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## Original Paper

# Anxiety and Depression in Adolescent Cancer: Findings in Patients and Parents at the Time of Diagnosis

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Adolescent cancer is uncommon and presents an exceptional stress for the young patient and their parents. The emotional needs of adolescents with cancer are a major factor in the recommendation for the establishment of adolescent cancer units in major cancer centres in the U.K. However, there have been no prospective, longitudinal studies assessing the psychological impact of a diagnosis of cancer on the adolescent patient and their family. In 1994 we began a longitudinal study of the emotional impact of the diagnosis of cancer in patients and their families presenting to an adolescent cancer unit and of the coping strategies they employ. This first report presents the results of the study at the time of diagnosis in 42 adolescents, 34 mothers and 27 fathers. The Beck Depression Inventory (BDI) was used to assess depression and anxiety levels were measured using Spielberger's State Trait Anxiety Inventory (STAI). Adolescents and their parents completed the questionnaires on first admission to the adolescent cancer unit. The median time since cancer diagnosis was approximately 3 weeks. To provide normative data for the U.K. adolescent population, control values were obtained from 173 pupils of the same age and background. The results showed that, contrary to expectation, adolescents with cancer were no more anxious or depressed than the control adolescent population. Nevertheless, a substantial minority of patients and controls had elevated anxiety or depression scores. Girls were significantly more anxious ( $P=0.011$ ) and depressed ( $P<0.0001$ ) than boys. Mothers were the most anxious family members and were significantly more anxious than fathers ( $P=0.038$ ). Parental anxiety scores, especially mothers, were much higher than reported norms. There was no significant difference between mothers' and fathers' depression scores. Although at the time of diagnosis adolescent cancer patients are not more anxious or depressed than their healthy peers, many adolescents without cancer are anxious or depressed. Staff on adolescent cancer units should therefore be aware of the frequency of emotional disturbance in this population. Mothers are the most anxious family members. Although the findings are relatively reassuring at the time of diagnosis, follow-up data from this cohort will show whether anxiety and depression change with treatment involving intensive chemotherapy, surgery and radiotherapy and will indicate the coping strategies which patients and their families adopt in dealing with both the disease and its treatment. © 1997 Published by Elsevier Science Ltd.

**Key words:** adolescence, bone sarcoma, mother, father, psychological well-being

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## INTRODUCTION

THERE ARE approximately 740 new cases of cancer in the age range 13-19 years diagnosed in the U.K. each year [1]. Normal adolescence is a period of physical and emotional change. At this age, the diagnosis of cancer, its treatment and the

disruption to schooling and family life can be anticipated to produce psychological distress for both the patient and their family [2,3]. Recent recommendations for major cancer centres propose the establishment of units for adolescents in the anticipation that the physical and psychological stresses of the disease might be better managed in a specialised environment [4]. There is, however, remarkably little information about the psychological state of these patients and their

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families, either at the time of initial diagnosis or as treatment proceeds.

Studies that have been undertaken with young patients and their parents have been cross-sectional rather than longitudinal. Previous studies have been conducted months or years after treatment has finished. Furthermore, these studies have often concerned long-term survivors, usually in children under the age of 12 years and have not studied patients and families [5–7]. The results of these studies have shown that anxiety scores in adolescents whose cancer is in remission are not significantly different from standardised norms [8]. Similar levels of depression have been reported in cancer patients and control adolescent groups in an assessment 2 years after the cancer diagnosis [5]. Canning and associates explored the relationship between repressive style of adaptation and depression comparing 31 adolescents (12–18 years) with 83 healthy controls [9]. The adolescents with cancer reported significantly lower levels of depression. However, this was a cross-sectional study in patients who had been diagnosed for a mean of 1.8 years, most having completed treatment at the time of the assessment.

