



Stressors, Coping and Coping Strategies among Young Adults with Cancer

Christina Snöbohm, RPT, MSci¹, Susanne Heiwe, RPT, PhD²

¹Karolinska University Hospital, Department of Physical Therapy, Division of Cancer Rehabilitation Karolinska University Hospital; Dept. of Medicine, ²Karolinska Institutet, Department of Clinical Sciences, Division of Nephrology, Clinical Research Center North, building 8

This is an Open Access article distributed under the terms of the Creative Commons Attribution License (<http://creativecommons.org/licenses/by/3.0>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited.

Abstract

Introduction: Research shows that young adults with cancer experience physical and mental changes that affect both their body image and their ability to cope with the situation. The purpose of this study was therefore to describe stressors, coping and coping strategies among young adults with cancer.

Study design: A qualitative interview study. Material and methods: Setting: Swedish university hospital. Data was collected through semi-structured interviews until saturation (12 informants). The interviews were transcribed verbatim and analysed using a phenomenographic approach.

Results: Four categories of stressors were identified: 'feeling physically ill', 'side-effects of the cancer treatment that caused negative wellbeing', 'how can I have cancer when I have none or few symptoms from my body?' and 'feelings of psychological distress'. Identified coping styles were 'physical exercise', 'seeking professional help', 'trying to regain control', 'finding new ways of thinking / acting' and 'seeking help from family and friends'. Coping strategies used were problem-focused, emotion-focused, meaning-based and social coping. The informants also used various forms of psychological defense mechanisms.

Conclusion: Young adults with cancer experienced stressors similar to older cancer patients but also specific stressors related to their youth based on a lack of previous experience of severe illness which is an important implication for health care personal. Physical exercise was identified as a coping strategy and further studies are needed to investigate if supervised physical exercise may increase internal locus of control and help young adults with cancer to cope better with their disease and cancer treatment.

Keywords Neoplasms, stress psychological, adaptation psychological, rehabilitation, qualitative research.

Introduction

Cancer and cancer treatments place substantial stress on the lifestyle of young adults with cancer. Young patients with cancer have to cope with

increased psychosocial and physical risks such as an increased risk of cardiovascular disease [1]. Being a young adult with cancer also include having to cope with fertility, sexual dysfunction, body image [2], being different compared with others the same age and peers reactions on the cancer disease [3, 4]. Previous research shows that young adults with cancer experience physical and mental changes that affect not only their body image but also their ability and capacity to cope with the situation and rehabilitation. The

Address for correspondence and reprint requests to: Christina Snöbohm, Karolinska University Hospital, Department of Physical Therapy, Division of Cancer Rehabilitation, Box 100 SE. 171 76 Stockholm, SWEDEN

Email: christina.snobohm@karolinska.se

Tomasz B et al. Licensee Narain Publishers Pvt. Ltd. (NPPL)
Submitted: September 13, 2013; Accepted: November 14, 2013; Published: November 20, 2013

research also demonstrated that these patients had faith in their bodies' ability to cope with the disease [5]. Patients with cancer are generally considered to be in a situation of low personal control, i.e. a low degree of internal locus of control [6, 7]. It is important for patients with cancer to try to maintain a sense of control; even when there are few opportunities to exert control [6] as a low degree of internal locus of control may lead to reduced health related quality of life. Internal locus assumes that events are conditioned upon one's own behaviour and are associated with psychological and physically well-being. External locus of control assumes that the outcome depends of luck, fate or others [8]. In order to find interventions aiming to increase internal locus of control, it is necessary to gain knowledge concerning experienced stressors and used coping strategies among young adults with cancer.

Stress has been defined by Lazarus and Folkman as: "Psychological stress is a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being." [9]. It can be mediated by the individual's cognitive appraisal of the situation [10] and or through the individual's coping and coping strategies [11]. Stress is not necessarily something negative. It can help the individual to achieve more than he or she thought could be accomplished [12]; but in some situations stressors are negative for the individual [13]. For instance, when being diagnosed with a severe disease and having to deal with stressors such as concerns for the ability to maintain responsibilities, relationship in the family, financial and legal matters, and existential concerns [14].

The way the individual is trying to handle stressors are called coping. Coping is defined as: "constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" [15]. Whether or not change creates stress and positive

or negative consequences, depends on how the change is appraised and coped with [16]. Individuals adjust their coping to address the unique challenges that each stressors present. Whether coping efforts facilitate adjustment depends on how well they match the challenges [17]. There are different ways of thoughts and behaviours that emerge as a result of the individual's coping style, and these different ways are called coping strategies [16]: problem-focused coping, emotion-focused coping [16], meaning-based coping [14] and social coping [18]. Problem-focused coping are designed to manage the external demand by solving the problem, whereas emotion-focused coping are aimed at reducing the emotional distress [16]. Meaning-based coping helps to make sense of what is happening, formulate new goals and appraise benefit when possible [14]. Social coping integrates cognitive factors with social and interpersonal factors [18]. All coping strategies are equally important and they interact and complement each other [12]. To cope the individual may also use psychological defense mechanisms derived from the psychoanalytic tradition [19]. Coping and defense mechanisms may be differentiated as conscious or unconscious processes and on their being intentional or non-intentional [20]. Research regarding stressors and coping among young adults with cancer is limited [21, 22], but can be found concerning older adults and children [23]. The aim of this study was therefore to describe stressors, coping and coping strategies among young adults with cancer.

Methods

In this study, a phenomenographic approach was used. Phenomenography seeks to define, describe and analyse peoples' experiences regarding various phenomena [24]. It has been found repeatedly that phenomena, aspects of reality, are experienced and understood in a relatively limited number of qualitatively different ways [24, 25]. The outcome space and its descriptive categories are the key features resulting from analysis of data in phenomenographic research

[26] and represent the qualitatively different ways in which phenomena are understood [27].

