



# Lessons Learned in Designing a Digital Therapeutic Game to Support the Treatment and Well-Being of Children with Cancer

Kamila R. H. Rodrigues<sup>1</sup>(✉), Daniel B. F. Conrado<sup>2</sup>, and Vânia P. A. Neris<sup>1</sup>

<sup>1</sup> Department of Computer Science, Federal University of São Carlos – UFSCar, São Carlos, SP, Brazil

[kamila.rios@gmail.com](mailto:kamila.rios@gmail.com), [vania@dc.ufscar.br](mailto:vania@dc.ufscar.br)

<sup>2</sup> Federal Institute of Education, Science and Technology of Minas Gerais – IFMG, Campus Sabará, Sabará, MG, Brazil

[daniel.conrado@ifmg.edu.br](mailto:daniel.conrado@ifmg.edu.br)

**Abstract.** Therapeutic games not only entertain but also support rehabilitation treatments and help patients and caregivers to understand the therapeutic practices. This kind of game requires careful and responsible development. To the best of our knowledge, there is no variety of methodologies in the literature specifically tailored to develop them. It essentially requires collaborative creation between different domain specialists. Moreover, it is necessary to avoid ad-hoc design processes and favor the structured ones, which can effectively involve and guide stakeholders. Thus, we have adopted a methodology based on Participatory Design and Organizational Semiotics artifacts to guide the design of a therapeutic game that could entertain and inform children who were diagnosed with cancer, as well as their caregivers. The methodology includes the enrichment of Personas, aiming to characterize the intended audience of the therapeutic application. This paper presents an instantiation of such methodology and also describes how the information obtained during that process can aid on therapeutic games design aiming to support the rehabilitation of children under treatment for cancer. We also report some lessons learned from that instantiation, regarding both the methodology application and the specificities of the target audience that should be carefully considered when developing games to support chronic pathologies, especially those involving children.

**Keywords:** Digital therapeutic games · Childhood cancer  
Design process · Personas · Participatory Design · Lessons learned

## 1 Introduction

Digital games are interactive software systems used for leisure, entertainment and, increasingly, as a tool for education and health [1]. Therapeutic games, in

turn, are games used as tools to support healthcare professionals on their practice [2]. The use of these games can promote the social and cognitive development of the user through activities that allow their evaluation by healthcare professionals [3]. As they serve therapeutic purposes, these games should be carefully managed and design should be well evaluated to ensure their contribution to the intended therapeutic goals [4].

To the best of our knowledge, there is no variety of methodologies in the literature specifically tailored to develop them. This application essentially requires collaborative creation between different domain specialists. Moreover, it is necessary to avoid ad-hoc design activities and favor the structured ones, which can effectively involve and guide stakeholders, as cooperation between healthcare and computer professionals is critical to the game adhesion.

Stakeholders are composed of a multidisciplinary and heterogeneous group of individuals. Conditions, treatments, patients and technical processes, in turn, may vary. Rodrigues et al. [4] point out that given the multiple variables involved to ensure success and quality, a structured process could assist in the design, implementation, evaluation and adoption of digital therapeutic games. These researchers proposed a methodology which requires a multidisciplinary team, with a comprehensive view of the development of this kind of computational system [4]. The methodology employs Participatory Design (PD) [5,6], Organizational Semiotics (OS) artifacts [7] and Personas [8] techniques, enabling stakeholders to participate more actively in the game development process.

In our research, we are developing a game to be used with children who were diagnosed with cancer and are currently admitted into specialized hospitals. Our aim is to transform the treatment in something lighter somehow, by providing to the patient and caregivers an entertainment and information resource, that can also be used by therapists as a work tool. To identify stakeholders and the game's requirements, we have used the methodology proposed by Rodrigues et al. [4]. Thus, we describe in this paper an instantiation of this methodology with the creation of three Personas who represent patients with childhood cancer.

