

Spiritual aspects of care for adolescents with cancer

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ABSTRACT

Aims and background. Adolescents with cancer have psychosocial issues that need to be adequately addressed. Spirituality is a fundamental aspect of their psychological well-being.

Methods. A chaplain is a daily presence in the Youth Project ward for adolescents at the Pediatric Oncology Unit of the Istituto Nazionale Tumori, Milan. The chaplain conducts daily visits to the ward and the outpatient clinic/day hospital, holds daily meetings with the psychologists on staff, and attends biweekly meetings with doctors and/or nurses. The cases of patients referred for spiritual assistance between January and December 2012 were analyzed by patient age and reasons for consultation, and were compared with cases referred for psychological consultation.

Results. A psychological consultation was offered to 84% of patients/families, and further support was needed for 23% of children and 45% of teenagers. Spiritual support was provided for 2 children and 20 adolescents (24% of the sample considered).

Conclusions. Acknowledgment of their spiritual needs helps patients to battle with their disease. The reasons patients and parents ask for spiritual assistance only partially overlap with the motives behind requests to see a psychologist. The care of adolescents with cancer should include catering for their spiritual needs by assuring the constant presence of a chaplain on hospital wards.

Introduction

Cancer patients may have particular, not strictly clinical needs that often go unnoticed. Managing these additional needs has become an increasingly important goal of care providers, particularly when dealing with cancer patients of adolescent age^{1,2}. Adequate management of the psychological and social issues of patients in their teens is especially important because they experience disease at a time when they are undergoing major psychological and physical changes, establishing their self-image, structuring their identity and personality, and their relationships with their peers^{3,4}. It is characteristic of adolescents to wonder about the meaning of life and what the future holds in store. Disease and suffering unavoidably interfere with such processes (which are already critical in themselves)^{1,5}.

Together with the family or peer groups, the medical staff can have an important role in coping with the complex psychological world of teenagers and the dramatic psychological impact of a diagnosis of cancer at this age, but this demands the support of a specialist. The Youth Project for adolescent patients organized at the Pediatric Oncology Unit of the Istituto Nazionale Tumori in Milan involves 3 specialists in clinical psychology and a social worker who attend the ward on a daily basis. Since spirituality is a matter of interest to adolescents suffering from cancer^{6,7}, there is also a chaplain on the multidisciplinary team, whose aim is to deal adequately with patients' need to have faith (for those who are believers), trust and hope^{3,8}.

Key words: cancer, adolescent, spiritual assistance, psychosocial.

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Everyone has spiritual needs, and some have religious needs. The importance of spirituality is highlighted in a document compiled by the US National Cancer Institute and available at <http://www.cancer.gov/cancertopics/pdq/supportivecare/spirituality/HealthProfessional/page2>: "Specific religious beliefs and practices should be distinguished from the idea of a universal capacity for spiritual and religious experiences. This distinction ... is important conceptually for understanding various aspects of evaluation and the role of different beliefs, practices, and experiences in coping with cancer. The most useful general distinction to make in this context is between religion and spirituality. There is no general agreement on definitions of either term, but there is general agreement on the usefulness of this distinction⁹⁻¹¹. ... Religion can be viewed as a specific set of beliefs and practices associated with a recognized religion or denomination. Spirituality is generally recognized as encompassing experiential aspects, whether related to engaging in religious practices or to acknowledging a general sense of peace and connectedness. The concept of spirituality is found in all cultures and is often considered to encompass a search for ultimate meaning through religion or other paths¹². ... Most individuals consider themselves both spiritual and religious; some may consider themselves religious but not spiritual. Others, including some atheists (people who do not believe in the existence of God) or agnostics (people who believe that God cannot be shown to exist), may consider themselves spiritual but not religious¹³".

The chaplain works to help patients, family members and staff address both spiritual and religious needs¹⁴. This paper explains what the chaplain does at our Unit.

Material and methods

The Youth Project is a specific, comprehensive project launched at the Pediatric Oncology Unit of the Istituto Nazionale Tumori, Milan in 2011 and dedicated to adolescents (over 15 years old) and young adults (up to 25 years old) suffering from pediatric tumors¹⁵. The project covers various aspects, ranging from the inclusion of patients in appropriate clinical trials to the provision of psychosocial support, from fertility preservation to the provision of multipurpose rooms and equipment, from the organization of activities and events suited to their developmental age to helping these older pediatric patients feel more at home in the hospital.

