



## Recruiting young adult cancer patients: Experiences and sample characteristics from a 12-month longitudinal study

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### ABSTRACT

**Purpose:** Studies among young adult cancer patients are necessary to improve their psychosocial care situation. However, achieving high response rates in this group is challenging. This study focused on the psychosocial life and supportive care situation of young adult cancer patients, and reports the recruitment and retention strategies, sample characteristics and preferences.

**Method:** Participants (aged 18–39 years at diagnosis) diagnosed within the preceding 4 years were recruited from various clinical settings and surveyed at two time points.

**Results:** In total, 514 participants completed both surveys. Most patients were recruited from rehabilitation clinics (39.5%) and tumour registries (30.2%). Internet-based self-registration resulted in the highest yield of participants. Participants in inpatient (rehabilitation) treatment preferred to complete a hard copy of the questionnaire at baseline (59.7%), but a strong preference for using the online form was found at follow-up (74.5%). The distribution of diagnoses in the sample was almost comparable to the national incidence rates in Germany. Males and patients with melanoma were slightly under-represented.

**Conclusions:** Recruitment of a large sample of young adult cancer patients is possible but requires intensive recruitment efforts, particularly in Germany. Social media and age-specific approaches were found to be effective for recruiting and retaining participants. Giving patients the option to complete a hard copy or the online version of the questionnaire, especially during inpatient treatment, may optimise participation rates. Psychosocial research and support programmes for young adults should consider that women are probably more likely to participate in psychosocial (research) programmes than men.

### 1. Introduction

While the age used in definitions of adolescents and young adults with cancer is not consistent in research, the US National Cancer Institute defines adolescents and young adults as a specific group of patients diagnosed with cancer between the ages of 15 and 39 years (National Cancer Institute, 2006). The biological and developmental characteristics of adolescent and young adult cancer patients differ from those of both older and younger groups of cancer patients (Bleyer et al., 2008). As such, it follows that adolescent and young adult cancer patients have unique medical and psychological needs (Ramphal et al., 2011; Tai et al., 2012).

It has been reported previously that cancer diagnosis and treatment during young adulthood can cause several specific problems, including loss of fertility, hair loss, other changes in body image, sexuality, fatigue, work-related problems (Nowe et al., 2017; Soanes and White, 2017; Zebrack, 2011), high emotional struggles (Kim et al., 2016), and profound effects on far-reaching quality-of-life issues (Husson et al., 2017; Sodergren et al., 2017). To understand and address the symptoms, and to support young adult cancer patients and their families, there is a need for quality-of-life studies in this age cohort (Bibby et al., 2017; Smith et al., 2016).

While a number of studies have been conducted on the psychosocial life of child cancer patients and older cancer patients, little is known, to

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date, about the quality of life and supportive care situation of young adult cancer patients (Smith et al., 2016). This could be related, in part, to recruitment challenges in adolescent and young adult cancer patients, as previous studies have shown that achieving a high response rate in this patient group is difficult (Harlan et al., 2011). The fact that adolescents and young adults constitute only 3% of the cancer patient population in Germany (Robert Koch Institute, 2015) increases the difficulty of recruiting larger samples. In fact, many medical facilities do not even treat a handful of adolescent and young adult cancer patients each year.

From 2014 to 2016, a study was conducted to assess the psychosocial life and supportive care situation of young cancer patients. This article describes the strategies used to recruit and retain young adult cancer patients for the study. Participants' preferences and characteristics of the recruited participants are outlined, and recruitment approaches are discussed.

## 2. Methods

### 2.1. Study design

This prospective study had two measurement points. From May 2014 to December 2016, young adult cancer patients completed the baseline survey upon completion of their acute medical treatment. Follow-up measurement was carried out 12 months later. A more detailed description of this study can be found elsewhere (Leuteritz et al., 2017). The study was funded by German Cancer Aid, and was approved by the Ethics Board of the Medical Faculty of the University of Leipzig (Ref. No. 372-13-16122013). The inclusion criteria were: (1) cancer diagnosis – first manifestation, all malignant tumour identities, Stages 1–4; (2) age at diagnosis: 18–39 years; and (3) cancer diagnosed within the last 4 years.