Cooper [8] defines a Persona as a concrete and realistic representation of a system user. This technique is indirectly applied by Rodrigues et al. [4] to collect and summarize information such as gender, age, interests, abilities, etc., about potential users. Rodrigues and her research group have identified that, when dealing with the health domain, it may be necessary to add therapeutic information to the Personas, e.g. the clinical profile and required treatment. They called this modification as Personas Enrichment Process [4]. The enrichment is carried out in a participatory way: hospital professionals contribute in proposing, improving, and evaluating the created personas.

The instantiation of the methodology was conducted in three meetings with therapists from the hospital who were specialized in treating childhood cancer. Peculiar aspects were identified during the Personas enrichment process and should be considered in the game design to support the treatment of childhood cancer. These aspects relate to the target audience, the genre of the game, its mode of interaction and the intended stimuli. The methodology instantiation

has also revealed other game features, requirements for the hospital scenario, and characteristics about the children's caregivers that should be considered in the design and development of the game in question. We observed that some characteristics and requirements differ from those identified by Rodrigues et al. in the context of games developed to support mental health treatments. In this paper, we describe some of these differences, in addition to discuss about the instantiation, how the Personas were used to guide the design process of the therapeutic game for children with cancer and some lessons learned during the process.

This paper is organized as follows: Sect. 2 comments about the childhood cancer; Sect. 3 describes some digital games in this context; Sect. 4 describes the Personas Enrichment Process: a methodology to created Personas aimed to support the development of therapeutic applications; Sect. 5 illustrates the creation of Personas using this methodology instantiation for childhood cancer; Sect. 6 describes lessons learned in designing of this digital therapeutic game; and Sect. 7 presents conclusions and future work.

## 2 Childhood Cancer

Childhood cancer epidemiology data has shown that scientific advances in pediatric oncology have considerably increased the likelihood of cure. According to Brazil's National Institute of Cancer (INCA) [9], there is a 70% chance of remission when cancer is early diagnosed and specialized treatment is provided. These advances have also brought the need for a patient care that addresses quality of life and emotional well-being. That is, the treatment should go beyond prolonging the lives of children with cancer and give support regarding emotional and socialization issues of children and their caregivers [10, 11].

Over the course of the treatment, the child patient is submitted to painfully invasive medical procedures such as chemotherapy, a resource commonly used to treat cancer and the most effective against leukemia (which is the most common cancer in children) [9]. The common side effects of chemotherapy includes fatigue, fever, vomiting, diarrhea, mouth sores, hair loss, among others. The conditions imposed by the treatment require considerable hospitalization time that some children actually live in hospitals. Frequent and long hospital stays are characterized by a period of physical and emotional stress for both, the child and her/his family. The child needs to adapt to that new situation, often apart from friends and family, and it requires strategies to deal with adverse circumstances [10].

To deal with those stressful experiences and invasive medical procedures, a child can play, which is a resource both her/his and caregivers use in hospitals. Healthcare professionals have indicated their application as part of therapy, as it provides stimulating and fun activities to help children feel relaxed and safe [10, 12].

The hospital's multidisciplinary team reported us that the way like patients and caregivers deal with the disease can affect the child's recovery both, positively and negatively. Considering these information, especially about the positive aspects brought about by playing in a hospitalization situation, it is possible

to think about the development of therapeutic games aimed at this purpose, which not only entertain patients and caregivers, but which can support therapists during the treatment of these children. The following section describes some initiatives in this regard.

### 3 Digital Games and Cancer Treatment

We have found some digital games specifically related to cancer treatment. However, these games were developed to explain the disease to patients and elucidate the human body reactions. Most of them are fighting games which simulate the “good soldiers” against the “mutant cells”. Such unilateral approach to the subject does not address other important aspects like positive thinking and collaboration with the family, and it also conveys violent mechanics. Those games includes: Re-Mission<sup>1</sup>, Bens’s Game<sup>2</sup> and Alpha Beat Cancer<sup>3</sup>.

