Meeting the needs of cancer patients: identifying patients', relatives' and professionals' representations

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Abstract. Background and aim: The literature on cancer patients agrees that most of the cancer patients' needs often remain unmet. How are these different needs perceived by patients, relatives and professionals? The present research has tried to make a contribution by analysing evidences of the needs, especially unmet, that different actors attribute to a cancer patient. Method: A total of 42 Italian participants (76.2% women) took part in the study. Patients, relatives, physicians, nurses, social care assistants and volunteers participated separately in six focus groups. Three face-to-face interviews were conducted with psychologist, general practitioner and social worker. All focus groups/interviews were processed through an analysis of thematic content. Results: The results showed a priority given to the need for information, and also the importance of psychological and social support needs, confirming that they remain unmet. Differences between participants are visible by looking at the needs cited more frequently. For example, the oncologists are more sensitive to information needs related to the illness and its treatment, while the social worker cited the need for social, economic and legal assistance more frequently. The nurses highlighted the need for continuity of care, and the psychologists underlined the importance of psychological support, while the relatives cited the need of support both from and for families. Conclusions: Results suggested that a comprehensive approach that addresses medical and psychosocial factors is needed. Cancer patients must be provided with a multidisciplinary survivorship care plan that addresses information related to their long-term care and identifies available psychological and social services. (www.actabiomedica.it)

Key words: cancer, oncology, needs, patients, relatives, professionals

Introduction

The literature about cancer patients agrees that most cancer patient needs often remain unmet (1-5). The problems are related to poor communication with medical staff, lack of knowledge about the disease and its treatment, but also the substantial underestimation by professionals concerning the psychosocial needs of cancer patients (6, 7). Many studies highlight that cancer patients need deeper and wider information about the disease and its treatments to better understand the challenges that the illness brings, and to be able to make informed decisions about different treatments, as well as improving adherence, increasing the ability to cope during the diagnostic and treatment/post-treatment stages, and reducing the probability of anxiety and mood diseases (8-11). The content of needs ranges from issues related to clinical

care to financial, employment and legal issues, such as ticket exemptions and/or recognition of disability (8, 12). Many studies have in fact demonstrated that patient satisfaction is enhanced when physicians attend to the emotional needs of patients and assess the patient's comprehension, satisfaction and well-being (13, 14). Patients require psychological support and interventions that promote their social and occupational reintegration (6). Nevertheless the studies that have investigated the suitability of the information offered during the medical examination, have shown that many patients were not offered sufficient tools to make informed decisions (15). For example, Gattellari et al. (16) found that in a group of patients with advanced disease: only 58% had discussed life expectancy, only 36% the impact of therapy on quality of life, only 60 % had addressed the uncertainty of the benefits of visits, and only 44% had considered the optional treatment or supportive care. A more effective dialogue between health professionals and patients would therefore facilitate the understanding of the information (12) and encourage the active participation of patients to care choices (17). In this process, the health providers not only have to offer clear medical information, but also sensitive communication, empathy and support. They have to evaluate patients' and careers' needs, and develop better communication channels to address gaps in knowledge and in existing support networks (11, 18). Nevertheless, especially after treatment, these needs frequently remain unmet. On leaving the hospital, patients may not understand how to manage their health-care condition or whom to call if they have a question or if the condition gets worse (19, 20). They asked in fact to be better cared for in the transition from hospital to home (21, 22). The continuity of care regards the extent to which the health information is coherent and linked, and it depends on the quality of information flow, interpersonal skills and coordination of care (23-25). The fulfillment of these needs could be enhanced through the integration of diagnostic-therapeutic continuity of care, in order to optimize the management of cancer patients, and integration with the non-profit sector and volunteering, to enable synergies of resources to support the difficulties encountered in the course of disease. A collaboration between Health Services and

Association may promote active participation of their patients/members (6). Indeed, optimal care no longer consists only in having the best medical therapy, but in maintaining a good quality of life from diagnosis until the advanced stage of the disease (26, 27). The assistance should define the timing and manner of care, to ensure hospital discharge pathways accompanied by a detailed assessment of the state of mental and physical health and an assessment of the network of family support. Realize the care should, therefore, be an active involvement of a multidisciplinary coordinated team which will provide, together with the patient and / or family members, the course of care and treatment more effective (6). While many studies have analysed the cancer patients' points of view, fewer studies have in fact analysed the points of view of others, such as the professionals, carers and volunteers . So the aim of this study was collect and analyse evidences about the needs that different actors attribute to a cancer patient. The research questions were as follows: What needs, including those mentioned in the literature, are shared by patients who have returned home? What perceptions do family members, health and social professionals have of these needs? What are the areas of correspondence / differentiation between the patient's perspective and that of the professionals? What are the implications of the differences and similarities of the needs reported throughout all the groups?

