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The waiting room as a relational space: young patients and their families' experience in a day hospital.

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The waiting room as a relational space: Young patients and their families' experience in a day hospital

Abstract

Background. Waiting in hospital is a condition of high stress for patients and their families, especially in childhood. The literature has investigated the emotional experiences of patients and their families, recognizing the need for a comfortable environment, attention from the staff, information and sharing emotions with others. Waiting time in day hospitals is a topic that has not yet been investigated in the literature, but is nevertheless interesting for researchers. This exploratory study investigates the experience of waiting that young patients and their families go through during treatments in day hospitals.

Method. Fifty children and adolescents from ages seven to 15 years, admitted to the day hospital of a paediatric haematology and oncology ward of an Italian hospital, completed the Emotional Reaction Instrument (ERI) and the Child Drawing: Hospital. Their parents or relatives completed a semi-structured interview on waiting.

Results. The data showed that the young patients displayed a low level of anxiety and negative emotion. In contrast, the adults' experience of waiting in the day hospital entailed boredom, anxiety and concern for the emotional state of the children. These conditions can be alleviated by relationships and sharing emotions with other adults.

Conclusions. This study has shown that day hospital waiting rooms should be organised and experienced by adults and children as relational spaces. It could provide useful suggestions in order to improve the organisation of day hospital waiting rooms.

Keywords

Waiting room, day hospital, hospitalised children, emotional states

Introduction

Waiting in a hospital is a condition of high stress for patients and their families, especially for children (Bournes & Mitchell, 2002).

Initial research literature dates back to the late 1970s and focuses on the needs and emotional experiences of families of patients in intensive care. Semi-structured interviews with families have highlighted some needs felt in waiting rooms in regard to patients: the need to feel hope, to feel that staff will take care of the patient and the opportunity to be physically close to him or her (Molter, 1979). Different studies, using a phenomenological approach, have shown the uncertainty and search for meaning that characterise families and patients during critical waiting periods (Plowfield, 1999). In particular, people in waiting rooms desire and expect assurance, comfort, support and information (Warren, 1993; Waters, 1999) from health professionals. Bournes and Mitchell (2002, p. 62), in an explorative research using a dialogical method with 12 family members of people in an adult critical care unit, describe the experience of waiting as a 'vigilant attentiveness' that accompanies an 'ambiguous turbulent lull', with contentment emerging through relations with others and engagement in activities. In another qualitative study, based on semi-structured interviews, Kutash and Northrop (2007) identified other structural and subjective aspects of waiting as reported by six family members of adult patients in intensive care. In particular they stressed the importance of the perception of close proximity to the patient and caring behaviour from the staff. Furthermore, the authors described the waiting room as a place where sharing emotions with others can provide emotional support, and underlined the impact of the design of the waiting room on family members' well-being.

With regards to this aspect, several studies have shown the impact of the physical and spatial environment of the care units on the patients and their family members (see Huisman et al., 2012 for a review). In particular, Campos Andrade and colleagues (2013), found that the quality of the

physical and social environment of health care settings, evaluated by 206 patients and two architects, could affect patients' well-being and their perception of the quality of care. Also, Becker and Douglass (2008), in an observational study with seven patients, reported a positive correlation between more attractive waiting rooms and higher levels of satisfaction, a reduction of patient anxiety and a perceived higher quality of care.

Most of these studies, however, have considered the waiting of family members of adult patients in intensive care or in critical conditions. There are few investigations addressing child patients and their families waiting in a hospital. This research has focused in particular on the time spent in ambulatory care, before a medical visit or check up, and has highlighted the importance of playing and other positive activities that could help to distract children. Along these lines, Pedro and colleagues (2007) pointed out that playing in the waiting room is an opportunity for young patients to express and elaborate negative emotions, such as anxiety and fear. Their research, using qualitative analysis of semi-structured interviews of 12 children, investigated the use of playing in paediatric outpatient clinic waiting areas. The authors identified three key themes: waiting as a necessity and involving a long amount of time; playing as an opportunity to turn the hospital into a pleasant space; and playing as a mediator in relations. This study highlighted that when children participate in playing activities before a clinical visit, they establish harmonious relations with their companions and health professionals and feel less anxious and afraid. In another study (Nascimento et al., 2011), qualitative analysis of semi-structured interviews of six nurses and five physicians of a paediatric outpatient service showed similar findings. Playing in the waiting room is considered by health professionals as an activity that helps the children to make better use of waiting time, decrease their anxiety and nervousness and improve their mood, as well as enhance interactions and communication with health professionals during the clinical visit. From the perspective of 'humanising children's health care', the authors concluded that it is necessary that waiting rooms be equipped with toys and pleasant physical spaces in order to help young patients relax and cope better with medical care. Similarly, Pati and colleagues (2011) focused in particular on the influence

