
From “invincibility” to “normalcy”: Coping strategies of young adults during the cancer journey

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ABSTRACT

Objective: Little research has been undertaken regarding the psychological impact of cancer on those stricken during the young adult years. Specifically, research on the coping strategies of young adults with cancer is limited.

Method: In this qualitative, Grounded Theory study, we did not set out to examine coping; rather, it emerged as a major phenomenon in the analysis of interview data from 15 young adults with cancer.

Results: These young adults used various coping strategies to come to terms with the cancer diagnosis, management of the illness, its treatment, and treatment sequelae. The coping strategies varied considerably from person to person, depended on the stage(s) of the illness, and were rooted in their precancer lives. We were able to discern a pattern of coping strategies used by most participants. The prevailing goal for all participants was to achieve what they called “normalcy.” For some, this meant major changes in their lives; for others it meant to “pick up” where they had left off before the cancer diagnosis.

Significance of results: To aid the understanding of the issues that influence coping, we have developed a model to illustrate the bidirectional nature and the complexities of the coping strategies as they relate to the phases of the disease and the disease treatment. The model also affirms Folkman and Lazarus’ coping theory.

KEYWORDS: Young adults, Cancer, Coping strategies, Coping theory

INTRODUCTION

Cancer is often referred to as an illness of the middle aged and elderly; yet substantial numbers of young people are diagnosed with cancer and undergo cancer treatment, eventually becoming cancer survivors. In fact, the incidence of cancer among young people between the ages of 20 and 44 has increased over the years. In Canada, between 1987 and 1996, the incidence rates of non-Hodgkin’s lymphoma, thyroid, lung, and testicular cancers increased between 2% and 5% (Cancer Care Ontario, 2006).

Although a growing body of research has been completed in the area of childhood cancers and childhood cancer survivorship in the United States and Europe (Meadows et al., 1989; Albritton & Bleyer, 2003; Langeveld et al., 2003, 2004; Boman & Bodegard, 2004; Oeffinger & Hudson, 2004), scientific articles on young adults with cancer are scant. A review article by Langeveld et al. (2002) concluded that most childhood cancer survivors report good physical and psychological functioning in adulthood, even though some survivors report educational deficits, have encountered difficulties obtaining health and life insurance, and experience relational and reproductive problems compared to control groups. It is assumed that young adult cancer patients have similar outcomes.

Despite the fact that many cancer patients have a good prognosis, a cancer diagnosis is almost al-

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ways stressful and has the potential to permanently alter people's lives (Kyngas et al., 2001). Coping strategies are a way to allay these stresses and often help people to adjust to a rapidly changing environment when they are overwhelmed by internal and external demands (Folkman & Lazarus, 1980). Ineffective coping can have serious consequences; it may create a lot of stress, it may negatively impact a person's health and morale, and it may disrupt social functioning. Effective coping will be able to control stress levels (Lazarus, 2006).

Cancer patients cope in diverse ways with their illness (Aymanns et al., 1995; Nichols, 1995). Some cope by seeking complementary hospital care whereas others seek information (Derdiarian, 1986; Carlsson et al., 2005). One study reported that patients who are realistic, but optimistic, about their prognosis score best on psychological adjustment scales (Classen et al., 1996). Cancer patients who had poor coping skills also seem to be at risk for affective disorders (Parle et al., 1996). Hack and Degner (2004) argue that passive decision making is a poor coping strategy and may result in higher levels of anxiety. Others have reported that escaping into make-believe or magic belief systems served as a coping strategy for some cancer patients (Salandier, 2000).

Focus of the Study

Coping processes are frequently described in the literature but are almost always measured by quantitative questionnaires (Lazarus, 2006). For example, the Coping Response Inventory (CPI), the Courtault Emotional Control Scale (CECS), and the Mental Adjustment to Cancer Scale (MAC) have been used in various studies (Classen et al., 1996; Hack & Degner, 2004). In our study, we have taken a completely different approach. We wanted to understand the experiences of young adults with cancer. Out of the analysis of the interviews, three central phenomena emerged: delayed diagnosis (Miedema et al., 2006), support issues, and coping strategies. In this article we will discuss only one phenomenon: coping strategies. The coping strategies discussed in this article were not derived from questionnaires but rather described by individuals who had been diagnosed and treated for cancer.

