Adult survivors of childhood malignant lymphoma are not aware of their risk of late effects.

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Purpose: Survivors after malignant lymphoma are at high risk of late effects. In order to take full responsibility for their own health they need knowledge about their diagnosis, treatment and risk of late effects. We assessed such knowledge in adult survivors after childhood malignant lymphoma.

Material and methods: In 2007-2009 128 five-year survivors after childhood malignant lymphoma participated in a national cross-sectional questionnaire-based survey combined with clinical examination. [Males:69, females:59, treatment period 1970-2000, median age (range) at diagnosis:14yrs (0-18), at survey:32yrs (19-55), Hodgkin lymphoma (HL):84, Non-Hodgkin lymphoma (NHL):44]. Prior to the clinical examination a semi-structured interview on the survivors’ knowledge was conducted by a study nurse. The individual survivors’ responses were compared with his/her medical record

Results: 121 reported their diagnosis correctly, 7 reported that they had cancer, but could not specify malignant lymphoma. Thirty-three could not differentiate between HL and NHL. 123 reported their treatment modalities correctly (radiotherapy vs chemotherapy vs combined). Eighty-five (66%) were not aware of any risks for late effects. The remaining 43 listed at least one of the following late effects; infertility, heart-problems, impaired dental status, hypothyroidism, breast cancer, reduced muscle growth, fatigue and reduced memory or concentration. Thirty-seven survivors who provided additional comments reported that they had received some information about risk of late effects from their therapists. Age at diagnosis or educational level were not associated with knowledge about possible late effects while treatment period was.

Conclusions: Norwegian long-term survivors of childhood malignant lymphomas are showing improved level of knowledge during the last decade of their diagnosis and treatment modalities. Independent of age at diagnosis and level of education, they are insufficiently aware of their risk of late effects.