Re-Mission is modeled like an interactive fantasy where players are nanorobots living inside a human body. They have to eliminate cancer byproducts along the game. Also, players have to monitor the patients’ health and notify any symptoms to the doctor. Each one of the 20 game levels is designed to inform the patient about different kinds of treatment, how they work, and the importance of receiving them. Ben’s Game focuses on destroying cancerous cells and collecting shields in order to protect the patient against side effects of chemotherapy. In a very ludic way, the game signifies that scenario with snow monsters (cold), vampires (bleeding) and balls (hair loss). The Alpha Beat Cancer, in turn, is a “point and click” game that works as an adventure guide. The player pass through 21 levels where cancer and the treatment are demystified and oncological terms are introduced in an objective, fun and optimistic way. Parents and family can benefit from those information as well.

Those aforementioned games have generally violent dynamics, focus on fighting mutant cells and informing about cancer. The game we are developing in this work aims to entertain but also to stimulate positive and important aspects in the child’s therapeutic process. It is designed to support healthcare professionals on collecting feedback data and to perform interventions along the treatment.

The following section describes the methodology proposed by Rodrigues et al., which was adopted in this work to characterize the design problem and identify the main interested parties to support the treatment of children with cancer.

### 4 Personas Enrichment Process: A Methodology to Support the Design of Therapeutic Applications

During the Personas Enrichment Process different interested parties are expected to be involved. For therapeutic applications, one reckons on engaging healthcare and computing professionals in a joint effort, where everyone applies design

<sup>1</sup> <http://www.re-mission2.org>.

<sup>2</sup> <https://www.giantbomb.com/bens-game/3030-19916/>.

<sup>3</sup> <http://www.sickkids.ca/index.html>.

practices and actively participates in the application construction, attempting to improve the chances of its adoption to ease treatment acceptance.

Since the therapeutic application domain is complex, the development of such computational systems demands a multidisciplinary team with a comprehensive view. It requires a research approach based on a theoretical background that holds an interpersonal, social and cultural perspective [13,14]. Since computing professionals have usually little knowledge about that subject, they should be constantly in touch with other interested parties, bringing about a cycle: “do together - assess - formalize lessons learned” [15].

We have used the methodology proposed by Rodrigues et al. [4], with a comprehensive view of the development of this kind of computational system, to identify stakeholders and the game’s requirements. The methodology employs Participatory Design (PD) [6], Organizational Semiotics (OS) [7] and Personas [8] techniques, enabling stakeholders to participate more actively in the game development process.

PD is a practice, or methodology, of information systems development that aims to collect, analyze and design a system with the participation of users, employees, customers, developers and other stakeholders [5]. OS [7,13], in turn, is a discipline that has roots in semiotics applied to organizational processes. It studies the nature, characteristics, functions and effects of information and communication in organizational contexts. OS provides a knowledge basis for promoting reflection and supporting collaboration between people with different backgrounds involved in the interaction design. The Stakeholder Analysis Chart is an OS artifact that provides a comprehensive view of the stakeholders in different points of interest [4,13]. The Evaluation Frame, in turn, is another artifact used by designers where they insert stakeholders’ interests, problems to solve and possible solutions raised at discussions with all participants [4,13].

The original technique of Personas, proposed by Cooper [8], defines Persona as a concrete and realistic representation of a system user. Optionally, it may include fictional user details like physical, psychological, and biological characteristics, her/his personality, profession and daily life. Rodrigues et al. [4] decided to add further information to their Personas created according to Cooper’s technique. Throughout the activities, the research group have identified that – on the health domain – it would be necessary to add therapeutic information to the Personas, such as the clinical profile and required treatment. They called this modification as Personas Enrichment Process [4]. The enrichment is carried out in a participatory way: hospital professionals contribute to propose, improve, and evaluate the created personas.

The Personas Enrichment Process for therapeutic applications has four steps: (1) it starts with the identification of the stakeholders interested on the development of the therapeutic application. (2) The design team identifies the application end-users, problems to solve, and possible solutions. (3) The design team creates the Personas with the gathered information during the participatory practices and also based in data from the literature. (4) Finally, the design team presents and validates the Personas with the stakeholders.

