



## Experiences of teenagers and young adults treated for cancer in Sweden



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### A B S T R A C T

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Quality of life

**Purpose:** Approximately 600 teenagers and young adults, TYAs (ages 15–29), are newly diagnosed with cancer in Sweden every year and treated in many different units. The knowledge about TYAs is limited and there might be a need for a new approach in the care for this particular age group. The purpose of this study was to identify requirements TYAs in Sweden acknowledge as important to them.

**Methods:** 44 participants aged 15–29 who were treated at either pediatric or adult cancer units in Sweden, participated in focus group interviews. They were interviewed in groups based on whether they were treated in pediatric (14–18 years old) or adult units (18–29). The focus group interviews were recorded, transcribed, and analyzed using qualitative content analysis.

**Results:** Results of the study can be summarized into four categories: personal professional interaction, knowledge and participation, age-appropriate environment, and support. Important TYA care needs vary over time due to individual situations. The time line of the cancer experience can be described as a continuum; at diagnosis, during treatment, and in life-after cancer treatment.

**Conclusions:** TYAs treated in Sweden have special needs that are not being satisfied, whether at pediatric or adult units. Areas that need closer attention are: close relatives' participation in the care, information on sex and fertility, age-appropriate social physical environments during treatment, and psychosocial support after treatment. In Sweden, there is a demand for increased knowledge on the special needs for TYAs in clinical practice.

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### Introduction

Approximately 600 teenagers and young adults, referred to as TYA's, between the ages of 15 and 29, are newly diagnosed with cancer in Sweden every year ([The Swedish Cancer Registry, 2010](#)). In Sweden, cancer care is regulated by the Health and Medical Service Act at the Ministry of Health and Social Affairs, and controlled by the National Board of Health and Welfare ([Health and Medical Service Act, 1982](#)). Healthcare is publicly funded in Sweden and the country is divided into county councils which are responsible for ensuring that cancer services are delivered in accordance with current regulations. The cut-off age for being treated at a

pediatric unit is 18 of age and patients over the age of 18 are treated at adult cancer units or transferred to one when reaching that age. Every year, healthcare professionals (HCP's) in a pediatric cancer unit care for approximately one teenager in every 20 patients, while in the same period of time HCP's working in adult cancer care sees one TYA in every 500 cancer patients ([The Swedish Cancer Registry, 2010](#)). Therefore, knowledge of TYA's as a special group of cancer patients is limited, new approaches to their care and the need for special units or special programmes of cancer care for TYA cancer patients, similar to other countries might be needed ([Ferrari et al., 2010](#); [McGoldrick et al., 2008](#); [Morgan et al., 2010](#); [Thompson et al., 2013](#); [Zebrack et al., 2006](#)).

The development of new TYA units is emerging in the world and several countries have established special cancer care for TYA's ([Cohen-Gogo et al., 2011](#); [Ferrari et al., 2010](#)). In some countries the programs for TYA cancer patients have been evaluated by interviews with patients and HCP ([Kelly et al., 2004](#); [Mulhall et al., 2004](#); [Olsen and Harder, 2011](#)). The results showed that the TYA

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units have a special culture which ensures that TYA's received the physical, social, psychological support that they needed in these units. In Sweden there are no special TYA cancer care units or programs for TYA cancer patients.

There are some studies highlighting the particular needs of TYA's, including their need to be treated at special units with age-appropriate environments where the culture of care is appropriate for TYA's (Morgan et al., 2010; Ramphal et al., 2011; Smith et al., 2007). There are also studies looking at communication and information to TY's with the results of increased need for knowledge of age-appropriate communication among HCP's (Bellizzi et al., 2012; Hedstrom et al., 2004; Wicks and Mitchell, 2010).

TYA patients are going through a stage in life when they are supposed to be establishing independent lives, and social relationships outside the family (Gibson, 2008). However, keeping a normal life can be difficult when a TYA needs to go through treatment for cancer. The question has been posed if TYA's receive the support they require from the healthcare system (Chambas, 1991; Evan et al., 2006; Gibson et al., 2013) Along with age-appropriate care; research shows the value of involving TYA in research evaluation (Fern et al., 2013).

