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Life beyond the disease: relationships, parenting, and quality of life among survivors of childhood cancer

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Advances in cancer therapies and supportive care have contributed to significant increases in survival rates for children diagnosed with a malignancy. As overall survival rates approach 80%, research has focused on the long-term effects and adverse health outcomes these individuals experience later in life. Nearly two-thirds of survivors report at least one chronic medical condition related to their prior therapy, with 25% being classified as severe or life-threatening.[1] These adverse outcomes stress the importance of ongoing monitoring and surveillance. Just as important as the medical implications are the social implications of childhood cancer and its long-term effects

upon relationships, family planning, and quality of life (QOL).

The psychological effects of cancer therapy include anxiety, depression, and post-traumatic stress and can significantly impact attainment of lifetime educational, vocational, and social goals. Long-term cancer survivors have been reported to have persistent or late occurring medical and psychosocial effects. However, at the same time, few perceive a significant impairment to their general health.[2] Survivors of childhood cancer may actually be more resilient than expected and overcome many of the social barriers forced upon them.

Using the large Off-Therapy Registry of childhood cancer survivors from the Italian Association of Pediatric Hematology and Oncology (AIEOP), Pivetta *et al.* add to our understanding of marriage and parenthood among survivors of childhood cancer.[3] The authors confirm findings of fewer marriages among survivors with 81% of males and 70% of females never marrying or having started a live-in relationship. Fertility among the women also appeared lower but statistical significance was lost after adjusting for marriage or cohabitation, suggesting that when a partner was found, these women produced offspring similar to their peers. As might be expected, marriage/cohabitation and pregnancy are not independent.

These findings confirm what has been reported from other cohorts of cancer survivors. In the Childhood Cancer Survivor Study, 46.1% had never married (49.2% for males, 43.0% for females), statistically higher than their siblings and compared to US Census data.[4] In the British Childhood Cancer Survivor Study, 56% had never married or lived as married.[5] The frequencies in all studies were highest for survivors of CNS tumors and those treated with radiation. Interestingly, rates of divorce and/or separation do not differ for childhood cancer survivors compared to their siblings and population norms.[4-6]

Decreased reproduction or delay in starting a family has also been noted in other populations of cancer survivors. In an earlier Italian study, there was a reported fertility deficit of 41%.[7] In Finland, only 15% of survivors parented at least one child compared to 58% of siblings.[8] The British Childhood Cancer Survivor Study reported only 31% of survivors having at least one child which is approximately two-thirds of what would be expected from British population statistics.[9] Just 3% of Dutch male and 15% of Dutch female survivors reported biological children.[10] Reports from the Childhood Cancer Survivor Study show 15% of men and 27% of women survivors with children.[11,12] While fewer children are produced, no increased risks of birth defects among offspring of childhood cancer survivors have been observed. However, prematurity and low-birth weights have been associated with abdominal radiation.[9-12]

Pivetta *et al.* use marriage and offspring as surrogate markers for the life-long impact of cancer therapy on the social and behavioral choices of adult survivors of childhood cancer. This raises important questions regarding measurement of QOL in this population. Are marriage and reproduction appropriate measures of normal social behavior to be used as indicators of psychological adjustment and achievement? If so, how can we best address these issues during cancer therapy and in long-term follow up?

Reports of QOL among childhood cancer survivors can be challenging to interpret given the variety of domains measured and lack of a universally accepted definition. Recent reviews have focused on four dimensions: physical, psychological, social, and sexual.[13,14] This is similar to the World Health Organization's definition of QOL as the individual's perception of his/her position in life in the context of the culture and value system in which they live and in relation to their goals, standards, and concerns. This definition adds additional domains to physical and psychological, including independence, social, environmental, and spiritual.[15]

Overall, most survivors function well psychologically but suffer from psychosocial deficits.[13,14,16] Health related quality of life (HR-QOL) is often normal or even better than standardized norms.[16] However, there may be increased global distress, with issues typically apparent on emotional sub-scales.[17] There are both positive and negative theories to explain some of these findings, including post-traumatic growth or psychological resilience on the one hand *versus* adaptive repression or biased reporting based on denial on the other .[14,16] Alternatively, it may be a matter of perspective; survival may enhance appreciation of life and conceptualization of QOL.[13,14] Despite this, many survivors have high current and future expected satisfaction.[16]

So if there are deficits in marriage and fertility and in psychosocial interactions, without reported deficits in QOL, perhaps the focus should be on how psychosocial adaption is related to marriage and parenthood among childhood cancer survivors. Concentrating on the intermediate issues may be most revealing. Many factors influence developing stable relationships, subsequent marriage, and eventual parenthood. These may include: coping, adaptation, social interactions, education, ethnicity, school absenteeism, attitudes toward the survivor as a sick child, prolonged dependency, and unusually strong parental bonds that jeopardize the normal development of autonomy and independence.[13,18,19] Many young adult survivors struggle to make contact with peers, develop friendships, or experience pubertal delay or an altered perception of body image. These can influence typical sexual development,[10,18-21] leading to isolation and lack of success at building healthy intimate relationships.[18]

Few studies have investigated psychosexual functioning among childhood cancer survivors, such as the ability to meet a partner, engage in a meaningful relationship, and subsequently experience deeper levels of intimacy. Twenty percent of survivors have limitations in their sexual life. Survivors are older at the time of their first boyfriend or girlfriend and older survivors (≥25 years old) have significantly less experience with sexual intercourse than age-matched population controls. Survivors encounter common sexual experiences later in life, particularly those who received their treatment in adolescence compared to those who were treated in childhood.[18,22] Delays in sexual development may be a factor in delayed marriage and offspring.

Care of the cancer survivor involves attention to both medical and social outcomes. Psychosexual issues are more difficult to define and identify in the clinical setting, but play an important role in a comprehensive understand-

ing of marriage, family planning, and quality of life. Research is needed to better understand how we can identify and address these issues for survivors in our long-term follow-up clinics.

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