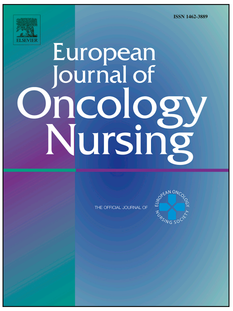

Spiritual pain as part of the hospitalization experience of children and adolescents with acute lymphoblastic leukemia: A phenomenological study

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ESSENTIAL INFORMATION

Spiritual pain as part of the hospitalization experience of children and adolescents with acute lymphoblastic leukemia: A phenomenological study

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HIGHLIGHTS

- Children and adolescents with acute lymphoblastic leukemia experience spiritual pain during hospitalization.
- Needle procedures are the most stressful part of their cancer treatment.
- The pain they experience during treatment is often underestimated.
- A more holistic and less nociceptive approach to pain is needed.

ABSTRACT

Purpose: To explore the experience of hospitalization among children and adolescents in treatment for acute lymphoblastic leukemia.

Methods: Qualitative phenomenological study informed by grounded theory and involving a convenience sample of children and adolescents attending an oncology unit in Spain. Data were collected through in-depth interviews with seven children aged between 9 and 18 years and analyzed using ATLAS.Ti 7.1. software in order to identify themes in the participants' narratives. Specific strategies were applied to support the validity and reliability of the findings.

Results: The analysis of interviews revealed three themes in participants' accounts of their experience of hospitalization: 1) It's normal to feel afraid when being treated in hospital; 2) Needle procedures are associated with pain, illness, and dying; and 3) Difficulty of expressing the suffering that is experienced in hospital.

Conclusions: A core experience among children and adolescents who are hospitalized for cancer treatment is the spiritual pain that results from feeling afraid. These fears are especially associated with the needle procedures that are routinely performed in the diagnosis and treatment of acute lymphoblastic leukemia.

Keywords: hospitalization; leukemia; needle procedures; nursing; person-focused care; post-traumatic growth; spiritual pain

MAIN TEXT

1. Introduction

Acute lymphoblastic leukemia (ALL) is the most common type of childhood cancer worldwide (Park et al., 2016), with an incidence of 27% in the USA (Linabery and Ross, 2008), 27.3% in Japan and the UK (Nakata *et al.*, 2017), 29.6% in Spain (RETI-SEHOP, 2016), 30% in France and Ireland (Desandres et al., 2004; Stack et al., 2007), 33% in Sweden (Dreifaldt et al., 2004), and 35% in China (Bao et al., 2009). Treatment usually lasts for at least two years (Kato and Manabe, 2017; Koh *et al.*, 2018) and involves long periods of hospitalization (McCubbin *et al.*, 2002). Due to improved chemotherapy regimens, five-year survival rates are now as high as 90% (Inaba et al., 2013; Ching-Hon and Mullighan, 2015).

Cancer is an experience that changes the lives of patients, families, and the professionals involved in providing care (Galligan, 2017). Children often struggle to understand the need for frequent hospitalizations or the pain and discomfort that goes with treatment (Hedström *et al.*, 2003), and experiences of this kind may lead to emotional or behavioral disturbances, whether in the short or longer term (Rennick and Rashotte, 2009; Rennick *et al.*, 2014). Bowlby (1952) was the first to warn that hospitalization could have a lasting effect on children, and research has subsequently confirmed that this experience is associated with a high risk of mental health problems such as anxiety and depression (Myrvik *et al.*, 2008; Doupnik *et al.*, 2017). In particular, studies have documented negative outcomes including sadness, anxiety, detachment, regression, hyperactivity, and aggression following medical treatment that involved hospitalization (Small, Mazurek et al, 2009). For children and adolescents who require in-patient medical or surgical care, as is the case of those with ALL, the emergence of psychological problems is associated with a greater number of hospital admissions and poorer therapeutic outcomes (Myrvik *et al.*, 2012), including difficulties with pain management (Myrvik *et al.*, 2008). It should also be noted that the psychological state of the child, which is determined by habits, beliefs, and behaviors, may influence the immune response and, consequently, the course of the disease (Méndez-Venegas, 2005).

Various studies have explored children's experiences of hospitalization or palliative care (Berríos-Rivera *et al*., 2008; Levine *et al*., 2017; Kaye *et al*., 2018; Lopes et al., 2021), especially from the perspective of parents and health professionals (Berríos-Rivera *et al*., 2008; Grimston et al., 2018; Sood et al., 2018; Abela et al., 2020). However, the impact of hospitalization on children and adolescents with ALL has not been widely studied, and even less from these young people's own perspective. There are many variables that can make hospitalization a stressful experience (Litke et al., 2012), and hence, in order to promote the recovery process of children and adolescents with cancer, it is essential to identify factors that may protect against or heighten the risk of sustained psychological problems (Rennick *et al.*, 2014) such as post-traumatic stress (Stuber *et al.*, 1991; Butler et al, 1996, 1996; Kazak *et al.*, 1997).

