

## Inquiries of discomfort: Cancer experiences in young adulthood

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**Abstract.** Young adults with cancer are regarded as an emerging field for research. Because of the particular life phase they are in they are particularly vulnerable, as they are often both marginalised and individualised and their experiences are seldom described due to their small numbers. By using an on-line free association narrative inquiry and an experimental writing format, the purpose of this paper is to explore the subjective perspective of what it means to be a young adult living with cancer, and to discuss whether this approach contributes something new to the emerging field. Seven condensed poetic products emerged from the analysis: 1) It came from nothing, 2) It sets off a chain reaction, 3) Being a bit into adult life, 4) No one shares your experiences, 5) Go on with your life, 6) My new me and 7) Maybe the lucky ones die? The results empirically support the emerging body of research regarding young adults with cancer. They stress the need for more specific research, clinically and politically appropriate services to this group of cancer patients. Thanks to technology, young people living with cancer, now have an opportunity to actively participate in providing information regarding their subjective experiences. This will challenge the traditional hierarchy of knowledge, where healthcare professionals and researchers reign over the power of knowledge and decisions.

**Key words:** Young adults, cancer, narrative, qualitative research, on-line study, postmodern

Please cite this article as:

Hølge-Hazelton, B. (2011). Inquiries of discomfort: Cancer experiences in young adulthood. *Qualitative Studies*, 2(2): 118-130.

### Introduction

Young adults with cancer have long been described as an overlooked or invisible patient group in the literature and in practice (Haase, Phillips, 2004, Woodgate, 2005, Aramaki et al. 2005, Johansen, 2007, Christensen, Hølge-Hazelton, 2009). However, in the past few years a growing attention has been seen and what is presently called Adolescent and Young Adult Oncology, is recognized as a *new field* appealing to practitioners and researchers from many existing fields (Thomas, Albritton, Ferrari, 2010).

It is now recognized that young adults with cancer often have to deal with unique medical, mental health and psycho-social issues (Hølge-Hazelton et al., 2010a, Treadgold, Kuperberg, 2010). Having cancer in young adulthood, like other serious and chronic illnesses (Hølge-Hazelton, 2002a), has a distinct affect resulting from what has been called “a disrupted biography at a critical transitional moment in the life trajectory that can have a chronic effect after the acute stage of illness is passed” (Grinyer, 2007, p. 265).

Empirically based research focusing on the subjective experiences of what it means to be a young adult cancer survivor has so far been studied using well-known research approaches and standardised measures. But these methods may unintentionally restrict the responses and reproduce medical discourses of cancer. In this article an experimental approach was chosen to investigate whether this kind of inquiry could contribute with new perspectives.

## Background

New medical evidence suggests that the biology of cancers among adolescents and young adults is different from those in younger and older persons, not only in the spectrum of cancers, but also within individual cancer types and within the patient (Thomas, Albritton, Ferrari, 2010, Bleyer et al., 2008).

Despite considerably improved cancer treatment possibilities and results, epidemiological studies show a disturbing and inexplicable increase in the incidence of cancer among adolescents and young adults between 13 and 40 years, as well as a poorer treatment response, compared to younger children and adults over the age of 40 (Thomas et al., 2006, Bleyer et al., 2008).

In a biological as well as developmental psychological perspective, however, it is difficult to address young adults with cancer as a group and even though the literature is inconsistent, the group can be divided into adolescents (13-17 years) and young adults (18-40) (Christensen, Hølge-Hazelton, 2009). This article focuses on the latter group.

All life stages have challenges but young adulthood invokes a particular attention and effort from the health profession. The youth identity includes several demands and choices regarding education, working life, relationships, family and friends, parenting young children and citizenship in society.

### *An unusual approach*

Problematic issues regarding young adult cancer experiences raised in the existing literature, are often based on well-known research approaches and standardised measures, such as surveys (Zebrack, Mills, Witzman, 2007), qualitative interviews (Olsen, Harder, 2009, Miedema, Hamilton, Easley, 2007), focus groups and participant observations (Woodgate, 2006), including education, careers, life plans, friendship, networks, appearance, sexuality and fertility. However, as shown by Suzuki and Beale (2006), such methods may unintentionally restrict the responses, whereas an Internet-based form of communication may afford greater freedom in how young people describe their cancer experiences.

Virtual ethnographic studies have shown that e-mails are suitable to approach sensitive issues of living with chronic and other serious illnesses in young adult lives (Hølge-Hazelton, 2006, 2002b).