Psychological support is provided on different levels. The first level focuses on the patient-physician relationship, seeking to identify any premonitory signs of psychological issues by investigating areas such as family, friends, school or work, boyfriends/girlfriends, and spare time activities. Basic emotional support is also provided. The unit's staff receives specific training in

these issues at meetings and courses. Clinical psychology specialists represent the second level of intervention, and 3 such specialists are permanent staff members¹⁶. Since 2011, the activities of a chaplain have been reorganized and better structured, and this figure is now acknowledged as a permanent member of staff. The chaplain is a Catholic priest who graduated from the Psychology Institute of the Pontificia Università Gregoriana, Rome, and gained a further qualification in pastoral health at the Pontificia Università Lateranense, Rome, which included training in counseling and hospital-based work. The chaplain is a member of the National Council for Pastoral Health of the Conferenza Episcopale Italiana. Some of the chaplain's time is spent on religious procedures, such as celebrating mass, giving blessings, saying prayers, administering the sacraments (sacrament of the sick, baptism, reconciliation, Eucharist and confirmation) at the request of patients and families; he is also involved in organizing religious experiences (such as pilgrimages) and cooperating with local religious communities.

In addition to these general practices, the chaplain's work includes:

- a) daily visits to the ward and the outpatient clinic/day hospital;
- b) daily meetings with the psychologists on staff;
- c) biweekly meetings with doctors and/or nurses.

Daily talks with patients, relatives and staff members enable the chaplain to assess patients' and their relatives' spiritual needs, identifying special cases that warrant particular attention and counseling, and discussing the management of cases. A typical scenario involves the chaplain providing support for terminal patients and their families, including individual support during the process of grief. This spiritual support is not only offered at the end of a patient's life; it is also available as a resource throughout the period of patient care.

Pastoral counseling and spiritual support are also offered to non-Catholic patients and families. For non-Catholic believers, the chaplain contacts the local representative for their particular religion. The topic of spiritual needs is generally also discussed with non-believer families. The chaplain also periodically attends meetings and events organized for adolescents involved in the Youth Project (taking an active part in sporting activities, for instance), and acts as a supervisor for volunteers working at the hospital and in social housing, as well as being involved in research work (relating to spiritual issues and patient care).

To better elucidate the type of spiritual support provided at the Unit, we retrospectively analyzed the number of patients referred for psychological consultation and for spiritual assistance, focusing on new cases diagnosed between January and December 2012. Our objectives were to identify the motives leading to the chap-

lain's intervention, and to compare the pattern of referral for children and/or their parents with the situation seen in adolescents.

Results

From 1 January to 31 December 2012, 274 patients with a new diagnosis of solid tumors were treated at our Pediatric Oncology Unit: 191 (70%) were between 0 and 14 years old ("children") and the remaining 83 (30%) were over 15 ("adolescents").

Specific support was provided by our chaplain for 2 children (11 and 12 years old) and 20 adolescents (24% of the sample). All but one of these patients were Catholic. The number of appointments with the chaplain usually ranged from 3 to 5, sometimes more. In some cases, the spiritual assistance needed to be prolonged, with several appointments even after patients had completed their treatments. It is noteworthy that 11 of the 20 adolescents took an active part in the events and activities organized as part of the Youth Project. Spiritual assistance was also provided for 29 parents of children (15%) and 9 parents of older patients (11%). In 3 cases, these parents were non-Catholic.

The reasons prompting a spiritual consultation with patients are schematically outlined in Table 1, and 3 examples of spiritual intervention are described in Box 1. In many cases, patients asked the chaplain about the meaning of their illness: "Why me? Why now? What did I do wrong?" (6 cases). Sometimes patients asked the chaplain for advice because they felt the burden of still having to depend on their parents (5 cases). Other commonly encountered issues related to patients' own religious communities (patients asked the chaplain to contact their own priest, for instance) (5 cases). More rarely, patients needed to talk to the chaplain about their religious doubts ("If God exists, why did he let me become ill?" - 2 cases), their sense of guilt for having mistreated their parents when their illness and treatments made them irritable (2 cases), or their concerns about death (2 cases).

As for the parents seeking spiritual support, their motives and needs varied (and were sometimes multiple). The more common issues related to a sense of guilt deriving from imagined failings that might have caused their child's disease (14 cases); behavioral or relational problems with their son or daughter (14 cases) (including the perceived risk of treating them like children who still needed to be looked after and protected at a time when these adolescent offspring also needed to grow up and detach themselves from their parents); doubts about whether they were doing enough for their child; and a sense of anger with their child's disease (11 cases), which sometimes focused on a superior being (God). The spiritual consultations occasionally involved parents asking the chaplain to pray for them (8

Box 1. Meetings with the chaplain

Story 1 A 24-year-old married woman suffering from medulloblastoma. She was very angry about her diagnosis and the need for treatment, and very afraid that she might be dying. During meetings with the psychologist, she said she was willing to speak to the chaplain. She told him, "I'm very angry with God." The chaplain had several meetings with the patient. He asked her, "How does being angry with God make you feel? Do you think your disease is God's will?" The patient reported feeling guilty about these sentiments. The chaplain answered, "I don't think your disease is God's will. But anyway you shouldn't feel guilty. Feeling angry, even with God, is not a failing. It is natural in the circumstances." The patient felt much calmer after the meetings with the chaplain and continued her course of treatment with a cooperative and positive spirit.

