

Opportunities to design for the wellbeing of children undergoing cancer treatment at a Brazilian Hospital

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This research aimed at identifying design opportunities to contribute to the wellbeing of children undergoing cancer treatment, focusing on laboratory and imaging exams. Subjective wellbeing is stimulated by increasing positive affect and minimizing negative affect. Participatory observations were developed with children admitted for oncology treatment at a Brazilian hospital. Researchers interacted with six children from 4 to 8 years of age multiple times for three times every week during their recreational play time. From the results, four design guidelines were drawn: design for personalization (and against depersonalization); use of technology to allow immersive experiences in learning about the treatment and medical condition; gamify experiences to allow positive reinforcement; and design for focus redirection (distraction or refocus on less aversive experiences).

Keywords: *Design for wellbeing; positive affect; negative affect; Healthcare; Brazilian context*

1 Introduction

The Brazilian healthcare system is organized into three sectors: public (services provided by the Union), private (financed with public and/or private resources), and supplementary care (through private healthcare plans) (Paim et al., 2011). Healthcare system's public and private components are different but interconnected, and users may access all services, depending on their availability to pay. With a population of more than 207,700,000 Brazilians, only 27.9% have private healthcare plans (IBGE, 2017).

Brazil's public healthcare system, called Unified Health System (*Sistema Único de Saúde - SUS*), "relies on the concept of citizenship by establishing universal and integral access to healthcare as a guideline." (Silva et al., 2011, p.3813). Created in 1988, its purpose is to guarantee healthcare to all Brazilians (IBGE, 2017).

SUS has been facing some challenges, namely: the reform of its financing structure, the renegotiation of public and private roles, the adaptation of the model of care to meet the Country's rapid demographic and epidemiological changes, and the improvement of quality

of care and safety (Paim et al., 2011). It is also challenging providing preventive care and improving patients' wellbeing, especially in public hospitals.

For children undergoing cancer treatment, SUS focuses on clinical issues. Direct care is already challenging, due to the Country's lack of resources to provide qualified and safe services. With basic needs to be fulfilled, the effect of product, services, and hospital environments on children's wellbeing are neglected. Therefore, this research explored design opportunities to enhance children's subjective wellbeing, focusing on laboratory tests and image exams – user journey.

Subjective wellbeing is not related to objective and material issues (e.g. having adequate and sufficient food and a safe place to live in). It focuses on the experience of positive affect, minimization of negative affect, and life satisfaction (Lyubomirsky & Dickerhoof, 2005) as predictors of wellbeing. By maximizing positive experiences and minimizing negative affect, children's wellbeing may be improved (Desmet & Pohlmeier, 2013).

This research was developed at a Brazilian public hospital – *Hospital de Clínicas de Porto Alegre*. Children's experiences with products, services, and environments were represented and observed through play, and design guidelines were drawn from it. This is part of a research project that will apply these guidelines to various prototypes focused on improving the wellbeing of children undergoing cancer treatment.

2 Research method

We used participant observation method, interacting with children admitted for oncology treatment to better understand their context (as recommended by Tonetto, 2016). A team of six researchers collected data for 2.5 months, interacting with six children (ages 4 - 8) three times per week, during their recreational play time. The hospital has rooms dedicated to Child Life for inpatient care, which include elements designed to support patients during their stay. In a large room with 4 desks (with 4 chairs each), computers and toys, children and adolescents play with other oncology patients and Child Life specialists through free play, arts and crafts.



Figure 1. Recreation room. Source: The authors.

The goal was to identify, from a designer's perspective, characteristics of hospital services that could contribute to the subjective well-being of children during their stay for treatment. We used Playmobil's hospital toys to represent each scenario (admission, room care, medical assistance, laboratory exams and scans) and invited the children to share their experience and/or the experience of a friend in those situations. Researchers worked in

pairs to facilitate video and audio recording of the interactions. To preserve the children's anonymity, they are presented as C1, C2, C3, C4, C5 and C6 (C standing for Child).



Figure 2. Toys used for data collection. Source: The authors.

The analyses took place at a tertiary referral, teaching hospital in southern Brazil with 845 beds, distributed as follows: intensive care unit (44), emergency department (47), inpatient unit (652) and other services (102). The paediatric oncology unit is a multidisciplinary service with 25 beds that cares for children from 0 to 18 years of age. Every year about 100 new patients receive treatment at this unit coming from all over Brazil. The study was approved by the hospital's Institutional Review Board (CAAE # 94028918.5.0000.5327).