One factor to consider is that the automatization and standardization of care, which is often a response to limited human resources, can lead to a dehumanized and impersonal approach to treatment (Lovato *et al.*, 2013). Several decades ago, Balint (1969) proposed a patient-centered model of care as an alternative to the disease-focused approach that sees the patient as a set of symptoms rather than as a human being with individual needs (Behruzi *et al.*, 2014). More recently, some authors (Starfield, 2011) have sought to distinguish between person-centered care, which still tends to be based around episodes of disease, and person-focused care, a more holistic approach that views the patient as an individual with a unique personal story in which illness is just one life experience among many. Accordingly, the person-focused approach aims to look beyond the disease and meet the needs of the whole person, it being recognized that these needs cannot be understood in isolation from the meaning that is ascribed to lived experience (Starfield, 2011).

In summary, the frequent hospitalizations that children and adolescents with ALL require (Kato and Manabe, 2017; Koh *et al.*, 2018) leaves them vulnerable to psychological distress and problems with pain management (Stuber *et al.*, 1991; Butler et al, 1996; Kazak *et al.*, 1997; Myrvik *et al.*, 2008; Doupnik *et al.*, 2017). Understanding more about how these young people experience hospitalization is therefore essential in order to offer them more person-focused care that can help them to cope with and integrate these challenging experiences into their life story. The present study aimed to add to our understanding of these issues by exploring, through in-depth interviews, the hospitalization experiences of children and adolescents with ALL.

2. Methods

2.1. Design and procedure

This was a qualitative study in which we used an inductive, phenomenological approach (Morse, 2012) to obtain a detailed description of the lived experience of participants based on their personal narratives (Creswell, 1998). Data were collected through in-depth individual interviews. The inclusion criterion was being a child or adolescent. Recruitment was by means of convenience sampling in a pediatric oncology unit that is a center of reference for the treatment of childhood cancer in Spain. Each year, the unit provides treatment to around 2,000 children and adolescents with various types of cancer. Although all participants had the same diagnosis (i.e., ALL), we sought to ensure maximum variation (Seidman, 2013) by including both boys and girls of different ages and family backgrounds. The characteristics of participants are detailed in Table 1.

Potential participants were first identified by a member of the research team who worked as a clinical nurse in the oncology unit. We then spoke to these children/adolescents and their parents in order to inform them about the purpose of the study and to request their participation. All those we contacted agreed to participate and were invited for interview on a date and time of their choosing (all interviews took place in a quiet meeting room in a building adjacent to the oncology unit, thus facilitating access for the hospitalized children).

Interviews were guided by the recommendations of Seidman (2013) and involved the sequential exploration of three topics so as to encourage expression of the participant’s lived experience and to situate it in a socio-historical context (see Table 2). Thus, we began by asking interviewees to talk about their illness and history of hospitalization in general, before moving on to explore and contextualize their current in-patient experience. Finally, we sought to explore the meanings they ascribed to hospitalization as a life experience. All interviews were conducted by a member of the research team who had had no previous contact with participants and who had specific training in the psychological care of children and adolescents. Prior to any data collection we obtained informed consent from participants and their parents, and in all but one of the interviews the young person's mother was also present. The process of explaining the purpose of the study and obtaining informed consent was facilitated by the use of a gamified infographic (created ad hoc for the present research). The content of the infographics (one for children, one for teenagers) was designed by a nurse with extensive experience of communicating with children, although the actual illustrations were created by an adolescent (the 14-year-old daughter of one of the authors) so as to maximize their appeal and age-appropriateness for our participants **(see Figure 1 and Figure 2)**. This tool was also used as a reminder at the start of each interview so as to provide a focus for the conversation. The number of participants required was established according to the criterion of sufficiency, with sampling ending when theoretical saturation was reached and interviews yielded no new information (Strauss and Corbin, 2002).

2.2. Data analysis

All interviews were audiotaped and transcribed verbatim. With the aim of extracting as much information as possible from the transcripts, we applied the constant comparative method, an approach informed by grounded theory. Accordingly, and following Strauss and Corbin (2002), we began by linking fragments of the participants' discourse to coding labels. This open (substantive) coding of data was followed by focused coding in order to identify the most frequently occurring codes, thus allowing us to draw up a provisional set of emergent categories and to describe their properties and dimensions (axial coding). Application of this coding paradigm throughout the analytic process enabled us ultimately to establish relationships between categories.