Very little is known of the psychological well-being of parents at the time of their child's diagnosis. Parents of children (mean age 6.8 years) diagnosed with cancer have been reported to have levels of anxiety higher than the standard norms 8 weeks after the diagnosis [10]. In a study of parents (93% mothers) at an average of 51 days since diagnosis of their child's cancer, the mean depression score was in the mildly depressed range [3]. The parents of children with cancer aged 3–18 years (average 12) who are both in remission and not had treatment for 6 months were found to be no more anxious or depressed than a control group of parents [11]. These differences point to the importance of conducting assessments over time attempting to determine at what point parents' levels of anxiety and depression decrease.

The adolescent cancer unit at the Middlesex Hospital was opened in 1990, being the first such unit in the U.K. We report here the first results of a continuing, prospective, longitudinal investigation into the impact of the diagnosis and treatment of cancer on the psychological well-being of adolescents and their parents. This report presents the completed findings at the time of first diagnosis. It provides, for the first time, data on levels of anxiety and depression in patients, controls and parents and will be of assistance to staff in adolescent cancer units in judging the level of initial psychological support which they will need to provide at this stage in the illness.

## PATIENTS AND METHODS

### *Subjects: patients and parents*

Since December 1993, 47 consecutively diagnosed adolescents (12–20 years) and their families have been invited to take part in this study. Patients and their families were excluded if they were not available for follow-up or if English was not the adolescent's first language. Ethical approval was given by the Middlesex Hospital's Ethical Review Committee. Informed written consent was obtained from all participants.

### *Study design*

At the time of first presentation to the unit, the patient and one parent were seen individually to record demographic data and establish rapport. All subjects were assured of individual

confidentiality. Parents completed the questionnaires alone and patients choose whether to complete questionnaires with the researcher or alone. All family members were invited to participate.

### *Psychological assessment*

All subjects were assessed for their current level of anxiety using the Spielberger State Trait Anxiety Inventory (STAI) [12]. The scale was developed to measure anxiety in normal adults. It has 40 questions and there are two subscales. One assesses state (situational) anxiety — anxiety that an individual feels at a particular point in time, a transitional emotional state. The other assesses trait (dispositional) anxiety — how an individual feels most of the time and is a measure of relatively stable individual differences in anxiety across people. The questionnaire has been well validated in adolescents and adults [8, 10, 11, 13]. The STAI is not designed to categorise levels of distress, but to place distress on a continuum from none to severe, a higher score indicating greater anxiety. Hence, there are no cut-off scores for clinically significant levels of anxiety, but comparisons can be made to norms reported by the authors. Research has defined 'low distress' as scores below the reported mean and 'high distress' as scores above [9]. For this research we chose to be more stringent and define high levels of anxiety as scores more than one standard deviation above the means reported in normal populations.

Levels of depression and depressed mood were assessed using the Beck Depression Inventory (BDI), a 21-item questionnaire [14]. The questionnaire has been used extensively with both adolescents and adults [5, 10, 15–18]. In contrast to the STAI, the BDI does have predefined levels of depression based on considerable research by both the authors and other researchers. Scoring is graded; 0–9 no/minimal depression; 10–18 mild to moderate; 19–29 moderate to severe depression; and over 29 severe depression [19]. The BDI question regarding interest in sex was removed as it was considered inappropriate for adolescents at the time of first presentation to the unit. The BDI has three questions which may be influenced by physical illness rather than reflecting depressed mood. These concern fatigue, loss of appetite and weight loss. It is customary not to use these items when assessing physically ill individuals in order not to confound physical illness and mood [20]. In order to categorise the extent of depression in the adolescent groups, an adjusted BDI score was calculated using 17 questions from the original 21-item questionnaire. The adjusted score was the mean of the 17 questions multiplied by 21. Although this is not a true normative score of depression, it is used for the purposes of comparison and in analyses of both adolescent groups reported in this paper. To validate this exclusion, our patients completed the entire questionnaire. Analysis of the data confirmed that these three questions were frequently scored at higher values even when other questions did not indicate depression implying that they were illness-related rather than due to depressed mood ( $t=5.39$ ,  $df 41$ ,  $P<0.0001$ ).