3 Results

Figure 3 synthesizes the research results. We investigated laboratory tests and image exams – user journey (Column 1). Several influences on the children's wellbeing emerged from the observations (categories – Column 2) and were related to wellbeing theme(s) (Column 3). It's also presented the type of affect connected to them: positive, negative or neutral (Column 4), and a description of design guidelines (Column 5), discussed in the following section.

1. Type of Exam	2. Categories	3. Wellbeing-related design theme(s)	4. Affective responses	5. Design guidelines
Laboratory	Needles used in catheter fixation	Discomfort caused by needles used in catheter fixation	Negative	Design for personalization (and against depersonalization)
	Relationship with the SS support	Amusement by embellishments Difficulties in keeping the connection between the support and catheter fixation	Positive Negative	
	Mobility of the SS support	SS support use as transport and play source Difficulties in getting around the hospital	Positive Negative	Use of technology to allow immersive experiences in learning about the treatment and medical condition
	Unity child / SS support	Child's denial regarding the SS support	Negative	
Image	Wheelchair	Wheelchair as a source of play, due to speeding	Positive	Gamify experiences to allow positive reinforcement
	Sedation	Sedation: exams do not evoke negative experiences	Positive	
		No recall of the exam	Neutral	
	Equipment	Loud sounds	Neutral	Design for focus redirection (distraction or refocus on less aversive experiences)
	Gel	Warm gel is preferred during exams	Positive	
	Rewards	Rewards for good behaviour	Positive	

Figure 3. Results. Source: The authors.

When representing "laboratory tests" through play, children spontaneously simulated the collection of blood samples, realized through an intravenous access device (catheter). Catheters also allow medication, chemotherapeutics and parenteral nutrition to be administered (Vasques et al., 2009).

The first category was denominated "needles used in catheter fixation". Children expressed negative affect in their relationship with the catheter, mentioning the needle as the main discomfort source. Some children had to implant catheters more than once, due to its obstruction, or to its removal (accidental or intentionally). Plays with C1 are examples of this category. When seeing the doll (a patient) without the serum wire (the connection to the catheter), he said: "He plucked the wire! Put the thread in it!". When the researcher asked if the wire couldn't be pulled out, C1 replied: "No. You have to put the needle back, and it hurts".

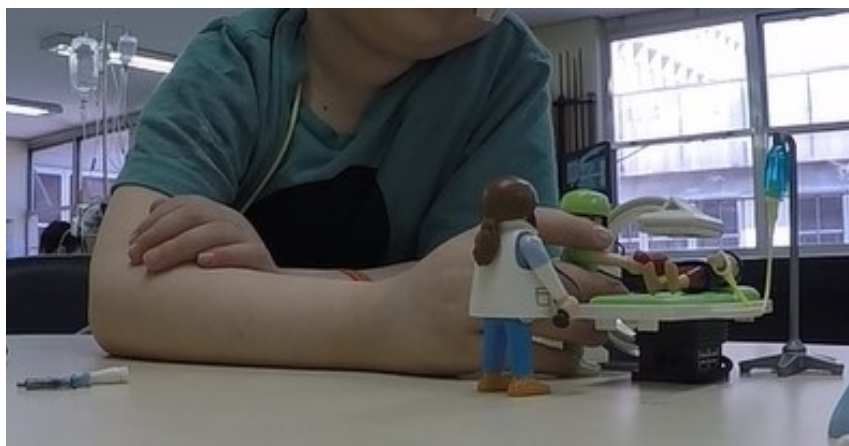


Figure 4. Patient demonstrating that the doll should remain connected to the wires. Source: the authors.

Children also associate the catheter with serum and equipment support, and this connection is made through tubes connecting these components to the catheter. Because of this perceived relationship, the support of serum and equipment were addressed in this paper as

“laboratory tests.” Three categories were identified: “relationship with the SS support”, “mobility of the SS support” and “unity child/ SS support”.

“Relationship with the SS support” concerns how the child appraises the support and the types of affect involved. Some children used adornments on their brackets, (e.g. superheroes, dolls, and balloons), while some parents made ornaments to hang on the stand. Positive affect was experienced towards these embellishments. In contrast, children see the support as an extension of the catheter and express negative affect towards the use of a needle to attach catheters to serum, supports, and equipment as a whole.