Hence, as an experiment, an Internet-based interview series was conducted between the researcher and 13 young adults with cancer aged 17 to 33 with the explicit aim of exploring the subjective experiences of living with cancer. The contact with the researcher had either been established at a special course for young adults with cancer where the researcher facilitated a workshop, or via participants who recommended peers with cancer to join. In contrast to other studies where recruitment can be difficult, this was not the case here. Rather, several young adults seemed eager to share their experiences, as they themselves had had difficulties finding relevant material for their generation. The results of these studies have been described elsewhere (Hølge-Hazelton, 2010b, 2008, 2007).

For the purpose of this article, a single case is chosen among the 13. Because of its complexity and richness it is identified as having the force of the example (Flyvbjerg, 2006). It contains more than 50 single e-mails, exchanged over period of almost 2 years, focusing not only on

single issues, but on the progression of experiences of being a young adult living with cancer through all the phases from remission, to control to relapse to palliation to facing death.

### **Methodological and Theoretical background**

The methodological point of departure takes place from a free association narrative interview approach (FANI) (Hollway, Jefferson, 2000) informed by postmodern epistemology.

The FANI has a radically different conception of meaning because it follows an emotional rather than a cognitively derived logic. According to Hollway and Jefferson, once that logic is followed, the result is a fuller picture than would otherwise have emerged, offering richer and deeper insights into a person's unique meanings (Ibid). Free-association in this context is a concept borrowed from psychoanalysis referring to the situation where the researcher ask the informant to say the first thing that comes into her mind, hereby eliciting the kind of narrative that is not structured according to conscious logic, but rather let the associations follow routes defined by emotional motivations, and not by rational intentions (Ibid: 37).

Postmodern researchers who claim that no method has a privileged status (Richardson, 1998) have for many years worked with ways to give a "voice" to those who have been "voiceless", both the researched and the researcher (Lincoln, 1997). One way of doing so is via writing as a dynamic, creative and experimental method of inquiry, or "writing as a method of knowing" (Richardson, 1998). Rolfe states that it is "in writing more so than in the data collection or data analysis that knowledge is constructed from data" (Rolfe, 2006, p. 13). Thus trustworthiness is not an issue in terms of the interpretation and presentation. Paradoxically, any attempt to present the research findings as objective or truthful, as the best or only interpretation, will be seen as untrustworthy (Ibid).

Richardson (1998) makes an important point about poems as a genre for academic texts: that "the metaphor is the message" (Ibid). Because poetry is a culturally well-known genre, the reader expects to read an evocative text, if this text, although academic, uses the form of poetry. Thus the academic-text-as-poetry is open to an evocative reading, where emotions become an important part of understanding what the text 'is about' (Richardson 1997). Poetry is a genre with 'open endings' – that is with no particular right or wrong way of reading it (Krøjer, Hølge-Hazelton 2008). A particular postmodernist thinking is poststructuralism suggesting that qualitative researchers reflectively understand themselves as writing from particular positions in specific times (Richardson, 1998) and that no text can tell *the whole story* (Lincoln, 1997).

#### *Objective*

Working from these premises, the objective of this paper is to:

Write an experimental text to explore a subjective perspective of what it means to be a young adult and live with cancer and to discuss whether this approach contributes something new to the field.

#### *Analysis*

The interpretation style is inspired by what poststructuralist Patti Lather calls situated methodology (Lather, 1997, Richardson 1998), which understands theory as analysis/interpretation and sees no break between empirical activities and theorising (Denzin, 1998).

It has something to do with a deconstruction of the theory/practice binary that gestures toward a third space of both/and and neither/nor of theory and practice, a space I presently call a theory of situated methodology. (Lather, 1997, p. 235).

This approach includes a humanistic and emancipatory perspective and includes text condensation (Krøjer, Hølge-Hazelton, 2008, Hølge-Hazelton, 2002a). The following steps were taken:

1. Reading all the emails to obtain an overall impression and bracketing previous preconceptions.
2. Identifying units of meaning representing aspects of subjective experiences of being a young adult cancer patient.
3. Condensing each of the units into poetic products.
4. Editing the themes brought forward in the poetic products concerning the subjective experiences, following an editing analysing style where existing research and theory supports the analysis, rather than being an inflexible frame.

