



## Dealing with fear – from the perspective of adolescent girls with cancer

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### A B S T R A C T

**Keywords:**  
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**Background:** Previously fears in adolescents with cancer has been identified in relation to medical procedures, death, altered appearance and as having an overall influence on life, but to our knowledge young people's perspectives on dealing with fear have not been previously investigated.

**Purpose:** To examine adolescents' perspectives on dealing with cancer related fear.

**Methods and sample:** Six girls participated in qualitative interviews focussing on their fear and how they dealt with it. Data were analysed by means of qualitative content analysis.

**Results:** The results revealed two perspectives. First, the adolescents' own personal battle with fear. Second, they reported that they were not alone with their fear, as they shared it with significant others. An environment characterized by emotional presence helped them to deal with their fear, as well as prevented it from occurring.

**Conclusions:** There is a need for staff and parents to be vigilant to the adolescents' need to feel cared for and allow them the opportunity to deal with their own fear, as at times they want to manage in their own way. Young patients have resources to cope with their fears and therefore should not be viewed as victims, but as young people with a great amount of competence, who benefit from a supportive environment.

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### Introduction

This study focuses on how adolescent girls describe their experience of dealing with fear when having cancer. In Sweden, 63 children and adolescents, aged 10–14 years, and 118 adolescents, 15–19 years, were diagnosed with cancer in 2008 (the distribution between the sexes was almost identical) (National Board of Health and Welfare 2010).

From a theoretical perspective, fear has been defined as an unpleasant emotional state that occurs as a response to a real threat or danger, whilst in the case of anxiety, the source of the threat is difficult to identify (Miller and Keane, 1987; Tamm, 2003). Fear related to personnel or procedures in a health care setting has been defined in the literature as medical fear (Broome et al., 1990; Tamm, 2003). Fear is believed to be biological as well as learnt and a highly individual emotion, present at all ages, although what is feared differs between age groups. There is also the cognitive perspective, where the child has an enhanced perception, in which he/she

overestimates the danger or threat and underestimates his/her own capacities to handle it (Tamm, 2003). In the literature, fear in children with cancer has been related to distress (Enskar et al., 1997; Hedstrom et al., 2004; Jacobsen et al., 1990). In the present investigation, the adolescent girls themselves defined what they regarded as fear.

According to the UNICEF, every human being under the age of 18 years is considered a child (UNICEF, 2010). In general, exposure to severe fear for an extended period of time puts children at high risk of developing negative emotional reactions. Support and a stable environment are believed to have a beneficial impact on such debilitating effects (Nicastro and Whetsell, 1999). The child's ability to handle the fearful situation is believed to influence the extent to which he/she considers him/herself vulnerable. The less successful the child's strategies for dealing with the fear, the more trepidation he/she may experience in the fearful situation (Nicastro and Whetsell, 1999). Although the latter refers to children in general, this study focuses on adolescents, aged 13–18 years.

It is acknowledged that suffering from cancer can cause fear (Chesler and Barbarin, 1987; Carlsson et al., 2008). Hedstrom et al. (2004, 2005) have described adolescents experiencing worry related to medical procedures and Hedstrom et al. (2005) and Stegenga and Ward-Smith (2009) have reported about the fear of

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not recovering from cancer. Fear of dying has also been reported (Enskar et al., 1997; Hedstrom et al., 2004). Furthermore, fear during adolescence is reported in the literature related to a changed appearance (Hedstrom et al., 2004, 2005), missing school, losing friends (Hedstrom et al., 2004, 2005) and giving up leisure activities (Hedstrom et al., 2004). Fear has been described as an embodied experience that has an overall influence on life and is, therefore, much more than merely situational (Carlsson et al., 2008). In contrast to the descriptions above, some adolescents 4–8 weeks post-diagnosis reported not having experienced any disease or treatment-related worries (Hedstrom et al., 2005), and Stegenga and Ward-Smith (2009) found that most of the adolescents in their study reported that they had become accustomed to their cancer diagnosis after 4–6 months.