Informants

Informants were recruited from the Oncological Rehabilitation Centre and from oncological clinics at Karolinska University Hospital, Sweden. Inclusion criteria: cancer, age 18–35. Exclusion criteria: patients treated by C.S., acute crisis or terminal phase, non-Swedish speaking, patients unable to manage 60-90 minute interviews and who did not want the interview recorded. Criteria-based sampling [28] was carried out by the staff based on inclusion- and exclusion criterions. All informants received oral and written information about the study and gave their informed consent prior to their inclusion in the study. Approval to conduct the study was obtained from the local Ethics Committee in Stockholm, Sweden. Informants were recruited until information saturation point [29]. Three pilot interviews were conducted, of which one was included in the study as in this one the interview guide and –technique was satisfying. Twelve informants were included in the study, all of whom were receiving or had received medical treatment. The gender distribution was six men and six women, ages 22-35. They had varied diagnoses, family relations and durations of

disease. One of the informants had palliative treatment whereas the others received curative treatment. Demographic data are presented in Table 1.

Data collection

Data was collected through individual 60-90 minute semi-structured interviews at Karolinska University Hospital. The interviews were tape-recorded and transcribed verbatim. Each interview used lead-in questions (Can you tell me about a situation that describes how you experience your body?), follow-up prompts (direct questions or nodding, saying “mm”...), probing questions (Can you tell me more about it...?), specifying questions (What did you do/think then...?), direct closing questions (When you say X, do you mean Y...?), indirect questions (How do you think that others...?), structured questions (returning the focus to the subject under study), silence (to give the informant time to associate and think), and interpretive questions (So you mean that...?). At the end of each interview, the informant was asked to draw, however they

Table 1 shows demographic data of the informants

Participants	Age	Gender	Diagnosis
1	35	Female	Breast cancer
2	26	Male	Testis cancer
3	31	Female	Ovarian cancer
4	26	Male	Sarcoma
5	32	Female	Breast cancer
6	22	Male	Thyroid cancer
7	23	Male	Testis cancer
8	26	Male	Testis cancer
9	33	Female	Thyroid cancer
10	28	Female	Thyroid cancer
11	27	Male	Testis cancer
12	31	Female	Breast cancer

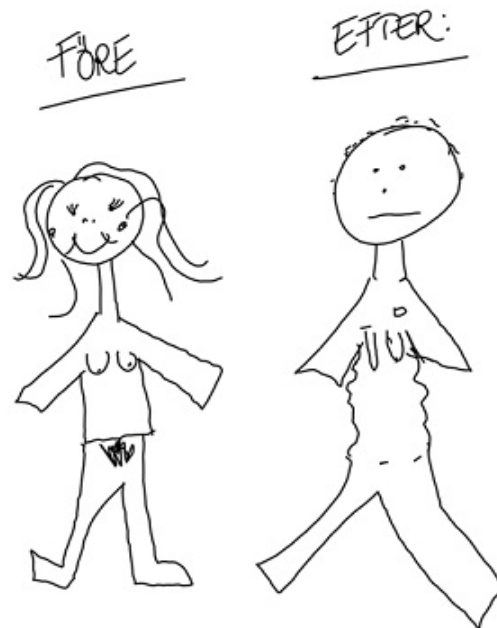


Fig. 1 An informant describes her body before (före) and after (efter) treatment

Table 2 Contextual Analysis Within A Phenomenographic Approach.

Stage	Description	Example
Stage 1	The transcribed interviews were read repeatedly without structure. The purpose was to become familiar with the content and gain a sense of the whole.	
Stage 2	<p>From all interviews, statements irrelevant to the phenomenon were discarded. The questions “what” and “how” were used to define relevant quotations:</p> <p>1) <i>What</i> did the informants describe as stressors?</p> <p>2) <i>How</i> did the informants cope with the stressors and what coping styles, coping strategies did they use?</p> <p>The analysis was continued by systematically noting differences and similarities in the participants’ experiences. This was done by contrasting excerpts from all interviews with one another. A preliminary pattern of descriptive categories was constructed.</p>	<p>1) "I think the toughest thing was ... that I felt like that sometimes doctors talked over my head you did not get it what the hell ... what it was that was wrong at all"</p> <p>2) "ehhh ...so I would ask that ... in the end so I saw to it that I wanted to see various acts to and fro I wanted to see x-rays how the hell the cancerous growth looked so that I knew what it looked like and a bit like that"</p> <p>action</p> <p>Problem-focused coping</p>
Stage 3	The preliminary pattern of categories was scrutinized by the authors and subsequently revised into a final complex of categories. These categories should distinctively and qualitatively differ from each other. The final descriptive categories were described in the outcome space.	<p>The environment</p> <p>Lack of a whole</p> <p>Ill or well</p> <p>Physical changes</p> <p>Not as before</p>
Stage 4	The internal relationships between the categories were described. The purpose was to study how the different categories interacted with one another.	See Figure 2

wished, their own body as they saw it before and after their cancer, see example in Figure 1.

Data analysis

Data was analysed according to a contextual analysis within a phenomenographic approach [30]. The results of a contextual analysis are both categorizations and relations between categorizations, in the form of combinations or patterns of categories. The analysis was carried out in four stages by the researchers; each stage had a specific purpose and is described in Table 2.

Trustworthiness

Data in the present study was analysed by two researchers’ (C.S., S.H.). There were no disagreements. Five standards were used in the preparation and compilation of the results 1) ensure that the aim guided the data collection and -analysis, 2) clarify the subjectivity of the researcher to the reader, 3) link results to theory, 4) explain the significance of the results, and 5) explain ethical circumstances [31]. Probing strategies (ask the informant to repeat, explain, develop, and confirm statements) were used during the interviews to achieve dialogue validity

[32]. To achieve communicative validity, the researcher’s theoretical assumptions, the selection of subjects and the stages of the research process were described [33]. To ensure correct interpretation and analysis, de-contextualisation/re-contextualisation was used [34, 35]. The results of the study are judged to have pragmatic validity as they contribute to the understanding of how young adults with cancer experience the phenomenon [32]. To meet the quality criterion of transferability [36], the readers must have sufficient information about the original research situation so that they can decide whether or not it resembles their own situation. Therefore, the context, data collection, and data analysis have been described in detail.