In step one, a multidisciplinary team instantiates the Stakeholder Analysis Chart [4, 13] to identify the main stakeholders of the application development. OS describes Stakeholder Analysis Chart as “an artifact to help the design team on understanding the real situation of the problem and the requirements for the solution” [4]. To use it, the design team discusses and identifies the parts that directly or indirectly influence the solution.

In step two, the design team’s goal is to identify the system end-users (possibly patients), the problems the application should address, and discuss possible solutions for those problems. The Evaluation Frame should be used on this step. It allows to identify clinical profiles of patients, medical procedures, patients’ relationship with other interested parties, problems involved in creating the application as well as possible solutions [4, 13].

In step three, the fictional characters pictured by healthcare professionals become Personas representing real people. The computer team should aggregate information from the literature (public health data) to detail the individuals with relevant information. Afterwards, healthcare professionals should evaluate the correctness of the Personas, approving them provided they are suitable (step four).

The following section presents a collaborative process for the enrichment of Personas that characterize target users of therapeutic applications for support cancer treatment.

## 5 Creating Personas to Represent Children with Cancer

We explored a participatory approach [4] to the requirement analysis and design. To instantiate the process, a group of professionals from the Brazilian State University of Minas Gerais carried out an extension project in partnership with healthcare professionals of a hospital specialized in treating childhood cancer (Hospital de Câncer de Barretos), currently named to as “Love Hospital”.

The project aimed to design a digital therapeutic game for children undergoing cancer treatment. Hospital therapists often employ strategies to help patients face the stressful conditions of the hospitalization process. Some of these strategies include play sessions (with board and digital games) and playing with toys [10]. As playing provides benefits for hospitalized patients, it reinforces the viability of developing digital games with therapeutic purposes.

Three meetings were conducted with a healthcare professional from the aforementioned hospital. In two of those meetings, we have followed the process and conducted participatory practices. The practices sought to discover the domain and target audience in order to clarify the game requirements and identify its desirable genre and other interaction characteristics.

Before the first meeting at the hospital, we did a brainstorming session with the computer team to discuss what we would need to understand about the scenario and how our strategy would be at that moment. A presentation and a list of issues were then drew up for the meeting.

At the hospital, we have also conducted a brainstorming session with an Occupational Therapist (a professional who accompanies patients through their

daily routines), in which we introduced the computer team and our project proposal, and were informed about her practices, hospital facilities, context characteristics, age groups and cancer treatment stages. As we were talking about how a game could be used as therapeutic support, we were trying to identify how much experience the child patients have with technology, what playful activities they have at the hospital involving both patients and caregivers, what should be encouraged in those patients, as well as aspects of the hospital infrastructure and whether mobile devices and Wi-Fi network were available.

We were also interested in knowing what draws the attention of those children, what they like to do to entertain themselves, what are their hobbies, what environments they miss, whether there are any physical (prescribed or not) limitations, content limitations (e.g. ethical and religious aspects), whether the family was always around, and the average time spent on therapy.

It was discovered that the hospital admits from newborns to people with 35 years old who have childhood cancer. There are at least three stages of cancer treatment: discovery and clarification, treatment and palliative care. Children are encouraged to play games. For instance, a mobile device may be given to a child when she is undergoing a procedure. The hospital also provides specialized rooms for playing and gaming. We also realize that a variety of stimuli can be provided by games but, for this context, the main ones are positive thinking and hope. We have also found out that children miss their home and school environments, that games can't have the "Game Over" concept, religious issues should be avoided, the game must have informative and ludic nature, and since children often feel nauseous due to treatment, 3D animations should be avoided and audio narratives is preferred, among other characteristics.

According to the occupational therapist, a multidisciplinary team of healthcare professionals works with both the child and her family to provide care. Pediatric cancer centers, like Love Hospital, often have extra support services for children and their families, such as child life specialists, dietitians, physical and occupational therapists, social workers, and counselors.

This first meeting in which teams discuss and clarify design problems is not formally considered in the Rodrigues et al.'s process. We find it essential to understand the dynamics of the hospital and to know the healthcare professionals, as well as to provide a better planning of the next stages of conducting participatory practices for Personas' creation.

