Psychological Referral and Consultation for Adolescents and Young Adults With Cancer Treated at Pediatric Oncology Unit

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Abstract

Purpose. Managing older adolescents and young adults with cancer is a challenge, both medically and psychosocially: it is important to assess these patients' psychological issues and the type of services they need when deciding who should treat these patients, and where.

Methods. This study describes the pattern of psychological referral and consultation for older adolescents and young adults with cancer being treated at a pediatric oncology unit, as compared with the case of younger patients.

Results. Between 1999 and 2006, 318 patients <15 (32% of the patients in this age group) and 117 ≥15 years old (30%) were referred for psychological consultation. The number of interviews per patient was 2.8 for patients under fifteen and 7.8 for older patients. Younger patients were referred by all members of staff, while most older patients were referred by doctors, mainly because they had trouble adapting to the cancer's diagnosis and treatment. An ongoing, weekly, long-term psychotherapy was needed for 1% of patients <15 and 10% of those ≥15 years old.

Conclusions. Adolescents and young adults with cancer have specific psychological needs. While awaiting the full development of programs dedicated to these patients, they would seem to benefit from being treated in a multidisciplinary setting of the kind usually developed at pediatric units, fully integrating the psychological operators with the other staff members. Pediatr Blood Cancer 2008;51:105–109.

Key words: adolescents and young adults with cancer; liaison; psychological support; referral.

Introduction

Malignant tumors are relatively rare in adolescents and youngadults (AYA), but their management poses more of a challenge, in both the medical and the psychosocial spheres: these patients inhabita "no- an's" land between pediatric oncology and "adult" medical oncology, and the problems of howandwhereAYAwith cancer should be treated remain controversial [1–4].

The malignancies occurring in adolescence form a set peculiar to this particular age group, the majority being tumors typical of pediatric age (i.e., brain tumors, leukemia and lymphoma, sarcomas), and the remainder tumors of adulthood (i.e., melanoma, thyroid and other carcinomas) [1,5]. It makes a lot of sense to assume that these patients should be treated according to their type of tumor, not according to their age, that is, pediatric tumors should

be treated by pediatric oncologists, adult tumors by adult medical oncologists;however, this solution seems right for the tumor, but not for the patient [4]. AYA are complicated individuals with particular emotional, social and psychological problems, very diverse levels of maturity and different needs. It is essential to bear in mind that a diagnosis of cancer at this age has a major impact not only physically but also psychologically, and the related treatment has to cover the psychological issues [6,7]. In recent years, oncologists have been learning to pay more attention to their patients' psychologicalsphere and psychological support has come to be considered a fundamental service, especially in children's wards dealing with cancer [8]. Assessing a patient's psychological needs and the services available at different centers must be part of the process to choose who should treat adolescents with cancer, and where.

This study outlines the psychological support given to adolescents and young adults treated at the PediatricOncology Unit of the Istituto Nazionale Tumori of Milan, Italy, which is a pediatric oncology unit that forms part of a cancer institute, not of a pediatric department, where the pediatric oncologists can treatAYApatients with pediatric tumors whatever the patient's age.We describe the pattern of referral for psychological consultation and the type of any psychotherapy provided, comparing the approach used to deal with younger versus older patients.

Materials and methods

At our department, psychological support for patients and their families is individually tailored on two different levels. The first level concerns the "medical psychological" approach: this involves the medical team (pediatric oncologists and nursing staff), social workers and teachers, and aims to provide initial emotional support for the anguish associated with the diagnosis of cancer and the prospect of therapies, while counseling can also be offered and any psychological needs identified. The second, clinical psychology level, where necessary, involves the clinical psychology specialists (who are

members of the staff and a daily presence at the clinic). Two specialists in clinical psychology are currently on the staff, one a medical doctor and the other a psychologist.

To identify any differences in the approach used for children and for AYA treated at our department between January 1999 and December 2006, we retrospectively analyzed and described the pattern of referral for psychological consultation, focusing on how and why patients were referred, and the nature of any psychotherapy. Patients were grouped by age, comparing the under 15 years old with those of 15 or more.

The main reasons prompting a psychological consultation were schematically classified as: (a) difficulty adapting to disease and treatment; (b) relational problemswith the hospital team; (c) particularly stressful treatments, for example, high-dose chemotherapy or mutilating surgery; (d) problems of compliance with treatment; (e) emotional distress and adaptation problems in long-term survivors; (f) terminal disease; (g) relational difficulties in the family; (h) psychosocial problems; (i) psychopathological conditions in patients or their parents giving rise to subjectively experienced concerns or interfering with care-giving activities. Chisquared tests were used for statistical analysis. This study was approved by ethics panel of our Institution.