Results

Four descriptive categories of stressors (‘feeling physically ill’, ‘side-effects of the cancer treatment that caused negative wellbeing’, ‘how can I have cancer when I have none or few symptoms from my body?’ and ‘feelings of psychological distress’) and five descriptive categories regarding coping style (‘physical exercise’, ‘seeking professional help’, ‘trying to regain control’, ‘finding new ways of thinking/acting’ and ‘seeking help from family and friends’) were identified. The experienced stressors had both a physical and a mental component and were related to the disease itself, the cancer treatment, and or side-effects. The

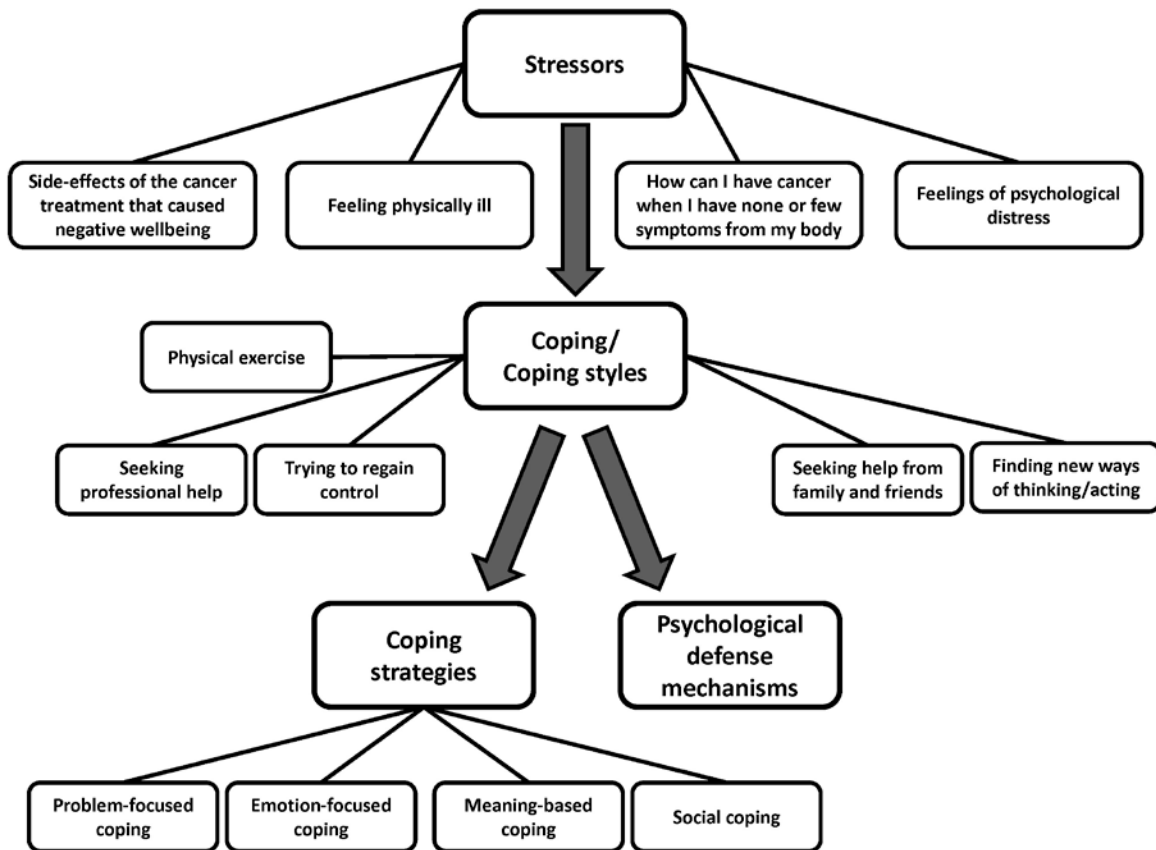


Fig. 2 The descriptive categories, coping styles and coping strategies and their internal relationships. The stressors lead to coping/coping style. The thoughts and behaviours that emerge as a result of the individual’s coping style lead to the coping strategies. The informants also used psychological defence mechanisms as coping strategy

various ways of coping involved all three of Lazarus and Folkman's coping strategies as well as social coping and psychological defence mechanisms, see discussion. The descriptive categories of stressors, coping styles, and coping strategies and their internal relationships are presented in Figure 2.

Feeling physically ill

The informants felt physically ill by physical sensations associated with their cancer and cancer treatment. The feeling of being weak and pain became stressors within the body. To cope they used; physical exercise, cover the ears, start working, trying to live as normal as possible, push their limits, and to talk to a professional therapist. Below follows a detailed description of stressors in the main descriptive categories and their subcategories, and coping style (presented in bold).

Being weak

The informants described that they experienced their body as weak, ineffective. They felt reduced physical strength and described this in terms of both having to sleep more and not being able to walk as long distances as prior to the disease. In order to cope some informants tried to regain control by living as normally as possible, for example by resuming their duties and some tried to find new ways of thinking or acting about the perceived stress, e.g. try to stretch their own limits and seek professional counseling.

"no, but if you go to his ... somewhere then you want to be able to walk around and check out ... I can only go a few hundred meters before I get tired so"

"yes, no, but I feel that I ... I cannot go around and wait until I have finished treatment because then ... as well as time passes and I want to find things in the meantime so that ...Yes ... try to live as normally as possible, squeezing me and do more things than what I really ... can actually etc ... "

Feelings of pain

Various experiences of pain were described by the patients. They experienced pain while exercising and this pain was located to the area of the surgical operation. This became a stressor that affected them in their everyday life and in order to cope with this pain they tried to adjust the physical exercise so that the movements hurt less. There were also descriptions of side effect of the cancer treatment that caused pain, such as increased sensitivity to sound. This caused feelings of pain that came unexpectedly and was very hard to endure. To reduce the experience of treatment related pain they tried to avoid noise or cover the ears.