#### *Ethics*

The project did not call for any different ethical codes than those applying to face-to-face interviews (Hølge-Hazelton, 2002b). However, there are some differences that e-mail researchers have to consider (Ess, 2002).

All human interactions are situated (Giddens, 1993), and interactions on the Internet are situated in a slightly other way (Hølge-Hazelton, 2002b). The Internet is a non-physical space where it is possible to deal with issues of everyday life as well as matters of great delicacy across countries and national borders, social class and gender. The messages are written not spoken. Cues that are nonverbal, gestural, and articulatory are missing.

In this case the issue of living with cancer is sensitive, and the responsible researcher must be aware of the thin line between data gathering and the therapeutic interviews, something e-mail research makes it even easier to cross (Hessler et al., 2003).

#### **Results**

The results of the analysis are presented as seven condensed poetic products. Following this, in the discussion section of the paper, each of these will be related to available relevant research and theory.

##### **1. It came from nothing**

All good advice on how to PREVENT CANCER is based on a  
LONG LIFE so WHY ???  
It came from NOTHING  
It might COME BACK from nothing

## **2. It sets off a chain reaction**

When you tell your family, friends and colleagues about it  
The chain reaction is set off:  
Oh my God! But you are so young ....  
.....that will surely get you through!

## **3. Being a bit into adult life**

Being a bit into adult life means  
I have to take care of MY OWN life and MY OWN illness too

## **4. No one shares your experiences**

Hospitalization is like becoming at retirement resident  
No one shares your experiences  
One feels so alone as a young person with cancer

## **5. Go on with your life**

Cancer is something you should *just* be over and done with:  
Go on with your life!

No one prepared me for all the things I now have to carry  
I try to do my work, become fit again  
But I am simply so unspeakably tired

## **6. My new me**

The question is simply: Who am I?  
What can I do in order for this to give meaning to my new me?  
It is SO hard to accept a disease that has left me with so deep scars

## **7. Maybe the lucky ones die?**

I have a question:  
Is it true that some young cancer survivors commit suicide?  
Sometimes I think that we survivors are not the lucky ones...  
Maybe the lucky ones, are the ones who die?

## **Discussion**

Much of the available research on subjective experiences in young adulthood indicates that issues regarding loss of independence and normality, the disruption to life trajectory, impact on friendships, families, appearance, sexuality and fertility are dominant (Grinyer, 2007). This is no

doubt because these issues are highly relevant and of major concern to young adults facing these challenges. However, in this study, the intention is to examine whether the described approach would broaden the spectrum of subjective experiences of being a young adult living with cancer.

**Ad. 1: It came from nothing**

Most research and accessible information regarding the aetiology of cancer is targeted at older age groups and the highly publicized lifelong cancer risk factors, such as smoking and alcohol consumption (Benedetti, Parent, Siemiatycki, 2009). It is stated on the homepage of the American Cancer Society under the subject prevention “What you eat and drink, how active you are, and other lifestyle behaviours all can affect your risk for cancer” (American Cancer Society 2009). This message seems to have come through clearly to young adults, who seem to find no help in their search for an understanding of their situation in information material and campaigns targeted at other age groups. According to Grinyer (2007) there is a cultural resistance to the diagnosis of cancer in young people; perhaps this is one of the explanations as to why young adults construct their own view of illness and treatment and that it is this view that influences their commitment to treatment regimens as research indicates (Haase, Phillips, 2004).

**Ad. 2: It sets off a chain reaction**

Most people who get cancer are older and progress has certainly been achieved in treatment, as indicated by the increased survival rates. However these improvements are not experienced at the same levels by adolescents or young adults: on the contrary, the incidence of cancer has risen faster in this group than in other age groups. According to Bleyer et al. (2009), among 20-39-year-olds, cancer causes more deaths than any other disease, apart from depression culminating in suicide. Hence, the “chain reaction” is partly based on what is known from this kind of research, most people who get cancer are older, but it is also based on a general discourse of youth as a time of positive progress and future development that can help the individual to cope with and get through life better. That this is not always the case is shown in Grinyer’s newly published work on life after cancer in adolescence and young adulthood. Here it is shown how cancer at this particular stage in life has far reaching and lasting impact on the rest of life. Not as a constant linear effect, but an impact where events can “catapult a survivor back into a stage resembling PTS” (Grinyer, 2009, p.167).