Method

Participants

The research has been conducted in a region within the center of Italy. Health Cancer Service' professionals, members of cancer associations, cancer patients and relatives – a total of 44 participants (34 woman) – took part in this study (Table 1). It was a convenience sampling.

Patients and relatives were contacted through voluntary associations, but unfortunately only a few of them have joined the research. The criteria for inclusion of patients were: be informed of the diagnosis and suffering from any type of cancer. Another criterion for inclusion was that they had to be, at the time of the

Focus group/interviews	Ν	Gender	Role	Affiliation
Patients	4	females		
Relatives	5	2 males	Brother Son	
		3 females	Wife Daughter Nephew	
Nurses	7	3 males	2 Nurses 1 Nurse	Oncological Day Hospital-University Teaching Hospital Home Care Service/Local Public Health Unit
		4 females	3 Nurses 1 Nurse	Home Care Service/Local Public Health Unit Oncological Day Hospital -University Teaching Hospital
Oncologist	10	3 males	1 Director of Oncology Department 1 Director of Complex Oncologic Unit 1 Director of Joint Oncology Unit	University Teaching Hospital
		7 females	4 Specializing Oncologists 3 Managing Doctors	
Health and social care assistants	7	females	/	"Pro.Ges" – Social Cooperative- Integrated Service for People
Volunteers	8	1 male	1 Volunteer	"A.Vo.Pro.Ri.T." – Voluntary Association of Cancer
		7 females	1 Volunteer 6 Volunteers	"A.Vo.Pro.Ri.T." – Voluntary Association of Cancer Research Promotion "Verso il Sereno"- Voluntary Oncology Association
Social Worker	1	female		University Teaching Hospital
Psychologist	1	female		University Teaching Hospital
General Practitioner	1	male		Primary Care/Local Public Health Unit

Table 1. Description of the participants (N = 44)

survey, in the remission stage of the disease. We excluded patients with cognitive deficits and/or aphasia.

There were four patients (all women) and among them three had breast cancer and one had a sarcoma, five relatives (three women), ten oncologists (six women), seven nurses (three women), seven social care assistants (all women) and eight volunteers from cancer associations (seven women). One psychologist (a woman), one social worker (a woman) and one general practitioner (a man) also took part in the survey.

Instrument and data analysis

Patients, relatives, physicians, nurses, health and social care assistants and volunteers from cancer associations participated separately in six focus groups. Because of numerically inadequacy of participants for the focus group establishment (28), three face-to-face in-depth interviews were also conducted with the psychologist, general practitioner and social worker who gave their informed consent. The focus groups/interviews were conducted by researchers in order to investigate the perception of the most important needs of cancer patients. The researchers used a topic guide (eg. "describe, in base of your own experience, the most important cancer patient needs"). The average length of the focus groups/interviews was 60 minutes. The focus groups were conducted by two researchers, while the interview required only one. All focus groups/interviews were audio-recorded, transcribed verbatim and processed through the analysis of thematic content. The analysis consisted in splitting the text into sentences and into their classification in synthetic cores or subcategories (29, 30). The data was analyzed together at the end (one thematic framework) and not throughout the data generation. The five researchers independently coded the needs into 10 different categories. They regularly met with another researcher to resolve disagreements during coding. At the end, the inter-rater agreement on the subcategories was excellent (Fleiss' kappa, 31). We report on the occurrence of each theme in the group of participants involved. Quotations offered by participants are provided in order to illustrate the emerging theme.

Results

This section illustrates the need categories and their occurrences. The reported frequency corresponds to the total count of times that each category has been used by each group of participants or by the three partecipants interviewed.

Clinical-therapeutic needs (N = 161 out of 283) This is a health-care area of needs and includes five subcategories of needs.

