communication tool with the affordances of compassion.

Geared towards providing a useful implement that enhance communication and resource to nurses to facilitate uncomfortable, but necessary medical procedures, such as catheterization. The best way to understand what nurses and children need to ask them directly.

Activity 1

(15-20 Minutes)

Create a patient journey in the Oncology Pediatric Ward.

The objective of this activity is to answer the questions:

What are the critical processes of communication where compassion is required as a tool? During critical moments and painful procedures design a journey of the interaction between patient and the nurses: How is the interaction and the communication? What emotions arise in the patient and in themselves?

The nurses will be asked to draw a timeline from the moment they have contact with a new patient until the treatment finishes, they will be asked to write an emotion they feel in specific touchpoints in the interaction with the patient.

Journey

- a. First contact with patient, introduction
- b. Catheter or canalization
- c. Studies: lab, blood, Xray, etc
- f. Procedures (operations, chemo, radiation, etc)
- f. Hospitalization
- eating - sleeping - routine everyday procedures.
- g. bad news

Questions:

1.On this stage what emotion arises in these conflicts? Here some examples: Sadness, excited, exasperated, distressed confused, insecure, loved, safe, guilty, grateful, relieved, happy, frustrated, heartbroken, at peace, worried, astonished, discouraged, etc.

Activity 2

(25-30 minutes)

Analyzing past efforts. The objective of this activity is to answer the questions:

What didactic tools they have been presented in the past that have been useful and which ones haven’t and why? What characteristics do they believe are key to create a successful communication tool?

The nurses will be presented with 3 different types of materials that have been used in the past to discuss.

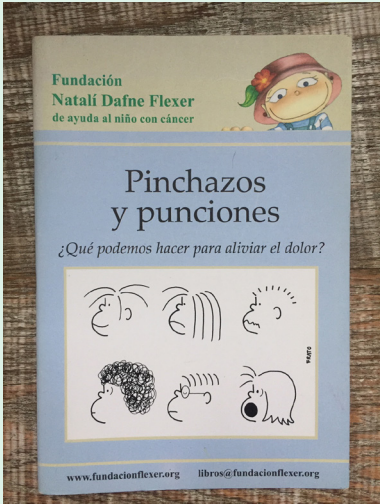
Category #1

Examples of the material that were presented to the nurses:



Category #2

Examples of the material that were presented to the nurses:



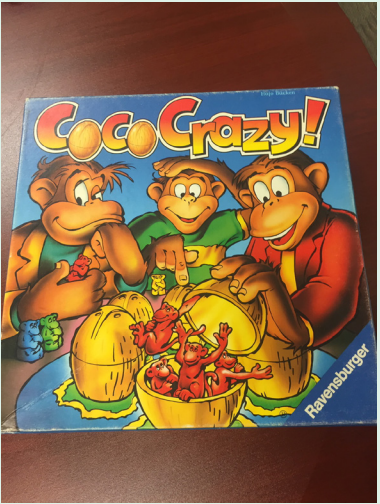
Category #3

Please observe this existing game that is often used, note how we in the past normally change the rules to suit every situation and we have created new rules and a new story.

Please answer the following questions?

- 1.What are the affordances this game, good and bad qualities?
- 2.Would you like to share an experience using this material? It can be positive or negative.

Examples of the material that were presented to the nurses:



Activity 3

(25-30 minutes)

Analyzing results and co-design a low fidelity prototype.

The objective of this activity is to gather characteristics for the new communication tool.

The nurses will be presented with a pre sketched paper that will have three columns. The nurses will have a pen and will be asked to write words/sentence in the three different columns here the instructions.

For column #1

Please write words or sentences describing what the communication tool must solve, be like and communicate.

For Column 2

Please write words describing what affordances the communication tool must have.

For Column 3

Please write words and adjectives describing what it must not be.

Conclusion and thank you

(5-10 minutes)

The psychologist will thank the nurses for their time and will remind them of ways to contact the researcher.