In parallel with the analysis of interviews, we conducted a literature search in the PubMed, CINAHL, Web of Science, and Scopus databases to identify any studies addressing the hospitalization experiences of children with leukemia. We initially filtered the search to the past five years, but as this retrieved only a small number of studies we expanded the timeframe to any year of publication. The purpose of the literature review was to construct a theoretical dialogue to support and contextualize the interpretation of interview data that is presented in the Results section below. We also generated a series of memos (code, theoretical, operational, and bibliographic) to support this dialogue and the analytic process as a whole (Charmaz, 2006). Note that the interview data were first coded independently by two members of the research team, who then met to share their interpretation and to highlight any discrepancies. The small number of discrepancies observed were resolved through discussion and review of the literature, and, if necessary, by consulting external experts. The process of reaching a consensus was recorded in methodological memos. Data analysis was performed using ATLAS.ti 7.1.

2.3. Validity and reliability

Several strategies were used to ensure validity and reliability in accordance with the criteria described by Guba (1981). On a general level, the use of work standards and the ATLAS.ti software (as operative support) helped to ensure a systematic approach throughout the analytic process, which was also subject to both internal and external audit. To support the credibility of our theoretical interpretation, the results are illustrated with verbatim quotations from the interview transcripts. Because the participant's mother was present in all but one of the interviews, any comments she made were also recorded and transcribed. Consequently, on a small number of occasions the quotation used to support our interpretation corresponds to the participant's mother. As regards transferability, we describe the sampling context and do not assume that our findings are generalizable to other settings. Finally, all the researchers involved in analyzing the data kept a reflexive journal in order to ensure the confirmability of results.

2.4. Ethical considerations

The study was conducted in accordance with the principles of the Declaration of Helsinki (World Medical Association, 2013) and was approved by the Clinical Research Ethics Committee of the NAME OF UNIVERSITY BLINDED FOR REVIEW. All the children gave informed assent and all adolescents and parents signed informed consent. A data protection protocol was established in accordance with current legislation in our country (BOE, 2018).

3. Results

Interviews were conducted with three children and four adolescents (four boys, three girls), all of whom were receiving treatment for ALL (see Table 1). Interviews lasted between 30 and 50 minutes.

The analysis revealed three themes in participants' accounts of their experience of hospitalization during treatment for ALL: 1) It is normal to feel afraid when being treated in hospital; 2) Needle procedures are associated with pain, illness, and dying; and 3) Difficulty of expressing the suffering that is experienced in hospital.

3.1. It's normal to feel afraid when being treated in hospital

The children and adolescents we interviewed considered that it was normal to feel afraid when in-patient treatment was required.

“I've always been someone who is really afraid of hospitals.” (P1)

“The other boy, he seems calm, but suddenly you hear him crying. You feel sad for him, but then you say to yourself: Well, it's normal. It's only normal in a hospital.” (P3)

“I can't stop thinking about it, having to come here, it goes round and round in my head. Nobody likes coming here.” (P4)

“He was crying and saying “Mum, I don't want to go there.” (P7)

Fear of this kind is a response to a present and imminent threat and it can trigger an active defense in the form of flight (Margarita-González, 2014). It may also result in the emergence of symptoms such as sadness and depression (López Naranjo and Fernández Castillo, 2006).

For children and adolescents with cancer, the fear of hospital is related to being separated from family and friends in what is experienced as a hostile environment.

"It's the only bad thing. Being shut away inside." (P3)

"Feeling OK, it really matters. But in a hospital, shut away like that…" (P6)

"You lose a sense of connection to the outside world: fresh air, the warmth of the sun, going for a walk…." (P2)

"Well, I miss my Dad and my little brother. I miss my little dog. I've got a little dog and I taught him to play. It makes me really sad." (P7)

In the view of López Naranjo and Fernandez Castillo (2006), the interruption of everyday family life, the loss of autonomy and privacy that goes with having to spend time in an unfamiliar setting with its own rules and routines, and the fear of the illness and of being separated from one's parents are all important stressors associated with hospitalization. Barrio and Mestre (1989) made a similar point years earlier when they argued that the hospital environment, insofar as it is a different and unfamiliar ecological setting, is a key factor in the impact of hospitalization, Cicogna et al. (2010) likewise suggest that the hospital environment can in itself be a source of intense suffering.