### *Control group*

There are no U.K. data in well adolescents to give normative values for the questionnaires used in this study. A control sample of 173 age- and sex-matched adolescents was therefore recruited from four sources in the community; a Catholic boys' school, a mixed comprehensive school, a Christian

youth club and colleagues' children. The children were recruited by approaching schools directly and questionnaires were completed during school time. The parents of the control group were not assessed because there are normative values which have been widely used [12].

#### Statistical methods

The internal consistency of the completion of the anxiety and depression questionnaires was assessed using Cronbach's alpha coefficients. Two-way analysis of variance (ANOVA) was used to examine differences in anxiety and depression scores between the patients and controls and the mothers and fathers. Pearson's correlation was used to assess the relationship between anxiety and depression scores.

### RESULTS

Of 47 families, 43 families consented to take part. Four families refused citing a reluctance to discuss feelings. One adolescent refused but her parents participated. 95% of patients and parents completed and returned the initial questionnaires. This report presents the analysis of questionnaires completed by 103 individuals near the time of diagnosis.

#### Patients

There were 42 participating adolescents within the first 43 families. Table 1 shows the diagnostic categories with bone sarcoma predominating. By the time of diagnosis, the

Table 1. Diagnoses of adolescent cancer patients

	n	%
Bone sarcomas	29	67
Periosteal/osteosarcoma	20	
Ewing's and round cell sarcoma	9	
Lymphoma	8	19
Acute leukaemia	5	12
Wilms' tumour	1	2

Table 2. Adolescent cancer patients and control group characteristics (percentages in parentheses)

	Study group (n=43)	Control group (n=173)
Age mean	15.4 years	15.8 years
Gender M/F	28/15	131/42
Ethnic origin		
Caucasian	38(88)	141(82)
Asian/Afro-Caribbean/Mid-eastern	3(7)	25(14)
Mixed race	2(5)	7(4)
Family structure		
Two-parent families	28(65)	134(77)
Parental divorce rate	26%	19%
Number of siblings		
0	5(12)	11(6)
1-2	28(65)	125(72)
≥3	10(23)	37(21)
Parental occupation	Blue/white collar	Blue/white collar
Father	33/48%	37/47%
Not working/unemployed	19%	16%
Mother	29/38%	35/39%
Not working/unemployed	33%	26%
House ownership	68%	82%

patients had on average missed 4 weeks of school. Forty-five per cent reported weight loss of 5 kg or more over the previous 2 months and 43% reported current disruptions to their sleeping pattern. In 31% of patients, there was an interval of 6 months from first symptom to diagnosis. 70% of the patients had been told their diagnosis within the previous 3 weeks. At diagnosis, 77% of patients had a performance status of 1 or better. Most patients knew the exact name of their cancer (68%) and 93% considered their cancer 'curable in most cases'.

The median time from diagnosis to completion of questionnaires was 3 weeks (range 1-9). The majority completed their questionnaires with the researcher (67%). Sixty per cent had not started treatment when interviewed, a further 28% were on the first or second day of their first cycle of chemotherapy.

#### Parents

Thirty-four mothers and 27 fathers within the first 43 families agreed to complete the questionnaires. There were 4 adolescents with no parents participating in the research and 8 adolescents were from one-parent families; 7 mother-only families and 1 father-only family. Three mothers and 2 fathers did not return their initial questionnaires. In addition, 2 fathers and 1 mother were unable to participate due to ill-health or language difficulties. One father did not take part because the family were in the pilot study and, at that time, the researcher aimed to meet each participant before administering questionnaires. The mean age of mothers on study was 43 years, fathers 46 years. The median time from the date of their adolescent's cancer diagnosis to completion of their questionnaires was 3 weeks for mothers (range 1-8) and 4 weeks for fathers (range 1-13).