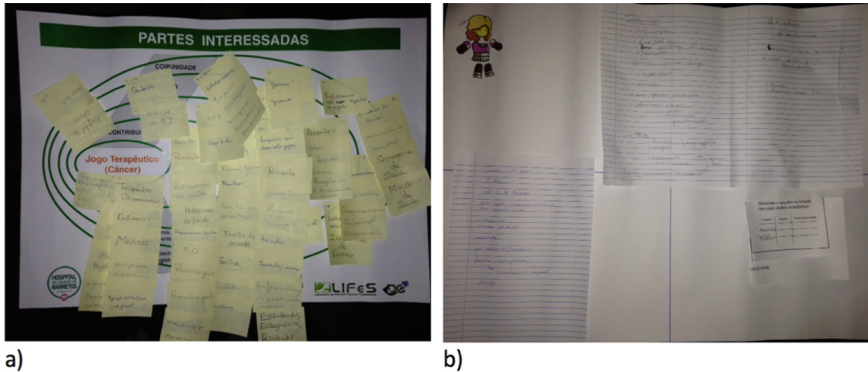
In the second meeting, we initialized the Personas enrichment process. The team attempted to understand the context and stakeholders and then create stereotypes of children undergoing cancer treatment. At this stage, the Stakeholder Analysis Chart [4, 13] was filled out by the multidisciplinary team.

Figure 1(a) illustrates the final result of the artifact generated in step 1 of the enrichment process.

By using the Stakeholder Analysis Chart, we identified the family, the patients and healthcare professionals as the main stakeholders in the game development. Other actors were mentioned during the practice and were put into the artifact, including: researchers, private and philanthropic companies, the hospital

and its agencies, and the government with its diverse representations (ministries and secretariats) [4, 13].

Step 2 of the enrichment process characterizes the users by applying the Evaluation Frame [4, 13]. Figure 1(b) illustrates the final result of the artifact generated in this step.



**Fig. 1.** (a) Instantiation of the Stakeholder Analysis Chart. (b) Instantiation of the Evaluation Frame.

With that artifact, we identified new aspects of the scenario and target audience, and refined those aspects pointed out in the brainstorming session previously mentioned, such as: the children’s clinical profile – most were in the age range of 0–35 years and the main kinds of cancer were Leukemia, Osteosarcoma and Central Nervous System (CNS) tumor –, the medical procedures they take (e.g. chemotherapy, radiation therapy and bone marrow transplantation), the patient’s relationship with other interested parties (including healthcare professionals and caregivers considered very protective), problems involved in creating and using the game (e.g. side effects of using a 3D style - like nausea -, reading difficulties after some procedures, mobile device hygiene, etc.), and possible solutions to those problems (e.g. choosing 2D formats, audio interactions and protecting devices with a casing). From those first participatory practices, three main Personas’ skeletons were identified. The artifact generated by the team has pointed to preliminary images and names for the fictitious patients in creation; they were called Luiza, Caio and Lucas.

Luiza is 12 years old, diagnosed with leukemia and in cancer’s discovery stage. Caio is also 12 years old, diagnosed with osteosarcoma (bone cancer), in the treatment phase and had his legs amputated below the knee, because there was disease recurrence and it returned more aggressive. Lucas is 6 years old, diagnosed with CNS tumor and also in the treatment phase. At the time, the computer and healthcare professionals judged that developing a game targeting at patients in palliative stage would be a task that requires more experience, especially from the computer team. The therapeutic goals and stimuli to be



considered for such a game would demand a more careful touch and greater sensitivity, since the child is more vulnerable. Therefore, no Persona was designed to represent such patients.

The collected data was enriched with information from the Literature regarding childhood cancer, including INCA Institute, as well as data and reports from scientific papers on the psychosocial aspects of pediatric cancer in Brazil [10] and aspects of life that are affected by the activity of “caregivers” [11]. The computer team added the new information to enrich the previously defined skeletons. They have gathered and organized data from different sources and categorized them to define each Persona’s characteristics. Literature data not only confirmed the healthcare professionals statements but also provided complementary characteristics about the individuals. At the end of this step, the computer team have created and enriched the three Personas mentioned above.