of positive distractions in paediatric waiting areas. Their study introduced some distractions (visual and audio stimuli on a flat-screen plasma monitor) in the waiting area of a paediatric care centre, and observed 158 children's behaviour in experimental and controlled conditions. A questionnaire on the waiting experience was administered to their parents. The results showed that children in the experimental conditions displayed quiet behaviour and exhibited less overall movement. Thus, pleasant distraction conditions during waiting time could have a relaxing effect on children. The data also showed correlations between children's behaviour and waiting time perceived by the children's parents. When children experience waiting time in a more relaxed way, the adults' perceptions of the quality of care and relationships with staff improve.

The studies above focused on the time spent by children in the waiting room of an ambulatory care setting, on their behaviour and on the role of playing and other distraction conditions to mitigate the waiting time. The emotional states of the children and their parents' perception of waiting have not been investigated specifically.

The aim of the present exploratory study is to investigate how young patients and their families experience waiting during treatment in a day hospital. Waiting time in day hospitals is a topic that has not yet been investigated in the literature, but is nevertheless interesting for researchers. A day hospital stay can be very long, because of waiting for test results or the completion of therapy. The children's and accompanying adults' waiting can be associated with boredom, fear of painful treatment or tests, or with concern for and anxiety about test outcomes. As hospitalised children's negative emotions are associated with a greater perception of pain (Caldas et al., 2004), it is particularly important to investigate children's emotional states in hospital waiting rooms.

Therefore, the first aim of the study is to examine young patients' emotional states and the families' perceptions of waiting; moreover, in accordance with a consideration of the above literature, the study intends to explore whether waiting times in day hospitals can be used as an opportunity to express and elaborate emotions, and to relate with others. In particular, we expect to find emotional states of boredom both in patients and their parents. We also expect that adults are

more anxious and worried than children, because of a greater awareness of the specific condition or disease, and that they express the need to share their emotions with others.

Method

Participants

Over a four month study period, all families (N = 50) of school-aged children (aged between 7 and 15) admitted to the day hospital of a paediatric haematology and oncology ward of an Italian hospital were asked to participate in the study. All these families (children: F = 26 and M = 24) took part. Twenty children were aged between seven and 10 years (M = 8.5; SD = 1.12) and 30 children were between 11 and 15 years (M = 12.5; SD = 1.5). Ten participants were suffering from haematological malignancies, five from solid tumours and 20 from blood disorders. The other 15 participants were suffering from unspecified general diseases. All patients had previous experience of hospitalisation and accessing the day hospital. Table 1 reports the time since diagnosis of the participants. 48 adults accompanying the children at the day hospital (37 mothers, nine fathers and two grandmothers) also participated in the study.

(insert Table 1 here)

The psychologist of the ward contacted the children's parents and explained to them the purpose and procedure of the research. Each participant and their family members gave informed consent. Ethical approval was obtained from the Research Ethics Committee at Hospital University of the Province of Parma (Italy) (Protocol No. 12078).

Instruments and coding

The Emotional Reaction Instrument (ERI- Kim et al., 2014), and the Child Drawing: Hospital (CD: H - Clatworth et al., 1999), were used to specifically assess the children's emotional state and anxiety during waiting times. Unlike the semi-structured interviews used in the literature to

investigate the children's experience of waiting in the hospital, they focus specifically on the emotional aspects and anxiety.

The ERI is a questionnaire that requires children to evaluate on a four-point Likert scale (from 'not at all' to 'very much so') how they feel at that time about 15 different emotional states (for example, '*do you feel afraid, bored, happy, ...?*'). After carrying out a pilot study with 10 children of the same age as the research participants, three items were excluded (*scared, lonely, scary*), in order to make the test less repetitive. In any case, the tool demonstrated acceptable internal consistency ($\alpha = .80$), ($\alpha = .82$ in the Kim's original study).

The CD: H is a task in which children are asked to 'draw a person in the hospital'. It allows assessment of the patient's state of anxiety during hospitalisation. For the drawing coding, several indicators have to be considered by the investigator, who on the basis of well-defined descriptors must assign a score from 1–10, with 1 being the lowest and 10 the highest anxiety level (see Table 2).

(insert Table 2 here)

Two researchers encoded the drawing indicators separately (Cohen's $K > .90$).

The authors of the CD: H also provide an interpretative model of the total scoring (see Table 3).