Need of Information (N = 63 out of 160)

According to general practitioner (N = 2), oncologist physicians (N = 10) and especially to nurses (N= 17) a core need of patients is to have adequate clinical information. They declaimed how difficult it is, despite the clarity of technical communication, to be sure that patients have understood what they are actually told: "Our information goes in and out, with high emotional content, and therefore is usually not captured. So we usually find ourselves faced with the need to repeat several times the same things to different people" (Oncologist 8). From the perspective of volunteers, the information (N = 3) should be accessible and simple, with particular care as to whether and how it is understood: "even young people are so confused" (Volunteer 7).

This is a high need for patients (N = 6) confirmed that the need for medical information is not met in a clear and simple way. They said that the manner in which this is offered has not yet been adequately organized. "So, the need to have things clear but not in this impudent way!" (Patient 3). From the quotes it seems the patients are more concerned with how the information is presented to them than with the actual content of the information.

Even for relatives (N = 5), information is often lacking, and should be provided with sensitivity and a certain delicacy, especially in the communication of bad news.

The psychologist emphasizes (N = 6) the need to ensure adequate clinical information, while the social worker (N = 10) and health and social care assistants (N = 4) place emphasis on wider information, rincluding also the local available resources: "Patients need to be informed about their illness, the chances that one has, about who can help the family [...] or in supporting the work. [...] All possible resources that can be found in social services and also monetary assistance" (Social worker).

Need for continuity of care (N = 47)

Nurses are the group that more frequently mention the patient's need to be assisted with continuity of care from hospital to home (N = 24). It means that the hospital continues to provide care for them. The lack of proper care can actually be seen after the discharge: *"The path of care has suffered from gaps [...]not being able to manage the assistance after the return home" (Nurse 3).*

Also, the volunteers highlighted the fragmentation of care (N = 8): "then [patients] lost points of reference" (Volunteer1). Even for oncologists (N = 5), practitioners (N = 2) this need is not satisfied. The social worker emphasizes (N = 3) that in hospital the expectations for the examinations are long and there is no case-manager physician: "Do not always have the same doctor [...] Today I saw this one, the next day I saw another." Continuity of care is rarely mentioned by health and social care assistants (N = 1), psychologist (N = 1), relatives (N = 1) and by patients themselves (N = 2): "I

felt abandoned by the hospital! Fortunately I had the association" (Patient 3).

Need to be considered as a whole person (N = 23)

The patients express how overwhelming the need is to be treated with dignity and humanity during care (N = 10); they reported the experience of being ghettoized as a sick person or otherwise classified as a patient. This, "make[s] you feel more sick than you are, you know?" (Patient 1). Some nurses (N = 7) and one relative (N = 1) emphasized the lack of attention to respect for the whole person, especially in the communication of a bad diagnosis: "Sometimes it lacks the human side" (Relative 4). Even for oncologists (N = 3) and social worker (N = 2), respect for the person is a weak point of the care: "It is important to focus on the wholeness of the person" (Social worker).

Need to be assisted with expertise (N = 14)

Physicians (oncologists, N = 5; general practitioner, N = 3) but also relatives (N = 4) underlined that patients need to be assisted with expertise, and through precise guidelines, supporting the care pathway. "*The patient should be understood above all in his family background and in his problem. You must try to make appropriate decisions and get out from the patient what he can endure, can understand, can hold*" (Oncologist 1). This need is less frequently mentioned by volunteers (N = 1) and patients (N = 1).

Need for pain relief (N = 14)

Nurses (N = 7), general practitioner (N = 3), health and social care assistants (N = 2) and relatives (N = 2) emphasized the need for patients to have pain relief treatments and pointed out that in Italy there is still not a well-established culture against the patient's suffering: "Doctors in Italy are really afraid to use opioids, perhaps because of the rules which see them directly responsible" (General practitioner); "The biggest problem was the pain [...] I had to beg for morphine!" (Nurse 7). Unexpected, this need was not mentioned by patients.

Psychosocial needs (N = 85 out of 283)

This area involves aspects of both social and psychological needs and includes three subcategories of needs.

Need for psychological support (N = 36)

As we may have expected, the psychologist (N = 8) gives greater emphasis to active listening and psy-

chological support, noting that this need is still not satisfied. The reason is a lack of staff, and of psychologists that visit patients at home: "There is a strong demand for supporting [...] talks soon after diagnosis, sometimes when there are decisions to be taken [...] there is the anguish and anxiety. This is very frightening for them. They feel guilty if their mood is not good" (Psychologist).