The purpose of this study was to identify aspects of care and the needs that Swedish TYA's stress as important to them during their cancer journey.

## Methods

### Participants

TYA's, who were treated for cancer and had finished their treatment at either pediatric or adult cancer units in Sweden, received a written invitation to participate in the study. Individuals treated for cancer at some time between the ages of 15 and 29 were eligible to the criteria of the study. Fifty-eight TYA's agreed to participate. The majority of the patients were recruited from five adult cancer clinics and two pediatric cancer centres, in the two main cities in Sweden, Stockholm and Gothenburg. All of the patients in this study were diagnosed at these units and some patients received part of their treatment at local hospitals. The groups were mixed according to diagnosis and gender (Table 1). Twenty-one participants had been treated at pediatric units or cancer centres (15–18 years.) and 23 had been treated at adult healthcare facilities (19–29 years.). There were five focus groups with participants who had been treated in a pediatric unit and six groups who had received treatment in adult cancer centres. The number of

**Table 1**  
Demographics.

Characteristics	Range	Median (IQR)
Age at interview, y	15–31	21 (7)
Age at diagnose, y	14–28	17.5 (8)
Months since completed treatment	3–48	16.5 (26)
		n (%)
Eligible participants N = 125		
Participants consenting to participate		58 (46)
Participants in all focus group interviews		44 (76)
Drop outs		14 (24)
Male		16 (36)
Female		28 (64)
Leukemia		12 (27)
Lymphoma		11 (25)
Sarcoma		12 (27)
Brain tumor		2 (5)
Testicular cancer		5 (11)
Gynecological cancer		2 (5)

participants in each group ranged from two to seven. In some of the focus group interviews there were one or two drop-outs on the day of the focus group interview, due to reported illness or with no reason given. The focus group interviews were conducted despite the missing participants.

### Data collection

Focus group interviews can be an efficient method for exploring opinions among young people (Gibson, 2007). The focus group interviews were conducted by a moderator and an assistant (Krueger and Casey, 2009). The moderator directed the discussions from a set of open questions about care needs. During the focus group interviews the moderator started by stimulating an open discussion by asking: What are your experiences of cancer care? What was important for you during your treatment? Is there anything you would change in the care if you could? This was followed by covering different areas using an interview guide (Table 2). The assistant took notes during the discussion and completed a summary at the end of each session for participants to approve or add and clarify their opinions. Digital audio recordings were also made. Two of the authors were moderators and the assistants were another of the authors, a research student and a nurse consultant. Each focus group interview lasted 60–90 min. The focus group interviews were conducted in conference rooms at the respective clinics.

Ethical approval for this study was granted from the regional ethical review board in Gothenburg, Sweden, DNR: 753-09.

### Data analysis

The focus group interviews were transcribed and analysed according to qualitative content analysis (Elo and Kyngas, 2008; Krippendorff, 2004). The text of each focus group interview was repeatedly reviewed to confirm the accuracy of the contents, and to ensure that the data met the requirements of prescribed analytical methods. The analysis continued until the descriptions of the generic categories and subcategories were close to the contents of the text (Elo and Kyngas, 2008). Three of the authors reviewed the material separately and discussed the results until a consensus was reached (Elo and Kyngas, 2008). The data from the focus group interviews with participants from pediatric versus adult care settings were analysed separately. However, the results are jointly presented because the results from the pediatric and the adult care settings were mainly congruent, even though it varied to some extent.

## Results

The results of the study can be summarized into four generic categories: **personal professional interaction, knowledge and**

**Table 2**  
Focus groups interview guide.

Types of care
Environment
Decision-making
Family/significant other
Respect and integrity
Communication
Close relationships
Competence (among HCP)
Continuity

Abbreviations: HCP, Health Care Professional.

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