**Ad. 3: Being a bit into adult life**

Becoming independent and personally responsible are clear indicators of the passage from childhood to adulthood. These especially reflect what is called the individualised patient culture of the 21<sup>st</sup> century (Hede, Andersen, 1999) – a culture that puts specific and increased demands on the individual to take responsibility for their own wellbeing and illness. This responsibility can on the one hand create space for inclusion in important decisions regarding treatment and care, but on the other hand can establish an overwhelming feeling of being responsible for issues related to life – and that that is a heavy burden to carry alone (Hølge-Hazelton, 2002a).

**Ad. 4: No one shares your experiences**

Being the only young cancer patient among mostly very old people makes many young adults feel isolated and alone with their problems. As addressed on a Canadian webpage for young adults with cancer:

Would you talk about sex with your grandmother? Most every young adult with cancer has had the experience of dropping in on the local cancer support group only to find they are a few decades younger than the average age, it's much the same as their trips to the chemo room, surrounded by people their parents and grandparents age (Young Adult Cancer Canada, 2010).

In a study conducted by Zebrack et al. (2006) young adult cancer patients ranked opportunities to meet other young cancer patients as highly important – even more important than support from families and friends. Even though there is a growing number of adolescent cancer units (Olsen, Harder, 2009) the majority of young adults with cancer seldom receive care in settings designed to meet their unique needs (Ibid, Haase, Phillips, 2004).

#### **Ad. 5: Go on with your life**

Young adulthood and late adolescence is a period described as manifested by high idealism and rigid concepts of right and wrong (Hendricks-Ferguson, 2006). The challenges facing young people are to be part of society, to plan careers, establish families and find their adult roles. For health-care professionals one of the main tasks in caring for and treating young cancer patients is to get them back on track as quickly as possible, in order to limit the *disruption* to the young people's lives. Oncology nurses describe "bending the rules" if they can, when the patients are young, in order to minimise administrative and time obstacles (Hølge-Hazelton, 2008). However, as Mattingly points out, recovery rarely means returning to the life one once had: rather, it means the remaking of a life (Mattingly, 1998). Consequently, the good intentions of helping young people to get on with their lives post treatment may overshadow the experience of having been through such an emotional and physical thunderstorm to the extent that there is a risk of isolating the individual with feelings of unpreparedness for the physical and psychological challenges that follow a cancer diagnosis and treatment (Grinyer, 2009).

#### **Ad. 6: My new me**

Woodgate (2005), in her study about adolescents' perceptions of how cancer affected their sense of self, found that the bodily changes impacted their sense of self and way of being in the world. This led on the one hand to a description of still being "pretty much the same" and at the same time significantly changed by the effects of having had cancer. Corbeil et al. (2009) describe in their study how young adults with cancer explain how they feel they get to know themselves better and at the same time look at life differently. The experience of having had cancer changed them forever.

Hope is consistently cited as an important resource for adults and young people with cancer and, according to Hendricks-Ferguson (2006), hope, understood as the degree to which young persons with cancer believe a positive future exists for them, can be seen as a protective factor or resource.

In this particular case it seems that there is almost nothing left of what used to be, so even though there is a sense of self, this is a new, deeply scarred self that seems difficult to understand, recognise and orient hopefully towards the future.

#### **Ad. 7: Maybe the lucky ones die?**

Rosendale (2009) calls for recognition of the phenomenon Survivor Loneliness described by breast cancer survivors who felt alone with the awareness of mortality and the experience of ongoing symptom burden.

By using a narrative inquiry form where both researcher and the young woman who contributed were able to reflect and pose questions, the question: Maybe the lucky ones die? came up by the end of the correspondence, signalling an almost unbearable loneliness. It was obviously a difficult question to raise and receive, but also an important one.

Wolgemuth & Donohue (2006) suggest that narrative research is a potentially transformative process that can change participants' and researchers' way of viewing and being themselves. In this process, stories containing painful, complicated, contradictory and ambiguous elements are often shared, leading to the development of the concept *Narrative as an Inquiry of Discomfort* (Ibid). This calls for a necessary ethic of empathy and friendship to provide a safe place for participants and researchers to examine and challenge beliefs and assumptions, and for the researcher to be constantly attentive to the research relationship (Ibid). Wolgemuth & Donohue pose the argument that "what we stand to gain from an inquiry of discomfort is a complex, nuanced, and honest knowledge of participants and researchers as they mutually engage in an exploration of values and beliefs" (Ibid, p. 1037).