#### Patients and controls

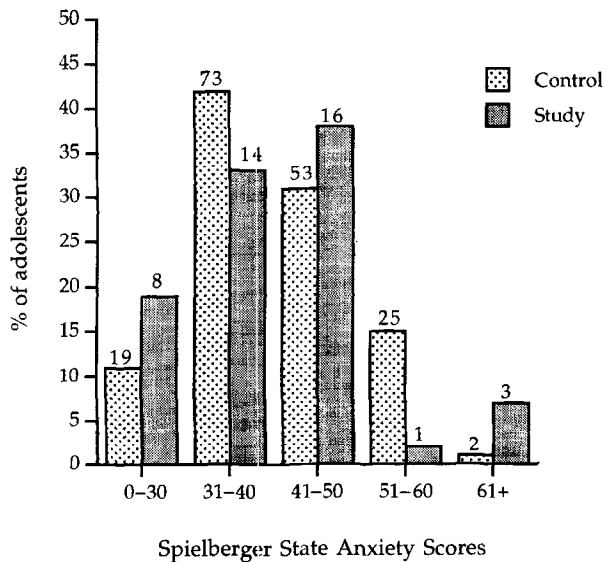
Details of the control and adolescent cancer groups are shown in Table 2. The control and study groups were comparable with respect to age, sex distribution, ethnicity, family structure and occupation. More of the control group adolescents than study group considered themselves religious (45% versus 27%) and were regular church-goers (37% versus 12%). This difference is likely to be due to the recruitment of some of the control adolescents from a religiously selective school and youth club.

#### Psychological well-being

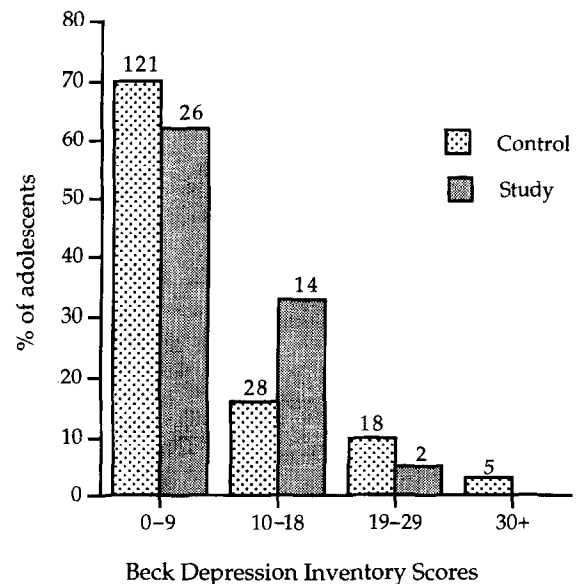
Table 3 shows the internal consistency (Cronbach's alpha coefficients) for the questionnaires completed by the different study groups. These scores indicate high internal consistency for the anxiety and depression scales in all groups of participants.

Table 3. Internal consistency (Cronbach's alpha) for the anxiety and depression questionnaires in adolescents and parents

	Adolescents			Parents	
	Cancer (n=42)	Control (n=172)	Combined (n=214)	Mother (n=34)	Father (n=27)
State anxiety	0.89	0.87	0.87	0.91	0.94
Trait anxiety	0.86	0.88	0.88	0.90	0.87
Depression	0.76	0.90	0.88	0.85	0.81



**Figure 1.** State anxiety scores in control and study adolescents. Scores  $\geq 51$  are more than one standard deviation above the mean reported by Spielberger and associates [12] for high school students.



**Figure 2.** Depression score in control and study adolescents. Level of clinical depression: 0-9 none to mild, 10-18 mild to moderate, 19-29 moderate to severe, 30+ severe.