In “mobility of the SS support”, some children tried to use the support to move, climbing on it and using the wheels to drive it, experiencing positive affect. On the other hand, the lack of mobility generated by the tubes, connections, and support was associated with negative affect. Since the support always accompanies them, they expressed that they feel like one (“unity child/SS support”). There is also limited autonomy in handling tubes and wires when playing and moving, as well as in their understanding of how these devices work. Figure 5 shows C2 explaining how the medication is handled by the nurses through their connection with the catheter. Whenever it was possible, children ignored the support, avoiding talking about it (evidencing the experience of negative affect).

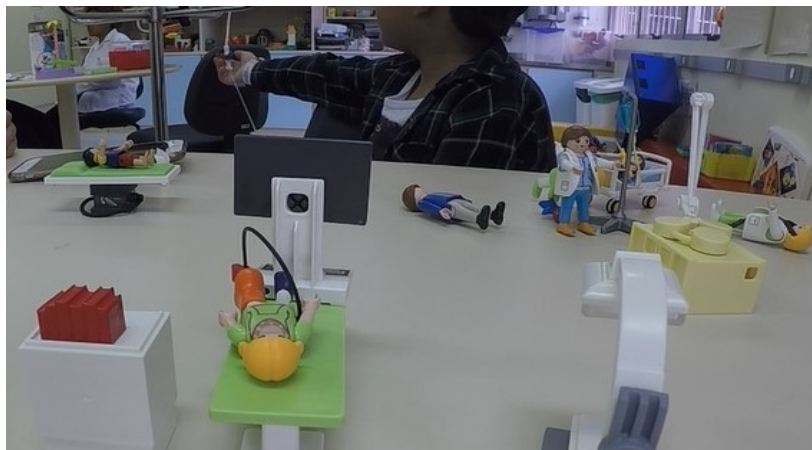


Figure 5. C2 shows the medication application. Source: The authors.

The exam described as “image – user journey” refers to the different types of imaging exams and the child’s journey to do them. The first category (“wheelchair”) corresponds to how they are transported to the exams. During play, children indicated a preference for using the wheelchair to take patients (dolls) to the exams. It is possible to identify the positive affect involved in one of the situations, in which C3 said the wheelchair amuses her because it moves fast.

Positive or neutral affect was evidenced in the analysis of the second category (“sedation”). C4 expressed she liked to be sedated because the exam did not hurt. Neutral affect was the most common reaction, since children did not know how to talk about sedation or did not recall these situations.

The category “equipment” grouped reactions to sounds of the equipment used in imaging exams. Some children (C1, C4, C5) explained exams using camera sounds (“tic, tic, tic”). Many parents and professionals explain to children that these exams are like “taking

pictures". Neutral affect was noticed, being an opportunity for design to evoke positive responses.



Figure 6. Image exams explained by children. Transport the patient to the exam using a wheelchair (left) and child on the stretcher (right). Source: The authors.

The “gel” used during some imaging tests (e.g. ultrasound) may be a source of positive affect. Its temperature (preferably warm) may be an amusing factor, the same way as toys and stickers obtained for good behavior in the exams (“Rewards”), demonstrating another opportunity to evoke positive affect.

4 Discussion and conclusions

To promote subjective well-being, design guidelines (see Figure 3) were proposed to minimize negative affect, maximize positive affect, and stimulate positive affect, when it is currently neutral. The design guidelines were based on the analysis of the observations. They were developed by the authors during group meetings, in which applications of the results were discussed. This is a work in progress, with projects and prototypes being developed. Examples of current design as references to these guidelines are shown in the Figures.

The guideline "Design personalization (and against depersonalization)" refers to the design of possibilities that allow customization. This can be applied in different contexts, as shown in Figure 7.