(insert Table 3 here)

The accompanying adults completed a semi-structured interview on waiting time (Kutash & Northrop, 2007), including the following open questions: (1) '*What is it like to wait?*'; (2) '*What is the most difficult part of waiting?*'; and (3) '*What would make waiting easier for you?*'.

Procedure

Once informed consent was obtained from the children and the accompanying adults, the experimenter administered the tests to the participants in the day hospital waiting room (see Figure 1). The administration of the tests required 30–40 minutes in total. All participants completed the ERI. Each patient received a blank 8½ x 11ink sheet of white paper and eight basic crayons, and was instructed to ‘Please, draw a person in the hospital’. He/she could orient the sheet as he/she preferred. No time limit was given. Nobody asked questions about how to perform the task. Six participants, who were 13/15 years old, did not want to draw because they considered it a task for small children.

(Insert Figure 1 here)

Results

Waiting and children’s emotional states

The descriptive analysis illustrated that 90% of the children experienced happiness and 76% of the children boredom while waiting. Overall, excluding boredom, young patients were shown to not experience negative emotions (see Table 4). However, part of the sample reported having experienced some feelings of nervousness, fear, sadness, aloneness, discomfort and worry.

(insert Table 4 here)

In order to verify whether the participants’ emotional state scores varied in relation to age, gender, pathology and time since diagnosis, a one-way Analysis of Variance (ANOVA) was conducted using age, gender, pathology and time since diagnosis as independent variables. Data analysis showed a significant difference between younger (aged from 7–10 years) and older (11–15) patients for the items ‘frightened’ [(M younger = .63; M older = .13); $F_{(1,34)} = 6.13$; $p < .05$; $\eta^2 = .12$] and ‘bad’ [(M younger = .68; M older = .10); $F_{(1,34)} = 9.09$; $p < .05$; $\eta^2 = .17$]. A gender difference also emerged for the item ‘worried’ [$F_{(1,34)} = 4.95$; $p < .05$; $\eta^2 = .10$]. In particular, males (M = .25)

were less worried than females ($M = .52$). As regards the pathology and the time since diagnosis, no significant differences emerged. Furthermore, no interactions between variables emerged.

Waiting and children's anxiety

The overall scores assigned to the patients' drawings indicated that 6% of patients showed a very low level of anxiety (scores < 43); 66% a low level (scores between 44 and 83); and 16% a medium level (score between 85 and 129). In order to verify whether the participants' anxiety scores varied in relation to age, gender, pathology and time since diagnosis, a series of one-way ANOVA tests were conducted using age, gender, pathology and time since diagnosis as independent variables. No significant differences emerged in the overall scores. Analysis indicated age differences in some drawings' anxiety indicators. In particular, younger patients (aged from 7-10 years) obtained lower scores ($M = 3.65$) than older patients (11-15) ($M = 5.24$) in the number of colours used [$F_{(1,34)} = 4.52$; $p < .05$; $\eta^2 = .12$]. In the strokes quality, an interaction between age and gender emerged [$F_{(1,34)} = 4.52$; $p < .05$; $\eta^2 = .12$]: namely, younger males showed lower scores ($M = 1.33$) than younger females ($M = 2.91$), and older females obtained lower scores ($M = 3.6$) than older males ($M = 5.09$) (see Figures 2 and 3).

(insert Figures 2 and 3 here)

A brief qualitative analysis of the drawings showed that over 50% of the participants drew health professionals, particularly doctors. Moreover, in most of the drawings (70%) hospital equipment was present.

Relationships between emotional states and anxiety

In order to explore the relationship between children's emotional states and their anxiety, a series of Pearson correlations was performed. Significant positive relations, although moderate, emerged

between the drawings of the hospital equipment and the following emotional states: 'terrified' [$r(50) = .33; p < .05$], 'afraid' [$r(50) = .41; p < .05$] and 'nervous' [$r(50) = .40; p < .05$]. The more the patients felt terrified, afraid and nervous, the more medical instruments (e.g. thermometers, needles, catheters) were drawn. In addition, a negative significant correlation emerged between the drawing of an action and fear [$r(50) = -.44; p < .01$].