Although some findings related to fear in adolescents with cancer exist, research related to dealing with fear in adolescents has not been studied extensively and evidence is limited. Yet, a few articles on coping have been found. McCaffrey (2006) described coping mechanisms related to major stressors in childhood cancer. The six children interviewed were aged 5–15 years and suffered from various malignancies. Watching TV was reported to be a strategy to pass the time and relax, while home-cooked meals were a strategy to enable them to eat when they found hospital food unappetizing. Wearing a hat to hide hair loss was also mentioned. Children also appear to use distraction techniques such as reading, listening to music and receiving massage. Painting was described as enjoyable as well as a way to express themselves (McCaffrey, 2006). Coping thoughts and behaviours have been measured in thirty-eight 11–18 year-old adolescents with various cancers. Generally, they reported using more engagement than disengagement in coping with stressful situations, and girls relied on engagement strategies more often than boys. Such strategies were problem solving, cognitive-restructuring, accessing social support and expressing emotions. The disengaged strategies were problem avoidance, wishful thinking, social withdrawal and self-criticism (Trask et al., 2003). Adolescents diagnosed with cancer described parents and friends as important sources of support (Woodgate, 2006; Stegenga and Ward-Smith, 2008, 2009). Talking to family members in an attempt to deal with fear was also reported (Stegenga and Ward-Smith, 2009).

As mentioned above, the literature indicates many sources of fear that adolescents with cancer may face and also that it is crucial for their well-being to find strategies to handle fear. We identified some research that described how adolescents cope with their stressors, but could find no study that focused specifically on adolescents' dealing with fear. Therefore, the present study aims to examine adolescents' perspective on dealing with cancer related fear.

## Method

This study uses a qualitative, descriptive design. Qualitative methods are considered appropriate when the aim is to understand an area that has been sparsely described, to gain knowledge of a person's experience of a phenomenon or to understand an emic (insider) perspective (Morse and Richards, 2002).

### *Sampling and participants*

Purposeful sampling was performed. A coordinating nurse at an outpatient clinic at a university hospital in a medium sized town in Sweden approached all nine families of adolescents (aged 13–18 years) who had received a cancer diagnosis and who were no longer undergoing active treatment but were attending the paediatric clinic for regular check-ups. This selection was based on

a wish to be inclusive of experiences at all stages of the cancer illness; the onset, the treatment and the completion of treatment. Six adolescents (all girls) agreed to participate. One of the researchers arranged for the interview to take place in connection to each adolescent's next visit to the outpatient clinic. This timing was based on the ethical principle of doing no harm (Hill, 2005; Polit and Beck, 2004). As the adolescents were considered cured, we did not want to remind them of their disease more than necessary, which a separate appointment for the interview might have done. The participants were 14–16 years old and had been diagnosed 1.5–6 years previously with leukaemia ( $n = 4$ ) or solid tumours ( $n = 2$ ). All of them had had some contact with the Regional Oncology Centre, but most of them had had their main treatment at the university hospital, at a general paediatric clinic.

### *Data collection*

Qualitative research interviews were performed, as these provide qualitative accounts of the life world of the interviewee in order to interpret the meaning of his/her experience (Kvale, 1997). The individual interviews were conducted as conversations between the researcher (first or third author) and the interviewees, governed by the aim of the study. They took place in a quiet room at the outpatient clinic, after the adolescents had seen their physician, and lasted from 14 to 44 min (mean 34 min). A few introductory questions were posed to make the interviewees feel comfortable before the main question about their experience of fear were asked. The two interviewers agreed in advance on some introductory questions, as well as on the main question, which was: "Can you tell me about any situation, in the period since the onset of your illness until today, when you experienced fear?" Some probing questions were also asked, which focused in various ways on how the adolescents dealt with fear, and their answers (narratives) form the basis of this publication. During the interview sessions, the interviewers adapted to the style of language used by the adolescents, as recommended by Kortelnuoma et al. (2003). The interviewers also explained to the adolescents that it was their experience of fear and their dealing of fear that was of importance. They were encouraged to elaborate on their perspective and assured that there were no right or wrong answers when talking about experiences. The interviews were audio-taped with the interviewees' permission and later transcribed by an experienced transcriber.

### *Data analysis*

The transcribed interviews were read repeatedly by all authors. Text that appeared to capture the meaning of how the girls handled their fear was highlighted and systematically coded by the third author. This was done by labelling sentences in accordance with the key concepts contained in them. Once the coding was completed, the first author examined all the codes, after which the first and last authors jointly grouped them into categories by sorting them on the basis of their interrelated content. Finally, sub-themes and themes were identified, based on the internal relationship within the categories (cf. Hsieh and Shannon, 2005). In order to achieve credibility and confirmability (Lincoln and Guba, 1985), the second author validated the findings by examining the agreement between the transcripts and the emerging themes. Final agreement was reached on two themes and six sub-themes, mirroring different aspects of how the adolescents dealt with fear.

According to Swedish laws and regulations, at the time of data collection it was not necessary to apply for ethical approval for interview studies Law (2003:460) on ethical review of research involving humans. Instead, the Regional Ethical Review Board in Uppsala, Sweden, was asked for an advisory statement concerning

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