3.2. Needle procedures are associated with pain, illness, and dying

Participants also related their fear of hospital to the pain that is inherent to needle procedures (Uman *et al.*, 2006).

"When I was ill here, and they had to put a catheter in, I hated it because they just couldn't find a vein. I remember once they tried six times and it wouldn't go in. It usually hurts a lot. The catheter is usually only good for three or four days because the vein tends to swell up and they have to change it." (P1)

"It hurt a lot, the pain I felt." (P2)

“Because my veins couldn't take any more. And later, when we found out that I needed to go into hospital, that meant more needles, more tubes… the whole of my arm.” (P5)

“Yes, but when they put a tube in I cry because it usually hurts a lot.” (P7)

Rennick and Rashotte (2009) argue that medical interventions of this kind can have various psychological consequences for hospitalized children and adolescents , and they are the main predictor of negative psychological outcomes . Various studies have shown that the pain associated with treatment and diagnostic procedures is the most difficult aspect of illness for children and adolescents (Enskär *et al.*, 2007; Peterson *et al.*, 2007).

The possibility of unexpected and potentially stressful procedures of this kind was also mentioned by our participants in relation to the fear they experienced in hospital.

“But the fear that they're going to stick a needle in you again and it's going to hurt, the fear is worse than the possibility that it will really hurt.” (P4)

“Yes, when I came here I was afraid they'd do something that hurt.” (P5)

“One day they took ages to get the needle in. And it hurt a bit and I got tense. Since then I've felt nervous every day. You think it's going to happen again.” (P6)

The individual response seems to depend not only on age and gender (Goodenough *et al.*, 1999) but also on previous exposure to painful procedures, insofar as their frequent repetition does not lead to desensitization of perceived stress (Liossi, 1999). In this respect, Nager et al. (2010) argue that children's emotional responses are exacerbated not only by the unfamiliarity of the hospital setting but also by a loss of control and the possibility that further painful procedures will have to be endured.

Participants also linked their fear of hospital and needle procedures to a deterioration in their condition.

“When I was unwell, and they had to put a catheter in, I hated all that.” (P1)

“When you have a disease, you need to keep track of it, to have check-ups.” (P5)

In the study by López and Fernández (2006) the fear of death as a latent threat due to a complication in their illness was the most important fear influencing the perceived stress of hospitalized children. The association of hospital with death (Morse *et al.*, 1986; Colville et al,

2008) is likely to be enhanced in the case of a disease such as ALL, (Méndez-Venegas, 2005), especially in the advanced stage.

Although, due to pharmacological advances, our participants did not report procedural pain, they did highlight psychological stress as an important source of suffering and helplessness.

> *"They put the cream on and I don't feel a thing." (P7)*
>
> *"With the EMLA® you don't notice any pain with the port-a-cath." (P4)*
>
> *"I think it's 100% psychological. That's the bad thing, that it's psychological." (P4)*
>
> *"And of course, my Mum tells me it's not going to hurt and all that. And it's true. But you get nervous all the same." (P5)*

A recent study by Hedén et al. (2020) found that children undergoing needle insertion with topical anesthesia experienced fear levels as high as pain levels. This highlights the importance of distinguishing between nociceptive pain and the suffering that is associated with a procedure (Dworkin, 1994). From this perspective, pain would involve nociceptive or neuropathic mechanisms, whereas suffering or emotional stress may be caused by the presence of nociceptive pain or by other factors (Chapman and Gavrin, 1999), such as undergoing needle procedures, a relapse of illness or facing the possibility of dying.

Our findings notwithstanding, it should be noted that some studies have found that the majority of hospitalized children continue to report the experience of preventable pain (Birnie *et al.*, 2014). Indeed, despite standardized care protocols and the application of good practice guidelines (Stinson *et al.*, 2008), treatment-related pain continues to be undertreated in hospitalized children and adolescents (Cummings, 2015).

3.3. Difficulty of expressing the suffering that is experienced in hospital

Another aspect that emerged in the interviews was that some parents felt proud of their child if he or she did not show fear or report pain in relation to needle procedures, and this was also considered to be something that health professionals appreciated.

> *"She doesn't have a problem. It doesn't hurt and she'll say: 'Why are the children screaming? What's wrong?' She never complains that it hurts. My daughter isn't anxious." (Mother of P3)*

"So like, it's always been 'it doesn't bother you'. It's like a relief for everybody. Everybody says it." (P3)

"If I don't cry, my Mum blows me a kiss." (P7)

"Well, because they shouted at you. Some people don't understand the pain a child feels." (Mother of P4)

"They've often come to her for teaching, to take advantage, you know, with new staff. Because then they can practice. Because they know she won't make a fuss." (Mother of P3)

As for the children themselves, they wanted nurses to give them the opportunity to express their feelings, and also to be honest if a procedure was likely to be painful.