Definitions

Two major terms, *young adult* and *survivors*, are used throughout the article. The term *young* in *young adult* is a variable one. Some studies refer to those persons between 20 and 44 years of age

whereas others use biological markers such as premenopause (Dunn & Steginga, 2000; Cancer Care Ontario, 2006). We have chosen to define a young adult as a person between 20 and 35 years of age for the following medical and social reasons: age 35 marks a transition for the development from epithelial to nonepithelial cancers (Wu et al., 2005; Cancer Care Ontario, 2006). Socially, many people in their 20s and early 30s may still be struggling to find emotional and financial independence and may still be in search of secure relationships and stable employment. However, there is tremendous variability in the life stages of young adults, and, to some degree, the age criteria is arbitrary.

The term *survivor* is a controversial one. It was first coined in an article by Dr. F. Mullen (Mullen, 1985) based on his personal experiences. Some argue that the term applies immediately after diagnosis; others argue that it needs to be applied after treatment has been completed. In this article we use the term survivor for all the participants, regardless of the stage of their disease. The American National Cancer Institute defines cancer survivorship as "the physical, psychosocial, and economic issues of cancer, from diagnosis until the end of life. It includes issues related to the ability to get health care and follow up treatment, late effects of treatment, second cancers, and quality of life" (National Cancer Institute, 2007).

METHODS

Design

Qualitative studies permit a detailed exploration of an individual's experience, which in this study will enable a rich understanding of the coping phenomenon. A Grounded Theory method is a systematic approach that generates hypotheses or theories. It is sometimes referred to as a "bottom-up" or inductive approach. Grounded Theory provides a framework to understand the process of phenomena by focusing on the perspectives of the participants and how these perspectives influence and shape actions and subsequent consequences.

Data Collection

Data collection included obtaining written consent, demographic data via the "social form," face-to-face interviews, and an extensive literature review. Open-ended audio-recorded interviews were conducted in a place of the interviewees' choosing; it could be their home, our offices, or on one occasion in a truck on the edge of a soccer field. The interview consisted of six general questions beginning with: "Could

you please tell me about when you were diagnosed with cancer and how you felt about that?" as the opening question.

Setting

New Brunswick is a province in Eastern Canada with a relatively small population of 760,000 people. The federal government considers half of the population in New Brunswick to be rural. The province has seven health care regions and each region provides different levels of health care service.

Interviews

RH, the male researcher on the team, interviewed the male participants and JE and BM interviewed the female participants. The reason for this gender-congruent interview process was the assumption that participants might be more comfortable when discussing intimate details with an interviewer of the same gender. After approximately 13 interviews, no new themes or subthemes emerged and the point of saturation was reached. The remaining scheduled interviews were completed and analyzed and the interview process closed.

Analysis

Interviews were transcribed verbatim. Transcripts were read individually immediately after the interviews were transcribed. The subsequent interviews were treated the same way and the codes were compared to the previous interviews (constant comparison); new codes were documented. During the team meetings, detailed codes were discussed and documented (open coding) and categories, properties, and links to core categories were noted in a computer file (memoing). Memoing is an important link between coding and theory development. If an issue was raised in one of the interviews, and the researchers felt a need for further exploration, probes were added to subsequent interviews.

To present a credible analysis of the data, the following were assessed: auditability, confirmability, credibility, and fittingness of the study (LoBiondo-Wood & Haber, 2002). Auditability was achieved by keeping a trail of documents from the raw data to the final analysis (memoing notes, transcripts, and coding schemes as well as minutes from our team meetings). Credibility was achieved by inviting comments from the participants on a study summary mailed to them. Confirmability of the analysis was achieved by analyzing the data with a team of four researchers. Finally, by cross

coding and categorizing the data, "fittingness" was ensured.

Although we identified several central phenomena, in this article we focus exclusively on coping strategies. We explore strategies and intervening conditions that influenced participants' coping approaches. To interpret the participants' experiences, we utilize Susan Folkman and Richard Lazarus' theory of coping (Folkman & Lazarus, 1980; Folkman, 1984; Lazarus, 2006). The data are presented as a visual model and the subsequent text is an explanation of the model.

RESULTS AND DISCUSSION

Participant Profile

Following ethics approval by the Research Ethics Committee of the Dr. Everett Chalmers Regional Hospital, we recruited a purposeful sample of 15 participants. The inclusion criterion was that participants had to have been diagnosed with cancer when between 20 and 35 years of age. The participants were in all stages of the cancer process: Some were still in active treatment, a number had recently completed treatment, others were long-time survivors, and one participant was in palliative care during the interview. Participants' ages ranged from 21 to 43 years. Four participants had experienced cancer twice: Three experienced a recurrence whereas one was diagnosed for a second time with a new primary cancer. A variety of cancer types were represented by the sample with the majority suffering from nonepithelial cancers (see Table 1).

