Childhood leukemia and non-Hodgkin lymphoma survivors lack of knowledge about their past disease and possible late effects. I-BFM ELTEC study with Chilean and Croatian participation

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March 07, 2024

Abstract

Background: Late effects in childhood cancer survivors are a major cause of morbidity and mortality. The objective was to establish knowledge about the disease, late effects, self-care practices, application of health knowledge/education, sources of information, and biopsychosocial impact of cancer, and compare the results of Chile and Croatia. Procedure: one hundred and seventy-one, five-year survivors who were treated for leukemia or non-Hodgkins lymphoma responded to a questionnaire (119 in Chile and 52 in Croatia). The instrument was reviewed by BFM- ELTEC. Results: health knowledge about past diagnosis and general treatment had 96% Chilean and 85% Croatian survivors. Ninety percent of Chilean and 73% of Croatian survivors were unaware of possible late effects, and half did not know which specialist to visit for follow-up. Forty-six percent of Chilean and 35% of Croatian survivors knew about healthy lifestyles, but most did not practice them. Health education was received during the treatment in 74% Chilean and 87% Croatian survivors. About 50% survivors in both groups had experienced fear or anguish, but it was also considered an experience to grow for 60% of Chilean and 42% Croatian survivors. Eighty-seven percent Chilean and 77% Croatian survivors considered themselves physically independent, while 76% and 75% felt psychologically independent, respectively. Conclusion: It was detected a significant lack of knowledge about the specific treatment, late effects, and future health in both countries. They did not achieve significant learning with the education received. Psychological sequelae were found that are important to prevent.

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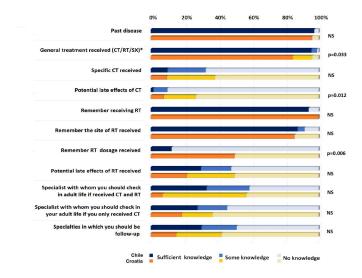
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 ${\it FIGURE~1~Section~B-Knowledge~of~survivors~about~their~disease, treatments, and~potential~late~effects.}$

^{*}CT: chemotherapy, RT: radiotherapy, SX: Surgery

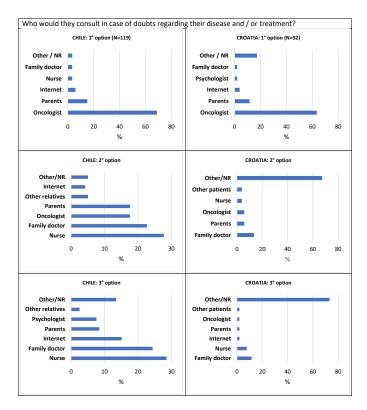


Figure 2 Section D:Survivals option of consultation in case of doubts about their disease and/or treatment

^{*}Option 2, p<0,001, option 1 and 3 not statistically significant. NR: not respond



 $\label{eq:FIGURE 3} \textbf{FIGURE 3} \ \text{Section E: Meaning of Cancer for Childhood Cancer Survivors.} \\ Global\ p<0.0001;\ **p=0.0002;\ *p=0.011$