“It'd be nice if the nurses didn't just talk to each other but also asked me things.” (P4).

“Being in a hospital where they tell you the truth, that's really important for how you feel. Not being in a hospital where they don't tell you anything…. For example, if it's going to hurt, then you want them to tell you. But they tell you it won't and then it does really hurt.” (P6)

Communication of this kind can play an important role in relation to the psychological wellbeing of hospitalized children, who may worry about whether or not their behavior is acceptable to others (Nager et al., 2010). Indeed, children commonly show signs of acute anxiety (e.g., crying, shouting, hostility, uncooperative behavior or even aggression) immediately before or during a needle procedure (Katz, Kellerman and Siegel, 1980; Jay and Elliott, 1990), but they often feel ashamed of their behavior once the intervention is over (Katz et al., 1980; Jay and Elliott, 1990), such that their anxiety grows with each new experience of this kind (Kellerman et al, 1983).

Overall, it is important to note that parents may struggle to openly acknowledge with their child the reality of cancer, and this can lead to a situation of mutual pretense or even a conspiracy of silence (Méndez-Venegas, 2005), defined by Ruiz-Benítez and Coca (2008) as "an implicit or explicit agreement on the part of families, friends, and/or professionals to withhold information so as to hide the diagnosis, prognosis, and/or severity of the situation from the patient who wishes to know”. Research shows that children with cancer are aware of their illness and its severity (Williamson *et al.*, 2010; Stayer, 2012). However, when they see that their parents are hiding information from them, it may become difficult for them to express their fears and concerns. They may then feel isolated, alone, and mistrustful of adults, all of which will make it harder to cope with the illness process (Méndez-Venegas, 2005; Pérez-Fuentes *et al.*, 2018). Our findings here, albeit based on a small number of interviews, suggest that both parents and health professionals may indeed, at times, resort to a 'conspiracy of silence' when relating to children with cancer.

4. **Discussion**

For the children and adolescents with ALL that we interviewed, hospitalization was an experience that evoked fear, especially because of the pain associated with the frequent needle procedures they have to undergo. However, they described this pain less in nociceptive terms and more as a form of suffering or emotional stress, related above all to the expectation that further such procedures would be required, and also because it brought home to them the reality of their illness and the possibility of dying. Studies have shown that when parents and health professionals do not create an environment in which hospitalized children are able to express their fears and concerns, especially in relation to needle procedures, then these children may end up feeling alone, isolated, and mistrustful of the adults around them (Méndez-Venegas, 2005; Pérez-Fuentes *et al.*, 2018). In this respect, the expressions of fear, anxiety, sadness, and isolation by our participants may be regarded as indicators of the presence of suffering or spiritual pain (Bartel, 2004).

According to Stinson et al. (2008), almost all children and adolescents experience physical pain at some point during the process of their illness, whether due to the disease itself, the side effects of treatment or the procedures they must undergo as part of their care (Duffy *et al.*, 2019). These young people are vulnerable to the psychological consequences of untreated pain, which may include heightened anxiety and post-traumatic stress, all of which can undermine their ability to cope with their illness (Alberts et al, 2018).

Suffering or spiritual pain of this kind can occur whenever a person is unable to find sources of meaning, hope, love, peace, comfort, strength, and connection to life or when there is conflict between their beliefs and what they are experiencing (Anandarajah and Hight, 2011). It has been defined as an all-encompassing, dynamic, individual phenomenon characterized by the experience of alienation, helplessness, hopelessness, and meaninglessness that is difficult for the sufferer to articulate (Best *et al.*, 2015). Importantly, this difficulty of expression was an aspect that emerged in our interviews with children and adolescents with ALL, and it is one of several potential barriers to the recognition of their spiritual suffering; others include an unwillingness on the part of cancer patients to burden others (Cherny et al, 1994; Boston et al, 2011) or a failure on the part of healthcare staff to respond to suffering even if they recognize it (Rodgers and Cowles, 1997), which can be due to their anxiety about death (Kahn and Steeves, 1995), something which may also be the case among families. Under such circumstances, the child or adolescent with ALL may wait for a cue that never arrives or simply assume that their parents are too preoccupied or staff too busy to listen (Strang, 1997). Some may therefore feel that there is no safe space in which to voice their fears and concerns (Moore et al, 2004). In this respect, it would be interesting to conduct a qualitative study involving participant observation so as to learn more about how parents and health professionals relate to children and adolescents with ALL during potentially painful needle procedures.