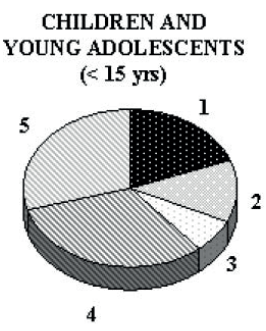
Results

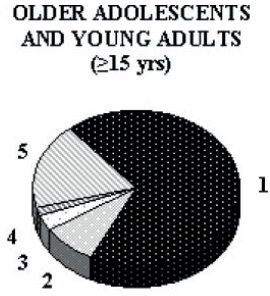
During the period considered, 1,386 patients with solid tumors were treated at our pediatric oncology unit: 991 were <15 and 395 (28%) were ≥15 years old. Of the latter group, 159 were older than 18 years (11% of the total). Overall, 435 patients received psychological support, amounting to a total of 1,810 interviews. Table I shows the percentages of younger and older patients requiring support, that is, 32% and 30%, respectively. The number of interviews per patient differed considerably, however, with 2.8 for the under 15 years old and 7.8 for the older patients.

Table I. *Psychological Support: Comparison Between Patients Under and Over 15 Years Old (1999–2006)*

Under 15 years old 15 and over		
Total patients	991	395
Patients given psychological support	318	117
%	32%	30%
Total number of interviews	897	913
Number of interviews/patient	2.8	7.8

Figure 1. *How patients were referred for consultation: comparison between patients under and over 15 years old.8*





		patients <15 yrs	≥15 yrs	p value
1.	DOCTORS	61	80	<0.0001
2.	NURSES	41	10	N.S.
3.	SOCIAL WORKERS	22	4	N.S.
4.	TEACHERS	100	2	<0.0001
5.	FAMILY	94	21	<0.04
	total patients referred	318	117	

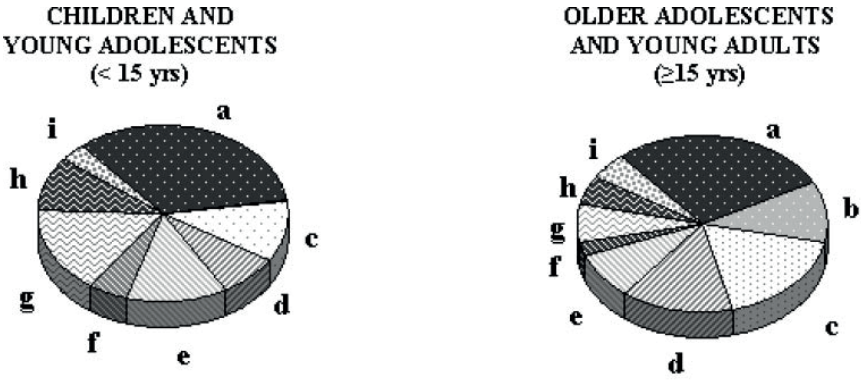
N.S. = not significant

Figure 1 shows how patients were selected for clinical psychological consultation, comparing younger (318 patients <15 years) and older patients (117 patients ≥15 years): doctors referred 19% of younger and 68% of older cases, respectively (P<0.0001), while teachers and playroom monitors referred 31% of children and 2% of adolescents (P<0.0001); in 30% of younger cases the request for an interview came from parents or the patients themselves, as compared to 18% of older patients (P<0.04).

The medical personnel were more involved in referring patients whose problems had to do with accepting the treatment, particularly treatments such as high-dose chemotherapy or mutilating surgery (doctors referred 66% of the patients with treatment acceptance problems), coping with terminal disease (63% of cases), and emotional distress in long-term cancer survivors who had completed their treatment (61%). The nursing staff tended more to report problems relating to poor compliance with treatment (nurses reported 47% of the cases of poor compliance). Social workers generally referred patients with relational difficulties within the family (25% of cases), while the teaching staff were much more active in identifying psychosocial distress (52% of the patients with psychosocial problems were referred by teachers) and difficulties in adapting to the disease and treatment (45% of cases).

Figure 2 shows the reasons why patients in the two age groups were referred for psychological consultation. In both groups, the main reason for referral concerned patients finding it difficult to adapt to the cancer diagnosis and related treatment (34% in the younger group and 28% in the older group). It is worth noting that quite a significant proportion (18%) of the younger patients had psychological consultation for relational difficulties within the family ($P<0.04$) (more between the parents than for the patient). These were the cases whose referral to the specialist was at the family's request. In the older group, a relevant number of patients had psychological support for problems of compliance with the treatment (15%) and relational difficulties with the hospital team (11%) ($P<0.0001$).

