

Prospective evaluation through questionnaires of the emotional status of cancer patients in the waiting rooms of a department of oncology

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Abstract

Objective: The aim of this study is to better identify the prevailing emotions and feelings of cancer patients during their stay in waiting rooms in a department of oncology.

Methods: In July 2014, patients in the waiting rooms of our Department of Oncology were asked to fill out dedicated questionnaires. Patients had to choose sentences that best described their feelings, thoughts and experiences; this part was differentiated according to the waiting rooms (Consultation Rooms versus Day Hospital). In another section, patients were asked to choose their prevailing primary emotions: joy, fear, sadness, anger, disgust or surprise.

Results: Two hundred eighty questionnaires were considered valid for statistical analysis. Regarding feelings, all patients in the Day Hospital and Consultation Rooms stated that they feel anxious (48% and 53%, respectively). By differentiating patients according to the setting, patients in the Day Hospital answered that they will face chemotherapy, thinking that it will be useful to defeat the disease (56%), and patients in Consultation Rooms answered that time in the waiting rooms goes more slowly (65%). Regarding the prevailing emotions experienced by patients, sadness was the most selected, followed by fear and surprise.

Conclusions: A prevalent emotional and cognitive state while waiting is anxiety, followed by positive thoughts. Patients presented anxiety and fear independently from the setting of care. We believe that each oncologist should be aware of the degrees of fear and sadness that patients experience during an oncological examination because these emotions can have an impact on communication and understanding.

KEY WORDS: cancer; emotions; survey and questionnaires; patients' rooms.

Riassunto

Obiettivo: L'obiettivo del nostro studio era di identificare le emozioni e le sensazioni prevalenti nei pazienti oncologici durante la loro permanenza nelle sale di attesa di un dipartimento di oncologia.

Metodi: Nel Luglio 2014 sono stati distribuiti ai pazienti presenti nelle tre sale di attesa (denominate "Ambulatorio", "Day Hospital" ed "Ecografia") del nostro Dipartimento di Oncologia dei questionari costruiti *ad hoc*. Nella prima parte del questionario (costruito in base alla specifica tipologia della sala di attesa) i pazienti dovevano scegliere le frasi che descrivessero nel migliore dei modi le sensazioni, i pensieri e il vissuto da loro percepito in quel momento. Nella seconda parte del questionario, invece, i pazienti dovevano scegliere l'emozione prevalente tra le seguenti proposte: gioia, paura, tristezza, rabbia, disgusto, sorpresa.

Risultati: Sono stati considerati validi ai fini dell'analisi statistica 280 questionari. Per quanto riguarda la sezione relativa alle emozioni, l'emozione che ha prevalso in tutti i pazienti presenti nelle sale d'attesa del Day Hospital e degli Ambulatori è stata l'ansia (rispettivamente nel 48% e nel 53% dei casi). Se consideriamo, inoltre, le differenze legate alla tipologia di sala d'attesa, i pazienti del Day Hospital hanno dichiarato che "affrontano la chemioterapia pensando che sia utile per combattere la malattia" (56%), mentre i pazienti in attesa in ambulatorio hanno dichiarato soprattutto di "aver avuto l'impressione che durante l'attesa il tempo scorresse più lentamente" (65%). Rispetto alle emozioni provate dai pazienti, invece, la più segnalata è stata la "tristezza", seguita dalla "paura" e dalla "sorpresa".

Conclusioni: Nel nostro studio l'emozione più frequentemente provata dal paziente in attesa nel reparto di oncologia è stata l'ansia, seguita dai pensieri positivi. I pazienti provano ansia e paura indipendentemente dal setting di cura in cui si trovano. Queste emozioni possono avere un impatto sulla comprensione dei messaggi comunicati dal medico al paziente durante la visita. Crediamo pertanto che ogni oncologo dovrebbe prestare attenzione al grado di paura e di tristezza che il paziente prova durante l'incontro.

TAKE-HOME MESSAGE

In our study, the most frequent emotions in waiting rooms of a department of oncology were sadness and fear, regardless of the reason for waiting (first visit, follow-up visit, chemotherapy or diagnostic procedure). These emotions can influence the communication between doctor and patient, so particular attention in preparing the environment and psychological impact of waiting rooms is desirable.