#### Anxiety

Figure 1 shows the distribution of state anxiety scores in adolescent patients and controls and Table 4 shows the mean state/trait anxiety and depression scores for these groups. There was no significant difference in mean state anxiety scores or in the distribution of state anxiety scores between the adolescent patients and controls. There was a difference in trait anxiety between the two groups with the control group having higher trait anxiety scores ( $f=5.81$ ,  $df1.207$ ;  $P=0.017$ ). Levels of state ( $f=6.53$ ,  $df1.207$ ;  $P=0.011$ ) and trait ( $f=9.54$ ,  $df1.207$ ;  $P=0.002$ ) anxiety were significantly higher in girls than boys. These anxiety scores are similar to those reported for American High School students [12]. In normative data reported by Spielberger and associates, the mean state anxiety score for girls was  $40.54 (\pm 12.86)$  and  $39.45 (\pm 9.74)$  for boys [12]. In this adolescent cancer group, the scores were  $43.14 (\pm 8.61)$  and  $39.14 (\pm 10.57)$ , respectively, for girls and boys.

Table 4 shows parental state/trait anxiety scores. Mothers had significantly higher state anxiety scores than fathers ( $f=4.52$ ,  $df1.56$ ;  $P=0.038$ ). Mean parental state anxiety scores in this study are  $53.03 (\pm 11.62)$  and  $46.44 (\pm 13.09)$  for mothers and fathers, respectively. There are no significant differences in trait anxiety scores. Spielberger and associates report mean norms of  $36.03 (\pm 11.07)$  and  $35.88 (\pm 10.52)$  for working women and men between the ages of 40 and 49 years

**Table 4.** Mean scores  $\pm$ (S.D.) of anxiety and depression in patients, controls and parents

		Cancer	Control	Mother	Father
State anxiety	M	39.14 $\pm$ 10.6	39.67 $\pm$ 8.6	—	46.44 $\pm$ 13.1
	F	43.14 $\pm$ 8.6	43.14 $\pm$ 10.2	53.03 $\pm$ 11.6	—
Trait anxiety	M	37.68 $\pm$ 9.9	41.65 $\pm$ 9.6	—	41.63 $\pm$ 9.9
	F	42.31 $\pm$ 8.4	46.55 $\pm$ 10.6	45.65 $\pm$ 10.9	—
Depression	M	7.54 $\pm$ 5.7	6.59 $\pm$ 7.6	—	9.00 $\pm$ 6.2
	F	9.62 $\pm$ 5.6	12.09 $\pm$ 9.7	12.55 $\pm$ 7.8	—

in America [12]. 60% of mothers (20 out of 33) and 40% of fathers (11 out of 27) had state anxiety scores more than one standard deviation above the reported mean. In the four groups, mothers, fathers, patients and controls, state anxiety and depression scores are highly positively correlated ( $P<0.01$ ).

#### Depression

There was no significant difference in the mean and distribution of depression scores between the adolescents with cancer and the control group (Figure 2; Table 4). Girls were significantly more depressed than boys ( $f=15.21$ ,  $df1.207$ ;  $P<0.0001$ ). Parental mean depression scores are shown in Table 4. There was no significant difference between mothers' and fathers' depression scores.

Table 5 gives the percentages within each group that fall into the different categories of depression as assessed by the BDI for the parents and adolescents. Thirty-three per cent of the adolescents with cancer had mild to moderate levels of depression ( $n=14$ ) compared with 16% controls ( $n=28$ ). Moderate to severe depression was detected in 13% ( $n=23$ ) of controls and 5% of patients ( $n=2$ ). Mild to moderate depression was reported in 30% ( $n=10$ ) of mothers and 38% ( $n=10$ ) of fathers, and 19% ( $n=11$ ) of parents reported moderate to severe depression.

**Table 5.** Percentage (number) of adolescents, mothers and fathers in each of the categories of depression (BDI)

Depression category	Cancer		Control		Mothers	Fathers
	Boys %(n)	Girls %(n)	Boys %(n)	Girls %(n)	%(n)	%(n)
None/minimal	68(19)	50(7)	78(102)	45(19)	43(14)	54(14)
Mild to moderate	29(8)	43(6)	14(18)	24(10)	30(10)	38(10)
Moderate to severe	3(1)	7(1)	6(8)	24(10)	21(7)	8(2)
Severe	0	0	2(2)	7(3)	6(2)	0

## DISCUSSION

The recognition that adolescents with cancer may have physical and emotional difficulties peculiar to that age group has led to the establishment of units specialising in the management of cancer for patients aged 13–20 years. There has, however, been very little research on the emotional accompaniments of the diagnosis of cancer at this age in patients, their parents and siblings. In the U.K. there are no normative data on anxiety and depression in normal teenagers with which to compare data derived from patients.