After coping strategies emerged as a major theme, we examined the coping literature and have drawn upon Susan Folkman and Richard Lazarus's (Folkman & Lazarus, 1980, 1988; Folkman, 1984; Lazarus & Folkman, 1984; Lazarus, 2006) theoretical framework to contextualize the experiences of the study participants. Coping is defined as a cognitive and behavioral effort to "manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of a person" (Folkman & Lazarus, 1988, p. 223). While people are continuously appraising the situation, some try to alter the distress (problem-focused coping) whereas others try to regulate distress (emotion-focused coping). Many people who are under great stress use both approaches. Coping is a multidimensional process comprised of several strategies that influence people's emotions. Emotions are a key component of being able to adapt to new situations, including stressful ones (Lazarus, 2006). In this article we demonstrate the importance of the social environ-

Table 1. Participant profile

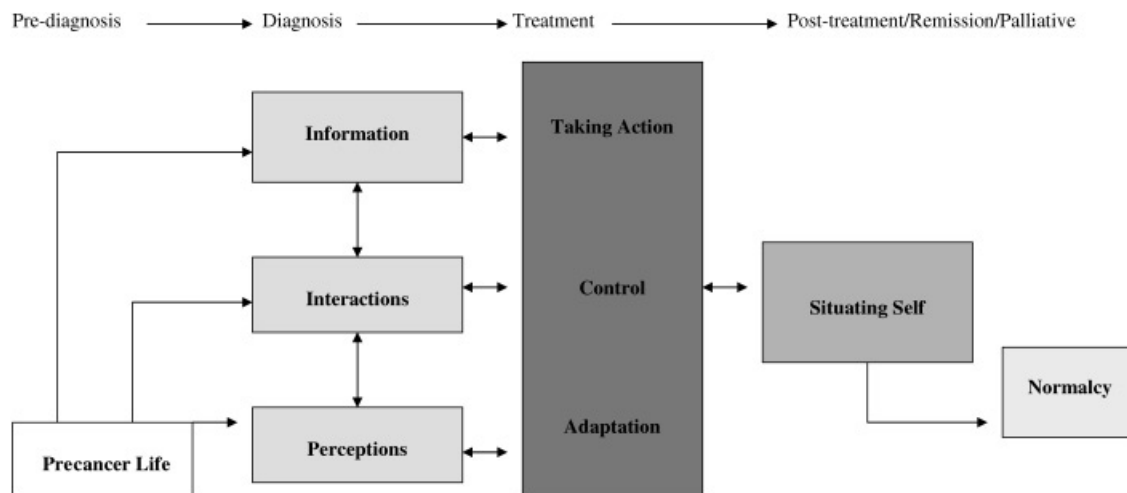
Participant code	Gender	Age at diagnosis	Current age	Status at interview	Type of cancer
JF01	Female	32	33	Patient	Thyroid Cancer
JF02	Female	17, 27	43	Survivor	Hodgkin's Lymphoma and Thyroid
JF03	Female	29	35	Survivor	Synovial Cancer
JF04	Female	15, 20	28	Survivor	Hodgkin's Lymphoma
JF05	Female	28	34	Survivor	Breast Cancer
JF06	Female	31	32	Patient	Breast Cancer
JF07	Female	25, 27	28	Survivor	Breast Cancer
JF08	Female	35	37	Patient	Melanoma
JF09	Female	23	29	Survivor	Hodgkin's Lymphoma
RM01	Male	24	26	Survivor	Osteosarcoma
RM02	Male	20	21	Survivor	Hodgkin's Lymphoma
RM03	Male	30, 33	35	Survivor	Fibrohystiocytoma
RM04	Male	20	20	Patient	Hodgkin's Lymphoma
RM05	Male	31	31	Patient	Leukemia
RM06	Male	29	31	Patient	Colorectal

ment on coping and illustrate both problem- and emotion-focused coping with examples.

The model (Fig. 1) is an illustration of the coping strategies utilized by the research participants during their cancer journey. The cancer journey spans roughly the time of the discovery of the first symptom(s), the diagnosis, the treatment(s), and the treatment sequelae. The coping skills and strategies used by the young adults in this study were deeply rooted in their “precancer lives” and further developed as they received information, endured physical hardship, interacted with others around the cancer, and reflected on their experiences. The ultimate goal throughout this journey for almost all participants was, first, to survive the cancer diag-

nosis and treatment and, second, to return to “normal.”