Competing interests - none declared.

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INTRODUCTION

The diagnosis of cancer changes the physical/psychological balance in the life of a person. The challenges patients have to face in this phase can be more emotionally complex and delicate than the illness itself. The impact of cancer on the global psychological functioning of patients as well as on factors potentially related to a psychiatric condition has been extensively evaluated. However, few studies focused on the experience and emotional impact on patients during their stay in hospitals. Catania et al., for example, investigated the different perceptions of clinical examination from both the doctor's and patient's point of view after a variable time spent in the waiting room. The authors underline the complexity of the emotional implications connected with waiting and suggest some strategies that could be useful in reducing the levels of anxiety while waiting. These strategies could also help create an 'anthropocentric' waiting room where time is spent constructively and patients could overcome boredom, unease and psychological suffering [1]. Other authors measured the perception and experience of cancer patients in waiting rooms of oncology and radiotherapy departments in Andalusia, specifically considering how the spaces were furnished and the quality of information offered. The authors concluded that attention to these parameters is essential to increase the satisfaction level and overall benefit of patients, not only the therapeutic benefit [2]. High levels of anxiety and stress were detected in cancer patients waiting to undergo diagnostic procedures. Flory and Lang conducted a study on the levels of anxiety in radiology waiting rooms, confirming that all patients were experiencing great distress due to the uncertainty of test results; such distress was more pronounced for women waiting for breast biopsies than for patients waiting for the results of other procedures [3]. Moreover, Yu and Chojniak reported that patients waiting to undergo invasive procedures who experience relevant emotional distress have a lower compliance rate during the test with worse treatment

outcomes and quality of life [4]. Diagnostic procedures, clinical examinations and treatments abruptly follow one another after the diagnosis of cancer. This causes dismay and a need to adapt to the new situation. Each of these phases is preceded by a specific common moment: the waiting room. The waiting room represents a space and time shared with other patients that could trigger the disclosure of different psychological reactions (identification, closure, anxiety, sharing and different emotions) [1]. However, the waiting room is also a place where patients can stay for different periods of time, which can also lead to different emotional experiences. In light of our daily experiences and previous data, we decided to investigate how cancer patients experience waiting rooms before their outpatient visits or chemotherapy treatments and what emotionally impacts them during their stay. Since most cancer patients are forced to repeatedly spend a lot of time in hospital waiting rooms, we believe that a dedicated study could help us understand the impact of the environment on these patients in order to make any necessary changes to improve their quality of life. The primary aim of this study is to identify, through a questionnaire, the emotions and feelings of cancer patients during their stay in the waiting rooms of our Department of Oncology.

METHODS

From 1st July 2014 to 12th July 2014, all patients in the three waiting rooms of the Oncology and Chemotherapy Department of the ASST Fatebenefratelli Sacco, PO Fatebenefratelli (Milan, Italy) were invited to take part in the study. Patients who had come for their first visit were excluded with the aim to only collect data from patients that had already experienced the oncological procedures. Each patient was individually approached by a dedicated nurse who had received specific training, and he/she was asked to fill out a brief questionnaire. The nurse clarified the aims of the questionnaire and informed the patient that the questionnaires were anonymous. The nurse also offered assistance upon request. Once each patient had filled out the

questionnaire, he/she was asked to drop it into special closed boxes. Patients were also allowed to leave the questionnaire blank or to only fill out demographic information. There are three waiting rooms at our Centre: the Day Hospital (DH), where chemotherapy and supportive intravenous therapy are administered to patients; the Consultation Rooms (CR), where the first appointments and follow-up visits occur; and other CR and Oncology Ultrasound Rooms (re-evaluation or interventional ultrasound), where biopsies of both superficial and deep tissues are performed. A multidisciplinary panel, which was comprised of two oncologists, two psychologists, a psychiatrist, two medical statisticians, a volunteer and a nurse, identified some working areas and formulated the questionnaires. The definition of the questionnaires included the formulation of homogeneous groups of questions which could be compared and, at the same time, representative of the specific situations experienced by patients in each waiting room. For this reason, the questionnaire for the DH included specific questions on the emotions experienced by patients while waiting to receive treatments (Fig. 1). For the CR, the questionnaire was specifically related to the emotions experienced while waiting for the examination and/or the communication of the diagnosis (Fig. 2). We decided not to use standardized and validated questionnaires because we aimed to investigate specific issues which were different for each of the waiting rooms. The questionnaire consisted of a single page divided into three sections. The graphics were simple, and the characters were easy to read. In the first section, a series of sentences regarding feelings, thoughts, experiences and strategies to reduce the unease of the waiting room were reported. Patients were asked to rank the four sentences that they could more readily identify with in that moment. The second section regarded the collection of simple demographic data such as gender, age and whether the patient was accompanied by somebody. In the third section, the eight primary emotions (joy, fear, sadness, placidity, anger, disgust, surprise and