Although cancer has a devastating impact on children's lives and seriously interferes with their physical, emotional, and social growth (Oeffinder *et al.*, 2006; Geenen *et al.*, 2007), it is important to note that many survivors also report positive outcomes (Molinaro and Fletcher, 2018). The term *post-traumatic growth* is used to describe the experience of positive change that occurs in the wake of the struggle with significant life crises (in the case of our participants, ALL) that severely challenge an individual's sense of the world and his or her place in it (Tedeschi and Calhoun, 2004). This implies effort on the part of the survivor to accept the negative aspects of the experience, re-construing and giving new meaning to it so as to achieve a sense of well-being and security (Park et al, 2010). Tedeschi and Calhoun (2004) identified five ways in which post-traumatic growth may be manifested: greater appreciation of life and a change of priorities; warmer, more intimate relationships with others; a greater sense of personal strength; a recognition of new possibilities and paths in life; and spiritual development.

For children and adolescents in treatment for ALL, the possibility of transforming this life crisis into an opportunity for post-traumatic growth (Calhoun and Tedeschi, 1990; Tedeschi and Calhoun, 1996, 2004) depends, in part, on their ability to maintain a sense of optimism and positivity throughout their hospitalization (Saleh and Brockopp, 2001). It is therefore vital to minimize all possible sources of suffering during their care and treatment, not least the pain associated with needle procedures, which both children and parents identify as being one of the most stressful aspects of the illness (Zeltzer *et al.*, 1980; Conte *et al.*, 1999; Ljungman *et al.*, 2000). In this respect, the results of this study highlight the need for specific strategies that can help to reduce the spiritual pain that these children experience. One such strategy might involve nurses talking to children about their emotional or spiritual concerns, insofar as research suggests that conversations with children on what is meaningful to them are important and add quality to their care (Kamper et al., 2010). More generally, Safavi et al. (2019) argue that hospitals should establish settings focused on promoting 'spiritual intelligence', which in the view of these authors can contribute to improved treatment outcomes among patients with cancer.

5. Strengths and limitations

Our use of an inductive phenomenological approach (Morse, 2012) involving in-depth interviews (Seidman, 2013) and an analysis informed by grounded theory (Strauss & Corbin, 2002) is an optimum way of gathering participants' lived experience of hospitalization. The fact that all the interviews were conducted by a member of the research team with training in the psychological care of children and adolescents facilitated the expression of their experiences.

The main limitation of this study is that all the researchers are female professional nurses, and hence any preconceived ideas they share may have influenced the analysis and interpretation of data (Bengtsson, 2016). To address this potential bias, all researchers involved in analyzing the data were required to keep a reflexive journal in which they recorded their decisions and the reasons for them, as well as reflecting on their values and interests. We also carried out an extensive literature review in order to compare our interpretation with previous findings and provide support for the theoretical narrative that we present in the results section of this paper. A further limitation has to do with the inherent difficulty of exploring with children (especially younger ones) their experiences of in-patient cancer treatment, as this is obviously a sensitive and complex issue. With the aim of minimizing this difficulty, all the interviews were conducted by a nurse with extensive experience of communicating with and caring for children in this situation. The infographic which she designed to explain the purpose of the study to participants also helped to focus the conversation at the start of interviews.

6. Conclusion

The primary experience that children and adolescents with ALL report in relation to hospitalization is the pain associated with needle procedures. However, this was less a nociceptive pain that could be managed pharmacologically, and more a form of suffering or emotional stress related to the expectation that further such procedures would be required, and hence the possibility that they might not get better or even die. If parents and health professionals fail to create an environment in which hospitalized children are able to express their fears and concerns, then these children may end up feeling alone, isolated, and mistrustful of the adults around them. Children who sense that their emotional or spiritual pain is not recognized by parents and health staff will likely find it more difficult to cope with their illness and be more at risk of negative psychological outcomes. This underlines the need for a more holistic and person-focused approach to the pain that children and adolescents with ALL experience, especially in relation to needle procedures. By addressing all facets of their suffering, what is obviously a life crisis might then also become an opportunity for growth.

Declaration of competing interest

None declared.