Figure 2. *Reason for referral: comparison between patients under and over 15 years old*



	patients < 15 yrs	≥15 yrs	p value
a) difficulty adapting to disease and treatment	107	33	N.S.
b) relational problems with hospital team	1	13	<0.0001
c) particularly stressful treatments	35	21	N.S.
d) scarce compliance with treatment	25	17	<0.05
e) emotional distress in long-term survivors	41	10	N.S.
f) terminal disease	16	3	N.S.
g) relational difficulties in family	51	8	<0.04
h) psychosocial problems	31	6	N.S.
i) psychopathological conditions	11	6	N.S.
total patients referred	318	117	

N.S. = not significant

Particular differences emerged between the two age groups as regards the types of problem encountered in long-term survivors, after completing their treatment and during the follow-up. This type of emotional distress was often reported by the patients themselves and usually related to difficulties in adapting to their return to normal life after the trauma of their cancer and its treatment. Three particular situations were seen in AYA: problems relating to pregnancy (two cases), drug addiction (two cases) and attempted suicide (three cases).

As for the psychopathological conditions diagnosed and disregarding patients with organic mental disorders or retardation, that is, following cranial irradiation, the younger patients had reactive depression (11 cases), while the older patients (6 cases in all) also

had anorexia nervosa (2 cases) and obsessive-compulsive disorder (2 cases). Psychological support was provided in the form of weekly, long-term psychotherapy in only 3<15 years old (1%) and in 12 older patients (10%).

Discussion

An adequate management of AYA with cancer demands a medical staff with specific skills, capable of recognizing and addressing all their various needs [7,9,10]. The ability to cope with the complex psychological world of the teenager is of fundamental importance, and it is increasingly recognized that conventional pediatric or adult healthcare units are not entirely suitable for such patients: the problem of where these patients should be treated, however, is still unsolved in most cases [1–4]. Pediatric oncology units may be naturally more appropriate, in clinical terms, for managing adolescents with pediatric malignancies [11,12], but these patients also seem to benefit from the multidisciplinary team typical of the pediatric oncology setting, where pediatric oncologiststeam up with surgeons and radiotherapists, but also with psychologistsand social workers.

Judging from our experience, the psychological supportgenerally provided by pediatric oncology units is suitable for AYA too, and may have an important added value for them. At our institution, psychological support is based on two completely different models in the pediatric and adult medical oncology settings. In the latter, the psychologist is outside the department and can be called in to visit a patient, give an opinion and recommend any clinical measures (consultation on request) [13–15]. Conversely, the Pediatric Oncology Unit has psychology specialists on the department's multidisciplinary staff, routinely present at the clinic (with two specialists for a unit serving 23 inpatients and 7 outpatients), based on the liaison model, which is characterized by close daily cooperation between the clinical psychologist and the other members of staff (oncologists, nurses, teachers, social workers), giving the specialist a chance to establish a genuine relationship with patients [13–15].

Our findings also show how important different members staffcan be in pinpointing patients for psychological support, taking the essential first step towards recognizing and treating a problem: the referral process has technical (diagnostic), relational and organizational aspects (different procedures), as well as the emotional element. We found different referral patterns for different professional figures, for example, patients having difficulty in adapting to their disease and accepting the treatment were referred mainly by doctors; problems of poor compliance with therapies were mainly reported by nurses; cases with social and family difficulties were reported by social workers. Our main concern, however, was to identify differences relating to the patients' age, distinguishing children and young adolescents from older teenagers and young adults.

First of all, we found a similar percentage of patients in the two groups in need of psychological consultation, which came as something of a surprise, given the previously mentioned particular emotional aspects of adolescence. The marked difference between the two age groups lay, instead, in the number of interviews conducted per patient and the proportion of patients requiring longterm psychotherapy, which were clearly higher for older patients. For the younger patients, the specialist often needed to assess their psychological problem and the quality of their adaptation with a view to helping parents cope with the changes in their children's behavior. The specialist was often able to address the patient's needs with relatively few interviews. For the AYA, the specialist's main goal was to help the patients themselves to cope with their emotional and behavioral difficulties, and this was more likely to take prolonged consultation and a closer relationship between specialist and patient. In short, the older patients were not referred to the psychologist more often than the younger ones, but their problems were more complicated and difficult to deal with.