Story 2 A 17-year-old girl with a refractory rhabdomyosarcoma that was progressing. The girl succeeded in confiding in the chaplain. "I'm afraid of dying," she said in tears. The chaplain did not let the matter drop but asked her why she was afraid when she thought about death. The girl was unable to answer and remained quiet and thoughtful. "We are all afraid of dying," the chaplain said, "because we are human beings." The girl thought about this and said, "I am a believer so I shouldn't really be afraid because after death we go to heaven." The chaplain answered that Jesus Christ was afraid of dying too, even though he knew he was going to heaven. Various meetings followed this first encounter and the patient returned often to the topic of death ("What will happen after I have closed my eyes and I die?"), but she went towards the event remarkably calm and with a clarity of mind.

Story 3 The father of an adolescent patient met the chaplain. He said he was a non-believer but he wanted to tell the chaplain about his past. He said he had lived a dissolute life and he saw his son's disease as a "rightful punishment God has inflicted on me; it's all my fault." The chaplain had several meetings with him and tried to take the matter further, asking how he could feel he was being punished by God and consider himself a non-believer at the same time. "I can't explain it," he said, "but the burden is intolerable, the sense of guilt is devastating." The chaplain told him, "God does not punish us for our sins. If He did, we would all be punished and we would all be ill." There remained the question of the reasons for suffering and disease, but the chaplain said, "Being gripped by a sense of guilt doesn't help you to do everything in your power to help your son in his battle against the disease." After his meetings with the chaplain, the father was less troubled and very helpful in the care of this adolescent patient.

cases), or talking to him about their fear of death (4 cases), or about conflicts arising between the 2 parents (2 cases).

Discussion

The aim of this work was to illustrate the importance of the chaplain's role as part of the psychosocial follow-up of cancer patients, and adolescents in particular⁸. Adolescence is a special time of life, when an individual's approach to spiritual matters and religion (and their relationship with God in the case of believers) often changes^{17,18}. Another characteristic aspect of this stage of development concerns the crucial changes tak-

Table 1 - Reasons for requesting spiritual support

Motives prompting spiritual consultations	No. of cases (1 January - 31 December 2012)	Reports of the consultations
Patients		
The meaning of illness	6	"Why am I sick? Why me? I'm still young... I have only just begun to live my life..."
Dejection due to persistent dependence on parents	5	"I was just beginning to become independent. I was pleased to grow up and start to take care of myself... Now I feel obliged to depend on my parents again, and this makes me angry."
Issues relating to patients' religious communities	5	"I'm lucky because, even when I'm here in the hospital, I can use Skype to attend meetings taking place in my parish and join up with my friends." "I'm glad the priest comes to visit me here in the hospital, and he comes to see me as soon as I get home."
Sense of guilt for mistreating parents	2	"I sometimes behave badly with my father and mother, then I feel guilty. They keep telling me not to do this or that, not to go out, that I should stay indoors, and keep away from crowded places... these things make me angry and I answer rudely, then I'm sorry."
Doubts about the existence of God	2	"If God exists, why am I sick? I keep praying, but my situation just gets worse, so I'm beginning to doubt. I don't know what to believe. The first time it was easier, but now..."
Concerns about death	2	"I keep thinking about death because the more time passes, the more I see my cancer getting worse. I try not to think about it, but I know you can die of this disease because I heard that Andrea died... Thinking about this makes me very frightened."
Parents		
Behavioral or relational difficulties with their child	14	"Since he's been ill, I no longer know how to deal with him. He has changed completely, I don't recognize him anymore... I try to tell him he can't claim all my attention all the time; there are his brothers at home too. I can't make sense of all this mess. Why does God allow all this pain and suffering?"
Sense of guilt	14	"I should have given my son life and instead I have given him death... Why didn't I realize earlier that he was ill? Maybe he told me he was hurting but I did not believe it, I thought it was an excuse to avoid going to school... I am not a good father. I was unable to avoid my son going through all this. I have not done well. Where did I go wrong?"
Anger	11	"I am angry with the doctors who did not realize what my daughter was suffering from. I took her to many specialists who didn't understand a thing. We went all over the place for more than 6 months without arriving at a conclusion..." "When I see my daughter's classmates who are healthy while she is still in hospital and always in pain, it makes me angry. Why my own daughter?"
Appeals for others' prayers	8	"Please pray for my son. Pray for us too. Many people are praying for us. It's a great help for us."
Fear of death	4	"I'm afraid my son will not live. I try not to think about it, but my thoughts always go to death, especially during the night."
Conflict between parents	2	"My husband does not understand and he will never say no to our son. He always lets him do whatever he wants." "Now my daughter is sick, but I can't stand my wife any longer. There is never anything good about what I do... I try not to let my daughter see it, but I wish I could send my wife away."

ing place in an adolescent's relationships with adults, which are a fundamental part of the process of constructing their own individuality. Paradoxically, their disease and its treatment oblige adolescent cancer patients to stay close to their parents and depend on adult figures (including their doctors).