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Table 1. Characteristics of participants

Participant	**Characteristics**
1	Female, age 13 years Acute lymphoblastic leukemia Presence of post-treatment sequelae No history of relapse Only child Parents together
2	Female, age 16 years Acute lymphoblastic leukemia History of relapse Has 12-year-old brother Parents together
3	Female, age 14 years Acute lymphoblastic leukemia Bone marrow transplant Has 19-year-old brother Parents together
4	Male, age 18 years Acute lymphoblastic leukemia Only child Parents together
5	Male, age 10 years Acute lymphoblastic leukemia History of relapse Parents separated
6	Male, age 10 years Acute lymphoblastic leukemia Only child Parents together
7	Male, age 9 years Acute lymphoblastic leukemia Has 3-year-old brother Parents together (but father currently in Venezuela)

Table 2. Themes to be Explored

Themes to be Explored	**Purpose of Exploring the Theme**
Theme 1: Tell me something about your illness since you first learned that you had cancer	*To provide a socio-historical context in which to understand the participant's lived experience*
Theme 2: Tell me something about what it's like for you when you have to undergo treatment that involves invasive procedures such as injections	*To gather information about the participant's lived experience in relation to the study topic*
Theme 3: Tell me something about what it means for you to undergo these kinds of procedures and treatment	*To gather information about the meaning of this experience for the participant.*