Another difference that emerged was that all members of staff referred younger patients for consultation, while most of the older patients were referred by doctors or the patients themselves asked for support. This is difficult to explain, but may be related to the

complexity of the emotional life of adolescents: on the one hand, they need a person to rely on, while on the other hand they may find relations with authority more difficult (in fact, a small percentage of the older patients were referred due to relational problems with the hospital team) [7,16].

AYA may experience particular psychological or psychopathological situations and the specialist working in a pediatric unit should be trained to recognize and address them: our series included patients revealing major adaptation difficulties after completing their treatment, patients who attempted suicide or became addicted to drugs, and patients with anorexia nervosa and obsessivecompulsive disorder [7,9,16,17].

These last considerations confirm the particular nature of the psychological problems of AYA. A clinical psychologist used to working with children may have some difficulties in attending to these particular needs, and the optimal solution is to train specialists specifically for this purpose. AYA deserve dedicated healthcare providers, specialized clinics and inpatient units, and dedicated research strategies [1–4]. Unfortunately, these needs are not often being satisfied. Our experience suggests that these patients benefit from being treated at a pediatric oncology unit rather than in an adult setting, and that future older adolescent and young adult oncology departments should adopt the model used at our and other pediatric oncology departments, fully integrating the psychological specialists among the other staff members.

References

1. Bleyer A, Barr R. Highlights and challenges. In: Bleyer A,O'Leary M, Barr R, Ries LAG, editors. Cancer epidemiology in older adolescents and young adults 15 to 29 years of age, including SEER incidence and survival: 1975–2000. Bethesda, MD: National Cancer Institute, NIH Pub. No. 06-576; 2006.

2. Bleyer A, Morgan S, Barr R. Proceedings of a workshop: Bridging the gap in care and addressing participation in clinical trials. Cancer 2006; 107:1656–1658.

3. Bleyer WA. Cancer in older adolescents and young adults: Epidemiology, diagnosis, treatment, survival, and importance of clinical trials. Med Pediatr Oncol 2002; 38:1–10.

4. Ferrari A, Bleyer A. Participation of adolescents with cancer in clinical trials. Cancer Treat Rev 2007; 33:603–608.

5. Albritton K, Bleyer WA. The management of cancer in the older adolescents. Eur J Cancer 2003; 39:2584–2599.

6. Lewis IJ, Fallon S, van Dongen-Melman J, et al. Cancer and the adolescent: The Second Teenage Cancer Trust International Conference, Royal College of Physicians, London, England, March 2001. Med Pediatr Oncol 2002; 39:198–201.

7. Abrams AN, Hazen EP, Penson RT. Psychosocial issues inadolescents with cancer. Cancer Treat Rev 2007; 33:622–630.

8. Spinetta JJ, Masera G, Eden T, et al. Refusal, non-compliance, and abandonment of treatment in children and adolescents with cancer. Areport of the SIOP working committee on psychological issues in pediatric oncology. Med Pediatr Oncol 2002; 39:114–117.

9. Hedstrom M, Kreuger A, Ljungman G, et al. Accuracy of assessment of distress, anxiety, and depression by physicians and nurses in adolescents recently diagnosed with cancer. Pediatr Blood Cancer 2006; 46:773–779.

10. Evan EE, Kaufman M, Cook AB, et al. Sexual health and selfesteem in adolescents and young adults with cancer. Cancer 2006; 107:1672–1679.

11. Klein-Geltink J, Shaw AK, Morrison HI, et al. Use of paediatric versus adult oncology treatment centres by adolescents 15–19 years old: The Canadian Childhood Cancer Surveillance and Control Program. Eur J Cancer 2005;41:404–410.

12. Boissel N, Auclerc MF, Lheritier V, et al. Should adolescents with acute lymphoblastic leukemia be treated as old children or young adults? Comparison of the French FRALLE-93 and LALA-94 trials. J Clin Oncol 2003; 21:774–780.

13. Weisman AD, Hackett TP. Organization and functioning of a psychiatric consultation service. Int Rec Med 1960; 173:306–311.

14. Greenberg IM. Approaches to psychiatric consultation in a research hospital setting. Arch Gen Psychiatry 1960; 3:691–697.

15. Meyer E, Mendelson M. Psychiatric consultation with patients on medical and surgical wards: Patterns and processes. Psychiatry 1961; 24:197–220.

16. Palmer S, Mitchell A, Thompson K, et al. Unmet needs among adolescent cancer patients: A pilot study. Palliat Support Care 2007; 5:127–134.

17. Clerici CA, Ferrari A, Albasi C, et al. Five questions for assessing psychological problems in pediatric patients cured of neoplastic disease. Pediatric Hematol Oncol 2004;21: 481–487.