



## Existential challenges in young people living with a cancer diagnosis



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### ABSTRACT

**Purpose:** In Sweden, approximately 500 people between the ages of 15 and 39 are diagnosed with cancer each year. When someone is diagnosed with a life-threatening disease, existential issues are easily triggered. Young adults are in a developmental phase of life and are exposed to an extra amount of pressure. The Internet and social media are a daily part of the life of young adults and the use of blogs is common. The aim of this study was to elucidate the theoretical framework of Yalom and his four 'givens' expressed in blogs written by young adults living with various cancer diagnoses in Sweden.

**Method:** This study used a qualitative method in which written stories from six public blogs were analysed using qualitative content analysis.

**Results:** The findings offer valuable in-depth knowledge about the existential issues in this population. The results can be described as a journey with several existential challenges and with death as an impending threat. The bloggers' awareness of their mortality was described as creating a sense of loss and existential loneliness.

**Conclusions:** This study shows that young adults are empowered by the writing of blogs and that blogs can play an important part in increasing wellbeing and a sense of coherence within this population.

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## 1. Introduction

Cancer primarily affects the elderly population worldwide. In Sweden and the rest of Europe the incidence in 2012 was 55.1 per 100,000 inhabitants aged 15–39 years (The National Board of Health and Welfare, 2011). This group is vulnerable, with unique needs for support over a long time period (World Health Organisation, 2012). Living with a life-threatening disease while young can have a considerable impact on the existential dimensions of life. The years between 18–40 symbolise the shaping of one's identity by means of education, starting a family and socialisation in society. The ability to be emotionally close to another human being is an important factor in the search for a stable identity. Young adults strive to form intimate, tender relationships with other people as a way to find self-confidence and harmony in life (Zebrack et al., 2010). Cancer treatments during this critical

transition affect psychological needs, and can have a tremendous impact on normal development in this group of people (Hajdarevic et al., 2014; Kumar and Schapira, 2013; Zebrack et al., 2010). Today, the Internet and social media are a daily part of life and the use of blogs is common. Previous research has highlighted blogs as a form of self-therapy (Tan, 2008).

Being diagnosed with cancer is commonly associated with an existential crisis. This means that the individual cannot avoid thoughts of death, loneliness, guilt and meaninglessness, often called a border situation. Border situations can be defined as important life events which can be both positive and negative for the person (Sand and Strang, 2013; Yalom, 1980, 2009). Irrespective of this, however, the outcome means that the individual involved has to change their approach to life, which affects their life situation in a dramatic and visceral way. However, in the long run the situation might also enable personal growth and lead to a re-evaluation concerning the meaning of life (Sand et al., 2008; Yalom, 1980, 2009).

In this study the researchers were inspired by the philosophical movement started by Kierkegaard in the 17th century, and developed further by Heidegger, Jaspers and Sartre in the early 19th

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century (Lübcke et al., 1988). The collective position of these philosophers comprises the basic condition of humanity where freedom, existential isolation, meaningfulness and death constitute the core base for quality of life over a life span. The work of the existential psychiatrist Irvin Yalom during the past three decades, concerning these four concepts, has enabled a deeper understanding of the complexity of today's secularized societies (Yalom, 1980, 2009).

This complexity is most prominent in man's relation to death. Death in our modern Western world is something that scares us at the same time as it arouses our imagination and fascinates people, as expressed in the form of horror stories and crime fiction (Sand and Strang, 2013). When an individual is afflicted with severe illness, death is no longer abstract; indeed, death becomes a reality for that individual. This insight may awaken anxiety and fear of dying. The ability of the individual to handle such a crisis depends on factors such as earlier experiences in his/her life, the coping strategies available to him/her, and the capacity of the individual to withstand separation and loneliness and ultimately their own viewpoint on life coming to an end (Folkman, 2010; Mazzotti et al., 2011). Freedom might be difficult to think of as a source of an existential challenge, because freedom is regarded as something desirable by most humans. Freedom is, in other words, something people strive for. Hence, to be dependent on each other could be viewed as wrong or unwanted. The kind of freedom that inspires an existential crisis is total freedom, as it lacks external structures (Sand and Strang, 2013; Yalom, 1980). Total freedom does not merge well with "the human" search for safety and humans' need for continuity in their lives. In its wake, total freedom creates a feeling of insecurity and uncertainty. Furthermore, total freedom implies that the individual cuts all ties to the people in their lives, which in turn creates loneliness. The highest price to pay in exchange for freedom is considered to be loneliness, while its counterpart is a suffocating sense of constant community. To meander between these two opposites, loneliness and community, becomes an existential journey for the individual (Cacioppo and Patrick, 2008; Yalom, 1980, 2009).