Previous research has suggested that adolescents diagnosed with cancer are not more anxious or depressed than adolescents in the general population [9, 21]. However, the study of Worchel and colleagues presented data from patients in a wider age range (7–18 years, mean 12.6) and, more importantly, 91% of the subjects were more than 3 months post-diagnosis, with 74% being more than 12 months postdiagnosis [21]. Canning and colleagues reported on a control ( $n=83$ ) and study group of adolescent cancer patients ( $n=31$ ) with a mean age of 14.7 years [9]. The adolescents with cancer were less depressed than the controls and the mean duration of illness was 1.8 years before the assessment. Previous research using the Spielberger anxiety scale has reported a mean state anxiety score in adolescents of 33.81 ( $\pm 6.31$ ) with no gender differentiation [8]. This is a relatively low score, the adolescents were in remission and time since diagnosis was not stated. Correlations between anxiety and depression scores are commonly reported [22].

The present study concerns only the adolescent age range and provides data at the time of diagnosis. The results are compared with data using the same questionnaires in 173 normal adolescents. Although the results are reassuring in that they do not show levels of anxiety or depression in patients above that found in a normal adolescent population, it is clear that an important minority of adolescents are very anxious or depressed. Girls showed increased levels of anxiety and depression compared with boys in both cancer and control groups. Gender differences in the reporting of depression, substantiated by this study, have been reported elsewhere [23–25].

Our findings show that parents, especially mothers, may need special help when their adolescent is diagnosed with cancer. Substantially elevated anxiety scores were found in both mothers and fathers. Dahlquist and associates, evaluating parents approximately 8 weeks after the diagnosis of their child's cancer (mean age 7 years), found higher levels of anxiety but lower levels of depression than reported here [10]. In our study, 27% of mothers reported moderate to severe levels of depression at diagnosis. Sawyer and associates found that mothers had high levels of anxiety at the time of their child's diagnosis, a year later they had high levels of depression [26]. Elevated levels of parental anxiety and depression may have an impact on the adolescent diagnosed with cancer since depression in mothers has been associated with higher levels of depression in children between 8 and 16 years [3, 27]. Relationships between psychological morbidity in family members have also been found in the families of palliative care patients [18]. Research has reported anxiety in the parents of cancer survivors (in remission and no treatment for 6 months) and found mean scores of 33.68 ( $\pm 10.66$ ) and 30.0 ( $\pm 9.21$ ) for mothers and fathers, respectively [11]. Over half the families presenting to the unit had at least one parent with high levels of anxiety. Parents were, as a

group, considerably more anxious than a general population and than the parents of cancer survivors.

The prospective design of the continuing study with further assessments at 3, 6 and 12 months will reveal whether parental levels of anxiety have an impact on the adolescent with cancer and whether the onset of treatment has an impact on the adolescents' levels of emotional distress. These data will be presented when the follow-up of patients and families has progressed further. The present study shows that even if the patients are not more anxious and depressed than their normal peers, medical staff working with adolescent patients, whether in oncology or other specialities, should be aware that some of their patients will be anxious or depressed at the time of presentation and that it is necessary to identify these individuals. It is possible that the patients, while fully understanding the diagnosis, have not grasped the full significance of the disease and its treatment at the time of diagnosis. Changing patterns of emotional reaction may, therefore, be revealed in further follow-up. The study will also allow an assessment of how family members and the adolescent cope during treatment and follow-up and, if it occurs, the additional stresses imposed by relapse.

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