Nurses (N = 7), general practitioner (N = 4), oncologists (N = 4) and social worker (N = 4) often cited the psychosocial needs: "patients need to be listened to in a more empathic way" (Nurse 4). To answer the psychosocial needs of patients, the physician identified, as the ideal figure, the psycho-oncologist, who supports the patient and family: "the psycho-oncologist is a figure present in other states, but still missing in Italy" (General practitioner). The need for support is also emphasized by the patients (N = 3), volunteers (N = 3), relatives (N = 2) and health and social care assistant (n = 1): "They sent me a nurse that was close to me, all the way. I could talk about everything with her. [...] Doubts, worries, things that were happening to me from time to time, new information that I did not understand [...]. I had great help (Patient 3).

Need for support from and for family members (N = 39)

The health and social care assistants (N = 5) and the social worker (N = 5) spoke about the difficulties that relatives faced in the role of carers, noting the lack of adequate support: "Relatives are often powerless in the face of this disease" (Health and social care assistant 5); "[Cancer] creates a huge difficulty in the family" (Social *worker*). The relatives themselves (N = 3), as well as the volunteers (N = 3) and the psychologist interviewed (N = 3), emphasize the importance of support for patients that live a sense of loneliness: "I felt very alone [...] I missed that one person to say to me, "Madam, your husband is in this condition, so you have to do so and so to obtain this or that" (Relative 1). "The family members are lost, they don't know which road to take" (Volunteer 5). "Yes, and they feel fear" (Volunteer 7). However, the physicians (oncologists, N = 2, general practitioner, N = 2) and the patients themselves (N = 2) are not insensitive to the family problems: "It's part of the humanitarian and empathetic role of the doctor" (General practitioner).

In particular, relatives acknowledge that their assistance and support can be of great help in dealing with the illness of a family member (N = 14). *"I think* Need to return to daily lives (N = 10)

The awareness of the need to return soon to personal routines is strongly felt by oncologists (N = 6). They recognized the patients' need to regain a "lost humanity", overlooked in the care pathways: "We had a morning dedicated to make-up and beauty treatments in our centre [...]there were some patients who were crying with emotion and with joy. For the first time, in many years, these women were putting on lipstick and felt like women again [...]Maybe you need to have these gathering and sharing moments, seeking relief from problems. They need something normal!" (Oncologist 9). Even volunteers (N = 2) and patients (N = 2) recognize "the patients' need to live a normal life" (Patient 4).

Instrumental needs (N = 25 out of 283)

This area includes the need to be supported materially, economically and at work. This need is particularly cited by the social worker (N = 11): "The patients need to be informed about their illness, opportunities, about who can help the family or support their work [...] About all of the possible resources that can be found in social services, such as civil disability" (Social worker).

Patients (N = 6) and relatives (N = 1) are sensitive to that need: "This becomes complicated if one is not informed well" (Patient 1).

Volunteers (N = 4) and health and the social care assistants (N = 3) pointed out the need that patients and families have regarding protection in work or economic subsidies, highlighting rights that often patients are not aware of: "The relatives are entitled to work permits and they don't know it" (Volunteer 5); "They need economical help" (Health and social care assistant 6).

Interestingly, this need was not mentioned by the nurses.

Need for cooperation between the various actors in cancer care (N = 12 out of 283)

This area includes the *need for cooperation between associations and social and health services*. The oncologists (N = 3) and the social worker (N = 3) recognized the need for increased collaboration between hospitals and associations dedicated to cancer patients, noting that the associations are often disjointed and compete with each other. Furthermore, many local services are not coordinated in a network: "It is possible to create a network of services [...] and it acts as a bridge between professional ward staff and external colleagues. All of them are useful reference points for patients to get information and be helped to access and use the local services, such as economic help, family support, applications for disability support and accompaniment" (Social worker). Nurses (N = 2) highlight the poor and inadequate communication between hospital and the community services. They underlined the importance of a global care and of a sharing treatment plan: "In 14 years we had two or three experiences of continuity of care in the hospital [...] These experiences were the best: talking with colleagues, with the doctor of the department and also with the general practitioner [...] This is the perfect customized care plan"(Nurse 4).