"Yes something like it that you don't know really because... you don't really know when to push it because it hurts as well"

"...maybe I do not have such heavy weights on when doing muscular resistance training or so instead I take it easy..."

Side-effects of the cancer treatment that caused negative wellbeing

Side-effects of the cancer treatment caused stress. The patients expressed how their treatment caused an increased weight which was experienced as stressful as it altered their body, made them feel uneasy. They also described how side-effects such as increased sensitivity to loud noises affected them in their daily life and forced them to try to avoid places where there could be loud noise. The side-effects thereby did not only work as stressors but also forced the informants to avoid certain situations, to cope, and therefore had a negative impact on their wellbeing. Questions about what side effects are acceptable to live with and which is not or what treatment have effect but gives acceptable quality of life was expressed as other cancer treatment related stressors. To cope with the feeling of uncertainty concerning their cancer treatment the informants described how they thought of the stressor as something that would pass, nothing permanent, bringing earplugs just to be on the safe side, try to

adjust and negotiate with themselves, set small milestones. *"everything is about the medicines about what side effects I get and what side effects that are acceptable to live with and which are not for longer periods"*

"but if they say that you have to continue this tough [treatment] even if you feel really bad 90% of the time, I..but then I would adapt to that to..if that was the only option"

How can I have cancer when I have none or few symptoms from my body?

The young adults described the stress that they felt concerning the occurrence of the disease. The lack of physical symptoms made the diagnosis difficult to understand and believe. Instead, they experienced the diagnosis as if it came out of the blue. The body did not tell them that they were ill with cancer, did not warn them of the danger from inside themselves. To cope they attempted to regain control by thinking that body did its best and that they as patients were safe, under supervision.

"...from the time I found out I had cancer because I've never felt bad sometime echo. And then it's so hard to believe that the body is sick, and like have any problem eh.. "

"My body Strangely enough, I would say healthy because I think it is"

Feelings of psychological distress

The informants described both how the disease itself and the side-effects of the cancer treatment caused mental stress e.g. waiting for reply if the treatment needed to be repeated. These psychological stressors could be categorized into eight subcategories: "disappointed and low", "being different from one's self and from others", "lack of control", "insight", "my own body is making me seriously ill and I have to fight against my own body", "health professionals' attitude, family and friends reactions to the cancer disease", "fear and anxiety" and "feelings of guilt and shame". The informants felt disappointed

with setbacks and that life did not turn out as planned. Loss of hair, scars and youth itself also made them feel different. Coming to insight of the situation and having to fight against one's own body was described as strange, difficult to manage. They experienced stress in having to deal with their own fear and anxiety as well as with the environment's reactions such as staring and comments. Feelings of shame and guilt were also expressed e.g. not being a good enough mum and being unable to have children at all. To handle these stressors the informants described how they tried to be physical active and sought professional help. Below follows a detailed description of the psychological stressors and the various activities that were used to cope with these stressors.

Disappointed and low

The informants described how their life had changed when diagnosed with cancer. They experienced disappointment of not being healthy and not being able to do or plan things as before the cancer. For instance, not being able to ski as before, maybe never have time to fall in love again and not being able to have a family. Their life had suddenly changed into something that was not at all what they had expected their life to be. In order to cope with the stressful feeling of disappointment the informants searched ways to regain control by thinking that the body is bruised, it cannot be like before but it is only to be reckon with, take one thing at a time, to try to see the positive in the situation. Some also tried to deny that both the body and the everyday life have changed or to purely intellectualize in order to cope with the experience of disappointment. "...but disappointment, perhaps, more disappointment ... life it would be this for me eh, it shall not be more than this"

"a little, and then I think I can still feel that I am very satisfied with my life, I am very satisfied with what I have done ... I am very satisfied with my family I am very satisfied with my friends, then I feel that"

Being different from one's self and from others

The young adults did not experience themselves as before they had received the diagnosis. They were now 'a cancer patient', and not like everyone else. This feeling of no longer being the person one had been and also being different from others caused mental stress. The informants tried to reduce this stress e.g. by mentally preparing themselves for comments and reactions from others, avoiding people or social events and by hiding their baldness with a cap. Some also focused on being physical active and eating well because of the sudden insight that the body is fragile. There were also young adults who wanted a different disease than cancer e.g. HIV because of better treatment options and young adults who boasted of their illness in order to appear more interesting as a person.

"ehhh, it has always been a bit of a when I have felt bad training has been a bit of a free zone for me I have come away"

"So I just went and exercised a little and it made me good to be there.. it becomes a free zone, so that mentally I feel good about it and I am able to let go of this.."

Lack of control

The informants described how they experienced a lack of control concerning appearance, fatigue and life in general. Some described it as from having been an individual with a strong internal locus of control, the disease had taken this from them and instead created feelings of lack of control which led to stressful emotions such as restlessness, anxiety, pressure and discomfort. The stressful experience was further stimulated by what was described as an increasing amount of concerns that all together became too much to handle, i.e. emotionally overload. To not be in control was expressed as tough, but they found ways to bring back the feeling of some control. To cope with the overload they either tried to deny the feeling or acknowledged the feeling by allowing themselves to feel like crap for a period

of time, to not put pressure on themselves and to ease worries by being an active patient.

"...but I cannot control the side effects of medicine I cannot control my hair growth ehh"

"I can control my appearance to such an extent that I can put make-up on and look spirited" (See Figure 1)

Insight

The sub-category insight describes how individuals understand that they will never be normal again, how sick they actually were, and that they needed physical exercise to feel good. Ways to cope with stress, for example to seek professional help and to resume physical exercise.