• Conclusion: 5 minutes

There is a 15-20 minutes buffer that allows for overtime and bathroom breaks if needed.

APPENDIX 3

Evaluation of Prototype

Workshop #1

Six nurses participants #4,5,6,7,8&9

Question #1

What do you think of the idea of recording voices, sounds, songs, and stories to create audios that help you through the most difficult times in the hospital?

- As a group they agreed they generally liked the idea.
- One nurse mentioned she felt insecure about sharing her feelings with the children. She felt that made them more vulnerable.
- There was a little concern on the accessibility of the app, because of social
- One nurse states that she believed it was practical because they miss family members a lot.
- Time was a concern since they feel that time is limited and they like having their routine.

Question #2

Is the application easy for you to navigate through it? Did you understand the instructions? What are they missing?

- All six participants understood the instructions. They did not have difficulties with the application’s usability.

Question #3

Do you like the design, colors and shapes?

- All participants agreed they would like the colors to be brighter.
- Participants requested illustrations and animations to make the app more child-friendly.
- When psychologist Mariana Campos explained to them that the colors were also to include them, they responded that since it was for pediatrics they didn’t mind.

Question #4

What do you think of the idea that there are pre-recorded meditations and breathing exercises so you can listen to them?

- The majority of the participants are interested in accessing reflective questions and breathing exercises to be in touch with their emotions, to relax, and to be more sensitive.
- Quote: I am interested in this app to improve my mood, I need help with that, and this could also help us reach between us.
- Quote: I am interested in using this app on my way home so I don’t arrive stressed with my family, so I don’t yell at my own children and get angry.

Question #5

Is there anything that you would like to add?

- The nurses displayed concerns about showing insecurity to the children. They don’t want to show they might be nervous during a procedure.
- They were concerned about the use of words with negative connotations such as “hurting”. They don’t like the idea of negative actions or comments.

Workshop #2

Two nurses, Nurse #3 and Nurse #4.

Question #1

What do you think of the idea of recording voices, sounds, songs, and stories to create audios that help you through the most difficult times in the hospital?

- They like the idea of incorporating audio and wanted to know if it was possible to incorporate images as well, such as pictures or emoticons.
- They like the idea of connecting with the children and getting to know them better through the application. They also like the possibility of using the Reflect section as a communication tool that enables both participants to understand each other’s emotions and connect.
- The commented on how children play games with friends and connect.

Question #2

Is the application easy for you to navigate through it? Did you understand the instructions? What are they missing?

- They understand instructions and mentioned no problems with usability.
- They suggested to change the word “Reflect” for something else. They believe it is difficult to understand, and believe the question “How do you feel?” is more direct.

Question #3

Do you like the design, colors, and shapes?

- They suggested more colorful shapes.

Question #4

What do you think of the idea that there are pre-recorded meditations and breathing exercises so you can listen to them?

They like the idea.

Question #5

Is there anything that you would like to add?

Children

Workshop #3

Children Participant #3

Question #1

What do you think of the idea of recording voices, sounds, songs, and stories to create audios that help you through the most difficult times in the hospital?

- Quote: I like it. I was not sure about the recording voice, but I like the idea. I would like the voice to be a kid, to feel more connected with someone my age.
- Quote: I like the idea of recording the voice of someone with relaxing background sounds. That makes me feel better.

Would you like a character?

- Quote: Yes, more than a photography of a child I don’t know.

Question #2

Is the application easy for you to navigate through

it? Did you understand the instructions? What are they missing?

- Quote: I understood everything, it is easy to use. I would only change the voice.

Question #3

Do you like the design, colors, and shapes?

- Quote: I would like a character with colorful features. I like the colors, but I would like them to be a little stronger or livelier. I like the colors but not the tone so much. I would like them more intense.

- Quote: I feel that the design and shapes make it easy to use.

Question #4

What do you think of the idea that there are pre-recorded meditations and breathing exercises so you can listen to them?