Volunteers also highlight how collaboration between hospitals and general practitioners is still a weak link in the system (N = 2). The health and social care assistants complain about the fragmentation of services (N = 2): "Many patients say: 'is it possible that there is not a figure here that gives me information, that tells me what to do, where I have to go? From an office they tell me to go somewhere else, then tell me that I need a paper there and then tell me that I need another.' Patients flock in this whirlwind of bureaucracy! [...] A common request of the families is a greater collaboration between our service and nursing home care. But because of the different organizations and different routines, this collaboration is weak" (Health and social care assistant 3).

Discussion

The aim of this study was to explore, through a qualitative study, the perceptions that patients, relatives and professionals had about the needs of people affected by cancer. For this purpose, the present study aimed to examine not only the patients' opinions about their needs, but also those offered by relatives and professionals from health services (doctors, nurses, health and social assistants) and from psychosocial services (psychologist, social worker), and by volunteers from oncological disease associations. The goal of the research was to offer a broader range of suggestions for future interventions.

The first notable result obtained is about the priority given to the *clinical-therapeutic needs*, and in particular to *the need for information*, as other studies have found. For example, Tunin (32) showed that almost all of the informational needs were ranked higher than support needs on level of importance. The issue of lack of information has been addressed by all participants in the present research both in terms of contents and of styles of communication.

With regard to the contents, participants spoke about the information needs especially with a medical, clinical and therapeutic meaning. Results confirmed the review of Ankem (8): the need for illness-related (about diagnosis, chances of cure, spread of disease, prognosis) and treatment-related (possible treatments, progress during treatment, side effects) information were cited more frequently than any other type of information from patients. However, in the present study, a broad examination of different perspectives offered by the social worker and health and social care assistants underlined the need for cancer patients to be informed about social assistance, legal and work protection, and monetary support (12). This is also confirmed by needs related to economical and legal support, well underlined by patients and especially by the social worker.

With regard to the "style" of communication, participants agree that good communications with healthcare professionals still remains an unmet need. Patients expected to be helped to understand the information they already knew and needed to have a more effective dialogue with health professionals (12). The importance of clear information was well recognized in health settings. But patients and professionals in the present study also reported insufficient exploration of the personal situation and poor information (33). Even if health professionals showed that they were able to reflect critically on their role, in providing information and identifying emotional factors that affect communication, they also assume that information is not necessarily understood or retained by patients and maybe incremental information is desirable (34). They also seem aware that the primary care physicians play a basic role in this process, providing medical issues and

offering psychosocial support (32, 35), improving significantly health-care satisfaction for patients (36, 37). But still, many misunderstandings voiced by participants arise from communication problems with health professionals underlining that this need deserves to be improved (38).

Results also highlighted the importance of the need for an integrated approach to cancer care, encompassing diagnosis, treatment and long-term recovery (19). Different studies (39, 40, 41) pointed out that continuity is an unmet need across the continuum of care, but primarily after treatment. So, more effort must rather be put into making transitions more effective, and increasing the perceived sense of care by the patients (39), addressing a breadth of patients' needs across the cancer trajectory. Our study also confirmed previous studies (24) by underlining that while for patients the continuity of care means that providers know what has happened before, agreement on a management plan and to be cared by the same providers in the future, for providers it means having sufficient knowledge to best apply their professional competence and to be confident that care inputs will be recognized and pursued by colleagues.

Moreover, the health professionals (oncologists and nurses), as well as the volunteers and the social worker, converge to identify as primary goal of patients' well-being the superordinate need to network health services, social services and associations, as previously suggested (6). In fact, both the hospital and social professionals complained about the lack of *integration* between services, in order to take care of the person and to improve the *coordination of care and communication* between patients, carers and health professionals.

The results of the present research also showed the importance of *psychological and social support needs* (42), confirming that they remain unmet (43). Oncological disease may have a strong impact on patients' psychological distress and quality of life, anxiety and depression at all stages of the disease. So, the participants of this research also need to return to daily life to be *psychologically supported* during the care path and *regain possession of their daily lives*, in terms of rhythms, habits and identity. They highlight the need to "patch up" a biographical gap between their present life and the onset of illness (2, 4, 44, 45). As Holland (46) pointed out, the psychosocial assessment and the management of the psychosocial distress is part of the cancer care. In particular, patients who report higher physical distress and lower satisfaction with their health care need to experience the highest level of supportive care (47). Also, the present study highlights the need for emotional and social support. Several psychosocial interventions have been found to be effective in reducing the level of distress and improving the quality of life among cancer patients (48). Nevertheless, the patients of the present study didn't like to be categorized as "a cancer patient" or "cancer group member". They need to be treated as *a whole person*, to be considered more than a patient and to be cared for and not just cured.

