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Self-perception and quality of life in adolescents during treatment for a primary malignant bone tumour

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A B S T R A C T

Purpose: Adolescents experience physical and psychosocial changes as part of their normal development. It can be hypothesized that they have lower scores on Quality of Life (QoL) and self-perception when additional changes occur due to cancer treatment. The purpose of our study was to assess self-perception and QoL of adolescents *during* or up to three months after adjuvant treatment for a primary malignant bone tumour.

Methods: Ten adolescent patients (median age of 15 years) were included. Every patient was matched with two healthy peers. Participants completed the dutch version of the Self Perception Profile of Adolescents (SPPA) to measure self-perception and the KIDSCREEN-52 questionnaire for QoL. For both instruments, normative data were available.

Results: Adolescents with a bone tumour had consistently lower scores on QoL as compared to healthy peers. Significantly on domains: physical well-being ($P < 0.002$), autonomy ($P = 0.02$), social support ($P = 0.04$) and school environment ($P = 0.02$). Scores on self-perception in this group were similar in both the study and control group.

Conclusions: Adolescents with a primary malignant bone tumour *during* or up to three months after adjuvant treatment had lower scores on QoL (KIDSCREEN-52), significantly on domains of physical well-being and social functioning. Unlike most other quality of life instruments, the KIDSCREEN-52 contains different areas of social functioning and has shown to be a useful instrument in our patient group. Scores on self-perception in this group were similar in both study and control group.

Introduction

Primary malignant bone tumours account for approximately 3–8% of all cancers in children younger than 20 years of age (Eyre et al., 2009; Heare et al., 2009; Esiashvilly et al., 2008). The most common primary malignant bone tumours are osteosarcoma and Ewing's sarcoma (Eyre et al., 2009; Heare et al., 2009). The total duration of treatment for both malignancies is about one year. It consists of neo-adjuvant chemotherapy followed by local treatment with surgery and/or radiation therapy, followed by adjuvant chemotherapy (Heare et al., 2009; Hinds et al., 2009a; Marina et al., 2009).

Adolescents experience physical and psychosocial changes as part of their normal development (Pinyerd and Zipf, 2005; Remschmidt, 1994). One can hypothesize that, when additional changes occur due to cancer treatment, a detrimental effect on the development of self-perception can occur (Dewan et al., 2010; Lahl et al., 2008). Physical changes that are related to cancer and cancer treatment are alopecia, stretch marks, loss of mobility and functionality of the affected limb, scars or amputation (Enskär

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and Essen von, 2007; Juergens et al., 2006). Examples of psychosocial disturbances are repeated and prolonged hospitalization, stressful interventions and the fear of dying (Westermann, 2004; Grootenhuis and Last, 2003). These adolescents have to find new ways to interact with peers, friends and parents (Westermann, 2004; Grootenhuis and Last, 2003). It has been suggested that children and adolescents with primary malignant bone tumours are at risk for psychosocial maladjustment (Paredes et al., 2012). Early recognition of problems related to self-perception and health related quality of life (HRQoL) can improve care of these patients.

HRQoL refers to the assessment of various aspects of health from the patient's point of view and includes physical, psychological and social well-being and functioning (Eiser and Morse, 2001). Most published data about HRQoL from patients with primary malignant bone tumours has been gathered from adult patients or adult survivors of childhood malignant bone tumours. These studies mainly focus on the physical function, the impact of quality of life after bone-sparing surgery versus amputation, or on late effects (Hinds et al., 2009b; Tabone et al., 2005). The aim of this study was to assess self-perception and HRQoL of adolescents *during* or up to three months after adjuvant treatment for a primary malignant bone tumour and to compare these results with those of healthy controls.

Materials and methods

Patients and healthy controls

This study has a cross-sectional design. Ten adolescents with a primary malignant bone tumour selected from the clinical database of the department Paediatric Haematology and Oncology of Radboud University Medical Center and twenty healthy controls participated in the study between January and April 2011. After approval was obtained from local ethics committee, eligible participants got an oral invitation and were sent a package consisting of a letter inviting them to participate in the study, a description of the study, standardized questionnaires (described below) and a stamped return envelope. All included adolescents were aged between 12 and 18 years and gave their informed consent. If adolescents were aged between 12 and 15 years, additional consent was given by their parents. This study was approved by the local ethics committee.