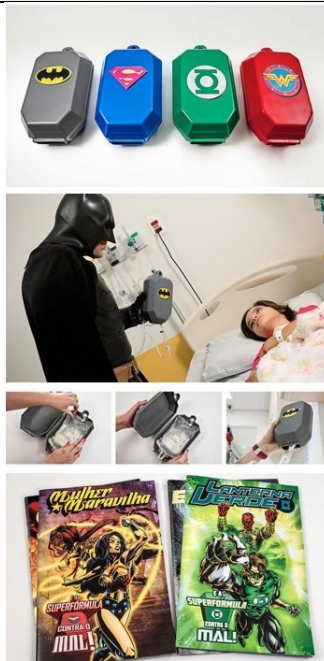
Guideline: Design for personalization (and against depersonalization)	
Categories and Application	Example
Needles used in catheter fixation: Minimizing negative affect through embellishments with playful design.	<p>"Super formula" was developed by the JWT agency for Pediatric Oncology of the hospital A.C. Camargo Câncer Center (São Paulo, Brazil), to improve the performance of chemotherapy applied to children and motivate them throughout treatment. Superhero adhesives were used in the chemotherapy room, as well as a capsule to wrap medication. JWT, Warner Bros., Vetor Zero, and pediatricians also developed comic books featuring superheroes recovering through Super Formula. The project was widely accepted and proved effective in motivating children in the fight against cancer.</p> 
Relationship with the SS support: Promoting positive affect through customization for serum support.	
Unity child/SS support: Connecting children positively to the support, promoting its customization.	
Wheelchair: Designing customizable accessories for wheelchairs, allowing the design of the patient's journey to the exams.	

Figure 7. Guideline, its applications, and example. Source: Silva, (2014).

The guideline "Use of technology to allow immersive experiences in learning about treatment and medical condition" uses technology to inform children about the treatment, minimizing the negative affect generated by unknown contents and uncertainty. Technology can also be used to create narratives that contribute to the generation of a more playful treatment context (Figure 8).


Guideline: Use of technology to allow immersive experiences in learning about the treatment and medical condition	
Categories and Application	Example
Needles used in catheter fixation: Use of technologies (e.g. videos, virtual reality glasses, and augmented reality) to help understand the disease and the treatment, to minimize negative affect of the unknown, pain and discomfort.	<p>A study conducted in three pediatric hospitals in Sweden (2012 – 2015), evaluated children's responses to the psychological preparation before radiotherapy procedures, which generally cause fear due to the unknown. HUGO, a preparatory kit, was created, containing information available on tablets, equipped with headphones, a stuffed animal, a booklet for parents, and models of the tomography and radiotherapy machines. HUGO explained the procedure to the family and the children and was made available 5 days before the examination. The children experienced the intervention as positive, and HUGO's strength came from the interaction it provided between the patients and their families.</p> 
Equipment: Using technological possibilities to resignify the procedures of imaging, telling stories and creating experiences.	

Figure 8. Guideline, its applications, and example. Source: Engvall et al., (2018).

The guideline "Gamify experiences to allow positive reinforcement", shown in Figure 9, suggests the gamification of treatment to motivate and encourage children, as well as promote positive reinforcement in different stages of the healing process. It is also possible to design artefacts to accompany the child throughout the treatment.


Guideline: Gamify experiences to allow positive reinforcement	
Categories and Application	Example
Mobility of the SS support: resignify the relationship and the children's mobility with the support through design, turning it into an amicable partner during treatment	<p>"Huggable" is an interactive teddy bear-shaped robot with an integrated system running through an Android application. It was developed by the MIT Media Lab, promoting the approach of children with their relatives and the medical team. The child interacts with the teddy bear through an application, which controls the actions of the robot, promoting a more welcoming interaction.</p> 
Wheelchair: The journey to the examination rooms may be redefined based on the phases that make up the gamified experience.	
Rewards: Offer medals of courage, awards and prizes at each successful stage.	

Figure 9. Guideline, its applications and example. Source: Fluture, (2015).

The guideline "Design for focus redirection (distraction or refocus on less aversive experiences)" concerns the design of artefacts that redirect the child's focus during procedures that may be perceived as negative or invasive (Figure 10).


Guideline: Design for focus redirection (distraction or refocus on less aversive experiences)	
Categories and Application	Example
Sedation: Designing environmental and informational data on what occurs throughout the procedure to minimize negative affect before, during and after sedation, or making the experience more positive.	<p>"Aquarius Carioca" was created by the Desiderata Institute (Rio de Janeiro) to establish a more inviting space for children. Playful interventions were designed in the environment and on devices. These impacted on the minimization of pain during the procedures, the perception of time (seeming to pass faster), and the reduction of anxiety.</p> 
Equipment: Designing playful interventions in environments and devices to evoke positive and minimize negative affect.	
Gel: Create distracting elements during procedures or make playful interventions with the gel.	