The boxes in this model indicate the coping strategies used by the participants. The changing shading of the boxes reflects the intensity of the strategies as they are used to deal with the stressors throughout the cancer journey, from the initial diagnosis to the treatment sequelae. Most arrows in this model are bidirectional, as participants moved back and forth between the various analytical categories and between problem- and emotion-focused coping. Of course, the boundary lines between the thematic categories and the types of coping strategies are not always clear; in fact, we would argue that many of these categories and strategies overlap. However, it

**Fig. 1.** Cancer journey coping strategies of young adults.

is clear that coping is multidimensional and non-linear, although a linear pattern that moves toward “normalcy” can be detected. What follows is a rich qualitative description of the coping strategies that go beyond dichotomized terms (Lazarus, 2006).

Prediagnosis Phase: Precancer Life

Before the participants were diagnosed with cancer, they engaged in regular taken-for-granted activities, such as sports, leisure activities, and visiting bars. They were students, workers, lovers, moms or dads, children and grandchildren, brothers, and sisters. Upon reflection after the cancer diagnosis, many used the term “invincible” to describe their precancer lives. They felt they were young, had a lifetime in front of them, and were enjoying themselves; the idea that they could have a serious illness had not crossed their minds. When diagnosed with cancer, many felt betrayed and suddenly overcome by feelings of vulnerability. One female participant who was diagnosed with breast cancer at the age of 28 recalled:

Well, like I said, the battle scars, having to live with those everyday. It's made me not as carefree as I used to be. 'Cause at that age, you think that nothing's going to touch you, nothing is going to go wrong, and that [being diagnosed] completely shatters everything you believe. (34-year-old female)

A complex, but highly important, aspect of coping during the cancer journey was the reliance on existing social networks. Due to the intensity of the disease and its treatment, many participants explained that they had very little energy to socialize and to make new friends (except for the participants who went to support groups). Hence, having an existing support network before the cancer was diagnosed became an important part of the coping strategy throughout the journey. This female participant relied very much on her friends during her struggle with cancer. She said:

I had a lot of friends, like you know, high school friends that I'm still friends with. Um, like, one girl, . . . she'd be my best friend, she was always there. And then I had another friend from [City], who came every second weekend. She ended up moving away, but she was very good. And, [boyfriend], and my family. When I would come home from my treatments, there would always be a household waiting for me, and there would always be something there. Like, I have an aunt

who, every time I would come home she'd have something waiting for me. (28-year-old female)

Having a large network of family and friends can have a positive impact on the cancer journey and assists in effective coping. On the other hand, a lack of family support or strained family relationships before the cancer diagnosis can carry negatively throughout the cancer journey and hinder effective coping. A woman who was an only child said:

My parents, I am an only child, it had a big impact on them. I'm currently going through problems dealing with that, because I've never forgiven them for not being there when I had my surgery. (34-year-old female)

In addition to feelings of betrayal and a reliance on existing support, many participants described feeling that they were thrown into a new world with a new language that they did not understand. They felt a sense of naiveté entering this hurricane of events that was suddenly thrust upon them, which exacerbated stress levels. A female participant diagnosed twice at age 17 and 27 described her feelings as follows:

I didn't really understand that a nodule on a neck may be, may in fact be cancerous. Even that word wasn't within my vocabulary. (34-year-old female)

Another participant was told that little could be done for him and he should seek palliative care. The participant responded:

I did not even know what that [palliative care] was. (26-year-old male)

This naiveté added to stress levels and may have initially hindered the coping process.

Diagnosis Phase

Information

The first step after the participants had learned that they had or likely had cancer was the problem-focused strategy of gathering information about their specific condition, its treatment, and its outcomes. The Internet was the easiest source of information; however, not all information was deemed useful, and sometimes the stories were too overwhelming. A female participant described her search for information as follows:

I went into shock. After I looked it up on the Internet, I was by myself when I looked it up because, I just ran up quickly just to check it out just so . . . I would be able to say what it was. . . . My brother was downstairs and I yelled and told him to come up so he could see this. I suddenly got thrown into this world where it was like I was cramming for an exam that I didn't know what the subject was. I couldn't get enough information, and I didn't know what it was that I was looking for. (29-year-old female)