The results have shown that, in meeting the psychosocial needs, the social support offered by the family plays a significant role. As we stated before, supportive social relationships contribute to psychological need satisfaction and psychological adjustment (49, 50). However, as the participants pointed out, the carers may have, in turn, need for support (51). A disease, in fact, often makes the family group fragile and unable to face the uncertainty of the future (52). A recent evidence-based study showed an increase in awareness of the long-term negative impact of cancer on the family caregiver's quality of life (53). The relatives and patients of the present study were well aware of this risk and required support and assistance in coping. The relatives can assist health professionals to address concerns in a timely and appropriate manner either themselves or through referrals to other care team members or specialist providers. Carers may offer a potential solution to the limited resources available in health services.

Differences between participants are visible in the cited frequency of each need. As expected, the different perspectives about the most important needs were strictly connected with the different roles of participants. So, for example, the oncologists was more sensitive to illness and treatment information needs and to the needs of daily life, while the social worker cited more frequently other kinds of information, such as economical and legal assistance. The nurses working in hospital and in the territory highlighted the need for continuity of care, the psychologist pointed out the importance of the social and psychological support needs, and lastly the relatives often cited the need to have support from and for families.

The patients mostly underlined the need to be considered as a whole person and not only as a person suffering. To be considered as a suffering person could, in fact, threaten their identity already threatened by the disease. Another priority was to be well informed about the disease and its therapy, receive support materially and economically, or be protected at work. It is interesting that other groups recognize this prioritizing need very rarely. The need to be considered as a whole person is well acknowledged by nurses, while oncologists recognized the need of information and the social worker recognize the instrumental needs. Implication is that other professionals need to be better informed about the most important needs declared by patients. Nevertheless, the different participants' points of view all agree that the cited needs are still not perceived or not completely fulfilled. The experience of oncological disease will lead the person towards redefining meanings, priorities, values, relationships, roles and habits. Giving care therefore means paying attention to the psycho-social and instrumental needs, as well as the clinical care of patients and their families, in addition to offering appropriate patient care pathways which are as personalized as possible.

Increasing numbers of cancer patients survive and the complexity of the care place large demands on care providers. The extent of care thought to be required for cancer survivors has changed to a more comprehensive approach that addresses medical, psychological and social factors, suggesting that a multidisciplinary perspective of survivorship care is needed (35). Cancer patients need to be provided with a survivorship care plan that addresses information related to their longterm care and identifies psychological and social services available over time (54). For this reason, a structural and organizational change could help professionals, relatives and patients manage the cancer care path. A recent Italian study contributes to this direction, by planning an "Integrated Operating Point" (I.O.P.) dedicated to cancer patients and their relatives handled by different professionals: psychologists, oncologists, nurses, social workers and volunteers, but also a plastic surgeon, beautician, physiotherapist, speech pathologist and radiation oncologist (55). The establishment of I.O.P. can address the different needs and aspects of assistance in an integrated manner, overcoming the fragmentation of social or health services and associations. In this sense, the I.O.P. is placed as a system characterized by strong interconnections between hospital and territory, including social and health care, in a culture that is centered on patient and families living the experience of oncological disease welfare.

Limitation

Focus groups are able to capture experiences and opinions from many people in a short amount of time with a facilitating effect because of the inclusion of patients, relatives and professionals who have had similar experiences (56). The limitations of the present research are the restricted number of each focus group's participants, the changes of attitudes due to dynamic group processes during evaluation, and the convenience sampling used here. Moreover, the focus groups are not always balanced between genders. It would also be interesting in future research to testify whether different results would be gleaned from different patients and professionals and to compare results obtained by mixed-method analysis. Other important limitations are the limited number of views point and the problems with generalizing data to other individuals. In particular, this concerns patients who have just received a diagnosis, and which is not currently in the remission stage of the treatment.

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