serenity) were listed: the patient was asked to state one or two emotion(s) prevailing in that moment. Filling out the questionnaires took (on average) between three and five minutes. Statistical analysis focused on the description of the distribution of absolute and relative frequencies of all answers collected from the questionnaires. All data were entered into a spreadsheet, and each sentence and prevalent emotion were represented as a percentage of the total number of patients.

RESULTS

Out of the 318 questionnaires delivered, 280 were considered valid for statistical analysis. The remaining 38 were left blank. Of the valid questionnaires, 32.5% ($n = 91$) were filled by males and 67.5% ($n = 189$) by females, equally distributed between the three waiting rooms. The mean age of the patients was 54 years (range: 39 – 84) for the DH, 62 (32 – 90) for the first CR and 57 (24 – 88) for the second CR/Ultrasound. The majority of patients who came to the DH (58%) and first CR (55%) were accompanied, while this percentage was slightly lower for patients at the second CR/Ultrasound (47%). The results of the questionnaire are resumed for DH in Figure 3A and for the CRs in Figure 3B. Regarding the analysis of the first part of the questionnaire (on the feelings perceived while waiting), the sentences that were more frequently selected in DH waiting rooms were the following:

- 'I face chemotherapy thinking that it will be useful to defeat the disease' (56%);
- 'I am waiting for treatment, and I feel anxious' (48%);
- 'I try to focus only on positive thoughts' (39%).

Other sentences that were selected by more than 30% of the patients were:

- 'I think it would be useful to have something to distract me in this moment' (35%);
- 'I feel like talking and sharing my feelings with the people I meet here while waiting' (34%);

- 'I am worried about the side effects of chemotherapy' (32.5%);
 - 'I think that listening to music could be a way to help spend the waiting time' (30%).
- For CR and CR/Ultrasound waiting rooms, the sentences most frequently chosen were:
- 'I have the feeling that here time goes by more slowly' (first CR 71%, CR/Ultrasound 59%);
 - 'I try to focus only on positive thoughts' (61% and 43%);
 - 'I am waiting for treatment, and my anxiety is increasing' (55% and 51%);
 - 'My thoughts are all focused on the outcome of the examination' (50% and 51%);
 - 'I think it could be useful in this moment to have something to distract me' (36% and 35%).

For the CR/Ultrasound (unlike the other CRs) the sentence, 'I feel like talking and sharing my feelings with the people I meet here while waiting' was chosen by 31.5% of patients. Upon the analysis of the third section of the questionnaire on prevailing emotions, these feelings emerged (Fig. 4):

- Sadness, 51% of all patients (DH 53%, CR 48% and CR/Ultrasound 46%);
- Fear, 29% (23%, 30% and 32%);
- Surprise, 16% (10%, 17% and 18%);
- Anger, 15% (16%, 14%, and 12%);
- Disgust and joy were reported only by a small group of patients (3% and 7%, respectively).

We did not collect any information on the disease or personal data of the patients other than age or gender in order to enable patients to freely express their thoughts while keeping the information anonymous.