Accompanying adults' perceptions of waiting

A qualitative analysis was conducted on the accompanying adults' answers to the three open-ended questions. In particular, with regard to '*What it is like to wait?*', 75% of the adults emphasised concern for the emotional and physical state of the child and 70% described waiting as a time of anxiety, stress and boredom. Concerning '*What is the most difficult part of waiting?*', 80% of the accompanying adults highlighted fear about the medical test outcomes and boredom due to the long waiting time (70%). Finally, with regard to '*What would make waiting easier for you?*', 90% of the adults reported that they accepted the waiting time as routine and that the presence of other adults to talk to and share emotions with helps them relax and better spend this time (80%). Even the possibility of having communicative exchanges with the health professionals makes the waiting time easier to bear for 80% of the adults. Finally, 90% of the adults hoped for a greater presence in the waiting room of entertainment activities for children and adults. These positive distractions could have a strong influence both on their emotional states and their relationship with the children while waiting (80%).

Discussion

The first aim of this study was to investigate young patients' emotional states and anxiety and their families' perception of waiting during the time spent in a day hospital.

As regards the patients' emotional states, descriptive analysis showed that while waiting, young patients did not experience negative emotions (excluding boredom). Only partially emotional states

of nervousness, fear, sadness, aloneness, discomfort and worry emerged. The low level of negative emotions and the presence of a high percentage of boredom allowed us to hypothesise that patients experience waiting at the day hospital as routine, well-known and they consider it as necessary. In fact, accessing the day hospital is an activity that is repeated over time and that the patients know very well. This finding is in line with Pedro and colleagues' results (2007), which emphasised that waiting is perceived by children as necessary and involving a long amount of time. One can understand, therefore, that the prevailing emotion for children was boredom. This aspect was also pointed out by the adults, who would like the presence of entertainment activities in the waiting room. Despite the low level of negative emotions, it was noted however that the younger participants were more frightened and felt worse than older ones. This may be explained in reference to the medical tests, which are often painful, that patients have to undergo in day hospitals. Also, as at this developmental stage the body is the main instrument of knowledge (Piaget, 1962), the loss of bodily bits makes younger children more vulnerable emotionally than older children, who may understand more about their disease processes and the consequences of day-hospital appointments.

With regard to anxiety, in general, the data obtained in this study confirmed results that have already been established about emotional states. During the waiting period, in fact, most patients experienced low or very low anxiety levels. This appears in contrast with results from the literature considered above (Pedro et al., 2007; Nascimento et al., 2011) that indicated negative feelings of anxiety and fear in children in waiting rooms. However, these data were related to different waiting situations. In the present study, the results showed that waiting in the day hospital is perceived as routine and this can alleviate the concern of the adults.

Despite the low levels of anxiety and emotional states in the patients, by taking into consideration some anxiety indicators from the drawings it is possible to note some interesting data. Firstly, the older children showed higher anxiety levels than the younger ones. In line with other research (Bartolozzi & Guglielmi, 2008) this finding may be related to adolescent patients' higher

awareness of their conditions or diseases. In addition, significant correlations between the hospital equipment drawings and certain emotional states emerged. Specifically, the more the patients felt terrified, frightened and nervous, the more they tended to draw hospital equipment, such as medical instruments. The reference to the knowledge and experience of medical technical aspects, both in language (Corsano et al., 2013a) and in drawing (Corsano et al., 2013b), has been interpreted in the literature as an attempt to control the anxiety of one's disease status, or to exercise control over a reality perceived as uncertain and painful (Barbieri et al., 2012). In fact, drawing qualitative analysis showed the presence of many medical instruments. In addition, the choice, in many cases, to draw the doctor and not a sick person, could be explained by an attempt to control, through denial, one's own anxiety. Moreover, a negative significant correlation emerged between the drawing of an action and fear. The more the young patients were afraid, the more their drawing was static, free of action. It is possible to hypothesise that the fear that the child could feel while waiting caused an inability to act, or take initiative, thus predisposing a sense of boredom. In summary, despite being within a framework of general well-being, patients of this study showed through their drawings the anxiety and negative emotions which they felt during the waiting time.

Adults' perceptions of waiting were partially different from those of the children. They also underlined the boredom they felt, but mostly they emphasised the strong sense of concern for the health of the children. Waiting was thus perceived as a condition of anxiety and stress, in line with data from Bournes and Mitchell (2002) and Kutash and Northrop (2007). Even though day hospital waiting is different from critical care waiting, because of the lack of emergency, parents and relatives are anxious about the treatments and the medical test outcomes. In fact, in the present study, the patients mainly suffered from serious illnesses, such as tumours and blood disorders. In this direction, the answers that the adults gave to the third open ended question, namely "*what would make waiting easier for you?*", seem particularly interesting. Most of the adults emphasized the importance of having the chance to interact with other parents in the same situation while waiting, in order to share their emotional states. In addition, they would like communication with

health professionals in the waiting room, in order to receive support and to make the waiting time easier to bear. These interactions with others, parents and health professional, would reassure the adult and promote better interaction with the children. This finding, consistent with Kutash and Northrop (2007), underlines that the adults' stress and anxiety could be alleviated by relationships with others, through sharing emotions, and by a more relaxed interaction with the children. As shown in other research, (Pedro et al., 2007; Nascimento et al., 2011), the quieter young patients were while waiting, the more they displayed good communication ability and better relationships with the health professionals during the medical sessions.