Relational Interactions

The knowledge that the participants suffered from a life-threatening illness required an appraisal of existing relationships, particularly with family, friends, and, to some degree, with the health care provider. Many felt that, as children, they should not have a life threatening illness before their parents. This turn of events upset the generational life span theories, resulting in trying to shield the parents, particularly the mother, from the bad news. One young woman said:

Anyhow, I came home and my mom hugs me and says, you know [name], this may not sound right, but if anything were to happen to you, you wouldn't have to worry about anything anymore, I would be the one left. And I was thinking, I knew how she meant it, how can she say that, I would be dead and I don't want to die!! But I knew how she meant it; I knew how she would have to go through the same thing after going through it twice. But that's my mom. So, it is better if she doesn't know until after. Tell her the good news. (37-year-old female)

Further, many participants developed a new and intensifying relationship with their physician. Often these relationships were positive, but for some these relationships were troubled. One participant's physician called her at work to give her the diagnosis. She said:

And then you know, less than a week later he called and said that it was synovial sarcoma, and he didn't know what it was. He said, I don't even know, all I can tell you is that yes, it is cancer and I have to go, I need to talk to people, I need to get you where you need to go, I can't talk to you right now. So, off he went and I am like, synovial sarcoma. So, of course me, just being like stunned and I went back to my boss and said, "I think I have to go home now." You know, I locked my cash up and [sine] let me go and then you get home

and you start thinking and all these questions come and I called him back and he wasn't here, he was at the medical library looking it up to find out exactly what he was dealing with. (35-year-old female)

Perceptions

Once the participants had accepted the diagnosis, had learned about the diseases, many engaged in what Lazarus called "emotion-focused coping" (Lazarus, 2006). They started to envision how they should deal with this condition and the treatment regimes. Precancer activities, support networks, and the knowledge gained all shaped their perceptions and their coping strategies. For example a young male participant who enjoyed playing cards described the cancer as an opponent who had all the good cards. Now the participant's task was to make the best of the situation in order to "win." A competitive hockey player, who was diagnosed at age 24, described his coping strategy as a hockey game. He said:

My mind has been conditioned through being an athlete, a competitive athlete throughout my life and my career. Umm, you know it's like when the doctor comes in and says we're going to quit before we start, I mean how many times do you do that in a hockey game? You go out there and do what you can and sometimes you might surprise yourself. (26-year-old male)

The emotion-focused coping strategy was deeply rooted in the experiences the participants had developed from childhood on and exemplifies the importance of the "precancer life" phase in order to understand current coping strategies.

The personification of the cancer by several participants was also an important emotion-focused strategy. For example one participant said:

I guess it's been long enough that it has become part of me. (37-year-old female)

Whereas, on the other hand, others saw it as something "outside" themselves. A young woman who was diagnosed with breast cancer twice at age of 25 and 27 described the cancer as

This is not really me, it is not really attached. (27-year-old female)

Ultimately, the way the participants perceived their cancer shaped their coping efforts to a certain degree.

Treatment Phase

Taking Action

Waiting for treatment was an enormously stressful challenge for some. Not only did participants want to “do” something, family and friends also wanted to see action. To ameliorate the tension that waiting created, several participants spoke of a number of problem-focused actions. One participant spoke of a small, but significant action. He said:

What can you do when you're waiting for a month for surgery? . . . I could do it [relaxation technique] for 20 minutes or half an hour and feel a bit more relaxed or you've done, you tried to do something, you did something. So, and that was a good thing. (35-year-old male)

The same participant felt that his coping efforts were pushed to the brink during the treatment phase. He was depressed after his first chemo. He said:

I remember at that point I wished I would die rather than having another round of chemo, I couldn't do it. That it was just too much, until I started feeling better, then the same thing, you know I can do it, but until that point it was tough.

Others used coping strategies aimed at both maintaining physical and psychological health and well-being during and after the treatment by eating properly and becoming more physically active. Many applied mental techniques such as goal setting and positive self-talk to ensure that they were keeping a positive perspective.

