KNOWLEDGE, ATTITUDES, ANXIETY, AND COPING STRATEGIES OF PEDIATRIC PATIENTS, PARENTS, AND HEALTH CARE PROVIDERS AFTER A LEUKEMIA DIAGNOSIS

Topic: 35. Quality of life, palliative care, ethics and health economics

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Background: Acute leukemia is easily recognized by physicians through bone marrow examination; however, it is not easy to inform pediatric patients and their parents about a leukemia diagnosis. Most information to date has been obtained from adults studies. As well, data on issues related to informing children about leukemia diagnosis are lacking.

Aims: The aim was to evaluate the knowledge, attitudes, anxiety, and coping strategies of pediatric leukemia patients, their parents, and health care providers related to a child’s leukemia diagnosis.

Methods:

Of the 350 participants, 100 were pediatric patients, 100 were patients’ parents, and 150 were healthcare providers (50 pediatricians, 50 nurses, and 50 interns). Each participant answered a short questionnaire regarding the appropriate person, time, and place for conveying a child’s leukemia diagnosis. The questions assessed the knowledge level, attitudes, anxiety, and coping strategies of the participant groups after this diagnosis. Patients’ and parents’ quality of life and anxiety levels were also evaluated using the 36-item Short-form Health Survey (SF-36) and the Revised Child Anxiety and Depression Scale.

Results:

The response rate was 100%. Patients’ parents (n=98; 98%) and health care providers (n=145; 97%) strongly agreed that a child’s leukemia diagnosis should be disclosed directly to the pediatric patient. Compared with health care providers, patients’ parents were significantly more likely to opt for disclosure by the parents in the doctor’s office after the start of chemotherapy (p<0.05). All 100 patients were asked detailed questions about their personal knowledge of their leukemia diagnosis. Sixteen (16%) responded that they were unaware of their diagnosis at the time of the survey. Of these patients, 13 (82%) were younger than 7 years old at the time of their initial diagnosis, and three (18%) were older than 7 years. All 16 of these patients responded during the survey that they wished to know their leukemia diagnosis. The remaining 84 patients (84% of total) stated that they were aware of their diagnosis at the time of the survey. Nine (10%) of them indicated that they wished they did not know about their leukemia diagnosis. These nine were all older than 12 years at the time of diagnosis. They had received antidepressant treatment and psychological support. Four (45%) of them had received chemotherapy. The mean anxiety score for the nine patients who wished they did not know their diagnosis was significantly higher than that for the 16 patients who desired to but did not know their diagnosis (p<0.05). Compared with patients, their parents had significantly higher anxiety levels and significantly lower quality of life (p<0.05). P Thirty-two percent of the pediatricians, 16% of the nurses, and 86% of the interns responded that they had received training in delivering bad news.

Summary/Conclusion: Detailed information about leukemia diagnosis should be avoided for adolescent patients, whereas patients who are initially diagnosed younger than 7 years of age should be re-informed of their diagnosis at an older age. Psychological support for parents and adolescents would enhance adherence to chemotherapy and would increase the quality of life and the ability to cope with anxiety. Providing targeted medical information about...
leukemia diagnosis and how to deliver bad news could positively affect the knowledge and attitudes of health care providers.