- Quote: Those exercises annoy me, I am very hyper-active, and they stress me. I get easily distracted.

Do you think this exercise could help others?

- Quote: Yes, because not all people or kids are like me.

Question #5

Do you enjoy the stories? What would you like to add? Would you like to share a story?

- Quote: I would like to share one of the 40 stories or more I have. I would add something to keep children busy or entertain them with the nurses, a game or an activity. I would love to give ideas.

Workshop#4

Children Participant #4

Question #1

What do you think of the idea of recording voices, sounds, songs, and stories to create audios that help you through the most difficult times in the hospital?

- Quote: I think it is a good idea because it could help to relax and not be so scared before procedures in the hospital.

Do you think it is good for nurses and children?

•Quote: Yes, because in this way it helps the nurses express themselves with the children.

Question #2

Is the application easy for you to navigate through it? Did you understand the instructions? What are they missing?

•Quote: It is easy to use for me yes, because I have interacted with phones it is easy.

Question #3

Do you like the design, colors, and shapes?

•Quote: I like it, but I would change the colors to more lively ones. I like the colors but make them more intense. I like the shapes and design.

Would you like a character?

•Quote: I would like if we could create our own character and interact with it. Maybe make a story of your life with your own images.

What about the voice?

•Quote: Depending on the character, match the voice. If I choose my mother, I would like it to have her voice.

Question #4

What do you think of the idea that there are pre-recorded meditations and breathing exercises so you can listen to them?

•Quote: Yes. I like the idea of the background sounds. The sound of the sea makes me sleep. I also enjoy nature sounds like wind, birds, or people walking on grass. I have heard on YouTube relaxing sounds and enjoy them.

Question #5

Do you enjoy the stories? What would you like to add? Would you like to share a story?

•Quote: Yes, I would love to share a story.

Workshop #5

Children Participant #1

Question #1

What do you think of the idea of recording voices, sounds, songs, and stories to create audios that help you through the most difficult times in the hospital?

•Quote: Yes, it could help many children say what makes them feel better.

What would you have recorded, for example, when you went to the transplant unit?

•Quote: Don't be afraid, it will never hurt, you are going to be safe, don't think about what's going to happen, don't be nervous.

•Quote: Everybody likes the sounds of nature; it makes everybody happy.

Would you have like for these phrases to be recorded by someone from your family?

•Quote: Yes, from my mother and father.

Question #2

Is the application easy for you to navigate through it? Did you understand the instructions? What are they missing?

•Quote: Yes, I think it would be easy for me. Maybe some words that I don't understand but my parents would help me.

Question #3

Do you like the design, colors, and shapes?

•Quote: I would change some colors, add a color blue so it looks more colorful. Light colors, not intense.

•Quote: I like the shapes.

Question #4

What do you think of the idea that there are pre-recorded meditations and breathing exercises so you can listen to them?

•Quote: Yes, I would like that. Maybe stories. That is a good idea, breathing exercise. I could use it during my PET SCAN that makes me super nervous. I never know if they are going to inject me, and I get super nervous.

Question #5

Do you enjoy the stories? What would you like to add? Would you like to share a story?

•Quote: I would like to share stories.

Workshop #6

Children Participant #2

Question #1

What do you think of the idea of recording voices, sounds, songs, and stories to create audios that help you through the most difficult times in the hospital?

•Quote: I like it, I have use recorded voices to relax.

Question #2

Is the application easy for you to navigate through it? Did you understand the instructions? What are they missing?

•Quote: Yes, it is easy. The shapes make it seem easy.

Question #3

Do you like the design, colors, and shapes?

•Quote: The shapes makes it easier, I like it.

Question #4

What do you think of the idea that there are pre-recorded meditations and breathing exercises so you can listen to them?

•Quote: Yes, I would like stories that help me to relax.

Question #5

Do you enjoy the stories? What would you like to add? Would you like to share a story?