"...but I will never be normal again, I do not think so ... and it is well a bit sad"

"Yes, at the same time you adapt, I think that I...I am not sure but I think that the mind has to adapt to the condition we have.. we just have to get used to it"

My own body is making me seriously ill and I have to fight against my own body

The informants described how they experienced that their body had betrayed them by giving them the cancer. They felt that their own body had become an opponent. Having to fight against one's own body caused feelings of disappointment over the fact that it actually didn't work, over the fact that the body had failed and the young adults had difficulties experiencing the body as a whole (soul and body). To cope, the informants permitted themselves to feel disappointed, sad, and they tried to find new ways of thinking and acting by giving themselves time to heal.

"In a sense you have always somehow been fighting against the body it is in the body the cancer is but you have made it now awaits the construction phase, it is strange to fight against one's body in some way"

"Yes, but it is this with the re-construction phase... the soul and body are both the same yet different things ... the exercise will come but I haven't reached that stage yet. It will, I know, but not when it is...not there yet, but I am not stressed"

Health professionals' attitude, family and friends reactions to their cancer disease

The cancer diagnosis, -treatment and the individual's own thoughts and emotions were not the only stressors that these patients had to deal with, family and friends' reaction as well as health care professionals' attitude also worked as stressors. They described how they experienced themselves as being met with ignorance and that health professionals tended to talk over their heads which made it difficult to understand the disease, to understand what was wrong. To not experience respect or understanding in the role as patient was experienced as tough for these young adults, but they found ways to cope by demanding to see x-rays, to get more information. The informants also described their own concern for how the social environment would react. They described how they experienced a lack of respect and understanding both from the social- and health-care environment. For instance, the head that said -call me when you are healthy, or the nurse that suggested public transportation after surgery. Some felt lonely, whereas others had feelings of not being allowed to be left alone and wanting to have time on their own. The informants also described how they tried to protect others from knowing too much. To achieve this, the informants described how they tried to balance between telling and keeping the knowledge to themselves. They did this both to protect others but also to protect themselves as they otherwise would have had to answer questions without knowing the answers. All these factors created an experience of mental stress. Patients decreased the experience of stress by talking to professionals, and by finding new ways to act e.g. to allow the environment to obtain information via another person in the family. Even aggression

against the social surroundings was used to maintain their own borders, as was trying to ignore the illness.

"I think the toughest thing was ... that I felt like that sometimes doctors talked over my head you did not get it what the hell ... what it was that was wrong at all"

"...that I knew what the hell I was fighting against... I mean... is it a small dot or is it a big fucking ball that I have in the stomach.. you know...I want to know"

Fear and anxiety

There was a constant concern for the disease. They struggled with thoughts concerning the cause of the cancer as well as if they really were cured from their cancer or if it had or would come back. There was also concern about not being able to sexual lust as prior to the disease and fear related to the continuous follow-ups at the hospital. Patients found several ways to manage the stressors e.g. to discuss a possible new survey with their doctor, to seek to ensure the rational, and to look for sensible argument. Some also tried to cope by calculating the odds for relapse. The individuals also used anger as a way to cope. This anger was turned towards others as feelings of contempt as well as against oneself through self-injury. Some also coped by denying the existence of the stressor because they so much wanted it to be nothing, nothing serious. Physical exercise was also mentioned as an activity used to reduce stress levels. "At the beginning I thought that it was a bit hard for the phase in that situation, it feels as if you could have a relapse at any time"

"I have anyway learnt to think differently because I think that is something you got to do to function somewhat sensible"

Feelings of guilt and shame

The informants expressed how they felt less worth as a human being because they might not be able to have children as a consequence of their cancer treatment. They also expressed feelings of

guilt related to thoughts of being the one that spread cancer in the family. One of the informants described how she felt that she had not been able to be the mother she would have wanted to be for her child, due to the disease and its treatment, which caused feelings of guilt and shame. There were also young adults who were ashamed to have turned against their own bodies instead of being able to cope with anxiety. In order to cope with these feelings of guilt and shame the individuals tried to regain a sense of self-control. This was done by seeking information and support from expertise, trying to find logical explanations but also, in some cases, by physically harming themselves. "...very easy to think that that it is true that you're like less ... worth, both as a woman and as a human being if you cannot have children"

"...can I choose...It was very important for me to have a feeling that it is I who choose...it is I who decide"

Discussion

The aim of this study was to describe stressors and coping among young adults with cancer. Previous research has mainly focused on the stress – coping process among middle-aged and or older adults with cancer. There are relatively few studies concerning young adults and their experiences of stressors and coping during cancer, and a majority of these reports include patients with childhood cancer [37, 38]. Stress is considered a natural part of life and makes coping necessary. In clinic it is important to consider that it is not only stress that affects the patient's health. How the patient handles stress is equally important [39]. If coping is ineffective, stress may have damaging consequences for the individual's health and social functioning; but on the other hand if coping is effective, stress can remain under control [12].

These individuals are so young that they have not experienced serious illness and symptoms before which means that very much is perceived as stressful. It is difficult to manage the stressors and

the whole situation in that they lack previous experience to fall back on. We identified four categories of stressors. These findings correlate with the findings of Dunkel-Schetter et al [40], but the young adults in this study also experienced stressors related to their youth concerning: fertility, breastfeeding, relations to parents and to the other sex, and being too young for cancer. Health and energy are coping resources; a frail and sick person has probably less energy to spend on coping [16]. In this study the young were very active in their coping, they described a fighting spirit and a belief in being able to influence. Link et al describe that younger patients were confident of being cured [41] and Miedema et al found that they used the term "invincible" to describe their pre cancer lives [22]. Important clinical implications for young adults with cancer compared to older patients is that they may have many years after cancer and cancer treatment and therefore need to cope with the experienced stressors effectively.