DISCUSSION AND CONCLUSIONS

Cancer is an organic disease with deep psychological implications that has an impact on the experience of patients from an emotional and relational point of view. Different studies de-

scribed these psychological implications in terms of a greater incidence of post-traumatic stress syndrome [6–10], a high incidence of depressive syndromes [11, 12] and marked levels of anxiety [13, 14]. This results in a poor quality of life, a reduction in tolerance and compliance to anti-cancer treatments with a negative impact on prognosis [15] and the need for emotional support during and after treatment [16]. The time spent in waiting rooms of oncology centres is an integral part of the treatment process. Therefore, it could be interesting to explore the way in which patients experience spaces and time in order to better understand their complex psychological situations. Domínguez-Nogueira analysed the experience of cancer patients in the waiting room and revealed that these patients need a comfortable environment [2]. In our study, the most frequently chosen sentence by patients in the DH was 'I face chemotherapy thinking that it will be useful to defeat the disease' (56%). The presence of a mental and emotional approach, focused on the acceptance of chemotherapy as a necessary process for the treatment of cancer, is considered positive. Regarding the implication of emotions, Coyne documented that 29% of patients with breast cancer in the waiting room met the criteria for 'distress'. Many of these women had to start pharmacological treatment [17]. Instead, in the CR and CR/Ultrasound waiting rooms, the most frequently selected sentence was 'I have the feeling that here time goes by more slowly'. We can speculate that, in the DH, patients are aware that they are waiting for a specific treatment that has already been decided upon. This helps to maintain a good mood and focus on a specific goal, i.e., to defeat the disease. In the CRs, the patients who are waiting for a diagnosis or follow-up visit do not see this association with a specific treatment, which leads to a higher level of anxiety ('I have the feeling that here time goes by more slowly'). Similarly, in her study, Catania indicates that cancer patients also experience anxiety and boredom during their stay in waiting rooms due to interaction with other oncological patients. The domi-

nant wish seems to be for entertainment with some recreational activities (TV, games), spirituality (a place of prayer) or meeting health practitioners (doctors or psychologists) [1]. In another study, significant levels of anxiety in patients waiting for diagnostic tests were reported [4], and marked levels of distress were documented in women in Radiology waiting rooms [3]. Despite the fact that the questionnaires and statistical analysis evaluated the answers given by each waiting room separately, the most frequently represented emotions in the sample were sadness and fear without any difference among the three waiting rooms. This finding may suggest that the prevalent emotional state of patients while waiting does not depend upon the reason for waiting. Interestingly, we could estimate that about 50% of patients claim that they feel anxious in all settings, whether they are waiting for chemotherapy or a follow-up visit. In our series, we didn't collect any data on patients' disease. This choice was made in order to focus only on patients' emotions without being conditioned by other factors. However, we certainly believe that each type of cancer has different implications for the patients, concerning medical and psychological aspects, but the analysis of these differences wasn't the aim of our study. For the same reason, we didn't collect data about the moment in which questionnaires were filled (before the beginning of the therapy or after its administration) or

data about the presence of caregivers in the waiting room. On the basis of these results, we believe that particular attention in preparing the environment, while considering the psychological impact of waiting rooms, could represent an important intervention both in reducing anxiety and depression as well as reinforcing a positive attitude of patients. These factors may help patients acquire flexibility and adaptability in their ways of thinking. Pruyn et al. showed that the use of TV in waiting rooms can distract patients, especially if the time spent waiting is long [18]; a recent study conducted in the waiting rooms of an emergency department showed the positive impact of 'visual arts' (image and sound to distract patients) both for patients and caregivers [19]. We believe that each oncologist should be aware of the levels of fear and sadness that patients experience during an oncology examination because these emotions can have an impact on communication and understanding, further confirming that communication between doctor and patient develops in subsequent steps. Our work could represent an interesting starting point for further studies, in which (by administering a validated questionnaire) it would be possible to define interventions in the environment, especially in waiting rooms, which could be effective in reducing the anxiety and fear experienced by patients and producing a positive elaboration of the disease.

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WAITING ROOM – ground floor

Brief questionnaire for a project that would like to improve the way you spend your time while in the waiting room

Dear patient, we are trying to improve the difficult moments spent in the waiting rooms of the Oncology Department. To help us better understand how you feel, we kindly ask you to fill in this anonymous questionnaire by selecting the four sentences in the list that best describe how you are feeling at this moment.

Please read all points before choosing the 4 answers.

