EDITORIAL

Follow-up into adulthood is critically important for survivors of pediatric transplant

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In this issue, the authors of 'Health-related quality of life in adult survivors after pediatric allogeneic stem cell transplantation' describe an exceptionally well-designed and executed study that successfully explores health status, health-related quality of life (HRQoL) and late effects in adult survivors of pediatric SCT. Survivors were evaluated in the context of existing late effects using an organ system approach and by self-reported symptom survey. Appropriately, SCT survivors of non-malignant disease were included as well. The authors use several tools including the Swedish HRQoL Profile,¹ the Sense of Coherence,² which measures a global tendency to view life situations as comprehensible, manageable and meaningful and the Hospital Anxiety and Depression scale,³ self-assessment scale for detecting depression and anxiety.

Stem cell transplant can be life saving, or in some cases simply life extending, yet the focus of most articles has been on immediate medical and psychosocial outcomes within the first few years post transplant. For those children who survive SCT, there has been little focus on very late outcomes observed in survivors who are now adults. As oncologists, we know that SCT can be life saving, yet as oncologists who specialize in late effects, we know SCT (along with many of our therapies) can be life altering as well.

Most survivors share a common need to 'feel normal' and to 'look like everyone else'. What we have not known until now is how these adult survivors of SCT truly view their lives and their outcomes. In a study of psychosocial effects of marrow transplantation in survivors transplanted as adults, the majority of patients described serious problems with fitness, pain, fear and emotional stress.⁴ Surprisingly, in this report, late effects scoring of organ system function, age at time of transplant, TBI and malignant vs non-malignant disease had little relationship to HRQoL. The group as a whole had an HRQoL not dissimilar from the norm in most areas, although poorer areas included general health, cognition, sleep, partner relations and sexual function. Older age at time of study, time since SCT and fewer reported symptoms had a favorable impact on HRQoL.

The authors make the very valid point that in most settings, the emphasis on the SCT survivor has been one of medical evaluation, medical support and medical intervention. Little attention has been paid to the equally important social, emotional and psychological outcomes

that survivors experience. Studies reported previously are quite limited. Relevant studies have included analyses of cognitive, academic and psychosocial functioning in survivors of SCT.^{5,6} In a report from the Bone Marrow Transplant Survivor Study, adult survivors of pediatric SCT were more likely to report performance limitations and participation restrictions than age matched controls when completing a self-report questionnaire.⁷

The authors cite their conclusions, which demonstrate that we should clearly increase long-lasting support and intervention for pediatric survivors of SCT. In particular, from this study it appears that sexuality, fertility, anxiety and depression are areas of great need. Pediatric SCT survivors may have decades of life to live following transplant, thus making this lasting support critical for ensuring survivors are able to become well adjusted, functioning members of society. Continued research in adult survivors of pediatric SCT will further our understanding of the needs of this truly unique population.

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