In the literature, the term "spirituality" commonly describes the concept of a meaningful life. Literature reviews have made professionals aware of the complicated nature of the definition of "spirituality". Spirituality can be understood to be synonymous with psychosocial care and therefore it is difficult to practice (Clarke, 2009). The Nordic countries are well-known for their secular societies, and therefore the term "existential issues" is more appropriate. Unlike "spirituality", where "God" has a central place, "existential issues" has a wider meaning than a religious term (Strang, 2002). Human beings are described as creatures searching for meaning and purpose in their lives, which inspires thoughts and questions in association with the above-mentioned existential challenges. Research has shown that the most important factor in fortifying quality of life when a cure is no longer possible, is the experience of feeling meaningfulness (Axelsson and Sjöden, 1998; Cohen et al., 1997). Meaninglessness is associated with feelings of hopelessness, despair, anxiety and death (Sand et al., 2008). When one's existence feels meaningless, Sand and Strang (2013) claim that the individual cannot fully exist.

The aim of this study was to elucidate the theoretical framework of Yalom and his four 'givens' which were expressed in blogs written by young adults living with various cancer diagnoses in Sweden. How can a person's existential conditions be visible in the text?

## 2. Methods

Written stories collected from public blogs were used for this

qualitative study. Written stories have been described as having a central role in the science of nursing, and stories from patients and relatives have created opportunities to gain valuable knowledge in nursing (Tevendale and Armstrong, 2015). Diaries and biographies exemplify stories of life. Through stories about people's lives, there have been opportunities to see how those individuals perceive themselves and their lifeworld throughout different episodes in their lives (Frid et al., 2000). The four concepts described by Yalom (1980) were an inspiring theoretical framework during the analysis process in this study. By using blog texts in social media we captured enriched portrayals of young people's thoughts and feelings in relation to existential issues and cancer. This approach can be a successful research methodology (Keim-Malpass et al., 2013; McGeehin Heilferty, 2009; Ngwenya and Mills, 2014).

### 2.1. Samples and setting

In Sweden, there are three main cancer organisations. These organisations have websites which provide lists of blogs. Initially, blogs by young adults (age 18–30) were singled out from those lists, resulting in 43 blogs. The 43 blogs were skimmed through to get an overview of the content. Thirteen blogs were chosen for the next step in the selection process since they matched the criteria of age and content.

The foremost criteria for participation in the study were that the bloggers were between the ages of 18 and 30 and that the blogs were written in Swedish. Other criteria were frequent use of a public blog (which in this case meant at least one blog post a month), blogging about cancer, and blog texts containing enriching stories about existential issues such as: hope/hopelessness, isolation, death and the meaning of existence.

There were variations of lived experience among the finally selected six blog authors. The blogs were written by four females and two males within the age criterion, with a median age of 26 years. Four out of six were cohabitating or married and the other two were single. Two of the bloggers had children and four were childless. The cancer diagnosis they had varied: two bloggers had leukaemia, two had lymphoma, one had a brain tumour and one had gastric cancer. The majority were going through curative treatment. The average time periods for the analysed blog texts were two years, but in one case a blog had lain dormant for six months.

### 2.2. Procedures and ethical considerations

The 13 blogs were read very carefully - in full - by all the researchers, one by one. After this reading, six blogs were finally chosen because they contained rich illustrations that were relevant to the study objectives. These six blogs were re-read and this time parts of the text were cut out and compiled into a separate document for analysis. Selected text included valuable stories about the blogger's thoughts on freedom, death, existential isolation and meaningfulness. Because the research was inspired by Yalom (1980), only sections of blogs that highlighted these four concepts were used for the analysis. This could mean that months of blog writings were not used. The researchers performed the reading process independently and then compared and discussed their findings among themselves. The document compiled for analysis included a total of 103 pages of blog text, font Times New Roman, size 12, single spacing.

In line with the Declaration of Helsinki, the interests of the bloggers were considered by the research group (World Medical Association, 2008). When the six blogs were selected, their authors were contacted by email to ask permission to use their blog material in the analysis. All of them agreed after receiving written

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