Figure 10. Guideline, its applications and example. Source: Rouvenat, (2015).

Our aim was to identify opportunities to design for the wellbeing of children undergoing cancer treatment, by stimulating positive and minimizing negative affect, with emphasis on processes that occur during laboratory and imaging exams.

When comparing the Brazilian context to the other countries' examples, we can see that there is still a long way to go, which can be a result of the challenges SUS has been facing

(e.g. lack of funding and problems regarding changes in the system). Research shows that although SUS delivers healthcare to Brazilian citizens, it neglects subjective needs and the affects experienced by the patients. Thus, even though it already receives money donations, we suggest that SUS would greatly benefit from more funding opportunities, directed to upgrading the healthcare system. More specifically, investing in ways of engaging with patients' affects, consequently making their experiences better and improving their wellbeing.

Next steps of this research are the actual design, prototype, and testing of artefacts, to observe their potential to contribute to children's wellbeing. An important limitation of this research is that it is context-dependent. Therefore, it may be developed in other hospitals, to understand if and how these guidelines can be applied more comprehensively.

5 References

- Desmet, P. M. A., & Pohlmeier, A. E. (2013). Positive design: An introduction to design for subjective well-being. *International Journal of Design*, 7(3), 5-19.
- Engvall, G., Lindh, V., Mullaney, T., Nyholm, T., Lindh, J., & Brännström, C. A. (2018). Children's experiences and responses towards an intervention for psychological preparation for radiotherapy. *Radiation Oncology*, 13(9). doi: 10.1186/s13014-017-0942-5.
- Fluture, S. (2015). Huggable, um urso de pelúcia inteligente para as crianças em tratamento de câncer. Accessed in: April, 2019. Available at: <https://www.b9.com.br/56546/huggable-um-urso-de-pelucia-inteligente-para-criancas-em-tratamento-de-cancer/>
- IBGE - Brazilian Institute of Geography and Statistics. Accessed in: September, 2017. Available at: <https://www.ibge.gov.br>
- Inocência Vasques, C., Diniz dos Reis, P. E., & Campos de Carvalho, E. (2009). Manejo do cateter venoso central totalmente implantado em pacientes oncológicos: revisão integrativa. *Acta Paulista de Enfermagem*, 22(5).
- Lyubomirsky, S., & Dickerhoof, R. (2005). Subjective well-being. In J. Worrel & C. D. Goodheart (Eds.), *Handbook of girls' and women's psychological health: Gender and wellbeing across the life span*, 166-174. New York, NY: Oxford University Press.
- Paim, J., Travassos, C., Almeida, C., Bahia, L. & Macinko, J. (2011). O sistema de saúde brasileiro: história, avanços e desafios. *The Lancet*, 5, 11-31.
- Rouvenat, F. (2015). Salas de quimioterapia se transformam em 'aquários' no Rio. *G1 Rio*. Accessed in: April, 2019. Available at: <http://g1.globo.com/rio-de-janeiro/noticia/2015/12/salas-de-quimioterapia-se-transformam-em-aquarios-no-rio.html>.
- Silva, K. P. (2014). Superman, Batman, Mulher Maravilha: Hospital de São Paulo usa Super Fórmula na cura do câncer infantil. Accessed in: April, 2019. Available at: <https://diariodebiologia.com/2014/10/superman-batman-mulher-maravilha-hospital-de-sao-paulo-usa-super-formula-na-cura-do-cancer-infantil-video/>
- Silva, Z.P., Ribeiro, M.C.S.A., Barata, R.B., Almeida, M.F. (2011). Socio-demographic profile and utilization patterns of the public healthcare system (SUS), 2003- 2008. *Ciência & Saúde Coletiva*, 16(9), 3807-3816.
- Tonetto, L.M. (2016). Pesquisa de Inspiração Etnográfica. In: Scaletsky, C.C. Design Estratégico em Ação. São Leopoldo: Unisinos.
- Vasques, C. I., Reis, P. E. D., & Carvalho, E. C. (2009). Manejo do cateter venoso central totalmente implantado em pacientes oncológicos: revisão integrativa. *Acta Paulista de Enfermagem*, 22(5). doi: <http://dx.doi.org/10.1590/S0103-21002009000500016>.

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