

Psychiatric morbidity in Egyptian children with acute lymphoblastic leukemia and their care providers

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AIM OF THE STUDY: To evaluate the psychological morbidity of acute lymphoblastic leukemia (ALL) on children and their parents at different stages of illness and to assess the crucial contribution of the psychologist in the pediatric oncology team.

METHODS: We recruited 103 children with ALL and their 96 parents, and divided them into five groups according to disease phase: diagnosis, initial remission, active treatment, survival and relapsing. We compared these to 22 healthy controls and their parents. Patients and controls were subjected to clinical assessments, the symptoms checklist of the International Classification of Disease ICD (ICD-10), and the Wechsler Intelligence Scale for Children. The parents of patients and controls underwent a general health questionnaire, the ICD-10 symptoms checklist, rating scales for anxiety and depression, post-traumatic stress disorder (PTSD) assessment scale, and the physical cognitive affective social economic ego problems (PCASEE) questionnaire for quality of life (QOL) rating.

RESULTS: Psychiatric morbidity was evident in nearly 60% of leukemic children and their parents and was significantly increased in comparison to controls. Children mostly suffered from adjustment and oppositional defiant disorders. The most common discriminators between patient groups were conduct and attention problems being lowest in newly diagnosed patients, and social aggression being lowest in patients in remission. The three parameters were highest in relapsed patients whose parents mostly had adjustment and depressive disorders. Risk factors for child psychopathology were older age, female gender, and parental psychopathology. Mothers and parents with lower education and professional level were found to be vulnerable. Performance and total intelligence quotient (IQ) were significantly lower in leukemic children, and these were most pronounced in the survivor group. Risk factors for cognitive dysfunction were younger age, longer chemotherapy duration, and lower parental education level.

CONCLUSION: Most patients and their caregivers suffered from significant psychiatric morbidity, highlighting the need for routine screening to improve psychological outcomes in such cases.

The remarkable history of treatment success in childhood cancer over the past 30 years has changed the landscape for psychosocial oncology care.¹ As pediatric patients and their parents learn of a cancer diagnosis and embark on an often lengthy and intensive course of treatment, they are at increased risk for new or exacerbated psychosocial

difficulties.² Psychiatric morbidity can adversely affect patients in many ways. It can impair quality of life,³ functional status,⁴ and energy level;⁵ it can increase symptom burden and pain intensity,⁶ and interfere with medical treatment.^{7,8}

Providing comprehensive care to pediatric oncology patients and their families necessitates the integration

of multidisciplinary psychosocial teams, interventions into treatment plans, and an increased presence of psychologists.⁹

In the pediatric oncology setting, children diagnosed with acute lymphoblastic leukemia (ALL) and their caregivers may be at higher risk of difficulties related to this significant stressor. Little is known about psychological distress in cultures outside of North America and Europe. Differences in treatment, the limited availability of psychosocial care, and/or family culture may influence how distress is perceived and managed.

Through trained psychologists as part of a pediatric oncology team, we aimed to assess the psychological morbidity of ALL in both diseased children and their parents at various stages of the illness.

SUBJECTS AND METHODS

One hundred and three children with acute lymphoblastic leukemia and their 96 parents, diagnosed and treated in the Pediatric Hematology/Oncology Unit, Children's Hospital, Ain Shams University, Cairo, Egypt, were recruited. Only patients and/or their attending parents who gave their verbal informed consent were included. The study protocol was approved by the Institutional Review Board at Children's Hospital, Ain Shams University. Initially, 200 patients were recruited over an 18-month period, but 49 patients were excluded because patients and/or parents refused to complete the interview and/or questionnaires. Another 45 patients were excluded due to poor clinical condition of the child (severe pain, non-cooperation, irritability or due to the child's disturbed consciousness), and another three patients were dismissed due to the presence of co-morbidity with Down syndrome.

The studied patients were 60 males and 43 females, aged 10 ± 2.4 years. They were divided into five groups according to their disease phase: Group I (GP I): 21 patients at initial diagnosis (less than one week of diagnosis); Group II (GP II): 21 patients in initial complete remission (within three months of diagnosis); Group III (GP III): 22 patients in maintained complete remission for one year or more but still under anti-leukemia therapy; Group IV (GP IV): 28 relapse free survivors (off therapy for at least two years); Group V (GP V): 11 patients in bone marrow relapse (patients with central nervous system (CNS) relapse were excluded).

The group of parents studied included the parent who was continuously with the child during therapy sessions and admissions. These included the mothers of 71 children and the fathers of 25 children; seven parents refused psychological assessment. Only

parents who were above 20 years of age and free of any premorbid psychiatric conditions were recruited.

Controls were recruited from non-medical university workers and their school children who were comparable to patients in relation to socio-economic conditions and had no history of chronic illness. Leukemia patients were compared to 22 healthy controls comparable in age (mean 10.4 ± 3.8 years; $P > 0.05$) and sex (female = 10; male = 12; $P > 0.05$). Their 22 care-giving parents were comparable to patients' parents in age (mean 36 ± 8 years), sex (16 females and six males) and education levels.

METHODS

- I. Both the patients and controls were subjected to the following:
 - Thorough clinical history and examination
 - Psychiatric interviews and assessments were conducted by trained qualified psychologist using the following instruments:
 - (1) Semi-structured psychiatric interview according to the International Classification of disease (ICD-10), a screening tool for psychiatric disorders.¹⁰ Psychologists were blind as to why controls were being interviewed.
 - (2) Wechsler Intelligence Scale III:¹¹ Verbal and performance subtests were applied to assess three areas: verbal comprehension (comprehension, similarities); perceptual organization (picture completion, block design) and freedom from distractibility (arithmetic, digit span, digit coding).
 - (3) Children's Manifest Anxiety (CMA)¹² in the Arabic version,¹³ a child self-report measure that assesses symptoms of anxiety for those above seven years of age. It consists of 36 statements and measures six aspects of anxiety (somatic, physiological, motor, emotional, mental, social features), with six statements for each aspect.
 - (4) Children's Depression Inventory (CDI)¹⁴ in the Arabic version,¹⁵ a 27-item self-report that assesses mood symptoms for those above seven years of age.
 - (5) The Revised Behavior Problem checklist (RBPC),¹⁶ a family self-rated instrument that surveys a broad range of difficulties encountered in children from preschool age through to adolescence, and which provides six scales: conduct disorder, socialized aggression, anxiety withdrawal, motor tension excess, attention problems, immaturity, and psychotic disorders.

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