Luiza is illustrated in Fig. 2. The excerpts written in italics represent data identified through the practices with professionals combined with data from the literature. The excerpts in bold represent data collected only through the practices. The underlined data, in turn, comprises the summarized literature data.

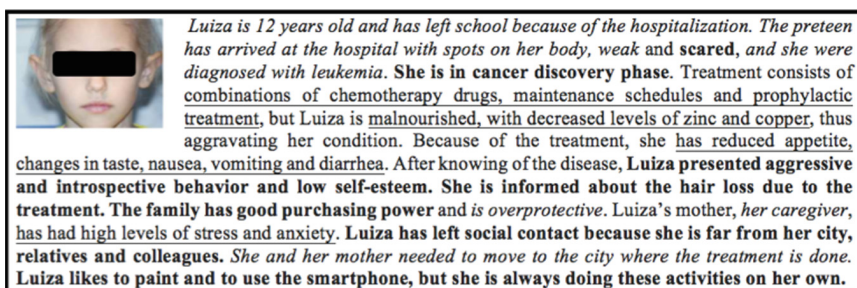


Fig. 2. Luiza’s persona resulting from the Process.

After the team completed the set of Personas, they presented and validated them with an occupational therapist of the specialized hospital, which is step 4 of the enrichment process. The professional answered the questions from the evaluation form provided by the Rodrigues et al.’s process asking about the profiles’ photos, the family history profile and context, and the clinical profiles of each persona. For example, the therapist suggested changing Luiza’s image since she would still be in the discovery stage and, therefore, she would still have hair.

As a result of the step for Design Problem Clarification, provided by the approach, peculiar aspects were identified and should be considered in the game development to support the treatment of childhood cancer. These aspects concern the gender, the form of interaction and the stimuli of the game. Each of the three personas created has different needs. These needs imply on the flexibility of the game regarding pretended stimuli for each profile, and in the flexibility

of the game to consider different ways a patient may react to the treatment. Chemotherapy and radiation treatments, for example, make children nauseous. So, a game with 3D interactions or using gyroscope would not be adequate. Another aspect raised in this stage is that, as children have different ages, some patients pre-teens. Pre-teens are in an age of discovering their body; due to treatment – in special due to hair loss (Luiza’s case) or limb amputation (Caio’s case) – their self-esteem is affected. The required stimuli for these cases are distinct from the average ones, ranging from improving self-esteem and promoting positive thinking, to clarifying the treatment and entertaining children and caregivers.

During the practices in the hospital, the team pointed out the difficulty of the caregivers to deal with children illness. They also pointed that more positive and less protective parents influence their child positively; consequently, their children respond in more positive ways to the treatment. However, some caregivers do not know the treatment and are frightened by the illness and fear of losing their children. In this sense, professionals emphasize the importance of creating games that can clarify children and caregivers, in a playful way, about the treatment and stages of it. So, Personas representing the caregivers were idealized. The professionals also report the importance of illustrating, in a playful way, the changes that occurred in the children’s body due to the treatment. A game for this scenario should also allow for a collaborative entertainment between patients, caregivers and even therapists. In this context, the multidisciplinary team understood, at the time, that only one game could not meet the different needs and expectations of users. In this way, a game library - configured and customized by the therapists for each patient - was the suggested solution. Although we have followed all the steps described in Rodrigues et al., other steps and guidelines might be proposed to design therapeutic games; they could especially focus on cases in which the role played by the caregiver is decisive and different profiles for the same pathology are identified.

The next section presents what we have learned when instantiating that process and how we dealt with different requirements. We also discuss how each personas requirements have guided towards a conception of games tailored to this scenario.