QUESTIONS (Q)

1. I am waiting for treatment and I feel anxious

2. I find the people around me irritating

3. I face chemotherapy thinking that it will be useful to defeat the disease

4. I feel like talking and sharing my feelings with the people I meet here while waiting

5. I think that waiting increases my fear of not feeling well

6. I think the decor of this room is comfortable

7. I think it would be useful to have something to entertain me in this moment

8. I have been waiting for a long time and I have the sensation of feeling more physical pain

9. I think of my disease as an opportunity for personal growth

10. All my thoughts are focused on the liquid they must inject

11. I try to focus only on positive thoughts

12. Waiting for chemotherapy increases nausea and/or other symptoms

13. I try not to look around

14. A book or a magazine helps me feel connected to my interests and keeps negative thoughts away

15. I'm worried about side effects that chemotherapy can cause

16. I think that listening to music could help spend the waiting time

Now choose 1 or 2 emotion(s) that you are experiencing most in this moment

<input type="checkbox"/> Joy	<input type="checkbox"/> Anger	Are you accompanied by someone?
<input type="checkbox"/> Fear	<input type="checkbox"/> Disgust	<input type="checkbox"/> yes <input type="checkbox"/> no
<input type="checkbox"/> Sadness	<input type="checkbox"/> Surprise	<input type="checkbox"/> Male <input type="checkbox"/> Female
<input type="checkbox"/> Placidity	<input type="checkbox"/> Serenity	Age

Figure 1. Questionnaire administered in Day Hospital

WAITING ROOMS – 1st and 2nd floor

Brief questionnaire for a project that would like to improve the way you spend your time while in the waiting room.

Dear patient, we are trying to improve the difficult moments spent in the waiting rooms of the Oncology Department. To help us better understand how you feel, we kindly ask you to fill in this anonymous questionnaire by selecting the four sentences in the list that best describe how you are feeling at this moment.

Please read all points before choosing the 4 answers.

QUESTIONS (Q)

1. I am waiting to be visited and I feel anxious
2. I find the people around me irritating
3. My thoughts are all focused on the outcome of the examination
4. I think the decor of this room affects my mood
5. I think it would be useful to have something to entertain me in this moment
6. I think that waiting increases my fear of not feeling well
7. I think of my disease as an opportunity for personal growth
8. I feel like talking and sharing my feelings with the people I meet here while waiting
9. I have a feeling that the time here goes by more slowly
10. Waiting increases some physical symptoms (nausea, fatigue, dizziness...)
11. I try to focus only on positive thoughts

Now choose 1 or 2 emotion(s) that you are experiencing most in this moment

- | | | |
|------------------------------------|-----------------------------------|---|
| <input type="checkbox"/> Joy | <input type="checkbox"/> Anger | Are you accompanied by someone? |
| <input type="checkbox"/> Fear | <input type="checkbox"/> Disgust | <input type="checkbox"/> yes <input type="checkbox"/> no |
| <input type="checkbox"/> Sadness | <input type="checkbox"/> Surprise | <input type="checkbox"/> Male <input type="checkbox"/> Female |
| <input type="checkbox"/> Placidity | <input type="checkbox"/> Serenity | Age |