We are convinced that providing for patients' spiritual needs helps them battle with their disease. There is widespread reserve in relation to the figure of the hospital chaplain, because it is often associated with the idea of imminent death. This misconception makes it more difficult for people to contact the chaplain and ask for help. There are also other reasons why it may be difficult to see the hospital chaplain¹⁹, one of which – to our mind – is inadequate awareness that the chaplain has been specifically trained to work with patients^{20,21}. Chaplains should be seen as an integral part of the hospital staff, with specific responsibilities. They have an important role, not only when administering the traditional sacraments, assisting the terminally ill or the bereaved. They should not be considered a resource to call to a bedside at the patient's request to deal with a spiritual emergency. The chaplain's role should be seen as an accompaniment throughout the various phases of a patient's illness and treatment, a constant and active comforting presence in the ward, right from the start of a patient's experience of cancer. It is important to remember that patients' and their families' emotional states can have a direct impact not only on the clinical picture, but also on the communication between the medical staff and the patients and their relatives²².

Our analysis goes to show that the reasons patients or members of their families ask to see the chaplain only partially overlap with the motives behind requests to see a psychologist. For some concerns, the psychologist may not be the most appropriate figure, and spiritual support may be essential.

The chaplain should be a constant presence in the department. Our experience indicates that the chaplain's informal involvement at Youth Project meetings was important for the purpose of establishing a relationship with our patients, and it was likewise important for the young people to become used to seeing the chaplain coming and going in the ward every day, and to make his acquaintance before they considered asking his professional help. It soon became evident that most of the adolescents who received spiritual support had also taken an active part in our Youth Project activities.

It is also indispensable to ensure a continuous exchange of impressions and opinions between the chaplain and the other staff to identify problems requiring attention and patients who need extra support, and to discuss methods for referring patients to the chaplain to discuss their spiritual needs. These exchanges could also lead to the preparation of protocols for patient referral for spiritual assistance, improving the way in which chaplains are introduced to patients.

Parents have their spiritual issues too. When their children become ill, they often experience a strong sense of guilt. Their child's disease sometimes feels like a punishment inflicted on them by some superior being because they have failed in some way. Some parents report feeling responsible for giving their child a severe disease instead of life and good health. Such ideas can cause anxiety and interfere with the parents' faith in the future. Parents may also become confused, experiencing contrasting feelings that are difficult to reconcile; they alternately feel hopeful and optimistic, then become angry with God for their child's plight, despite their faith. The chaplain can help them deal with these issues and regain a sense of confidence²³.

It is worth mentioning that the Joint Commission International Accreditation Standards for Hospitals state that, given the need to safeguard patients' rights in the broadest possible sense, a modern hospital should have in place "a process to respond to patient and family requests for pastoral services or similar requests related to the patient's spiritual and religious beliefs"²⁴. The purpose of a chaplain should not be to convert individuals to a given cult, but respond to their spiritual appeals and provide comfort, thereby facilitating communication, relationships and future projects (sustaining patients' and their families' confidence and hope). Ideally, attention should be paid to a patient's spiritual history as soon as their disease has been diagnosed. Chaplains are therefore being asked increasingly by public health institutions to witness and vouch for the spiritual needs of patients²⁰, be they believers (whatever their faith) or non-believers. The new spiritual perspective focuses on human beings who are suffering, with a view to supporting them in their personal journey through life, irrespective of their chosen religion. This is probably quite a challenge for multidisciplinary care-providing teams that have to combine different forms of expertise and different approaches (not necessarily in opposition) in an effort to benefit patients and their families²².

Based on these considerations, we would suggest that ensuring the constant and active presence of chaplains in hospital wards as members of multidisciplinary care-providing teams is one way to address the specific emotional and spiritual needs of cancer patients, and adolescents in particular. Too few data are currently available on the efficacy of such a model (obtained, for example, by patient satisfaction questionnaires) to enable any scientific conclusions to be drawn, but the proportion of adolescents in our sample who consulted the chaplain supports the utility of this approach.

It is likewise essential to train chaplains specifically in coping with hospital work and the types of patient they will meet. The chaplain must come to be seen as an indispensable resource not only for adolescent patients and their parents, but also for the medical teams. This professional figure can support all their spiritual (and not only religious) needs²⁵.

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