## 6 Lessons Learned in Designing of this Digital Therapeutic Game

As mentioned, different specificities, for the same pathology, did not arise in the context of the hospital that the Rodrigues’ group supported and the pathologies that the hospital attended (depression and chemical dependency). The aforementioned specificities emerged in the context of the Love Hospital and to support the cancer treatment. These are features that make the game with more points of flexibility.

The main lessons learned shall be presented as well as some advices for researchers looking forward to instantiating Rodrigues et al.’s approach, which

might have specificities that weren't take into account in the Personas enrichment process described earlier.

*Brainstormings* - Before participatory practices and personas enrichment process, it was needed to introduce the teams, therefore they could know each other, align and elucidate thoughts and plan better the next steps. Our advice: formalize a brainstorming session prior to starting the process.

*Overprotective Caregivers* - the healthcare professional have emphasized that caregivers play an important role during cancer treatment. On the other hand, there are some pathologies which they aren't so demanded. When caregivers, as well as their health, directly affect the patient's clinical evolution, the design team, while having identified their importance, must study their impact and analyze how is their relationship with the patient, the disease, the treatment and the health professionals. Our advices: when identifying the caregiver importance and possible pathologies that could appear because of her role: (a) elaborate specific Personas to represent caregivers; (b) design games in which patients, caregivers and therapists can collaborate; (c) identify therapeutic stimuli to them that could be addressed by the game; (d) provide resources with information about the disease and treatment in an entertaining way.

*Diversity and Flexibility Aspects* - we have aimed at alleviating the negative aspects of hospital stays by means of a therapeutic game tailored to children with cancer, but the participatory practices we followed has unveiled that there are different types of infantile cancer, different treatments, and a variety of profiles of children and caregivers, which we didn't foresee. Therefore, we have noticed that it is not possible to develop just one game that could address all the patients. Such diversity for a single context was not predicted in the Rodrigues et al.'s approach. We then decided to design various game modules to fit such diversity. Our advices: when facing such a scenario, design a game that has flexible points and offers a set of possibilities which health professionals can configure according to desired therapeutic aspects. The game may allow customizations for different health professionals such as doctors, psychologists, dietitians etc. That is an important characteristic when a multidisciplinary team is involved (as it is at the Love Hospital).

Following in this direction, a first therapeutic game module idealized met the requirements of the Luiza's persona. Playful and colorful, the game should promote clarifying the treatment of leukemia, stimulating the child's self-esteem and positive thinking, as promoting collaborative interaction with the caregiver. The game would be characterized by characters with human traits and customizable depending on the type of clarification. Positive reinforcements should also be provided to stimulate the child's positive thinking and self-esteem, as well as of the respective caregiver.

## 7 Conclusions and Future Work

By following the steps proposed by the Rodrigues et al. [4] design process, it was possible to involve healthcare professionals in the creation of a game that

also supports their activities as therapists. In addition to involving them in the process, the collection of requirements, containing possible actions; stimuli and therapeutic objectives of the game, is more reliable to the domain under study and may allow more adhesion to the proposed therapeutic application.

While instantiating the process, we could identify additional aspects that can be incorporated into Rodrigues et al.'s approach, by considering the same pathology, such as dealing with the diversity of profiles and treatments in the early stages of game design. It is also important to consider the caregiver and identify her role during treatment.

Studies from computer professionals have also stated that when developing games for children it is essential to follow some guidelines. Most children are curious and interact with objects to find out how they work. They also like movement and fun. Those aspects must be taken into account while designing the gameplay. Colors and visual references to things they enjoy, such as candies, animals, places etc. should be considered as well.

After clarifying the design and identifying the interested parties, our team adopted the Interaction Modeling Language [17] to model scenarios and interactions of the therapeutic game to treatment cancer support. The purpose of the modeling is to verify if the different stakeholders understand the language and the scenario modeled in it, for the later development. This step is not provided by the Rodrigues et al.'s approach, but can be incorporated into the process as stage of a structured and complete methodology for the design of therapeutic solutions.

In this sense, as future work, we advocate an extension of the approach to provide this structured and a well-defined process for a complete creating therapeutic games, with stages of modeling, design materialization and evaluation.

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