Figure 2. Questionnaire administered in Consultation rooms and ultrasound

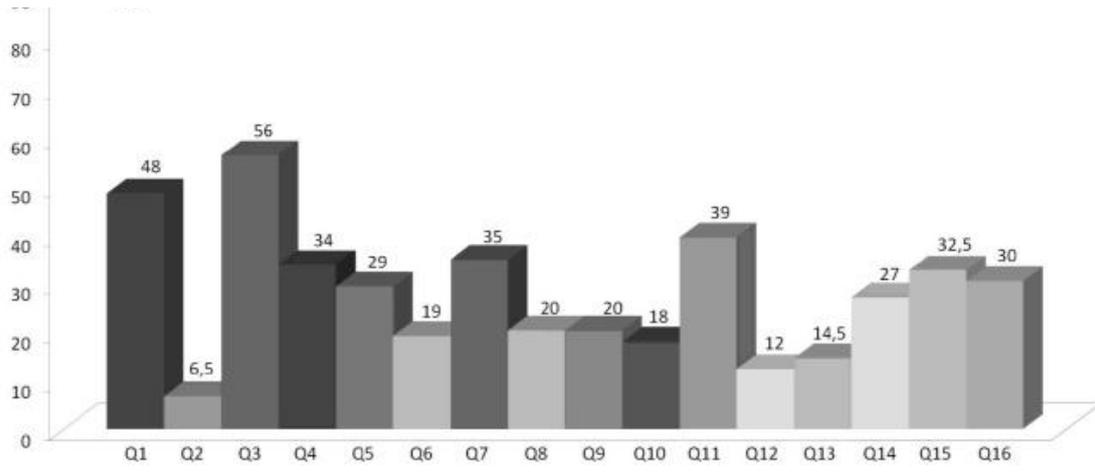


Figure 3b - Responses to the questionnaire at CR

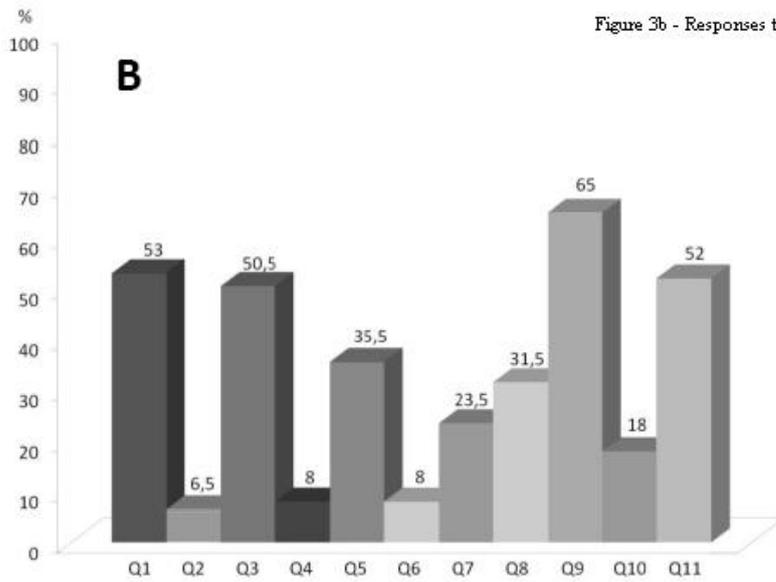


Figure 3. A: Responses to the questionnaire in DH (Day Hospital)
 B: Responses to the questionnaire in CR (Consultation Rooms)

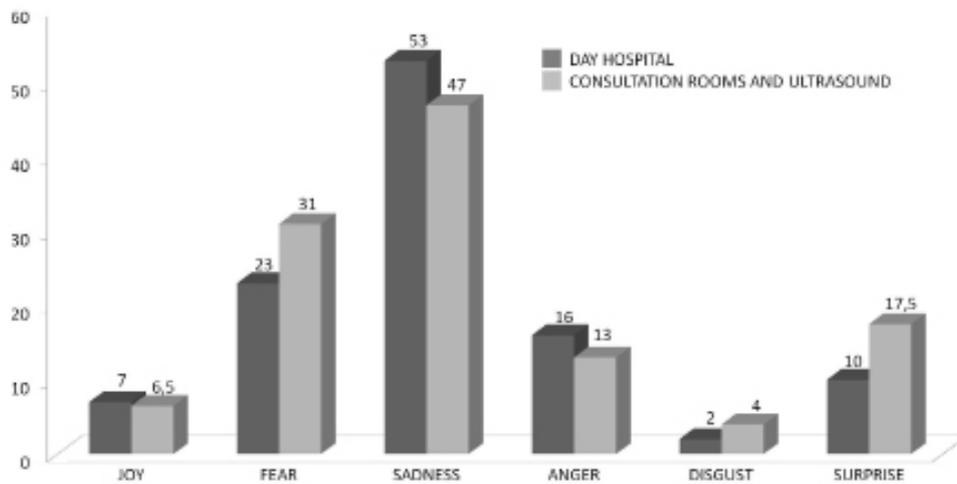


Figure 3. Responses of the most frequent prevailing emotions at DH, CR and CR/ultrasound

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