An interesting sub-finding was that death anxiety was not a stressor in this or the other studies of young adult cancer patients but it was evident in the study of Drageset et al (2010) who interviewed elderly women with breast cancer. They found that the ability to cope with threat of death came from a general positive self-perception and from coping experiences based on earlier successful dealing with suffering and illness [42]. One might wonder if this generation has not had to deal with death before. Further, is death anxiety a stressor for young adults with cancer but one that is unfamiliar and intolerable? Maybe young adults can cope with the stress of having cancer so well that death is not even perceived as a stressor.

Coping strategies found in the present study was problem-focused coping, emotion-focused, meaning-based, and social coping. Problem-focused, emotion-focused, and social coping has been described by other authors [22, 40, 42, 43] as has meaning-based coping [40, 43]. The informants in the present study were very flexible in choice of coping strategy and this behavior has

been described by other researchers [22, 40, 41]. Informants in this study also used psychological defense mechanisms as a way of dealing with the stressors and to our knowledge this have not previous been described. Most used was denial followed by rationalization and distraction, aggression, and acting out. The aim appeared to be to resolve tensions rather than solving the problem and the informants used defense mechanisms as a complement to coping to reduce the feeling of threat and danger in order to obtain a temporary alleviation of the stressful situation. In clinic defense mechanisms have proved to be useful in the short run for reliving anxiety but in the long run defense could prevent adaptation [44].

This study revealed gender differences in stressors and in choice of coping strategy. In the subcategory fear and anxiety women experienced more than four times as much stress compared to the men; and only women experienced feelings of guilt and shame. The young women primarily used emotion-focused coping followed by meaning-based, problem-focused, and social coping. The young men used problem-focused coping followed by meaning-based, emotion-focused and social coping. Few authors describe gender in relation to stress and coping while it may be of clinical importance, but Hilton et al found that both gender described stress about alopecia although it was previously argued that loss of hair is more threatening for women [45]. The findings of gender differences in the present study are an important implication for health care personal to consider in terms of how personal can help young cancer patients accomplish coping and it would be interesting to see if these differences between genders persist in a larger material and with study participants in different ages.

Can physical exercise, supervised by a physiotherapist, help young adults cope better with cancer? The result of this studies suggest this in accordance with others studies. In this study patients used physical exercise as a coping style for mental recovery and as a way to regain normality in body and in life. The informants used

physical exercise as problem-focused coping in order to bring back the body as it were and as emotion-based coping to help them dispel thoughts. In previous research we found that cancer changed the body and that the bodily changes significantly impaired the patients' quality of life and rehabilitation [5]. Physical exercise can alter the way the patients perceived their bodies, help endure treatment better and help maintain physical and mental strength (Adamsen et al., 2009; Drageset et al., 2010; Miedema et al., 2007). Physical exercise interventions might also help in reducing the elevated risk for cardiovascular disease that young adults face [46]. It is interesting to note that the coping strategies included in commonly used coping scales does not correspond to the coping strategies that emerged in the material, physical exercise were missing for example (Manuel et al., 2007). An implication of this study is that randomized exercise trials are needed to learn more of how young adults with cancer can benefit from physical exercise. Future research also need to study this population's experiences prior to and following cancer treatment.

Locus of control is considered an important aspect of coping and of clinical importance is that locus of control may change within the individual from external, for example hospital care, to internal when you're back home again. In this study, the individuals used both internal- ("//last time when I also loosed my hair, the I promised myself that I would never feel ugly again... and that I have kept") and external locus of control (I would only have been able to make that choice if the doctors would have said yes //need to have confirmation from...from the doctors"). The informants described lack of control as a stressor which led to stressful emotions and the informants tried to regain control. In order to do this they used problem-focus and meaning-based coping. Loss of control was described by Meidema et al (2007) as loss of independence from parents and loss of friends (Miedema et al., 2007) and Adamsen et al (2009) describes how patients went from physical and mental control to reduced control with changes in identity from someone

they liked to a powerless cancer victim (Adamsen et al., 2009). Kempen et al (2005) says that in older age an increasing number of uncontrollable situations, such as own disease and others disease or death lead to declining control [47]. One might hypothesize that young adults may experience more internal locus of control, which would affect the coping ability. Theorell believes that the ability to exercise control over their own situation is a prerequisite for the handling of negative stress; and that rehabilitation efforts where the care providers determine direction can lead to passiveness of the patient and an external locus of control. Disease often initially mean dependence of the environment and it is therefore important that rehabilitation efforts are designed to shift locus of control from external to internal locus of control in order to help patients achieve greater independence [48]. Health-care providers and researchers need to develop interventions that can help this population to regain a strong sense of internal locus of control, as this will improve the coping capacity among young adults with cancer and thereby their well-being.

Limitations

This study has both strengths and limitations. The study sample was adequate in that saturation of data was reached. The study is considered to have communicative validity since its procedure has been carefully described and pragmatic validity as its results are of significance to the care of young adults with cancer. This study is limited by the relatively few diagnosis types and that only young adults undergoing treatment were included. The aim of the study was however to explore experiences of young adults during cancer treatment. It is also important to bear in mind that culture, both individual- and group culture, ethnicity and gender affect our results in the results section in terms of what we experience as stressors and how we choose to manage them.

Conclusion

In this study young adults with cancer experienced stressors similar to older cancer patients but also specific stressors related to their youth which is an important implication for health care personal. This study also shows that the young adults were very active and flexible in choice of coping strategy and that they experienced and had to cope with different stressors than elderly patients based on a lack of previous experience of severe illness. Physical exercise as a frequently used coping style was an important finding in this study and further studies are needed to investigate if supervised physical exercise may increase internal locus of control and help young adults with cancer to cope better with their disease and cancer treatment.

Acknowledgements

We gratefully acknowledge the contributions of the young adults who participated in this research and were so generous in giving their time and valuable insights.