Figure 1. Gamified infographic for aiding data collection from children

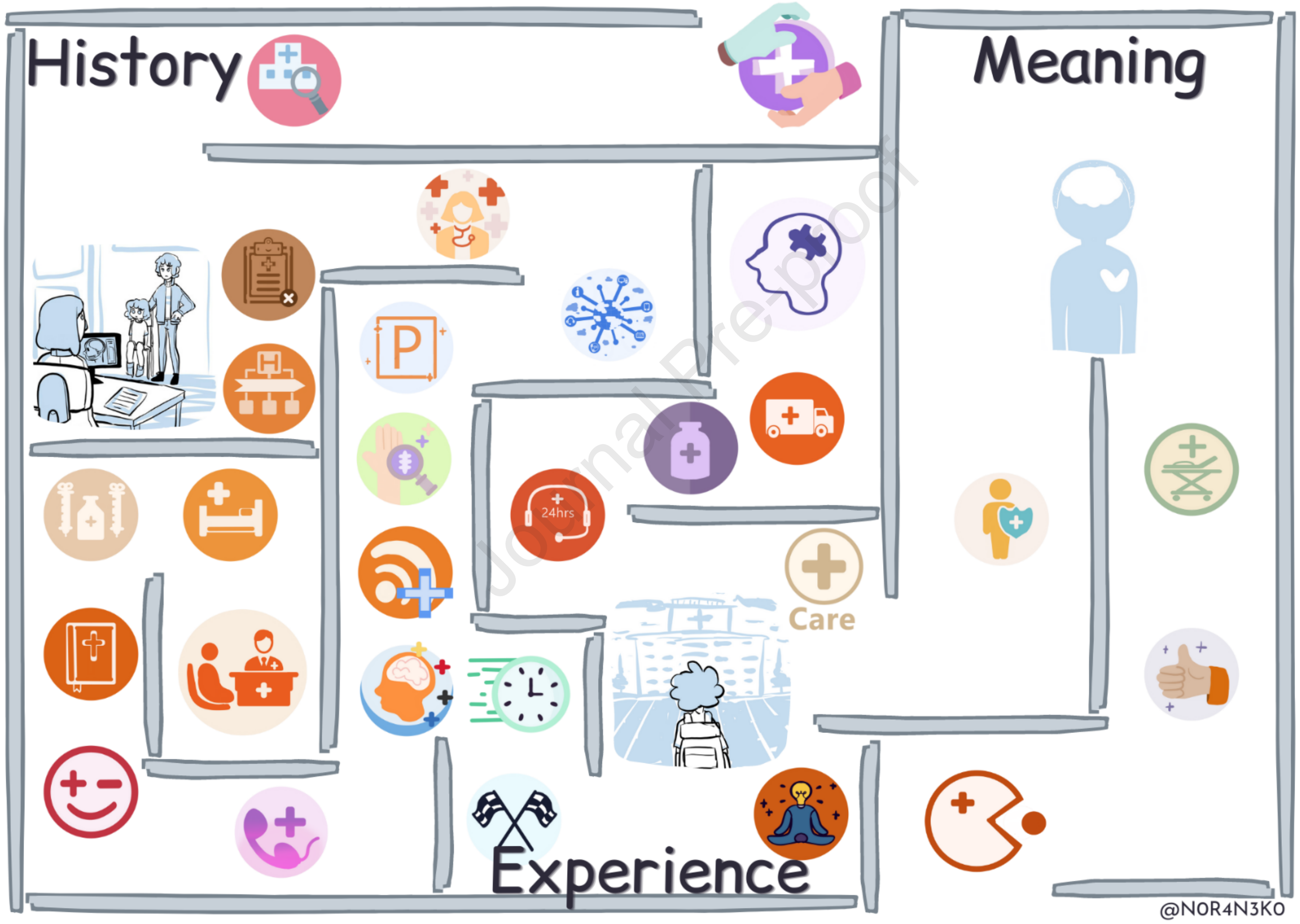
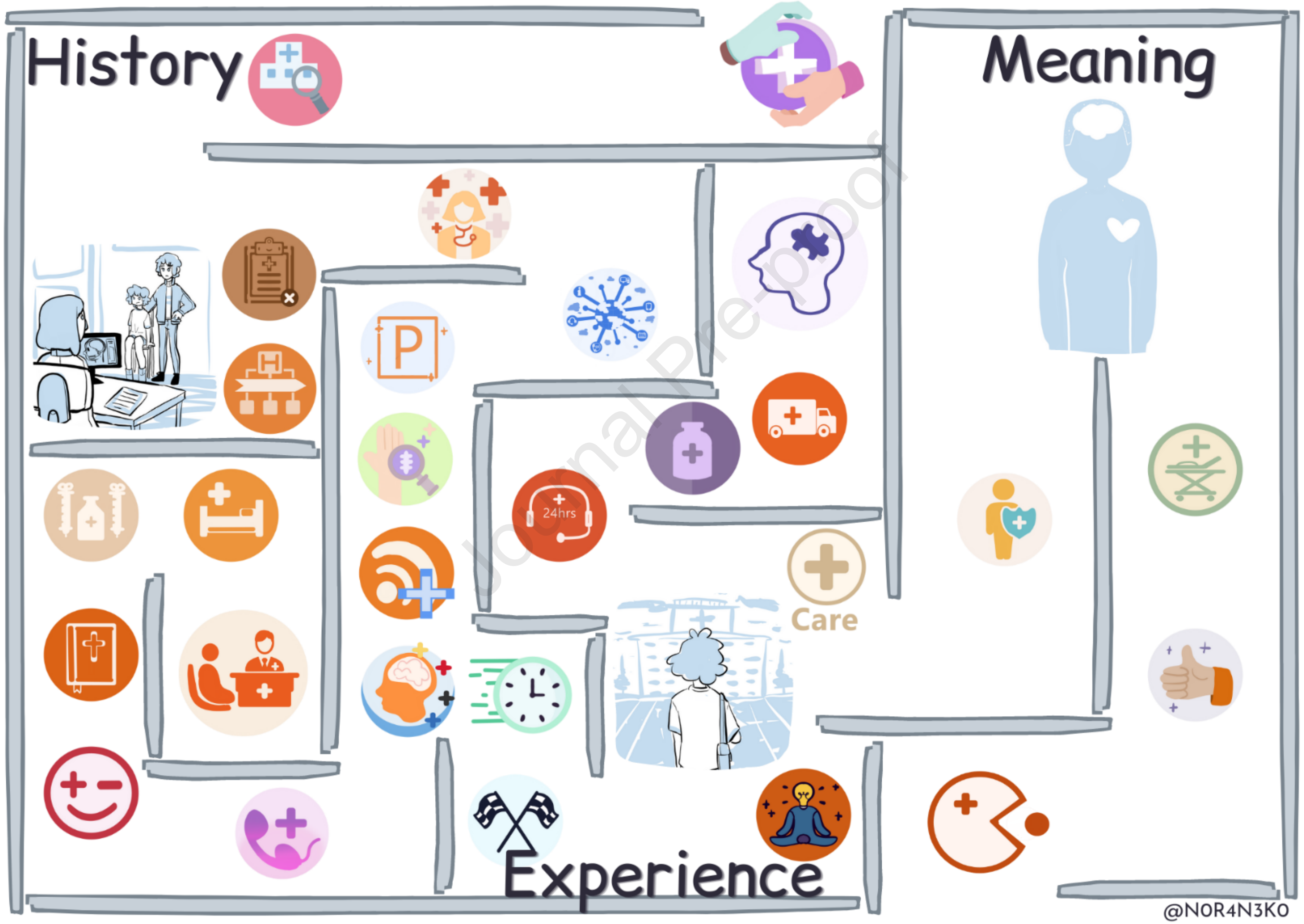


Figure 2. Gamified infographic for aiding data collection from teenagers



Conflict of Interest Statement

We attest that we have herein disclosed any and all financial or other relationships that could be construed as a conflict of interest and that all sources of financial support for this study have been disclosed and are indicated in the Funding Statement

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