Control

Trying to remain in control was another application of a problem-focused coping strategy. Almost all described some sort of loss of control in their lives since the cancer diagnosis. For example, a number of participants described the loss of the newly gained independence from their parents; others mentioned the loss of friends. Perhaps due to loss, some described taking action to try and remain in control. A young male said:

I know that when I called . . . to find out about the health card, that I probably could have saved myself a lot of headaches just by calling here [Oncology Unit] and having the social worker go through it. . . . I wanted to solve the problem as quickly as possible so not to have to worry about it. (31-year-old male)

Adaptation

An important emotion-focused coping strategy was to adapt to the new reality of being sick due to the chemotherapy or radiation. One female cancer patient described it as follows:

My biggest thing is that you have to learn to be sick, which was a huge thing. You don't realize that you have to do that, but you really have to learn what it is to be sick. (29-year-old female)

Adaptation also included problem-focused strategies. Participants described how they adapted to long treatment sessions or how to moderate treatment side effects such as nausea. Some described how they were able to fall asleep while undergoing chemotherapy; others utilized alternative therapies to alleviate stress and treatment side effects.

Situating Self

As participants finished treatment and entered the posttreatment and remission stages of the cancer journey, they often entered a reflective phase. They appraised and gave meaning to their experiences by comparing themselves against other cancer patients they had met during their journey. As a result many reflected on the fact that they perceived to have had a “unique” type of cancer. Others felt that they were “lucky.” One male stated:

I'm sure a lot of people want to get their hands on me, just because it was a rare case and to have that feather in their cap, but, they realized the severity of it and all pointed right back to the guy we initially contacted . . . (26-year-old male)

Another participant said:

I was lucky enough that he [surgeon] could go down deep enough, took the lining right off my muscle, he went down that deep, and was able to take everything out and had a good circumference around it that he felt that I didn't have to have radiation or chemotherapy. (35-year-old female)

Regardless of how they perceived their experiences, for most the cancer journey was a transformative process that set the stage for life-altering philosophies. One male participant said:

I like working and I love the work I do and I want to still do it, um, but I also want to take vacation and taking time with the family. (35-year-old male)

Posttreatment/Remission/ Palliative Phase

Normalcy

The predominate goal for all of the participants was to return to a level of “normalcy” after they had completed their treatments. However this “normal” was not necessarily that of the prediagnosis phase. The feelings of invincibility and naiveté were gone and the cancer journey had matured them in comparison with their peers, and in some cases transformed them compared to how they saw themselves before the cancer diagnosis. One young male said:

Just knowing that everything, going through the treatments and the end, looking forward to the end and hoping to get better as soon as possible so that I could get on with my life. Get back to normal. Really that’s all that drove me. (21-year-old male)

A female participant said:

The thought of trying, how would I ever go back to “normal” when this is such a life-changing event. It was huge and I knew I wasn’t the same person from even the mention of it, let alone afterwards. (29-year-old female)

CONCLUSION

In this study we did not set out to examine coping strategies of young adults with cancer; we wanted to understand the lived reality of this group. However, as we analyzed the interviews, it became clear that coping strategies were an important component of the cancer journey. Hence, we explored the coping literature that is mostly based on quantitative measures (Lazarus, 2006). The discussion of coping that emerged from our analysis provides a rich illustration of the coping strategies as theorized by Susan Folkman and Richard Lazarus. However, we do want to caution that in many instances the boundaries between problem- and emotion-focused coping are not clear. Nevertheless, we have presented a model that highlights the complexity and the bidirectional nature of the coping strategies for young adults with cancer. We believe that the unique contribution of our study is that young adults, even though their life experiences may be limited, do draw on previous life events and activities to cope with the disease and its treatment. The coping strategies evolve throughout the cancer journey and are used to meet a variety of demands and

stressors. During the treatment phase, effective coping is especially challenging as emotional and physical strain is at a peak. Because young adults may have many years of living ahead of them after cancer treatment, it is extremely important that they cope effectively at all points throughout the cancer journey. As pointed out by Parle, ineffective coping may lead to serious long-term mental health issues (Parle et al., 1996). Hack and Degner (2004) argue that when women take more active roles in their treatment protocols, they are less anxious during follow-up care. Our model demonstrates that effective coping does not begin and end at set points in time. Rather, it is rooted in previous experiences and develops throughout the cancer journey.

Folkman and Lazarus stated that coping is a “constantly changing cognitive and behavioural effort.” The coping strategies as described by the participants were indeed constantly changing, non-linear processes deeply rooted in their lived experiences. Some focused more on emotional coping whereas others preferred action-oriented coping strategies. Based on the analysis of the data, we developed a model that illustrates the complexity of the coping strategies and the movement between the various identified concepts. This model may be useful for service providers to understand young adult cancer survivors’ coping responses to an unanticipated illness and to better design resources and interventions to deal with their unique needs.

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