Adolescents with osteosarcoma were treated according to the Euramos-1 protocol (Marina et al., 2009) and with Ewing's sarcoma according to the EURO-EWING-99 protocol (Ladenstein et al., 2010). All adolescent patients were included *during* or up to three months after adjuvant treatment for a primary malignant bone tumour. Exclusion criteria for patients were the presence of metastatic disease, for healthy controls the presence of a chronic disease. There are known background variables that can influence the study results, such as age, gender, education level, family composition and ethnicity (Remschmidt, 1994; Tabone et al., 2005; Frances et al., 2007; Nagarajan et al., 2004; Pentley et al., 1997). Therefore, we asked each adolescent with a primary malignant bone tumour to invite two healthy peers from their school class (education level, low grade versus high grade secondary school) with the same age (plus or minus one year in age was accepted), gender family composition (one or two parent family) and ethnical background (Caucasian versus Immigrants) to participate in our study as controls. In this manner we obtained a matched dataset in which each patient was matched on age, gender, education level, family composition and ethnicity to two healthy controls. If healthy controls would not participate in the study other healthy controls were approached.

Instruments

All adolescent patients and healthy controls received the Dutch version of the Self Perception Profile of Adolescents (CBSA) for testing self-perception and the KIDSCREEN-52 questionnaire for testing HRQoL and were asked to complete both questionnaires individually and at the same time. The instruments were anonymous en could be returned with a stamped return envelope.

SPPA

The Dutch version of Self Perception Profile of Adolescents (SPPA) was used to asses self-perception was used to assess self-perception. This survey gives an impression of seven specific domains (school skills, social acceptance, sports skills, physical appearance, behavioural attitude, friendships and self-perception), obtained by self-assessment of the adolescent (Treffers et al., 2002, 2004). Each domain consists of five items (total 35 items). The items were constructed from two propositions. All adolescents had to indicate which proposition they recognized the most *e.g.* some do/become/feel X, others not do/become/feel X. Then they had to indicate whether they identified it as a bit or as completely. The questionnaire uses a 4-point Likert scale. For each domain, the relevant items are summed and scaled to a score with a range of 0–100. A score of 15–85 is considered as normal. A score of 85 or higher and a score of 15 or lower is considered as an abnormal score (Treffers et al., 2002). Completing the SPPA takes about 15 min.

The questionnaire is a well-validated measurement tool testing by a pool of 1375 Dutch adolescents. It allows comparisons with the Dutch general population (Treffers et al., 2002). Cronbach's alphas values were calculated for all domains and were mostly around the 0.80. The test-retest reliability correlations were between 0.72 and 0.76 and in all cases significant ($P < 0.01$).

KIDSCREEN-52

Quality of life was measured using the Dutch version of KIDSCREEN-52. This is a 52-item generic instrument for HRQoL in children and adolescents aged 8–18 years (Ravens-Sieberer et al., 2006). This questionnaire can be used in healthy and chronically ill children and adolescents aged 8–18 years (Ravens-Sieberer et al., 2006). The time required for completing this questionnaire is 15–20 min. Ten domains of HRQoL are assessed: physical well-being, psychological well-being, mood & emotions, self-perception, autonomy, parent relations & home life, financial resources, social support & peers, school environment and social acceptance (bullying). All adolescents were asked to assess the domains over the week prior to completing the questionnaire. The questionnaire uses a 5-point Likert scale.

For each domain, the items are summed and scaled to a score with a range of 0–100. Higher scores indicate better QoL and a score between 45 and 55 is regarded as normal (Ravens-Sieberer et al., 2001). The Dutch version of the KIDSCREEN-52 is a well-validated measurement tool tested by a pool of 1270 Dutch adolescents, and allows comparisons with the Dutch general population (Ravens-Sieberer et al., 2008). Reference data are available for gender and two age groups: 8–11 years and 12–18 years (24,26). Cronbach's alphas values were calculated for the ten domains and varying between 0.76 (social acceptance, bullying) and 0.89 (Financial Support) (Ravens-Sieberer et al., 2006).

Statistical analysis

All domains of the SPPA and the KIDSCREEN-52 are analyzed as described in the questionnaire manual. All analyzes were performed using the Statistical Package for Social Sciences (SPSS, version 16.0). Data are presented as means and standard deviation.