•Quote: I like the stories if you are going to hear them while you are getting punctured. When they tell you they are going to puncture you or use a needle, you get super nervous.

How could we use this app for those moments?

•Quote: I would like to hear the voice of someone from my family, especially my mother. They often take my mom out of the room.

•I would like to hear a voice of someone counting.

APPENDIX 4

Instructions Audio Script



This application seeks to help you in difficult times when you are in or outside the hospital. It can help you calm your body and mind so that you can feel better by recording feel good sounds, songs, voices, agreements, stories, jokes, riddles that relax you. You can create many beautiful recordings from the sound of the sea, to your grandparents telling a joke or your brother saying a phrase like "Everything will be fine". You can organize, hear and rate them over and over while you reflect on how your creations are helping you.



This application is divided into three sections: Create, Listen and Reflect. Click on each one to learn how to use them.

Click 1 Create: Here you can record all the sounds that make you feel good. Let's create sounds that make you feel calmer in the hospital.

Click 2: Listen: Here you can listen to your beautiful creations and organize them. Also you can find some fun examples to get you inspired and some meditation exercises to help you relax even more.

Click3: Reflect: Here you can decide which of your creations have helped you and how.

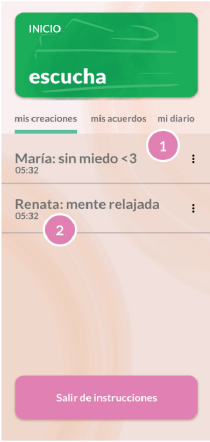


Create: Here you can record all the sounds that make you feel good.

Click 1 My creations: Record your powerful creations and check out the background sounds.

Click 2 My agreements: Make a compromise and a powerful pact between nurse and patient so you can both give and receive. Need an example? Check out the listening section.

Click 3 My Diary: Create your audio diary feel free to record anything you desire.



Here you can listen to your beautiful creations and organize them, create your own playlist for each special moment. Also, you can find some fun examples to get you inspired and some meditation exercise to help you relax even more.

Click 1 Maria's example: Listen to Maria, a patient in the hospital tell her story on how she overcame her fear of needles.

Click 2: Renata's example: Listen To Renata's story a nurse that got very stressed during central venous catheterization and how her loved ones helped her overcome the fear.



Maria's example: Hi my name is Maria and the first times I went to the hospital, I was very afraid that my catheter would be connected, every time my mom warned me that we would soon go to the hospital, it came to my mind that they were going to inject me and that's why I didn't want to go to the hospital. When I went to the hospital, I didn't have such a bad time, it was just that one moment in particular that scared me the most and made me angry with the nurses. It made me so nervous that I couldn't control my body, so I moved, the nurses became super nervous, then sometimes they hurt me more ... Then one day, my psychologist and I decided to make a regulation between the nurses and myself, these regulations included agreements that would help me and my nurse in difficult times. One of the agreements was that nurses, my parents, psychologists and I danced to my favorite song, which I recorded in my application. Another agreement was that my mom took me by the hand and recorded my dad saying to me: "It is going to happen, it is going to end, everything is going to be okay" "It will not hurt so much, the nurse will do it with great affection". And so he could have the support of mom and dad, even if one of them wasn't there.



Renata's example: My name is Renata and I am a nurse in the hospital. Sometimes it makes me nervous, uncomfortable and very stressful to central venous catheterization in very young patients for fear of hurting them. Actually, I am capable of it, only sometimes at that particular moment I get stressed. Sometimes I get so nervous that I cant control my body. So one day I recorded sounds of nature that I like and relaxed in the application, I listened to those before stressing, then I recorded together with my patients, sounds that relaxed both of us, we put those sounds during the catheterization. I also recorded my husband, my daughter and my coworkers saying phrases like: YOU CAN! You are a great nurse and everything is fine!". And I listened to this audio in my most difficult moments, especially before going through problematic patients.

