


Discussing communication issues and needs with adolescents with cancer

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Abstract

Adolescents with cancer face unique medical and psychosocial challenges and it is important for their doctors to understand the psychological manifestations of cancer diagnosis and treatment in this age group. Using patient dialogues, we describe how simultaneous participation of physicians and patients could help to give voice to patient needs, in particular concerning communication.

Keywords

Adolescents, cancer, communication needs, psychosocial support

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Adolescents with cancer face unique medical and psychosocial challenges that differentiate them from older or younger patients. A diagnosis of cancer can disrupt the developmental process underway during adolescence, affecting the individual's physical appearance and body image, relationships with others and social life, sense of independence, and plans for the future. Adolescent patients strongly need to ensure their life is not dominated by their disease.^{1,2} Professionals caring for adolescents and young adults need to find ways to engage with their patients.^{3–5} As physicians, we must be aware that young people with cancer have many unmet needs. We should let our patients tell us what they need.

We describe our experience at the Adolescents and Cancer conference, Rome, November 11, 2019. The meeting was organized by the Committee on Adolescents of the Italian pediatric cooperative group Associazione Italiana Ematologia Oncologia Pediatrica (AIEOP).⁶ In addition to physicians, psychologists, nurses, and parents' associations, the meeting was also attended by 35 young patients from 15 different Italian centers. These patients ranged from 16 to 24 years of age. One in four of them were being treated at the time; the others were being followed up after completing their therapies. The sample of patients had been invited directly by the organizers to take part in a 2-hour plenary session, and their participation was based on a structured interview. The aim of the session was to

gather the young people's experiences, particularly regarding doctor–patient communications at the time of their diagnosis and during their treatment. The questions covered various stages of the cancer pathway, from their first talk with a doctor to the communication of their diagnosis to their friends. The interview touched crucial aspects, such as the moment when patients became aware of the severity of their disease, the times when they felt afraid and angry, or their return to normal life (Table 1). The sessions were moderated by two doctors, who used slides

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Table 1. Questions in the structured interview designed to gather young patients' experiences during the conference.

Question	Topic
1. When and how did you realize you had a severe disease?	Building awareness of the disease's severity
2. What happened when it was diagnosed? Who were you with? What were your first thoughts at the time?	Patients' subjective experience when notified of their diagnosis, and the thoughts and emotions it aroused
3. Who was the first person you told (apart from your parents)? How did you tell them (by phone, social media, face to face)?	The action taken to communicate their predicament to others
4. What about your friends? How have they reacted to all this?	How their friendships were shaped by their experience of cancer
5. Were there times when you were afraid?	The experience of fear and how it was managed
6. Were you missing some important explanation? If so, what about? Were there any questions you did not dare ask?	Unmet needs for more information, whether it was because doctors did not provide it, or because patients did not ask
7. Have you ever cursed about what has happened to you?	Patients' angry reactions on learning their diagnosis
8. Did anyone cross the boundaries you set up around your personal space? Did it bother you, or did you appreciate it?	The disease and its treatment as a borderland
9. What things have you found helpful?	Resources and strategies used to cope with the situation
10. Who was your reference figure during your experience?	Public health operators considered as a reference figure
11. Would you have liked to talk to somebody who had been through the same experience as you?	The role of other patients
12. Have you ever written about what happened to you?	The function and use of writing as a coping mechanism
13. In adolescence, people tend to do things they ought not to. Have you ever done something your doctors told you not to do?	Compliance and adherence to medical recommendations during and after cancer treatments
14. How has your relationship with your body and your personality changed? Did you notice this yourself or did somebody point it out?	Patients' feelings about their physical self and their character after their treatment

to introduce the various topics and projected the questions on the screen in the conference room. The young participants were free to answer each question from a personal standpoint. They could raise a hand to ask to speak, and were given 2–3 minutes to have their say. The session was recorded (with the consent of all patients involved, or their parents). Some of their answers are listed, with some specific comments, in Table 2.

The young patients took part in this experiment with enthusiasm and maturity. They joined in without hesitation, and seemed unflustered by the large adult audience. They lived the conference as a genuine opportunity to get together in a safe place, where the high degree of attention of the participants generated an environment that, in many young people, facilitated the need to express themselves. When they spoke, they described the “utter darkness” that enveloped them when they were told they had cancer (they often used terms like “blackout” or everything “froze”). They also said how important it was to them to be informed properly. They explained how they told their friends about their condition (generally using their smartphones), and how they tried to get their thoughts in order: how they came to terms with the question “Why me?” They talked about how angry and lost they felt, and told us that cursing could help express such feelings (parents being often the

target), but also they talked about the importance of having a professional to guide them, and friends on the ward to share their experiences with.⁷ They told us that things were difficult from the psychological and relational standpoint afterwards, when the treatments finished, experienced as a disorienting time of uncertainty: returning to daily life was difficult because patients saw themselves as having changed and the world looked differently from before.