### 2.2. Patient recruitment and data collection

Recruitment was undertaken throughout Germany in cooperation with 16 oncological acute care hospitals, four (cancer) rehabilitation clinics and two tumour registries. Existing German data protection laws do not allow research institutions to retrieve patient data from regional cancer registries without the express permission of the patients. In cases where it is possible to use data from such registries at all, this can only be done by special arrangement, such as with the two tumour registries in this study. Moreover, in Germany, patients aged < 18 years are treated at paediatric oncological facilities, and cannot participate in studies without their guardian's explicit permission. For simplification, patients aged 18–39 years (young adult cancer patients) were recruited for this study.

Study candidates were informed about and invited to participate in the study by physicians, (study) nurses and clinical psychologists practising in the oncological stations where they were being treated. Additionally, other interested participants could register themselves via the Internet. Interested candidates were given information about the research project via flyers, posters, the project website, and a Facebook page with a direct link to apply for the study (Leuteritz et al., 2017).

After consenting to take part in the study (patient master sheet and consent form), participants were provided with a link to answer the standardised study questionnaire online with LimeSurvey (LimeSurvey Project Team, 2015) or, if so desired, a hard copy of the questionnaire was sent by post with an addressed and stamped return envelope. An employee of the tumour registry at University Medical Centre Leipzig screened registered patient data, filtering for the study inclusion criteria, and provided the addresses of potential candidates. The study team contacted these people about the study and invited them to participate. Candidates who agreed to participate were sent a hard copy of the questionnaire by post, along with an addressed and stamped return envelope. As German data protection laws do not allow the retrieval of

patient data from regional cancer registries without the patients' express permission, an employee of the tumour registry at University Medical Centre Rostock (not affiliated with University Medical Centre Leipzig) contacted the potential candidates by post with information about the study, and provided them with the necessary materials for participation (hard copies of the questionnaire and stamped addressed return envelopes).

To maximise the participation rate, participants received a compensation fee of 10 Euros for completing each questionnaire. After inviting participants to fill out the online survey form, they received two e-mail reminders (once every two weeks), followed by a written reminder supplemented by a hard copy of the questionnaire. If a patient still did not respond, they were telephoned. Patients who received the hard copy survey form were reminded once by telephone after 4 weeks. If a person could not be reached by telephone after three attempts, they were sent a hard copy of the questionnaire. If a candidate did not respond after 6 additional weeks, they were excluded from the study. Additionally, the authors were in constant contact with the patients of the baseline sample; all of the study participants were sent thank you cards, and Christmas and Easter greetings. In addition, age-specific information and information about the study was posted regularly on the Facebook page between baseline and follow-up.

### 2.3. Follow-up survey

A follow-up survey was conducted to examine life situation changes and psychosocial care outcomes 1 year after the baseline survey. Participants were contacted by e-mail or, if no e-mail address was available, by post 11 months after baseline asking them to complete the questionnaire again, either online or as a hard copy (respondent's choice). If necessary, participants were reminded every 5 days by e-mail, once by post along with a hard copy of the study materials, and once by telephone over the course of 8 weeks after the due date. If none of these efforts were successful, the patient was considered to be lost to follow-up.

### 2.4. Measurements

The survey took approximately 50 min to complete, and focused – at baseline and at follow-up – on psychological distress, quality of life, psychosocial living situation, supportive care needs and use of psychosocial support services. Standardised questionnaires were mainly used (see Table 1). More details can be found elsewhere (Leuteritz et al., 2017). To get a deeper understanding of the participants' life situation, quantitative data were supplemented by qualitative semi-structured interviews at both measurement points with a subset of selected participants ( $n = 18$ ) who had previously given their consent (Breuer et al., 2017; Mentschke et al., 2017).

### 2.5. Statistical analyses

To draw comparisons between the study sample and the official data from the German Centre for Cancer Registry Data at the Robert Koch Institute, the deviation of percentage points for sex and diagnosis was assessed between the study sample and the official data for the general population. Chi-squared test for independence was used to compare the number of percentage points in the study sample with that in the cancer registries. The Chi-squared-based coefficient Cramer's V (CV) was used to measure the difference between the percentage points in the study sample, and the percentage points that would be expected if they did not differ between the two groups (official data and study sample). Both comparisons can be interpreted in the same way as the Cohen's  $w$  effect using the following cut-offs (Cohen, 1988): small CV = 0.1–0.3, medium CV = 0.3–0.5 and large CV  $\geq 0.5$ . Differences in socio-demographic variables between completers and drop-outs were assessed using  $t$ -test for independent groups and McNemar's Chi-squared

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