As suggested in themes 1-6, it is not only a physical and psychological thunderstorm to go through cancer treatment, it can also be a lonely and painful process to reorient oneself as a survivor. It is known that cancer is associated with an increased risk of suicide, especially in the first years after diagnosis (Stenager, Stenager, 2000) and although some studies have found a relation between post-traumatic stress disorder (PTSD) and unaddressed treatment distress (Ozone et al., 2007, Lee, Santacrose, 2007) there seems to be a major lack of knowledge and services regarding illness-related distress among young adult cancer survivors.

### **The experimental approach**

An experiment like the one presented in this article calls for discussion: What can it be called, can others use it, and what are its possibilities and limitations?

In an article describing a methodological experiment on poetic representation, the authors switched empirical data (qualitative interviews). The background was an interest in understanding what it means for textual representations that researchers are present, have met and spent time with the research participants. What do researchers add to and detract from the material they work with, and can texts like poetic accounts in this article represent more than a representation of the relationship between the researcher and the persons met in "empirical time"? (Hølge-Hazelton, Krøjer, 2008). A paradox of poetic representations can be described as "on the one hand (in research) there is no (access to) absolute and complete truth and on the other hand trying to or implying that it is important and possible to get close to something original or authentic" (Krøjer, Hølge-Hazelton, 2008, p.27). The experiment showed similarities and differences, the latter mainly related to feelings and relationships of being physically present. In the present work, the author was not present physically, and never in the same "empirical time" as the young woman with cancer, because the emails were written in staggered time. It is possible that poetic products created from emails or other written material will be even more similar if reproduced by other researchers, but it is neither the intention nor belief of this author that there is such a thing as "getting it right" but rather to construct new, less false stories (Wolf, 1992, p. 126).

### *Significance of research*

The easy access to homepages, blogs and chat rooms has been welcomed by many people affected by cancer around the globe. Here they seek information, knowledge and support. For millions of people this borderless world provides an opportunity to be updated with the latest research on specific illnesses and treatment and allows communication with other people in similar situations, not least allowing them to tell their stories and share their experiences. For people living with cancer, one of the consequences of this is that they now, on a scale never seen before, have the opportunity to actively participate in the course of their treatment in ways that challenge the traditional hierarchy of knowledge, where the healthcare professional reigns over the power of knowledge and decisions.

Traditionally, qualitative research approaches to capture subjective experiences of illnesses such as cancer, have used face-to-face interviews or observations. However, an increasing number of patients and family members are using blogs or “online expressions of the narrative of illness” to describe the experience of illness (Heilferty, 2009). Even though very little is known about this phenomenon it is obvious that its use is pushed forward by teenagers and young adults who are also called the “digital generation”, being significant users of new information technologies (NTIA and the Economics and Statistics Administration, 2002). The young woman who contributed to this article describes her own blog like this:

*YES, it was natural for me to share my experiences, thoughts and not least my frustrations of the side effects and inconveniences cancer give. That is why I have set up a blog where I describe those things and clearly also use it as a way to deal with all the thoughts I have like fear of recurrence, changes in my personality, stress et cetera. And in one way it's barrier-breaking to write about those things, partly because it shows my weak sides.*

This “naturalness”, combined with a previous face-to-face meeting reassuring her that the researcher was in fact whom she claimed to be, was probably also the reason why she did not question the use of e-mails for the qualitative exploration of her subjective experiences living with cancer. Rather she described the process like this:

*I think it is very interesting and a good way for me to get some things sorted, writing together like this. It is a kind of talk and your replies can be rather illuminating for me. And then it just proves how important it is to focus on this subject! Keep up writing 😊*

The 7 condensed themes represented in the poetic products correlate well with the emerging research in the field of young adults with cancer. What the Free Association Narrative Inquiry approach has contributed is the subjective focus of living with cancer in young adulthood, giving direct and honest responses of how much one must carry alone as a young adult with cancer. Getting this insight is an invitation to take on the responsibility for researchers, practitioners and policymakers to create more knowledge, be aware of the special and vulnerable situation it is to live with and survive a life-threatening illness when one is only *a bit into adult life* and to secure the necessary funding for appropriate education and relevant settings designed to meet the unique needs of young people with cancer.

### **Acknowledgement**

This research has been supported by The Danish Agency for Science, Technology and Innovation, by the Research Unit for General Practice in Copenhagen and by The Novo Nordic Foundation.

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