Finally, the adults would also like entertainment activities and positive social and spatial distractions, in order to promote a climate of well-being and to facilitate more relaxed interactions with others. This finding, although qualitative and related to a single open ended question, supports all the studies (Campos Andrade et al., 2013; Huisman et al., 2012; Pati et al., 2011) that underline, in the care setting, the influence of the environment on patients and relatives' well-being.

This study has some limitations. First, it investigates waiting adults' perceptions through only three questions. It would be interesting to investigate this issue through direct observations of their interactions with the children and with other adults, in order to better illustrate the idea that the waiting room is a relational space. Moreover, the ERI is a limited and repetitive tool. Patients' emotional states should also be investigated with narrative tools, such as talking about the emotions experienced. Finally, the study did not consider if the perception of waiting on this particular day was whether the clinic was always running late or usually prompt.

Despite the identified limitations, the study can provide useful suggestions in order to improve the organisation of day hospital waiting rooms.

Key Messages

- Parents would like a waiting room with positive social and spatial distractions.
- Children experience waiting at the day hospital as routine, well-known and considered as necessary.
- Waiting was perceived by their parents as a condition of anxiety, stress, and strong sense of concern for the health of the children.
- The adults' stress and anxiety could be alleviated by relationships with others, through sharing emotions, and by a more relaxed interaction with the children.

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Tables

Table 1. Participants' time since diagnosis

Time since diagnosis (Years)	N
1	18
2	11
3	3
4	7
5	2
6	1
7	1
8	1
9	2
10	1
11	2
12	1

Table 2. Scoring of the CD:H¹

PART A: Add from 1 to 10 points for each	PART B: Add 5 points for 1,2,3 and 10 points for 4,5,6,7,8	PART C: add from 1 to 10 points to the gestalt of the picture (sense of anxiety the whole picture portrays)
Person: position	1. Omission: 1 part	
Action	2. Exaggeration of a part	
Length of person	3. De-emphasis of a part	
Width of person	4. Distortion	
Facial expression	5. Omission: 2 or more parts	
Eyes	6. Transparency	
Size of person to environment	7. Mixed profile	
Color: predominance	8. Shading	
Color: number used		
Use of paper		
Placement		
Strokes: quality		
Hospital equipment		
Developmental level		

¹ Child Drawing: Hospital

Table 3. CD: H¹ Scoring and anxiety level

CD:H scoring	Anxiety level
<44	Very low
44-83	Low
84-129	Average
130-167	Above average
>167	Very high

¹ Child Drawing: Hospital

Table 4. Percentage of children's responses on emotional states

Emotional states	Not at all	A little + pretty + really
Happy	10%	90%
Sad	62%	38%
Terrified	78%	22%
Afraid	58%	42%
Frightened	78%	22%
Nervous	48%	52%
Alone	62%	38%
Bad	73%	27%
Worried	62%	38%
Hurt	70%	30%
Uncomfortable	60%	40%
Bored	24%	76%

Figure 1. The day hospital waiting room



Figure 2. An 8 year old boy

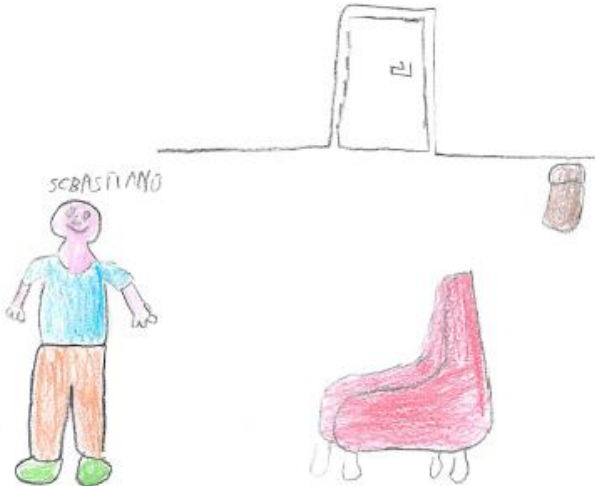


Figure 3. A 14 year old girl



MARTINA