For the doctors, this was an opportunity to hear directly from our young patients what happens psychologically when their cancer is diagnosed and while it is being treated. We learned how important it is to let them voice their needs, and to involve them directly in any projects concerning them.^{8,9} It is crucially important to give patients a chance to be heard. They need to move on from being patients to having a more active role.¹⁰

To be more specific on the discussion on communication, the patients attending the conference reminded us that communication between doctors and patients is a multidimensional, constructive process that can strongly influence the experience of disease as a whole, in both the immediate and the longer term. They told us that communication is not just about exchanging medical and technical information, but should offer interactive solutions suited to the individual patient's priorities. The young patients said they need a

Table 2. Some of the patients' answers to the questions posed at the conference.

"What made me realize I had a severe disease was when I heard its name, osteosarcoma. Then I heard it again in slow motion inside my head. It was a pretty hard blow."

(Marta, 18 years old)

"The moment you're given the diagnosis is very important because it's when you are suddenly catapulted into a reality that you can't believe can happen to you."

(Mari, 20 years old)

"Then I understood. But I have to say that, from then on, there was a—how can I put it? A sort of blackout, a slo-mo, where you don't understand, and you don't know how to cope."

(Alessandro, 19 years old)

"The first thing I thought was 'it's just another obstacle in my life.' I mean, I couldn't have cared less about the news I was given. It was just one of many."

(Martina, 19 years old)

"The first person I told was one of my best friends, and I did so via WhatsApp. At the start they obviously couldn't believe it. They thought I was joking, because I'd been fine the previous day."

(Mari, 20 years old)

"This experience made me start writing again. I have 200 notes on my mobile phone, every tiny thing about my experience, every state of mind."

(Alessandro, 18 years old)

"I dropped my smartphone the other day and the first horrible thought I had was that I hadn't saved my notes anywhere. But I don't read them often because I realize they are wounds that are still healing over, not yet proper scars."

(Elisabetta, 24 years old)

"I never wrote during that time, because I'm awful at writing and that was not what I needed, but I did write a lot in the post because I was feeling crazy and writing helped me to explain my feelings."

(Anna, 21 years old)

"I needed to let off steam, take it out on someone, be angry. . . and obviously who better than a mother or father, who are there and who love you unconditionally."

(Stephen, 18 years old)

"There were two moments when I was really afraid: at the start, when you're told the diagnosis and then everything freezes—I mean, just like a bucket of frozen water in your head—and you say 'Now what do I do?'; then at the end, when you have to start your daily life again after living for a long time in a parallel world."

(Stefano, 19 years old)

"One kind of information was missing. I would have liked someone to tell me how difficult it is to get your life back on track, and the mental, psychological consequences afterwards. I discovered that I wasn't the only one to have had this thing; I would have liked to know that before. I would probably have had the means to cope with the aftermath without feeling guilty."

(Anna, 21 years old)

"There are two types of friend. There are the ones who stick very close to you at the start, write to you every day, ask how you're feeling, ask for information, then after a while you hear no more from them. Then there are the friends, the real ones, who—despite everything, even though I could be angry with them or need to let off steam, whatever the reason—they were always there. They support you and always stick by you."

(Alessandro, 20 years old)

"At the end of the therapies I felt like somebody else. I could no longer interact with these people, or not the way I did before. You've gone forward and the others have gone forward a bit less quickly than you."

(Anna, 19 years old)

"I don't think any information was missing, and I really appreciated the fact that the doctor was honest with me. He told me everything, and he talked to me as if I were a real adult even though I was only 14."

(Alice, 18 years old)

"I had no desire to socialize with other young people. I curled up in myself completely like a hedgehog, and that's where Matthew, the youth worker, comes in. He was really important. He managed to grab me and make me open up again."

(Cecilia, 19 years old)

"Those 5 minutes were very important because they gave me a chance to have a chat with someone going through the same disease as mine. They helped me find the courage to write to her, and the second time we met we were practically friends, although we had really only seen each other for 5 minutes."

(Anna, 18 years old)

"I trusted the kids more than the doctors because, being the same age, they knew how to speak much the same language as me."

(Erika, 18 years old)

relationship based on a sense of their doctors "being there" (meaning that they are emotionally accessible). Patients need to feel honesty and respect in the information they

receive. They need a professional and therapeutic relationship, but they want also to see a smile and to be looked in the eye. What they do not need is a detached, medicalized

relationship, to feel infantilized, hasty and limited verbal communications, a lack of body contact, or evasiveness or inconsistency in answers to their questions. To address their needs, doctors should prepare the ground, make appropriate use of the patients' questions, also with the aid of facilitation techniques, and know how to respond with empathy. Good communications can give patients a sense of greater control over their disease, improve each individual's intrinsic capacity to cope with the critical aspects of the cancer pathway, and facilitate their adaptation and compliance with treatment. This can nurture a patient's psychological autonomy and self-esteem, better enabling them to deal with future challenges.^{11,12}

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