References

- [1] van den Belt-Dusebout AW, Nuver J, de Wit R, Gietema JA, ten Bokkel Huinink WW, Rodrigus PT, Schimmel EC, Aleman BM, van Leeuwen FE. Long-term risk of cardiovascular disease in 5-year survivors of testicular cancer. *J Clin Oncol*. 2006 Jan 20;24(3):467-75. PubMed PMID: 16421423. Epub 2006/01/20. eng.[[pubmed](#)]
- [2] Avis NE, Crawford S, Manuel J. Psychosocial problems among younger women with breast cancer. *Psychooncology*. 2004 May;13(5):295-308. PubMed PMID: 15133771. Epub 2004/05/11. eng.[[pubmed](#)]
- [3] Adamsen L, Andersen C, Midtgaard J, Moller T, Quist M, Rorth M. Struggling with cancer and treatment: young athletes recapture body control and identity through exercise: qualitative findings from a supervised group exercise program in cancer patients of mixed gender undergoing chemotherapy. *Scand J Med Sci Sports*. 2009 Feb;19(1):55-66. PubMed PMID: 18266788. Epub 2008/02/13. eng.[[pubmed](#)]
- [4] Hilton S, Emslie C, Hunt K, Chapple A, Ziebland S. Disclosing a cancer diagnosis to friends and family: a gendered analysis of young men's and women's experiences. *Qual Health Res*. 2009 Jun;19(6):744-54. PubMed PMID: 19342703. Pubmed Central PMCID: 2715137. Epub 2009/04/04. eng.[[pubmed](#)]
- [5] Snöbohm C, Friedrichsen M, Heiwe S. Experiencing one's body after a diagnosis of cancer--a phenomenological study

- of young adults. *Psychooncology*. 2010 Aug;19(8):863-9. PubMed PMID: 19862694. Epub 2009/10/29. eng.[\[pubmed\]](#)
- [6] Ranchor AV, Wardle J, Steptoe A, Henselmans I, Ormel J, Sanderman R. The adaptive role of perceived control before and after cancer diagnosis: A prospective study. *Soc Sci Med*. 2010 Jun;70(11):1825-31. PubMed PMID: 20338679. Epub 2010/03/27. eng.[\[pubmed\]](#)
- [7] Thompson SC, Sobolew-Shubin A, Galbraith ME, Schwankovsky L, Cruzen D. Maintaining perceptions of control: finding perceived control in low-control circumstances. *J Pers Soc Psychol*. 1993 Feb;64(2):293-304. PubMed PMID: 8433275. Epub 1993/02/01. eng.[\[pubmed\]](#)
- [8] Rotter JB. Internal versus external control of reinforcement. *American Psychologist*. 1990;45(4):489-93.
- [9] Lazarus RS, Folkman S. *Stress, appraisal, and coping*. New York: Springer; 1984. p. 19.
- [10] Lazarus RS, DeLongis A. Psychological stress and coping in aging. *Am Psychol*. 1983 Mar;38(3):245-54. PubMed PMID: 6870040. Epub 1983/03/01. eng.[\[pubmed\]](#)
- [11] Folkman S, Lazarus RS. An analysis of coping in a middle-aged community sample. *J Health Soc Behav*. 1980 Sep;21(3):219-39. PubMed PMID: 7410799. Epub 1980/09/01. eng.[\[pubmed\]](#)
- [12] Lazarus RS. Emotions and interpersonal relationships: toward a person-centered conceptualization of emotions and coping. *J Pers*. 2006 Feb;74(1):9-46. PubMed PMID: 16451225. Epub 2006/02/03. eng.[\[pubmed\]](#)
- [13] Johnson JE. Self-regulation theory and coping with physical illness. *Res Nurs Health*. 1999 Dec;22(6):435-48. PubMed PMID: 10625860. Epub 2000/01/08. eng.[\[pubmed\]](#)
- [14] Folkman S, Greer S. Promoting psychological well-being in the face of serious illness: when theory, research and practice inform each other. *Psychooncology*. 2000 Jan-Feb;9(1):11-9. PubMed PMID: 10668055. Epub 2000/02/11. eng.[\[pubmed\]](#)
- [15] Lazarus RS, Folkman S. *Stress, appraisal, and coping*. New York: Springer; 1984. p. 141.
- [16] Lazarus RS, Folkman S. *Stress, appraisal, and coping*. New York: Springer; 1984. xiii, 445 s. p.
- [17] Folkman S, Moskowitz JT. Coping: pitfalls and promise. *Annu Rev Psychol*. 2004;55:745-74. PubMed PMID: 14744233. Epub 2004/01/28. eng.[\[pubmed\]](#)
- [18] Greenglass ER. The contribution of social support to coping strategies. *Applied Psychology-an International Review-Psychologie Appliquee-Revue Internationale*. 1993 Oct;42(4):323-40. PubMed PMID: ISI:A1993MG72600005.
- [19] Bouchard G, Thériault V. Defense mechanisms and coping strategies in conjugal relationships: An integration. *International Journal of Psychology*. 2003;38(2):79-90.
- [20] Cramer P. Defense mechanisms in psychology today. Further processes for adaptation. *Am Psychol*. 2000 Jun;55(6):637-46. PubMed PMID: 10892206. Epub 2000/07/13. eng.[\[pubmed\]](#)
- [21] Kent EE, Parry C, Montoya MJ, Sender LS, Morris RA, Anton-Culver H. "You're too young for this": adolescent and young adults' perspectives on cancer survivorship. *J Psychosoc Oncol*. 2012 Mar;30(2):260-79. PubMed PMID: 22416959. Epub 2012/03/16. eng.[\[pubmed\]](#)
- [22] Miedema B, Hamilton R, Easley J. From "invincibility" to "normalcy": coping strategies of young adults during the cancer journey. *Palliat Support Care*. 2007 Mar;5(1):41-9. PubMed PMID: 17461370. Epub 2007/04/28. eng.[\[pubmed\]](#)
- [23] Bleyer A, Barr R. Cancer in young adults 20 to 39 years of age: overview. *Semin Oncol*. 2009 Jun;36(3):194-206. PubMed PMID: 19460577. Epub 2009/05/23. eng.[\[pubmed\]](#)
- [24] Marton F. Phenomenography- describing conceptions of the world around us. *Instructional Science*. 1981;10(2):177-200.
- [25] Svensson L. Contextual analysis - the development of a research approach. In: Svenson L, editor. *Proceedings of the Second Conference of Qualitative Research in Psychology*. Luesden.1985.
- [26] Marton F. Phenomenography: exploring different conceptions of reality. In: Fetterman D, editor. *Qualitative Approches to Evaluation in Education: The Silent Revolution*. New York: Praeger; 1988. p. 176-205.
- [27] Bowden J. The nature of phenomenographic research. In: Bowden J, Walsh E, editors. *Phenomenography*. Melbourne, Victoria: RMIT University Press; 2000.
- [28] Miles M, Huberman A, Saldana J. *Qualitative data analysis: a methods sourcebook*. CA: Sage; 2013.
- [29] Creswell JW. *Qualitative inquiry and research design : choosing among five traditions*. London: Sage; 2012.
- [30] Alexandersson M. Den feneomenografiska ansatsens fokus. In: Starrin B, Svensson P-G, editors. *Kvalitativ metod och vetenskapsteori*. Lund: Studentlitteratur; 1994. p. 125-8.
- [31] Howe K, Eisenhardt M. Standards for qualitative (and quantitative) research: a prolegomenon. *Educational Researcher*. 1990;19(4):2-9.
- [32] Malterud K. *Kvalitativa metoder i medicinsk forskning: en introduktion (Qualitative methods in medical research: an introduction)*. Lund: Studentlitteratur; 2009.
- [33] Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Educ Today*. 2004 Feb;24(2):105-12. PubMed PMID: 14769454. Epub 2004/02/11. eng.[\[pubmed\]](#)
- [34] Malterud K. Qualitative research: standards, challenges, and guidelines. *Lancet*. 2001 Aug 11;358(9280):483-8. PubMed PMID: 11513933. Epub 2001/08/22. eng.[\[pubmed\]](#)
- [35] Malterud K. The art and science of clinical knowledge: evidence beyond measures and numbers. *Lancet*. 2001 Aug 4;358(9279):397-400. PubMed PMID: 11502338. Epub 2001/08/15. eng.[\[pubmed\]](#)
- [36] Guba E. Criteria for assessing the trustworthiness of naturalistic inquiries. *Educational communication and technology: a journal of theory, research and development*. 1981;29:75-91.
- [37] Kyngas H, Mikkonen R, Nousiainen EM, Ryttilahti M, Seppanen P, Vaattovaara R, Jamsa T. Coping with the onset of cancer: coping strategies and resources of young people with cancer. *Eur J Cancer Care (Engl)*. 2001 Mar;10(1):6-11. PubMed PMID: 11827269. Epub 2002/02/06. eng.[\[pubmed\]](#)
- [38] Zebrack B, Chesler MA, Kaplan S. To foster healing among adolescents and young adults with cancer: What

helps? What hurts? Support Care Cancer. 2009 Aug 20. PubMed PMID: 19690897. Epub 2009/08/20. Eng.[[pubmed](#)]

[39] Folkman S, Lazarus RS, Pimley S, Novacek J. Age differences in stress and coping processes. Psychol Aging. 1987 Jun;2(2):171-84. PubMed PMID: 3268206. Epub 1987/06/01. eng.[[pubmed](#)]

[40] Dunkel-Schetter C, Feinstein LG, Taylor SE, Falke RL. Patterns of coping with cancer. Health Psychol. 1992;11(2):79-87. PubMed PMID: 1582383. Epub 1992/01/01. eng.[[pubmed](#)]

[41] Link LB, Robbins L, Mancuso CA, Charlson ME. How do cancer patients who try to take control of their disease differ from those who do not? Eur J Cancer Care (Engl). 2004 Jul;13(3):219-26. PubMed PMID: 15196225. Epub 2004/06/16. eng.[[pubmed](#)]

[42] Drageset S, Lindstrom TC, Underlid K. Coping with breast cancer: between diagnosis and surgery. J Adv Nurs. 2010 Jan;66(1):149-58. PubMed PMID: 20423441. Epub 2010/04/29. eng.[[pubmed](#)]

[43] Manuel JC, Burwell SR, Crawford SL, Lawrence RH, Farmer DF, Hege A, Phillips K, Avis NE. Younger women's perceptions of coping with breast cancer. Cancer Nurs. 2007 Mar-Apr;30(2):85-94. PubMed PMID: 17413773. Epub 2007/04/07. eng.[[pubmed](#)]

[44] Suls J, Fletcher B. The relative efficacy of avoidant and nonavoidant coping strategies: a meta-analysis. Health Psychol. 1985;4(3):249-88. PubMed PMID: 4029107. Epub 1985/01/01. eng.[[pubmed](#)]

[45] Hilton S, Hunt K, Emslie C, Salinas M, Ziebland S. Have men been overlooked? A comparison of young men and women's experiences of chemotherapy-induced alopecia. Psychooncology. 2008 Jun;17(6):577-83. PubMed PMID: 17957733. Epub 2007/10/25. eng.[[pubmed](#)]

[46] Rabin C, Simpson N, Morrow K, Pinto B. Behavioral and Psychosocial Program Needs of Young Adult Cancer Survivors. Qual Health Res. 2010 Aug 12. PubMed PMID: 20705863. Epub 2010/08/14. Eng.[[pubmed](#)]

[47] Kempen G, Ranchor A, Ormel J, Van Sonderen E, Van Jaarsveld C, Sanderman R. Perceived control and long-term changes in disability in late middle-aged and older persons: An eight-year follow-up study. Psychology and Health. 2005;20(2):193-206.

[48] Theorell T. Att kunna utöva kontroll över sin egen situation - en förutsättning för hantering av upprepad och uttalad negativ stress. In: Ekman R, Arnetz B, editors. Stress. Stockholm: Liber; 2005. p. 282-91.

